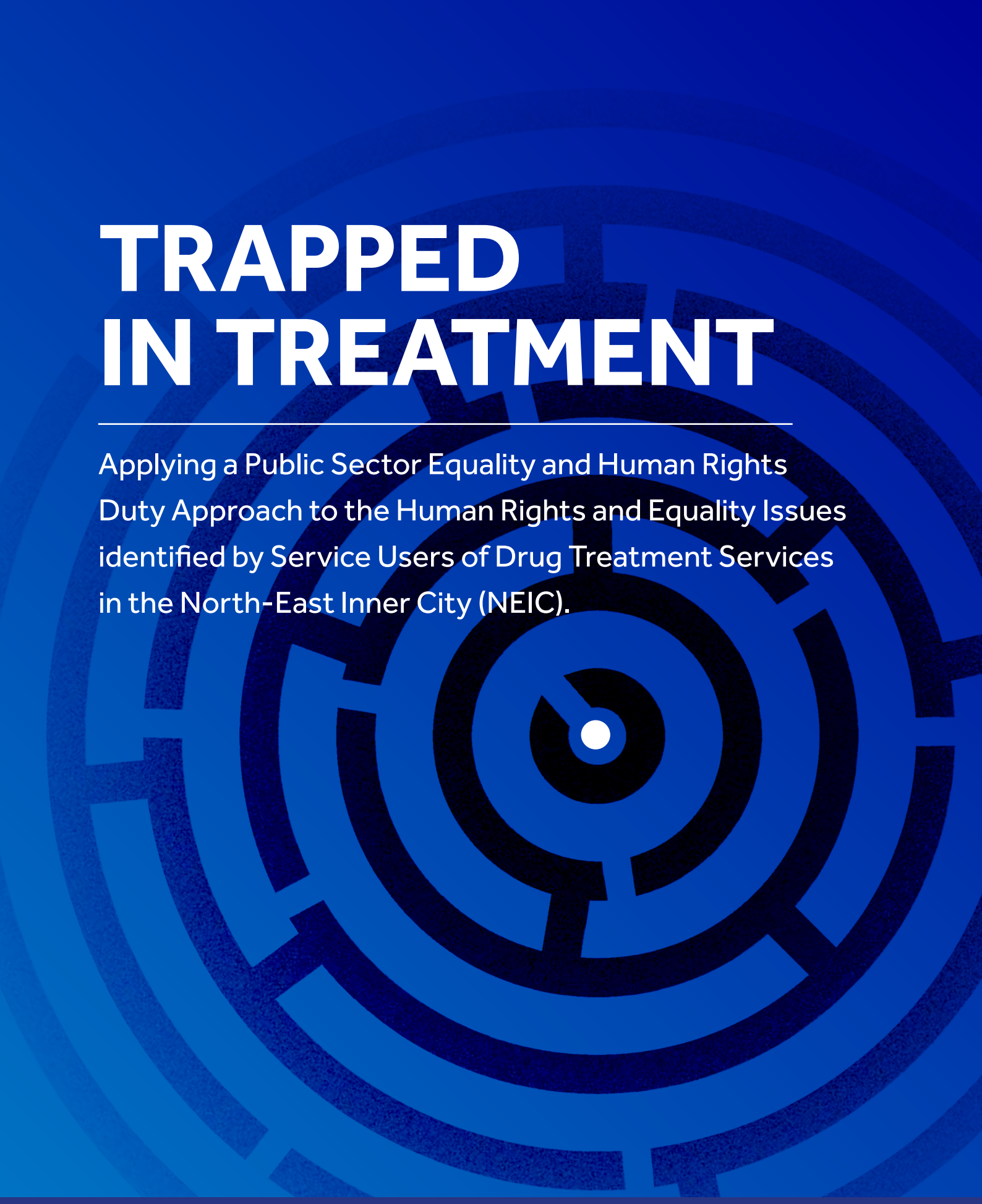
TRAPPED IN TREATMENT

Applying a Public Sector Equality and Human Rights Duty Approach to the Human Rights and Equality Issues identified by Service Users of Drug Treatment Services in the North-East Inner City (NEIC).



can
Placing People at the Heart of Change

SURIA
Service Users Rights In Action

ICON

ACKNOWLEDGEMENTS

We would like to thank all those who were involved in the production of this report. We would especially like to thank the interviewees who were willing to share their lived and living experience and for being so generous with their time. The breath of this work would not have been captured without our peer researchers who worked tirelessly to capture the experience of service users.

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ACRONYMS

MMT	Methadone maintenance treatment
OST	Opioid Substitution Treatment
POCT	Point of Care Tests

THE PROJECT TEAM

Inner City Organisations Network (ICON)

ICON is a community network comprising of community and voluntary organisations and individuals living and working in the north east inner city. The broad functions include:

- Acting as a source of information
- Campaigning and lobbying around issues identified within the community
- Encouraging local policy making through debated and discussion forums
- Promoting partnership approach
- Providing a catalyst to initiate relevant service responses to issues identified

Community Action Network (CAN)

Community Action Network (CAN) is a social-justice Non-Governmental Organisation (NGO), that places people at the heart of change. We seek to create a more just and equal society that has the well-being of people as citizens at its heart.

We work with people to assert their rights to participate fully as subjects of their own lives, to have their voices heard and to have their choices respected, within a human rights framework. We seek to develop leadership and participative democracy.

Service Users Rights in Action (SURIA)

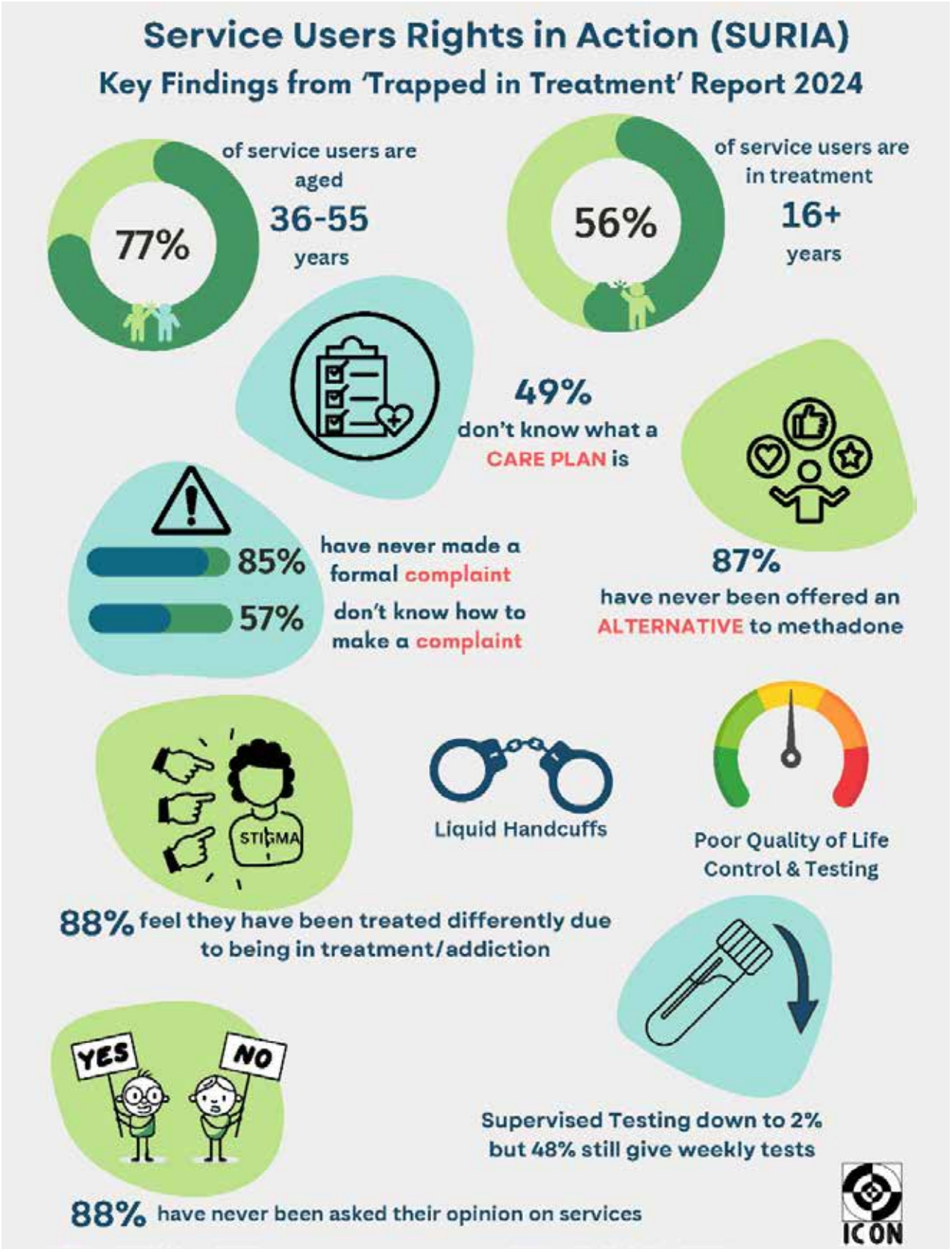
SURIA is a coalition of drug service users, service user representatives and community activists. SURIA came together in 2009 to address concerns relating to the human rights of people who are on long-term methadone treatment.

GRANT DONORS

Irish Human Rights and Equality Commission

The Irish Human Rights and Equality Commission is Ireland's national human rights and equality institution. We are an independent public body that accounts to the Oireachtas, with a mandate established under the Irish Human Rights and Equality Commission Act 2014 (IHREC Act 2014). The IHREC Act includes and further enhances the functions of the former Irish Human Rights Commission and the former Equality Authority. Our purpose is to protect and promote human rights and equality in Ireland and build a culture of respect for human rights, equality and intercultural understanding in the State.

KEY FINDINGS



INTRODUCTION

In 2022 ICON successfully secured funding from the Irish Human Rights and Equality Commission (IHREC) to carry out a project entitled 'Applying a Public Sector Equality and Human Rights Duty Approach to the Human Rights and Equality Issues identified by Service Users of Drug Treatment Services in the North East Inner City (NEIC).'

The project aimed to apply a public sector equality and human rights approach to issues identified by service users of drug treatment projects in the NEIC and deliver evidence based, peer led research as well as raising awareness of the duty in a broader context through community events. In addition, the process aimed to:

- build on the extensive research carried out by Community Action Network and Service Users Rights in Action on applying a public sector equality and human rights approach to issues identified by service users of drug treatment services and apply it to the NEIC (see Appendix 1).
- review the key monitoring points from the previous research and assess what changes came about from the HSE Action Plan.
- facilitate service users to communicate lived experiences and empower them to have a say in the decisions that affect their lives from a rights-based perspective.
- support their active involvement and leadership to address human rights and equality issues identified by themselves.
- address the experience of services users in their treatment by public bodies and promote positive actions to fulfil responsibilities and act on non-compliance
- raise awareness in the NEIC of the function of the duty and how it can improve access to and experience of public services

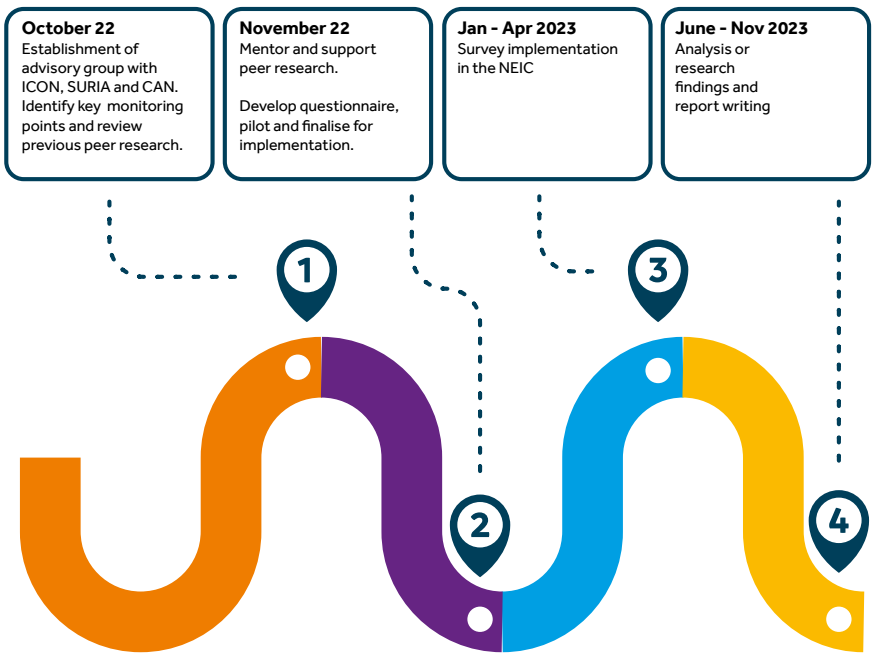
PROJECT METHODOLOGY

Methodology

The project team chose peer led research as the main methodology. The three groups involved in the project have a long history of working in this way to ensure that the target group are active participants in the research being carried out about them.

The project commenced in October 2022 on receipt of funding from IHREC and the report was completed in December 2023.

Project Timeline



The project designed ethical, non-exploitative research that did not stigmatise or disempower. The research was based on informed consent of all participants and was carried out with consideration to the centrality of ethical and participatory research approaches. Interviews were carried out with respect for participants, and responses were confidential and based on consent. Participants' identities are protected.

The purpose of the research was explained in a meaningful way to participants. Participants were made aware of their right to refuse to participate and that they could withdraw from participation at any time in the process. All work is fully complaint with GDPR. All aspects of the research from start to publication of results have been conducted with honesty and integrity.

Each participant was offered a cup of tea or coffee by the researcher when completing the questionnaire or follow up with an item that they might need, such as gloves or socks or shoes.

Questionnaire Development

The development of the questionnaire was carried out by the project team and the peer led researchers. The two questionnaires used previously were both reviewed in 2012 and 2020 and the key monitoring points were noted. The questionnaire is similar to the previous iterations with some changes in questions asked and some changes in language.

The questionnaires covered the following areas:

- Demographics
- Treatment Choice and Treatment Plans
- Supervised and Frequency of Urine Sampling
- Engagement and Participation for Service Users
- Complaints Mechanisms

A copy of the questionnaire can be found in Appendix 2.

When reviewing the research responses and from discussions with the peer led researchers the project team noted that the use of language in this survey e.g. care plan, personal goals etc. was at times at variance with the language used by service users themselves and was clinical speak rather than colloquialisms or culturally appropriate language. We felt it was important to highlight this issue as some questions such as 'do you have personal goals?' may not have been understood clearly as in some instances the open ended questions clearly demonstrated that they had personal goals but may not have understood them in those terms.

We have also chosen to print all the responses from service users in order to amplify their voices, which often go unheard.

Why peer led?

Serious human rights and equality concerns have been expressed in relation to the lived experience of service users as far back as 2009 when CAN first began working with service users in a coalition, which eventually became known as Service Users Rights in Action (SURIA). This is a coalition of drug service users, service user representatives and community activists. The key areas of concern are:

- The practice of and over reliance on urine testing,
- The lack of an annual review for each person where there is meaningful engagement and choice.
- The lack of information, availability, and choice on pathways to health
- The absence of information on and access to an effective, transparent, and accountable complaints mechanism within the drugs services

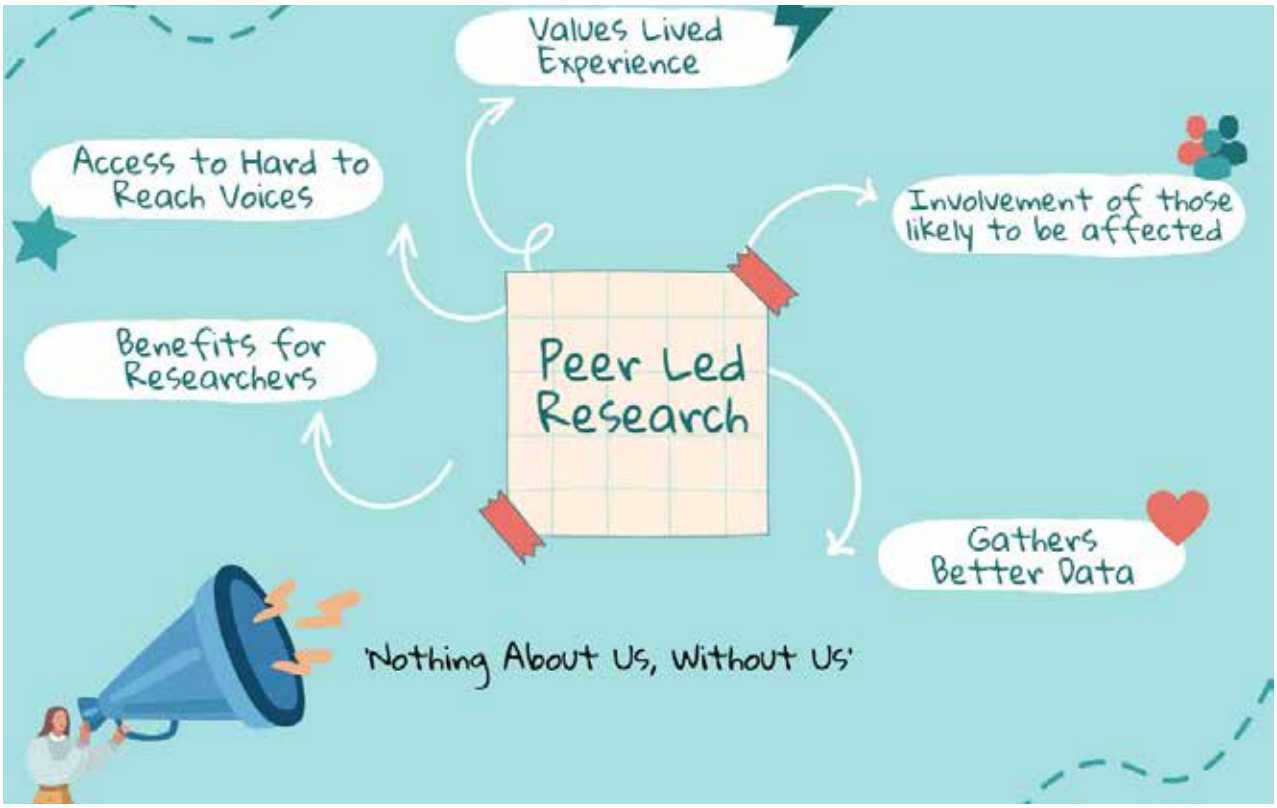
When these issues were first named in 2009, a link to human rights and in particular, the right to health and the right to participation was established. From then onwards, we have framed these issues as rights rather than as needs and have sought to hold service providers accountable for the systems, policies, procedures, and attitudes that perpetuate the failure to respect, protect and fulfil the rights of drugs service users. To date, CAN has facilitated and equipped SURIA to conduct four rounds of peer led research, the first in 2012 to establish base line data on the experience of the named issues. The subsequent rounds have been focused on monitoring the progressive realisation of their right to adequate health.

In a previous SURIA report Nothing About Us Without US[1], we outlined how the peer research we do is part of a methodology known as Participatory Action Research (PAR). Essentially, this is a cyclical research methodology that is beneficial in research with marginalised and disempowered populations. It follows a cycle of Plan, Action, Observe and Evaluate and is ideal for monitoring the progressive realisation of rights over time through regular rounds of peer research. As such, it is both a philosophy and a means of helping people to:

- Identify their issues and link them to human rights.
- Come up with possible solutions.
- Assess the solutions.
- Create indicators for change.
- Mobilize for action.
- Monitor and evaluate progress over time.

Working directly with service users to identify their human rights and equality issues, to design, pilot, conduct peer to peer interviews, to analyse the findings, set indicators, engage with service providers, and monitor progress over time has facilitated their voice to be heard and validated. In so doing, it recognises and values the unique knowledge and experience of lived experience and the power it has to bring perspective and expertise to the design and delivery of services that are both appropriate and based on respect and rights. On each occasion, we have reflected on the process, extracting key insights and learning which in turn has informed the next round of action and research.

1 *Healy Phd, Richard (2021): Nothing about us without us The Current Voices of the Irish Methadone Service Users Suria 2020*



CAN and SURIA have collaborated with ICON in this project both as a means of bedding down the process within a community setting and conducting a fifth round of research on the issues named back in 2009. Two service users from SURIA with direct experience of living and working in this community reviewed the previous questionnaire, added in relevant questions in line with the purpose of the project as outlined earlier in this report 138 people using the drugs services within the community. As part of our model of practice, we wish to capture their insights from that experience on this occasion and to do so in the words of the peer researchers.

Power of Peer Research

'As peer researcher, I have access in a way that is different from a person with no lived experience. I might even be known to the interviewee - I am known even when they do not know me personally. I let people know I understand, and they are more open with me.'

'I can identify with them and relate from where they are at.'

'I am not providing a service and they do not have to tell me what they think I want to hear. They ae not fearful of consequences and are freer to tell me how they really experience the services.'

'The questions shine a light on the services for the interviewee as well as for the services.'

'As a peer researcher I can use the interviews to

- have more open conversations, say for example in relation to stigma and how it operates overall for service users in society.
- give information e.g. in relation to new treatments such as Bufadol, Suboxone.
- generate an awareness of rights and encourage interviewees to have greater expectations of services without being fearful of rocking the boat or being punished.
- questions internalized feelings of being unworthy.
- shine a light on degrading language such as 'clean" unclean.'
- be a role model, an inspiration to others that they too can move on in life with the right supports.
- be a carrier of hope and convey the message that this experience should not have to define you listen and empathize and be respectful, knowing how much that in itself means to people

"It was really important to recognize and time the interviewee gives in answering very personal questions. Offering tea and coffee or in case of people in projects, being able to give socks and underwear was a huge recognition of the respect for the person and their life.'

The findings that stand out for researchers

"Stigma stands out – feeling looked down upon, being followed because of the way the interviewee looks, being told that "I feel like I am being stepped upon all the time."

"The reaction to questions such as

- Have you ever been asked your opinion on services?
- Have you ever been told your rights?
- Have you ever made a complaint?

The reaction was either of disbelief, or who would listen to me? Or why bother? What rights? What choice of treatments are there? What alternatives exist to methadone?

'There is a strong belief that doctors have no faith in the notion of progression or that interviewees are ready or able to move on.'

'Homelessness is huge and the large number of homeless hostels in the area has a significant impact on the lived experience and findings. People living in homeless hostels have little or no hope. They often have to travel for their scripts.'

Impact on Peer Researcher

'I have been there, and I understand what the interviewee is going through, and I get frustrated that there has been no real action taken.'

Having conversations around the questions gets to you. It is important to debrief and pay attention to how I can be triggered and overwhelmed by the experience.'

'People pour their hearts out - when you leave them you feel you are abandoning them.'

'One or two people I had to leave after the interview – stayed with me and worried me". I took their information and then left them with whatever information I could give but it was difficult.'

'One person I interviewed has since died...stays with me.'

'I become more aware of how much I have developed, and I have a heart to help others. I have the freedom to speak out and I can highlight the issues.'

'I keep asking who is looking at the lives of these people and telling them it does not have to be like this? Who is giving them hope?'

Survey Analysis

The project team requested that SURIA provide a commentary on the survey findings as they have built up extensive expertise on the subject.

DUBLIN NORTH EAST INNER CITY

Historically the area defined as the north-east inner city of Dublin (NEIC) is from Dublin Bay to the east and Drumcondra Road/ Dorset Street/Bolton Street and Arran Street East to the west. To the south, the area is defined by the river Liffey while to the north the border is a wide arc made up of the Tolka River to the west and all of East Wall to the east. This area is inclusive of all of Dublin 1 and parts of Dublin 3.

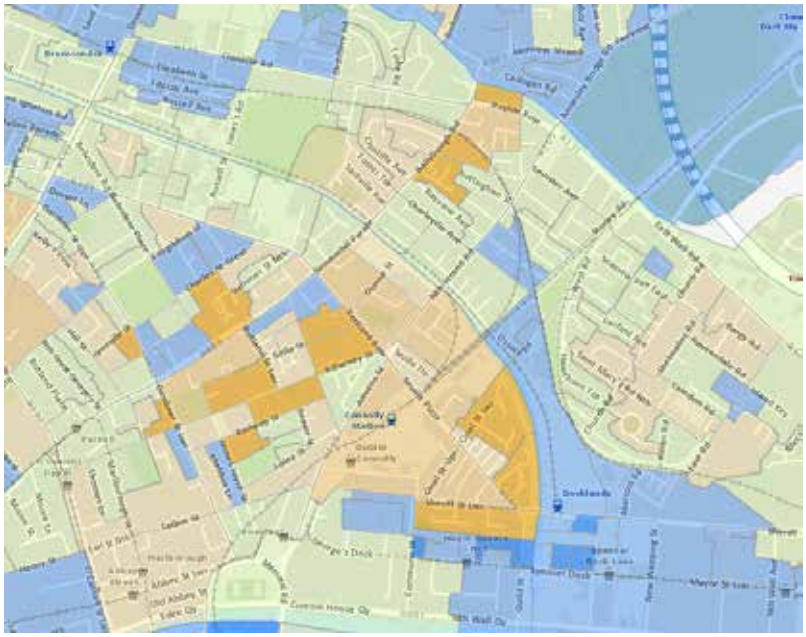
This is the wider NEIC area; within that, there are smaller distinct communities, such as the communities of Sean McDermott Street, Summerhill, Ballybough, East Wall, North Wall, North Strand, the Five Lamps and Mountjoy Square. There are also new community strongholds such as Parnell Street, the communities of Dominick Street, the NCR, and the shopping and commercial districts including the IFSC and Henry Street/ Mary Street/ North Earl Street/Talbot Street as well as the historically significant O'Connell Street and Moore Street.

This is not a homogenous community, but it is a community that has experienced and continues to experience disadvantage and marginalisation, more saliently a series of communities that experience relatively higher levels of disadvantage than Dublin City and nationally. Key to understanding inner city communities is to be aware that the overall statistics and information on the city masks the deprivation therein and that macro average figures tell us nothing about the true experiences of the most disadvantaged.

The Pobal HP Deprivation Index[2], in simple terms, is a method of measuring the relative affluence or disadvantage of a particular geographical area using data compiled from various censuses. A scoring is given to the area based on a national average of zero and ranging from approximately -35 (being the most disadvantaged) to +35 (being the most affluent). In addition to this, percentage data for the area is given under the following categories:

Relative Index Score	Standard Deviation	Label	Colour Scheme
over 30	> 3	extremely affluent	Dark Blue
20 to 30	2 to 3	very affluent	Medium Blue
10 to 20	1 to 2	Affluent	Light Blue
0 to 10	0 to 1	marginally above average	Light Green
0 to -10	0 to -1	marginally below average	Light Yellow
-10 to -20	-1 to -2	Disadvantaged	Medium Yellow
-20 to -30	-2 to -3	very disadvantaged	Orange
below -30	< -3	extremely disadvantaged	Red

The small area map below shows there are areas of the north-east inner city that are still classified as very disadvantaged, surrounded by pockets of very affluent communities.[3]



The most recent Pobal maps also show that disadvantaged areas are further from the average in Ireland than they were in 2016 and disadvantage remains a spatially entrenched phenomenon in parts of Dublin's inner city.[4]

2 *https://data.pobal.ie/portal/apps/sites/#/pobal-maps*
3 *https://www.pobal.ie/pobal-hp-deprivation-index/*
4 */https://www.pobal.ie/app/uploads/2023/11/Pobal-HP-Deprivation-Index-Launch-Presentation.pdf*

The National Drug and Alcohol Survey (NDAS) 2019–2020[5] found that drug use impacts disproportionately on more deprived communities. in areas which are most or least deprived, there is little difference in the prevalence of drug use, while communities with high levels of deprivation are disproportionately impacted by the negative effects of drug use activities in their local area.

More than one-third (37%) of respondents reported a 'very big' or 'fairly big' problem with people using or dealing drugs in their local area, this ranged from 44% in the most deprived areas compared to 20% in the least deprived areas. Commonly reported problems included drugs being too easily available, people dealing drugs, and children and teenagers taking drugs. Those in deprived communities were twice as likely to experience drug-related intimidation than residents in less deprived neighbourhoods.

- Figures from the Health Research Board (HRB) on drug-related deaths show there were 409 poisoning deaths in 2020. There were also 397 non-poisoning deaths, with hanging the most common cause of these deaths. [6]
- 409 deaths were poisonings and 8 in 10 of these deaths involved more than one drug.
- 7 in 10 involved opioids. Methadone was implicated in 3 in 10 poisoning deaths and heroin was implicated in 2 in 10 poisoning cases
- Almost 6 in 10 involved benzodiazepines and many of them had more than one type of benzodiazepine
- 3 in 10 involved cocaine
- 2 in 10 involved alcohol (as part of a poly drug poisoning)
- Almost 6 in 10 involved other prescription drugs, most commonly antidepressants and antiepileptics

Socio-demographic characteristics of people who died from poisoning

- More than 6 in 10 were male
- More than half of men were aged 42 years or younger
- More than half of women were aged 45 years or younger
- Half had a history of mental health issues
- 1 in 8 were homeless
- 1 in 5 had never injected
- In 4 in 10 of poisoning deaths, the person was alone
- 11% died in homeless accommodation
- 9% died in a public place or building

5 *//www.drugsandalcohol.ie/php/national_drug_and_alcohol_survey_use.php#:~:text=The%202019%2F20%20NDAS%20collected,all%20five%20surveys%20are%20available*

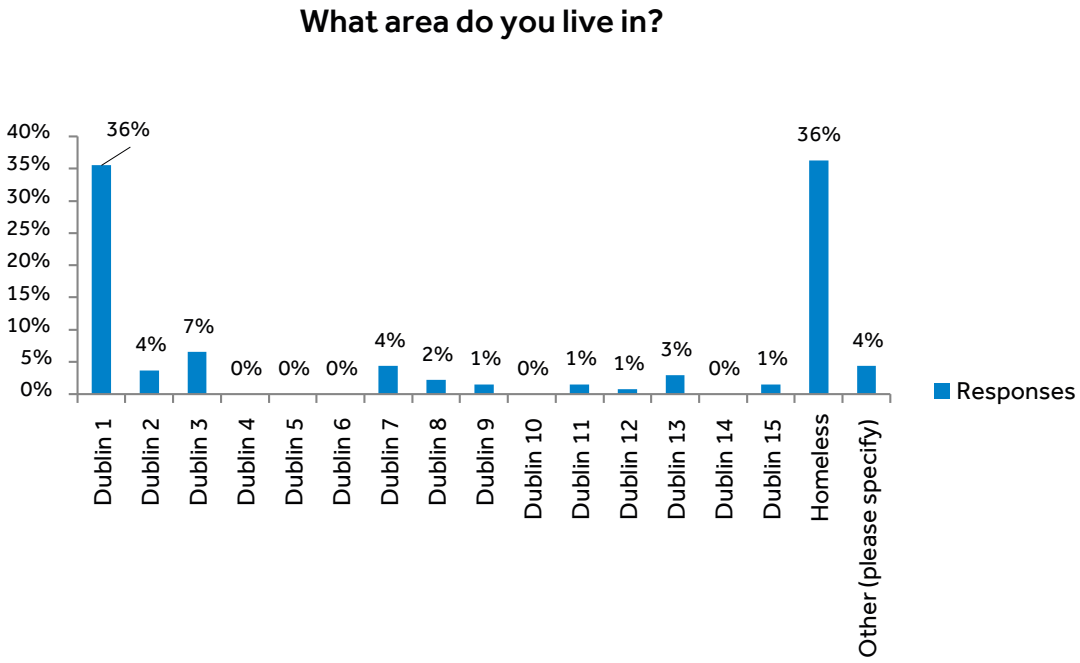
6 *https://www.hrb.ie/news/press-releases/single-press-release/article/health-research-board-reports-latest-drug-related-death*

SURVEY RESULTS

There were 138 surveys completed by peer led researchers in the north east inner-city area of Dublin which is slightly higher than the 121 surveyed in 2020 and 107 in 2017.

Profile of Respondents

Question 1: What area do you live in?

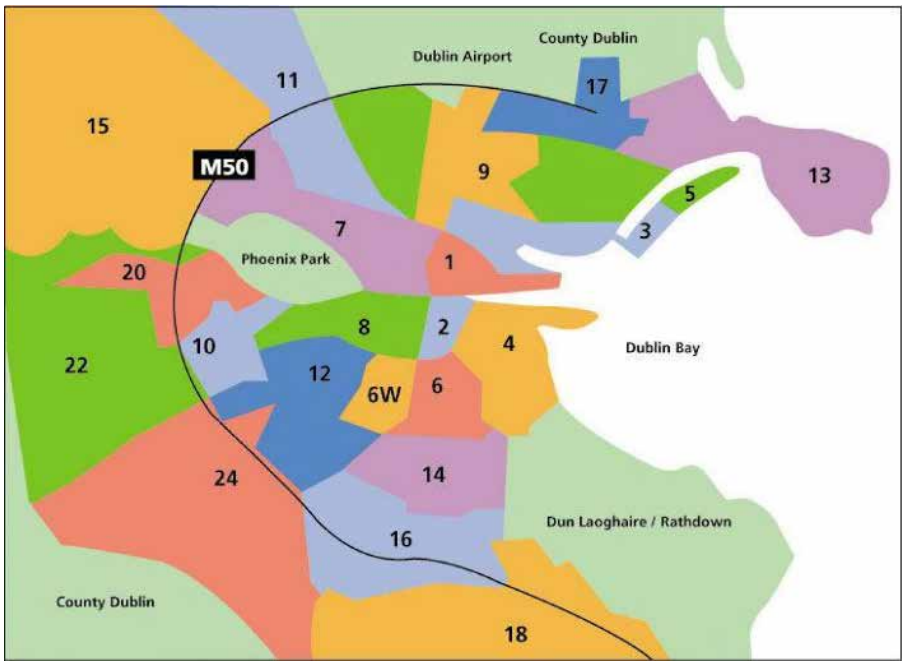


Answer Choices	Responses	
Dublin 1	35.50%	49
Dublin 2	3.62%	5
Dublin 3	6.52%	9
Dublin 4	0%	0
Dublin 5	0%	0
Dublin 6	0%	0
Dublin 7	4.35%	6
Dublin 8	2.17%	3
Dublin 9	1.45%	2
Dublin 10	0%	0
Dublin 11	1.45%	2
Dublin 12	0.72%	1

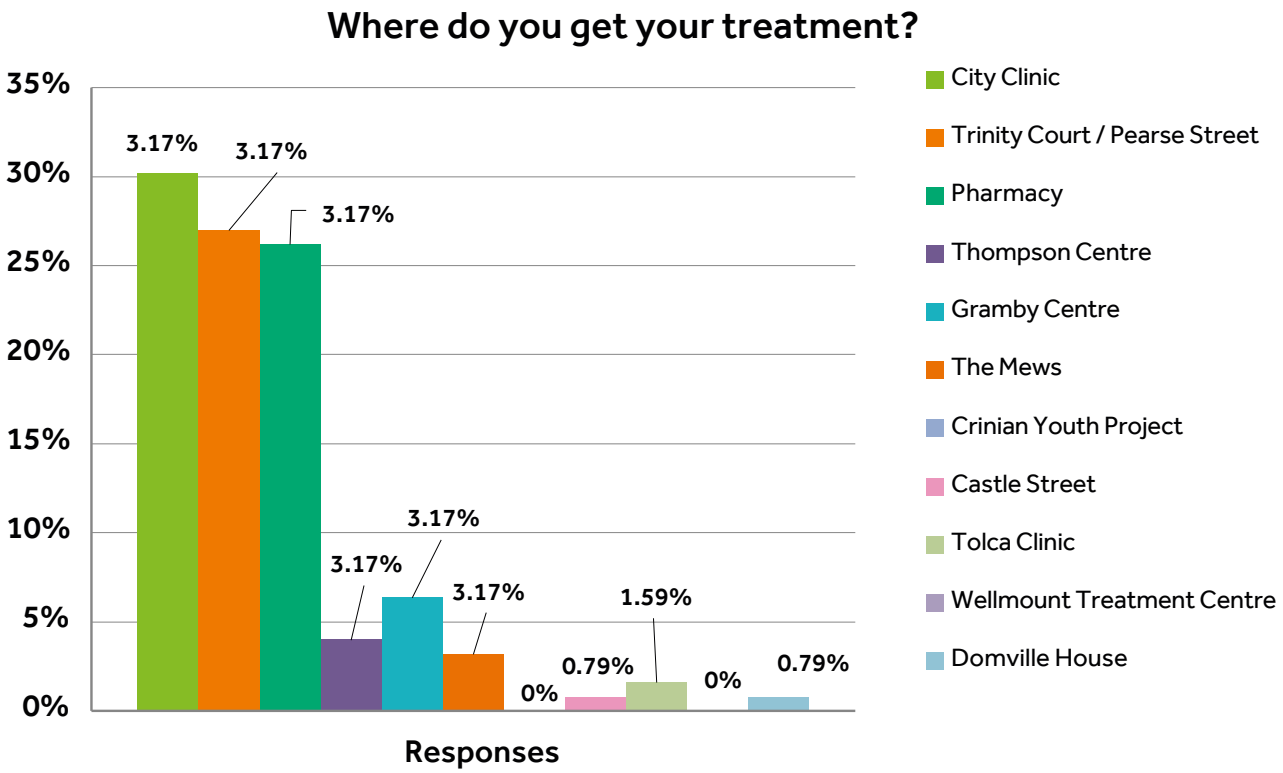
Dublin 13	2.90%	4
Dublin 14	0%	0
Dublin 15	1.45%	2
Homeless	36.23%	50
Other	4.35%	6
	Total	138

The research took place on the streets, in community-based addiction projects and in homeless accommodation in the north-east inner city which is reflected in the breakdown of the areas where people live with 42% living in the Dublin 1 and Dublin 3 areas. Many answered the question listing homeless accommodation in the Dublin 1 area which we have chosen to reflect as being homeless rather than residing in Dublin 1 because being homeless presents additional difficulties when in treatment. Consequentially 36% of respondents are classified as homeless, which creates an additional burden on service users as they have to navigate both the addiction and homeless services in Dublin.

It should also be noted that many service users come to the north-east inner city to avail of services based there.



Question 2: Where do you get your treatment?



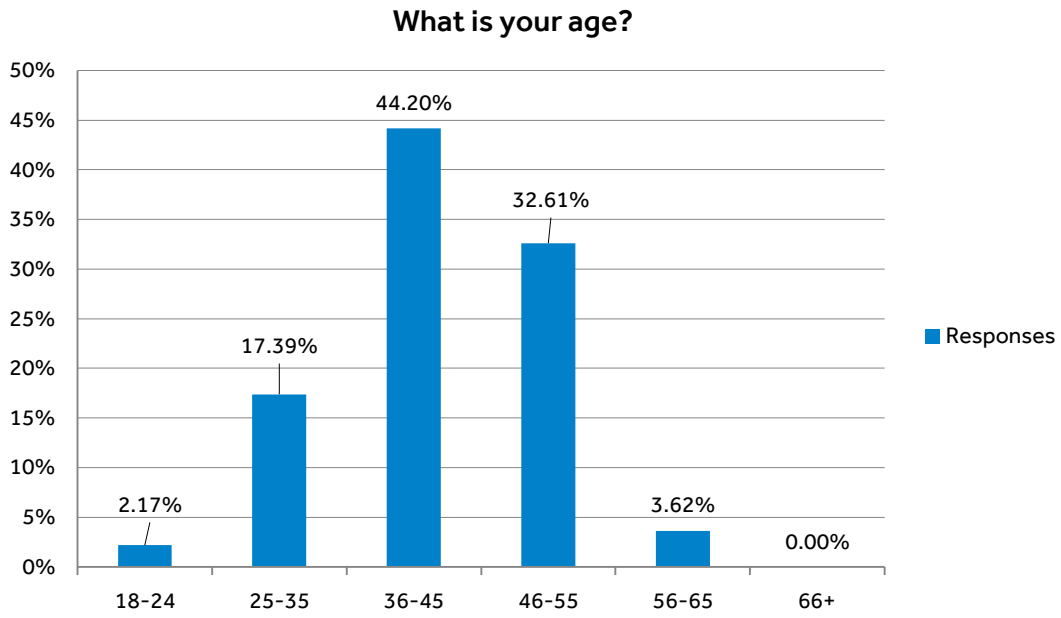
Answer Choices	Responses	
City Clinic	30.16%	38
Trinity Court/Pearse Street	26.98%	34
Pharmacy	26.19%	33
Thompson Centre	3.97%	5
Gramby Centre	6.35%	8
The Mews	3.17%	4
Crinian Youth Project	0%	0
Castle Street	0.79%	1
Tolca Clinic	1.59%	2
Wellmount Treatment Center	0%	0
Domville House	0.79%	1
	Answered	126

The three main places services for accessing treatment were the City Clinic[7], based on Amiens Street in Dublin 1; Trinity Court on Pearse Street in Dublin 4 and in pharmacies (the specific location of the pharmacy was not requested). The Gramby Centre and Thompson Centre were next in terms of numbers accessing services.

Several interviews took place in community-based addiction projects and service users may have come from other areas to access these services. For example, a number of interviews were carried out in the SAOL Project on Amiens Street which is the only 'women only' project in the city, therefore many of the women attending there would not live in the inner city and travel to access the specific services available in SAOL.

It should also be noted that the City Clinic and Trinity Court were the focus of the IHREC Equality Review (March 2019).

Question 3: What is your age?



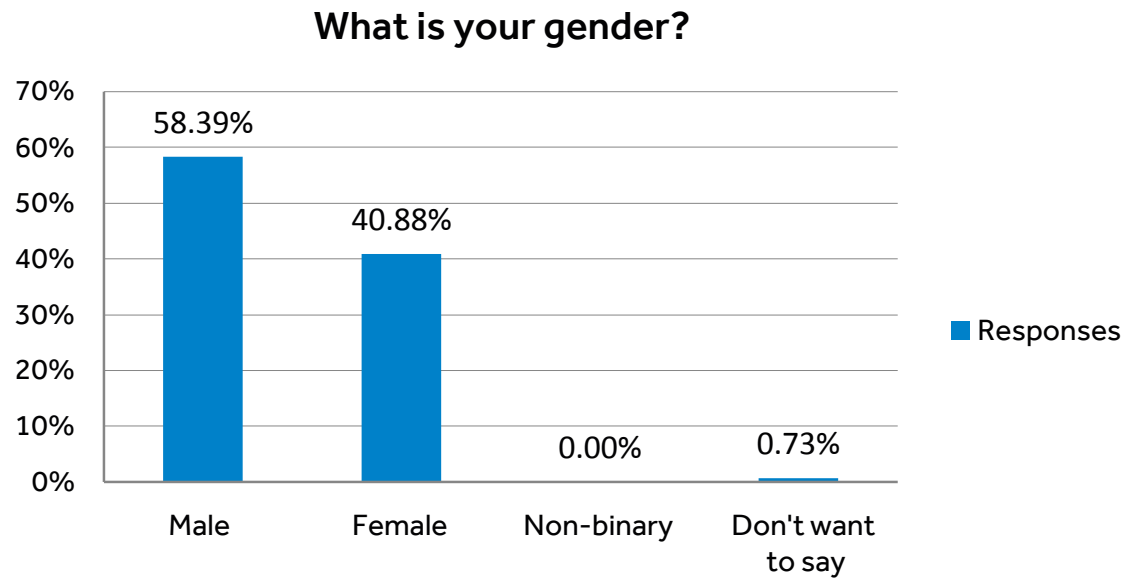
Answer Choices	Responses	
18-24	2.17%	3
25-35	17.39%	24
36-45	44.20%	61
46-55	32.61%	45
56-65	3.62%	5
66+	0%	0
	Answered	138

7 *The City Clinic is a HSE funded drug treatment centre located in Dublin North inner city. It was established in 1993 as a public health and harm reduction response to the heroin injecting and HIV epidemics that were devastating the community at that time. It was set up in the backdrop of local community activism directed at local drug dealers and anger at the lack of treatment facilities for those affected by opioid addiction and HIV and the numbers of young people dying of AIDS.*

Respondents were asked to identify their ages in the following categories, 18-24, 25-35, 36-45, 46-55, 55-65 and 66+. The numbers were highest in the 36-45 category at 44% and 46-55 category at 33%, meaning that 77% of all those who answered were between 36-55 years old. This age group could be described as the 'prime' years in a life and for these service users they have spent them in opioid substitution treatment.

The high numbers of long-term methadone use raise the question of care planning and assisting people to progress off methadone. Only 2% of respondents were from the 18-24 cohort with no respondents being from the 66+ category. Stigma also plays a role in terms of accessing services.

Question 4: What is your gender?

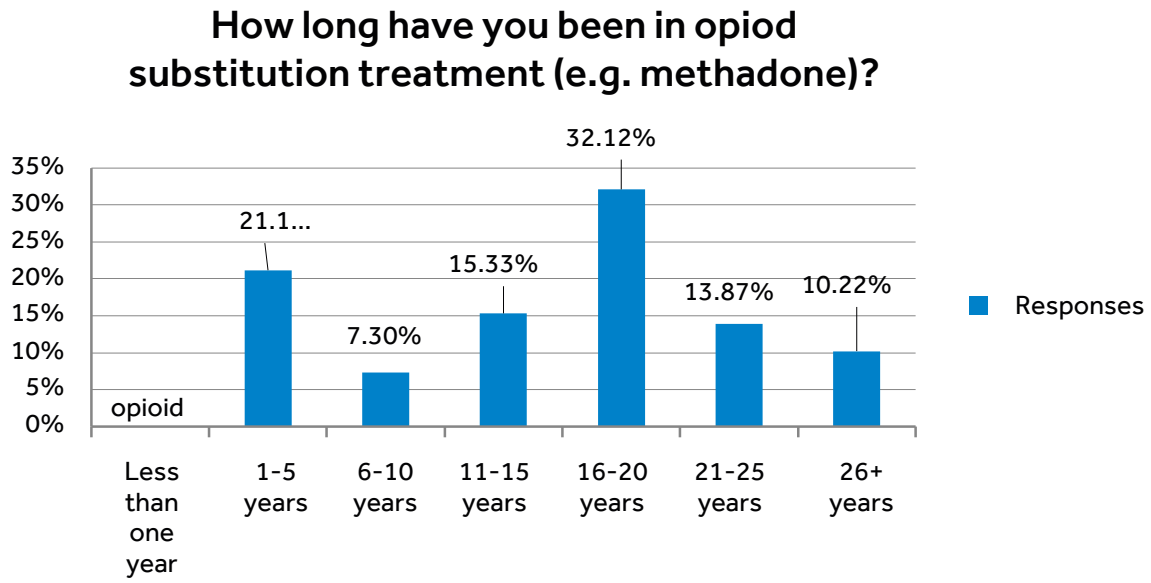


Answer Choices	Responses	
Male	58.39%	80
Female	40.88%	56
Non-binary	0%	0
Don't want to say	0.73%	1
	Answered	137

Of the 137 people who answered this question, 80 or 58% were male and 56 or 41% were female. The ratio of men to women can be understood by the fact that men tend to access services more than women due to the additional barriers women experience when accessing treatment e.g., stigma, motherhood etc.

One respondent preferred not to say.

Question 5: How long have you been in opioid substitution treatment e.g., methadone?

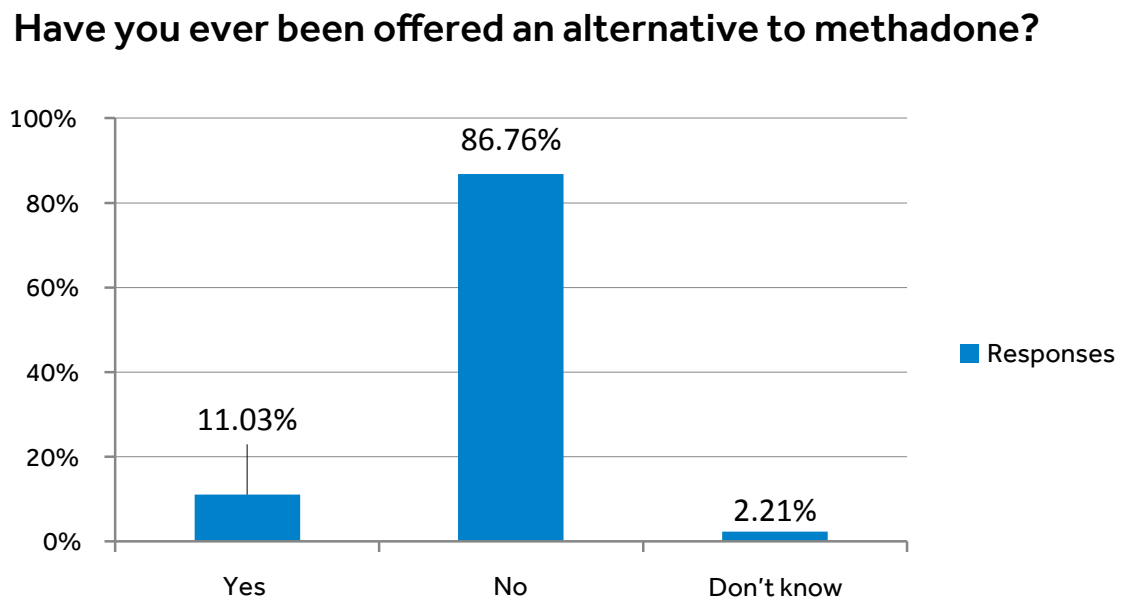


Of the 137 service users, 32% have been in treatment between 16-20 years, 14% for 21-24 years and 10% for over 26 years. Collectively 56% of service users have been on methadone from 16 to more than 26 years, a stark figure. 79% have been on methadone or an opioid substitution for more than 10 years of their lives.

This raises some serious questions about service users access to care plans, treatment choices and people centred care/ treatment options.

Answers	Responses	
Less than one year	0%	0
1-5 years	21.17%	29
6-10 years	7.30%	10
11.15 years	15.33%	21
16-20 years	32.12%	44
21-25 years	13.87%	19
26+ years	10.22%	14
	Answered	137

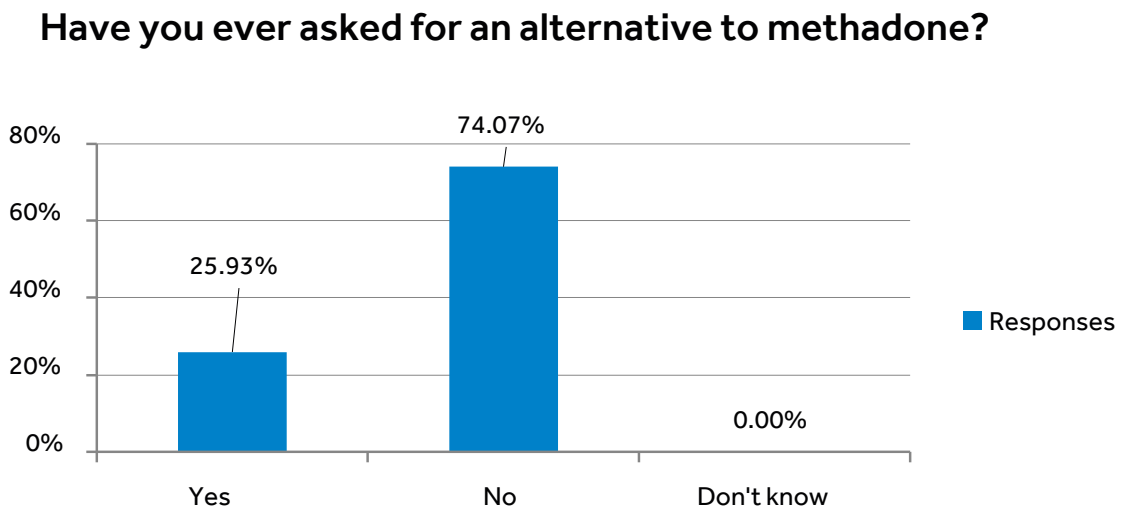
Question 6: Have you ever been offered an alternative to methadone?



Answers	Responses	
Yes	11.03	15
No	86.76%	118
Don't know	2.21%	3
		136

87% stated that they had never been offered an alternative to methadone, only 11% reported they had. When accessing medical interventions for illnesses, medication is frequently reviewed to make sure that it is addressing the needs of the patient and the illness. A type 2 diabetic and a service user on opioid treatment are often subject to stigma with a perception that the illness is self-inflicted or related to trauma but why is one group stigmatised more than the other? A type 2 diabetic would not be left on the same medication without review or alternates if it wasn't helping.

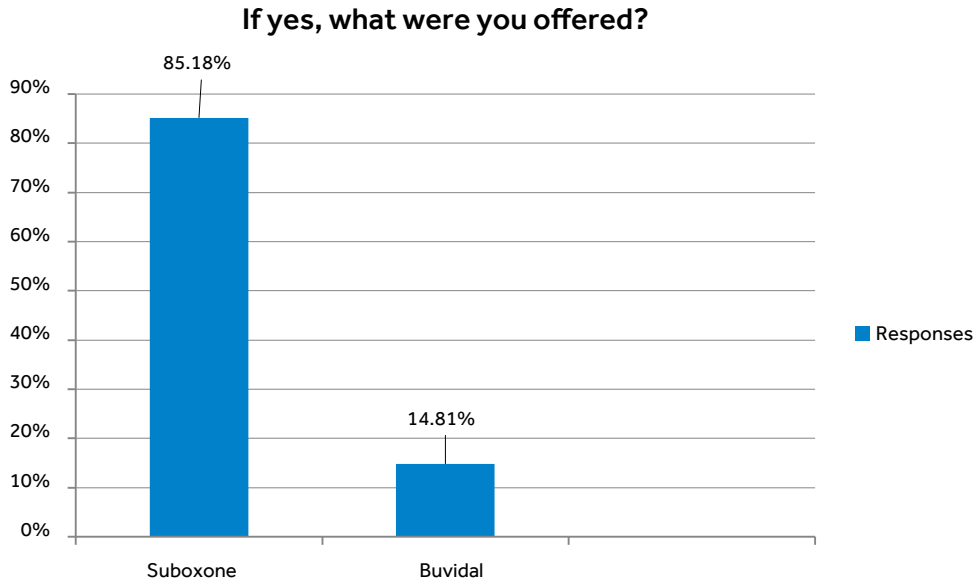
Question 7: Have you ever asked for an alternative to methadone?



Answers	Responses	
Yes	25.93%	35
No	74.07%	100
Don't know	0%	0
		135

74% of those interviewed stated that they had never asked for an alternative to methadone and 26% had asked for an alternative.

Question 8: If yes, what were you offered?



Answers	Responses	
Suboxone[8]	85.18%	23
Buvidal[9]	14.81%	4
Other	0%	0
		27

85% of respondents were offered Suboxone and 15% were offered Buvidal with no reports of any other alternatives. The comments below detailed respondents' experiences when seeking an alternative treatment, for many they were told that had to stay on methadone as they were not ready to detox from methadone, for some they did not know they had a choice or that they could ask for an alternative to methadone. People were asking for an alternative to methadone, but their requests were not being listened to and their voice in their treatment choice was not being heard.

8 *While Suboxone is similar to methadone, Suboxone does not contain methadone and is a distinct drug. Suboxone contains the active ingredients buprenorphine, a partial opioid agonist that helps fight the symptoms of withdrawal, and naloxone, a drug used to reverse opioid overdoses.*

9 *Buvidal contains the active substance buprenorphine and is a 'hybrid medicine'. This means that it is like a 'reference medicine' containing the same active substance, but Buvidal is given in a different way. Buvidal is given as an injection under the skin, either once a week or once a month.*

Buvidal

I am waiting to go on Buvidal but it is only a couple of clinics that do it. I hate having to go to a clinic but at least it will be just once a month.

I am on suboxone but want the needle one (Buvidal) but have to wait to see if I can get it.

Suboxone

I asked for suboxone but was told that I wasn't suitable for it because I sometimes have a slip on heroin.

Going to try and get back on it, ended up in prison and they gave me phy in there.

Brown physeptone but then switched to methadone when the clinic start using it.

I asked for Suboxone but I was told I wouldn't be able to handle being off methadone till they gave me Suboxone.

I asked for Suboxone. They don't want me to come down to 30mls.

I was offered it (Suboxone) in Pearse Street. I asked for it as I had been on it when I lived in Northern Ireland.

I asked for Suboxone, Doctor was willing, but I got sent to prison.

Remain on Methadone

I had heard about others, but I am too long on this to try anything else.

At the start but I chose methadone.

I asked and got refused.

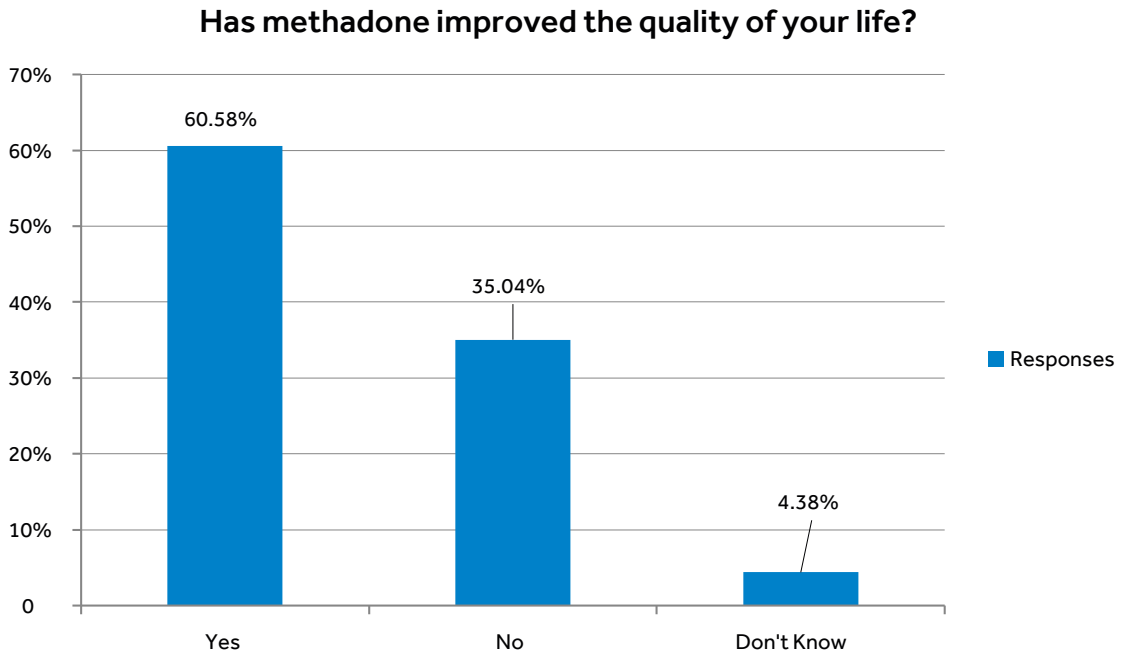
No, can't put you on anything other than methadone.

They always say you're not ready.

I asked but was dismissed, then told I am not ready.

All they keep saying is that I am not ready. Just go up on phy.

Question 9: Has methadone improved the quality of your life?



61% felt that methadone had improved the quality of their life and 35% said that it did not. There were a range of responses when asked to further explain their answer but there was a clustering of responses in relation to the following issues:

While 61% said that methadone had improved the quality of their life which would appear to demonstrate positive support for the treatment programme, the quotes below present a different picture of life on methadone as one focused on control, internalised powerlessness and stigma and a low expectation of it ever getting any better.

Control

Going to clinic every day, it's control.

They have left me on Trinity Court drug treatment centre and when I asked to be moved, I was told No, and it's always been a no since.

The thing is I can't make plans cos I have to collect it and I feel trapped.

It's like I am chained to my clinic, I can't just go on a holiday because if I have had a slip, I can't get takeaways.

I can't get a job because I have to go to the clinic every day except Christmas and when it is closed.

It has stopped me from getting work cos I could never get full weeks takeaways.

Liquid Handcuffs.

I feel it traps me to the clinic, my kids all know the clinic and they shouldn't.

It was like a set of handcuffs, trapping me day to day, it put a block on me and my kids.

Helps me function but it also does stop me going on holidays and take aways are not always offered.

It's hard being in the chemist every day.

Going to clinic every day, it's control.

Temporary positive experience

Did for a short while. At the moment I'm fine but I just tired of methadone.

Just a little bit, found it quite difficult to get off this.

Only for a few weeks, I am detoxing myself now.

I have always smoked crack or drank being on methadone.

I still use on top of my phy, find it difficult to just not use.

Lost my teeth, they just want to keep putting it up.

Replacing one drug with another

I still use other drugs, can't cope without drugs.

It stopped me taking street drugs, but it is still a drug.

It helps me stay away from street drugs, but I rather not be on this.

It now feels like I'm addicted to methadone and most days it feels like I will never be free.

It stopped me using heroin but it just substitute, one addiction for another and has contributed to the decaying of my teeth.

If I didn't take drugs with it, I could function.

Helps me stay clean but I want to be off it.

It's just another habit and I sometimes use drugs on top.

When I'm not using on top yeah but when I do have a smoke, I wonder what's the point.

It hasn't changed it, just swapped one addiction for another.

It did in the short term but would like to get off it.

It's just one drug for another.

It's like I am a prisoner to liquid handcuffs.

If I understood in beginning, I took detox not long term methadone.

Rotting my bones- won't let me come down.

It helps me to not go into bad sickness but if I stopped topping up with drugs it might get better.

It just gave me another addiction on top of heroin.

I still use heroin sometimes but not every day.

Yes and No, in the beginning, now it's an addiction so I can't do without it.

When I started years ago, now I see it as I have to take it, can't do without it.

In the beginning, now I need it to function.

For many years, I got 5 years clean but I detoxing myself down 20, at clinic they give me 30.

From taking drugs it helped me, but I am addicted to this methadone.

It stopped me using heroin but it just substitute one addiction for another and has contributed to the decaying of my teeth.

Stigma

I am able to go to my family home, when I was using, they didn't want me there.

Having to go to the clinic, people watching you, I hate it.

I feel my family think I am still a drug addict because I am on methadone.

Some level of stability

It helps keep me stable and don't use as much.

Yeah, it helped me as I relapsed after years of being in recovery.

It has good points like I don't wake up as sick as when I was using but then the bad points.

Stops me from waking up feeling like I'm freezing and gonna vomit.

Helped me with my addiction though it makes me lazy.

It's helped me with heroin withdrawal.

It got me off drugs and it help keep me stable.

That I was able to give up drugs for a long period.

Yeah, it helped me as I relapsed after years of been in recovery.

I'm not using as much as I was, I'm not robbing, and I was able to look after my mother with dementia. I'm not sick daily.

Not so much methadone but Buvidal has given me freedom to live as I don't have to be tied to the clinic.

Just take the sickness from the body, makes me feel normal.

It helps keep me stable and don't use as much.

Deterrent from street drugs and associated behaviours

I can have a better life with treatment than I had when I was using.

It's stopped me taking drugs.

Takes pressure off, don't have to steal anymore.

It saved my life to be honest and I don't have to risk my freedom for a fix.

Stopped me using heroin and other drugs.

That I was able to give up drugs for a long period.

I'm able to attend my course, before I was on molly I had to go out shoplifting every morning to get money to get gear.

Stopped me using heroin.

It's helped me cut down on taking gear.

Not sick, I can get up and do things, not go and get gear.

Get up and out rather than have to score looking for drugs.

I didn't have to rob for addiction and I was a functioning addict and mother.

It's kept me straight and away from other drugs.

Saved my life to be honest and I don't have to risk my freedom for a fix.

Stops me feeling sick and I don't have to rob to feed my habit.

Wasn't waking up as sick as I did with gear.

Liquid handcuffs - don't have to be out stealing anymore.

Being able to have no sickness and being able to have money on pay day.

Don't have to rob anymore so it's helped.

It kept me away from drugs, no charges now so I am doing well.

Less using, harm reduction. Don't smoke as much since the methadone.

It helps me not want street drugs, but I still crave drugs.

Helped to improve other areas of their lives

It helped me get up and I went on a course in Henrietta Street.

Able to mind my children and play, gave me a better life.

I was able to keep my appointments and it helps me have a healthy relationship with my son

Able to keep going in life and see my kids and not use street drugs

Positive Experience

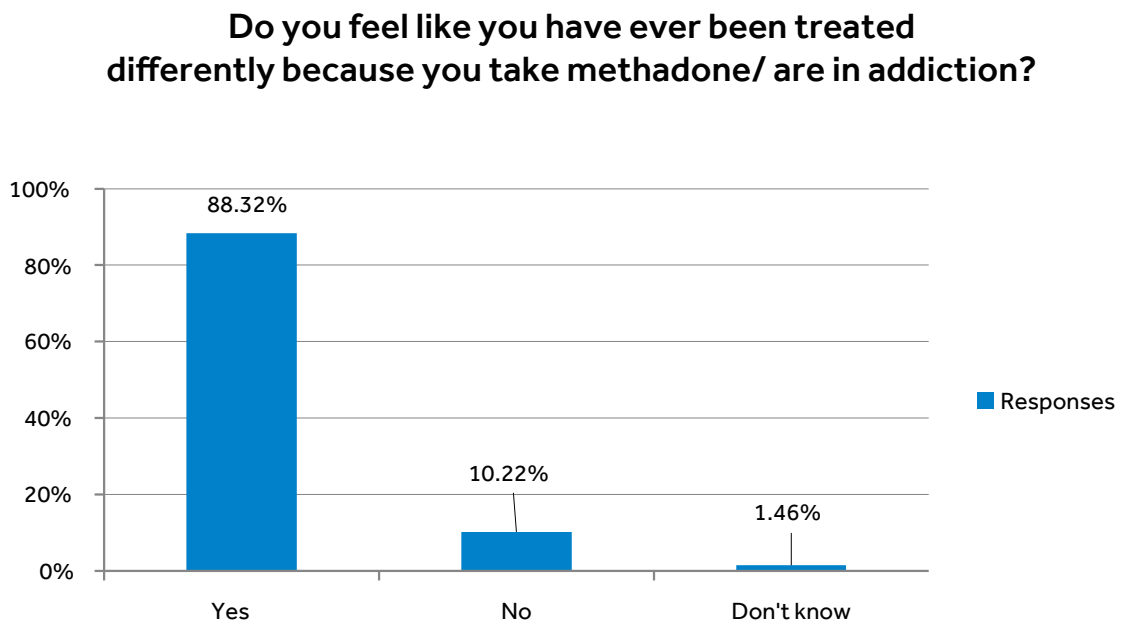
I haven't took any heroin in 9 years.

It helped me focus and get stability.

100% feel like I got my life back, it's been a life saver.

It saved my life to be honest and I don't have to risk my freedom for a fix.

Question 10: Do you feel like you have ever been treated differently because you take methadone/are in addiction?



Answers	Responses	
Yes	88.32%	121
No	10.22%	14
Don't know	1.46%	2
		137

88% reported that they had been treated differently because they had taken methadone or were in addiction. Research carried out by Citywide[10] demonstrates that drug related stigma can make it extremely difficult for people to move beyond their addiction and prevents people from seeking support. The stigma experienced by people dependent on drugs can prevent them seeking help and support. It can push them into isolation.

The answers given here centred on the feelings and experience that society was looking down on them particularly in shops, hospitals, doctors, dentists and their families and the impact that it had on them.

Like they judge you, shops etc.

People putting labels on me.

Shops, feel people look down on you

Feel I am not trusted, family, shops etc.

10 *https://stopthestigma.ie/why-stigma-matters/*

Even when I get clean I was still the junkie at the shops etc.

People look at you also its a drug.

By the doctor and the dentist.

GP won't take on a person on methadone as a patient.

In the dentist, they always look down on you.

In chemist, I'm treated differently, I have to go into a room to take my methadone.

The moment people know they become undermining and dismissive of my views.

In hospital, when they hear you're on methadone, they treat you worse.

In hospital, I felt like I had to beg for my methadone.

I attended the hospital for a hand injury and as soon as the physio seen I was on methadone, her attitude changed completely.

I feel that people look down on you and look for a way to get away from you.

Ranked an addict and feel like you're looked down on.

If you're at the hospital, you are rushed in and out.

Jobs, guilty of life, people look down on you.

People look down at you, doctor does not believe you.

People think they have the right to treat me like shit just because I am an addict. They think they're better than us.

I've been followed around shops just because I look like an addict, I've never robbed a thing in my life, my family always gave me money and my fella sold for our habits.

Shamed and judged by everyone.

The nurses and security guards in hospital and in the shops follow you around as if you can't be trusted. it's horrible and embarrassing.

In NA, I got told I wasn't drug free cos I was on a clinic.

Even by my family I am judged and looked at like dirt.

All the time, if I go to hospital for anything, they treat you like something beneath them, even in town, I get followed everywhere, that wouldn't happen if I wasn't in addiction.

The dirty looks and smart comments from some people really hurt, I didn't choose to be this way and I try not to let it get to me but I am human.

As addicts we are always facing stigma.

Feel even the stand in doctor I see looks down on me.

People talk about you, classified as a junkie.

I was ignored when I wanted to get clean. I was told whether I was fit to get drug free.

Sometimes feel other people on the street are looking down on me.

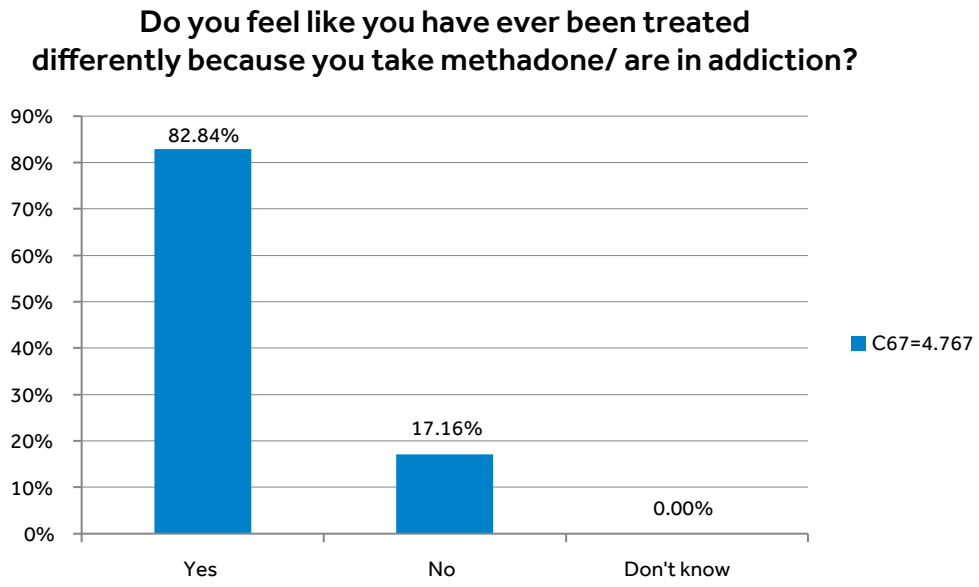
People treat me differently by not associating with me.

Question 11: Overall, how you would describe the experience of being on methadone on a scale of 1 to 5

Answers	Responses	
0	1.51%	2
1	9.09%	12
2	21.96%	29
3	50%	66
4	11.36%	15
5	6.06%	8
		132

When asked to describe the experience of being on methadone on a scale of 1- 5 (one being the worst and 5 being the best), the average response was 3 at 50% but 17% responded at 4 and 5. As is evident from many of the comments throughout this report, methadone has a role in keeping people stable and allowing them to feel stable.

Question 12 Have other treatments been offered to you?



Answers	Responses	
Yes	82.84%	111
No	17.16%	23
Don't know	0%	0
		134

Of the 134 respondents who were asked had other treatments been offered to them, 111 (83%) answered yes and 17% answered no.

The following shows a breakdown of which services were offered; respondents could tick multiple services.

Answers	Responses	
Counselling	74%	83
Hepatitis C Treatment	60%	67
Rehabilitation	45.9%	51
Support Programmes	42.43%	47
Other	7.2%	8

Respondents were asked when was the service offered and what was your experience? The responses below show responses to each service and are divided by experience of the service offered. Each service is significant in terms of addressing addiction and there are mixed responses to their experiences and if and when they were offered the service.

Counselling		
Satisfactory	Unsatisfactory	Neutral
Couple of months ago and it did help.	Years, decades. Done counselling for years but left open after.	A few years ago.
Good when I done it.	Didn't click with the two counsellors I was offered.	2023 - haven't done it yet
Done the counselling it worked well for a while.	Years ago, found I couldn't talk as the doors are too thin and I can hear others when waiting.	I was offered counselling in clinic, but I didn't take it.
Helpful at time, would like to go back to it.	2001 - wasn't great, it took years to get the right one.	I got it in recovery years ago.
Good I go to the Snug.	3 years ago, I tried but don't like talking about things.	All the time, it depends on the counsellor.
I asked myself - good experience.	Left you leave feeling shit.	It was okay, I rather speak to women.

I do see someone once a month, lots of deaths.	Years ago, didn't like it, they just sit and want to hear all the gory details of your life and then.	Got offered counselling but never followed it up.
I'm doing counselling now and it helps keep the head clear.	Over the past 15 years, I worry because my counsellor changes so much.	After finding a young man dead.
I done counselling loads of times but most recent was last year, it helps clear my head and talk about the reason I am addicted.	Only went twice, it was not a comfortable place.	Starting to do it in the next few days.
2019, I got counselling, and it worked well because she listened and understood me.	Yes but I didn't click with the counselling.	Offered but didn't take it.
When I started on clinic about 6 years ago, it was ok.	I had a bad experience where my file was left out and my neighbour was able to ask how my treatment is going.	Waiting on counselling.
I asked but then started 5 years ago, I was lucky I got a good counsellor	Did it about 2 years ago and this year. my first one was good, this one talks to me like I'm stupid.	In Mother and Baby Unit
About 6 years ago, helped me deal with stuff that happened to me.	The year before. I just never get a counsellor I get on with.	Just a bit but can't stop using to be honest.
Good when I done it.	Didn't listen, insisted put blame on my parents, felt patronised.	It was offered before but I never went.
When I was on a clinic a counsellor that worked with others asked me to do it. the experience wasn't very good but the course I am on now, the counsellor is very good.	Only went twice, it was not a comfortable place.	It was a few years ago and I can't remember the experience.
	Yes, but I didn't click with the counselling. Done it, it worked when it worked.	All the time and the experience depends on the counsellor it worked for a while.

Hepatitis C Treatment

Hep C treatment has changed in recent years, earlier treatment protocols were very invasive with some patients experiencing hair loss and pain. Treatment for Hep C used to involve injections and taking tablets for up to a year, but it is now treated using direct-acting anti-viral tablets which are effective at clearing the infection for more than 95% of people[11]. In the NEIC, both the SAOL Project and UISCE are part of the Hepatitis C Partnership and both have been proactive in raising awareness of the disease and the treatment. The difference it can make in having services available to those on MMT can be seen in the comments below.

5 years ago, I could not finish it as I was homeless, and it was hard.

I did this twice, first was with the longer treatment, I was too sick and couldn't finish it but second time it was much easier and now I don't have Hep C.

4 years ago, so far I am Hep C clean.

Just got cleared 2 years ago, made me sick during treatment though.

I did the old treatment, it was hard, I got every side effect possible, but I finished it, I was clean at the time so that helped but I have slipped since but I'm not using (injecting), just smoking.
3 years ago, very hard, got every symptom but was worth it in the end.

2 years ago, it was hard but worth it.

I did it years ago and it was horrible, it was before the new treatment, I can't remember the year.

3 years ago, I cleared Hep C so am delighted, I feel much better about myself and my health.

I'm talking to my doctor about it now, was supposed to do it before but I was scared, now I know people who say it's not as bad as the old treatment so am willing to try.

Rehabilitation		
Satisfactory	Unsatisfactory	Neutral
2019 and it worked great for me.	Done, it didn't work.	Not offered but I am on the list cos I asked, I feel it's the right time but hope I'm not left waiting.
	I referred myself- could of been better but got clean for 4 months.	Went into treatment 4 years ago, I was clean for 1 and a half years but then slipped again.
	2020- It was focused on God, not on rehabilitation.	I was on the list for treatment but when my place came up, I wasn't ready to go so lost my place, I will try again.
	This year, still waiting.	Went to treatment but paid myself and sought it out.

11 *https://www2.hse.ie/conditions/hepatitisc/treatment/#:~:text=Treatment%20for%20hepatitis%20C%20used,more%20than%2095%25%20of%20people.*

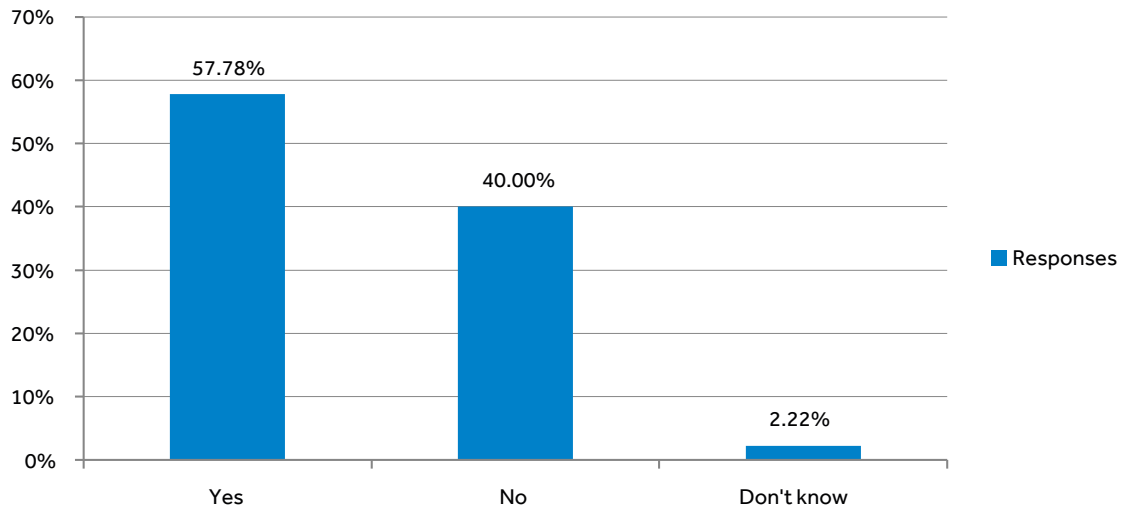
	I wasn't offered, I had to ask. I was held over a barrel, I had to wait till they said I was ready.	It was offered but I didn't take it cos my kids were still young.
	Not really, when I asked to detox, they say I am not ready.	5 years ago I tried treatment but I found it worked better when I tried it in the community with supports
	Was in Barrymore, that was okay but cos I was a day late for Lantern they refused me.	
	6 months ago - too many drugs in there	
	2 years ago, more inside than out.	
	2 years ago. I worked hard but I came out to homelessness, so I slipped.	
	15 years ago but it only lasted 6 weeks.	

People accessing services and living in the NEIC have access to additional beds in Barrymore on a rolling 6 week basis. This plays a significant role in having treatment beds accessible, but the results outlined above are far from satisfactory.

Support Programmes *** For the most part, the support programmes are provided by community-based addiction services.**		
Satisfactory	Unsatisfactory	Neutral
I attend a support service which is good for me.	Over the last 4 years, still waiting on a detox bed.	Done a 12 step programme
In my course I get great support and that's how I have decided its time.		I went to a support service for a while and it helped me meet new friends but then when I slipped back I stopped going.
I started my course and the support I get is great.		Day programme when I was drug free
202- Anna Liffey very good		I went to the Spellman Centre myself
UISCE and Snug Women's Group		
I wasn't offered, I found them myself. Soilse - and that's where I got educated and I got hope and learned I could get clean and meetings.		
20 years ago - SAOL project helped me get my life back		
Now - DAVINA has helped me work on myself, has been a great support. This helped me more than anything		
With SAOL, I get good support and my personal development has grown.		

Anna Liffey from meeting them on the streets	
Saol for the past 3 years, I've learned a lot and have great support. I got QQI level 3 and many other certs, became a peer worker so loads of personal growth.	
I started SAOL and worked on myself and love peer work.	
Anna Liffey and Coolmine. great places at times once you're willing to make the right changes	
This course I am on they have been excellent.	

Have you discussed detoxification or ongoing methadone maintenance treatment with your treatment team?



Answers	Responses	
Access	11.90%	5
Childcare	21.43%	9
Confidentiality Concerns	21.43	9
Other	83.33%	35
		42

83% stated that there were barriers, some of which are detailed below. The difficulty of remaining drug free or entering recovery is more difficult when staying in homeless hostels or on the streets. The relationship between homelessness and problem drug use is complex. Problem drug use can put people at an increased risk of homelessness and can also be caused and exacerbated by traumatic experiences, including homelessness.

Women also experience additional barriers when accessing treatment through both their own trauma and their roles as mothers. Mothers are expected to make huge leaps in recovery in order to get their children out of care and or a spotlight placed on those with their children, all feeding into the assumption that because they are on an opioid treatment programme they are not capable of looking after their children.

21% cited childcare as a barrier to accessing treatment but it should be noted that a portion of the women interviewed in the SAOL Project have access to childcare so this number could have been higher.

Other please describe:

Homelessness stressed me out as I did not know where I was going to stay and many times I was rough sleeping.

Homeless, can't access services.

I don't trust a lot of professional people.

I wanted to go into treatment before when I had my kids, but I had no one to mind them.

Very close to my brother and I need to support him as he was a stabbing victim.

People may want to change your recovery plan if it doesn't suit them.

I was in jail, doing the HEP C treatment in prison.

In hatch you can hear everything, barriers there cos I'm left feeling open after drugs outside.

When I was on daily's it was hard to fully engage in services.

Some men have made unwanted advances.

My life is under threat so have to be careful.

I felt like there was revolving doors through prison etc.

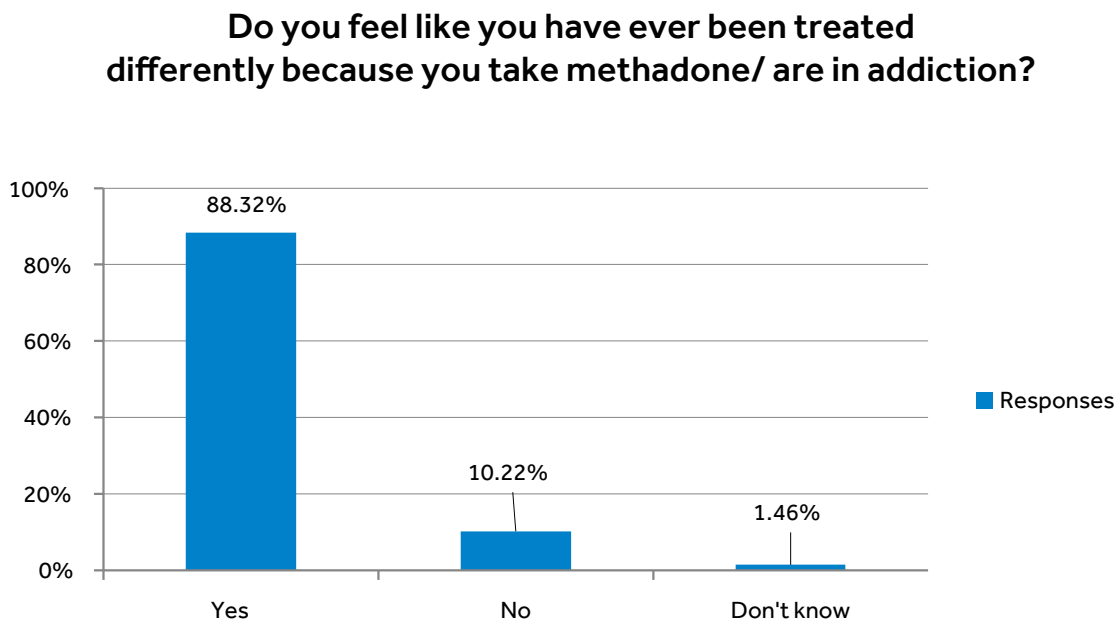
Helping to raise my sister's children.

Ain't no way I could do treatment, my son depends on me.

My doctor told me he get me treatments but he never there, all different doctors.

I have a dog, if I need treatment, who minds the dog?

Question 19: Have you discussed detoxification or ongoing methadone maintenance treatment with your treatment team?



Answers	Responses	
Yes	57.78%	78
No	40%	54
Don't know	2.22%	3
		135

58% stated that they had discussed detoxification or ongoing methadone maintenance treatment with their treatment team, 40% stated they had not discussed either option with their team and 2% said they did not know.

Question 20: If yes, with who?

Answers	Responses	
Doctor	77.7%	63
Nurse	2.46%	2
Me/myself	3.7%	3
Friends/ Family	1.2%	1
Key Worker	8.64%	7
Nurses	2.46%	2
Prison	1.2%	1
Don't want to Come off it	2.46%	2
		81

Doctors (78%) were the most common member of the treatment team with whom they discussed detoxification or ongoing methadone maintenance followed by key workers at 8.64%. The next highest figure was 4% who had discussed their options with themselves only. It is worth reflecting on the comparison with other medical treatments, could we imagine 4% of cancer patients only discussing treatment options with themselves or with non-medical professionals such as key workers?

Questions 21: When?

Answers	Responses	
Last few days	5.4%	4
Last week	2.7%	2
3 weeks ago	9.45%	7
1 month ago	13.51%	10
2 months ago	10.8%	8
3-6 months	18.9%	14
7-12 months	0%	0
1 year	18.9%	14
2 years	1.35%	1
3 years	4.05%	3
4 years	0%	0
5 years +	4.05%	3
All the time	9.45%	7
On and off	1.35%	1
		74

Answers ranged from a few days (5.4%) to 5 years or more to all the time (9.45%) and everywhere in between. The most common answers were 3-6 months (18.9%) or over 1 year (13.51%).

4% of respondents hadn't discussed treatment options in over 5 years. 4% hadn't discussed options over 3 years, 1.35% over 2 years and 18.9% in over year. Therefore 28% had not discussed treatment options in more than a year. Again, a comparison to other medical treatments should be considered, would asthmatics or diabetics be made to go more than 1 year with no review of their medication?
It is worth noting that patients receiving Buividal treatments are subject to a physical and mental health questionnaire on an ongoing basis when receiving their treatment, there is no equivalent for methadone.

Question 22: Who initiated the subject?

Answers	Responses	
Me	61.25%	49
Doctor	13.75%	11
Both (doctor and me)	17.5%	14
Key worker	6.25%	5
No one	1.25%	1
		80

In 61% of service users, it was they who initiated the subject, 14% was by the doctors, 18% was a combination and 6.25% was with a key worker.

No one, they don't ask.

I was doing well at the time so the doctor and me start talking about it.

Both of us because my using at this time.

It's so hard to get into detox.

They did because I overdosed.

Question 23: How often has detoxification been discussed?

Answers	Responses	
Regularly	23.4%	15
Every couple of months	4.7%	3
Rarely	18.7%	12
Sometimes	10.9%	7
Never	25%	16
Once	9.4%	6
Twice in the last few years	4.6%	3
Only when I ask	3.1%	2
		64

25% of respondents have never discussed detoxification with their treatment team; 18.7% have discussed it rarely, 9.4% have discussed it once and 4.6% have discussed it twice meaning that 58% of respondents have rarely if ever discussed detoxification.

When asked to elaborate further, service users highlight a number of issues:

Increasing methadone rather than offering treatment

Deemed not ready/ refusal to offer detox

Lack of engagement

Change in doctors

Increasing Methadone

Twice in the last few years, they put you up quicker.

Never, I want to come down, they put me up.

They want to put me up, so I don't go near them.

Unless I bring it up, they never want to bring it down, just put me up.

My doctor put up, not down.

Just get my script and go. He very freaky about touch or looking at me if I show him even a sore on my body every few weeks, been asked do I want to go up on methadone.

I wanted detox, he wants to put me up so I am detoxing myself.

Deemed not ready/ refusal to offer detox

When I brought it up and now there's a bed for me in Garrettstown RCD but Doctor won't sign me off and support me cause he thinks I'm not ready. One sided (his view).

They won't detox me.

Lack of engagement

They don't engage with you.

Does not be offered, I am in and out.

They don't help at the clinic.

Never, you're only a number.

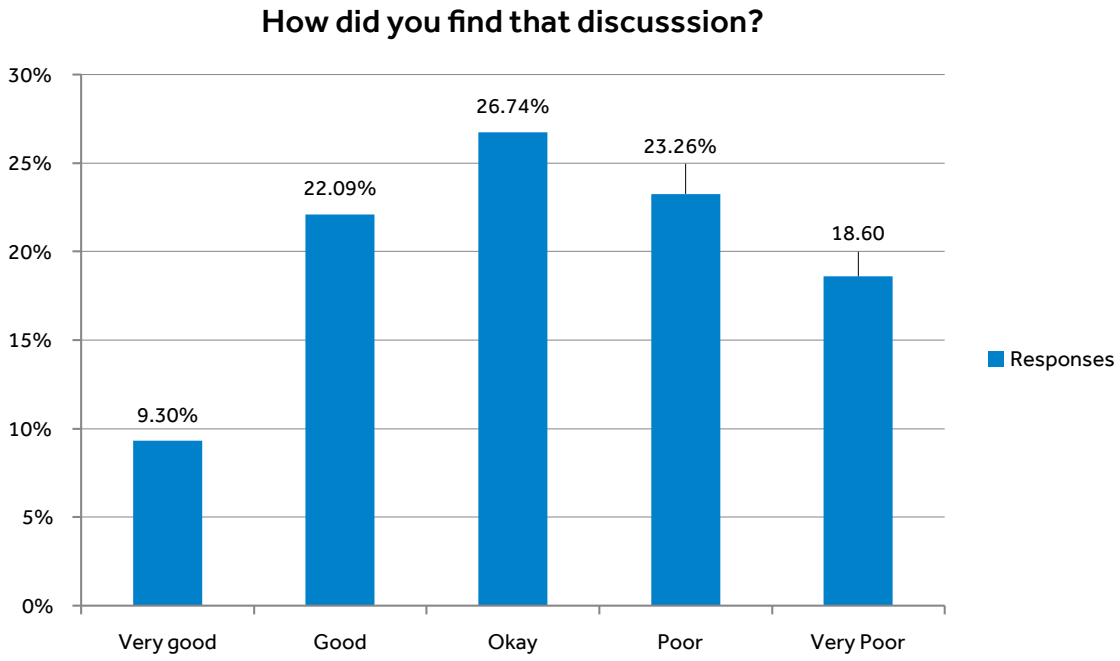
Changes in Doctors

Doctors change a lot.

I have not seen my doctor in years, they change doctors every few months.

Never, I asked him all the time, but I see different doctors.

Question 24: How did you find that discussion?

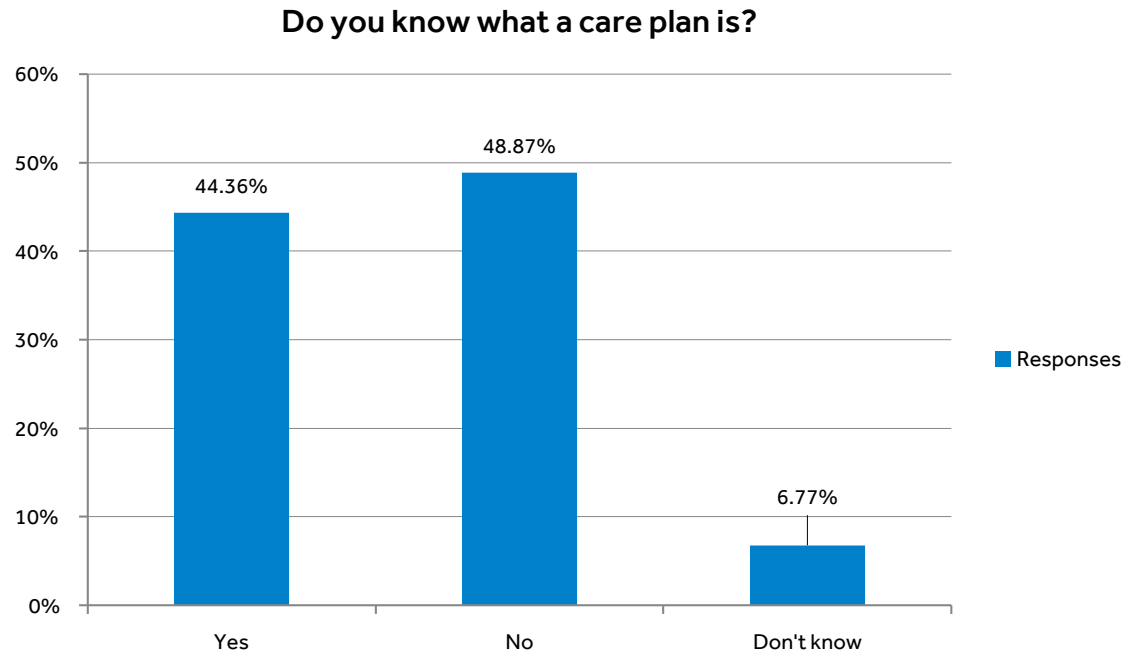


Answers	Responses	
Very Good	9.3%	8
Good	22.0%	19
Okay	26.7%	23
Poor	23.2%	20
Very Poor	18.6%	16
		86

For those who had the opportunity to discuss detoxification or ongoing methadone maintenance treatment with their treatment team a combined 42% found it poor (23.26%) or very poor (18.6%) while 31% found it very good (9.3%) or good (22%).

Question 22 showed that 61% of service users initiated the conversation themselves so again it raises the issue of the experience of service users and how steps to be pro-active about their health and treatment options are described by 42% as poor or very poor.

Question 25: Do you know what a care plan is?

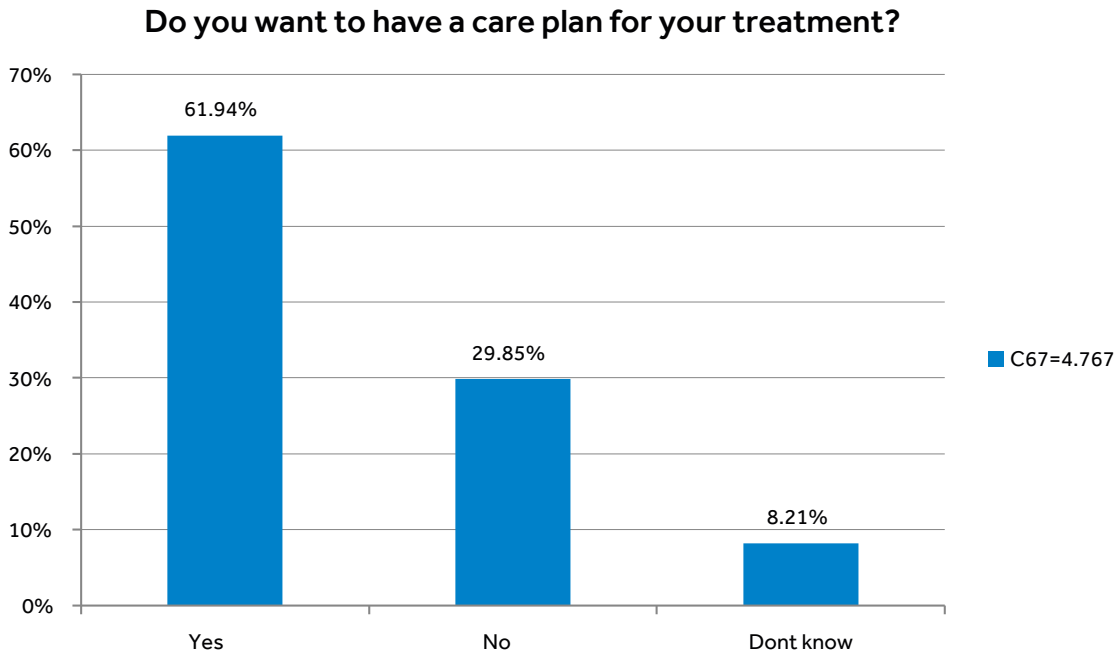


Answers	Responses	
Yes	44.36%	59
No	48.87%	65
Don't know	6.77%	9
		133

49% did not know what a care plan was despite care plans being a component of methadone treatment. 44% stated that they did and 7% said they did not know.

For those that did not know, the researchers would explain what a care plan was and for those who stated that they did, clarification was given to ensure that the term was understood.

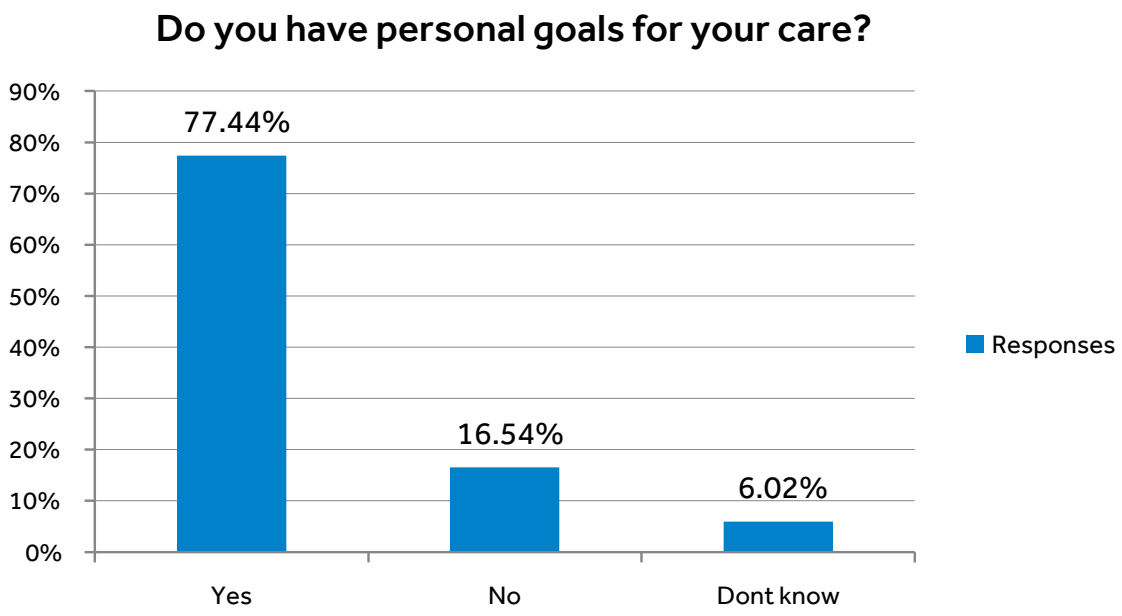
Question 26: Do you want to have a care plan for your treatment?



Answers	Responses	
Yes	61.94%	83
No	29.85%	40
Don't know	8.21%	11
		134

62% stated that they would like a care plan for their treatment, 30% said they would not like a care plan and 8% stated that they did not know.

Question 27: Do you have personal goals for your care?



Answers	Responses	
Yes	77.44%	103
No	16.54%	8
Don't know	6.02%	8

77% of respondents had personal goals for their care which centered on a number of areas:

Change treatment type

Entering into treatment/ detox

Becoming drug free

Improving quality of life

Children

Change treatment type

to get on the injection and not have to collect medication daily.

to change my treatment and eventually detox completely.

to do the HepC treatment again.

to get off the clinic.

I would like to sit down with doctor and make plans for my ongoing treatment.

to discuss another way of treatment like take aways.

To get on the suboxone injection (buvidal) so that I can work cos I'll only have to go to the clinic every few weeks.

If I get a care plan, get offered subtex but I have never been offered this.

If I had a care plan, I like to get off this methadone.

Entering into treatment / detox

Treatment, it's hard trying to get in to Barrymore.

Stable on this phy and do proper detox.

I would like to get off phy. I just done a detox from tablets.

I went and got help myself in Coolmine and I am on 40 mls.

I like to get off this methadone. I like to go to Cuandara, waiting over two years and have after care.

Just to get treatment, detox and get into recovery.

To detox slowly, to get help, to do it in a hospital type detox.

I want to detox off it all, no access to care plan at Pearse Street.

My goal is to get my own place and do Barrymore and get out of Dublin.

Becoming Drug Free

to be drug free and get back talking to my family because they got sick of trying to help so eventually gave up, I miss just dropping into them but understand that they have to do this.

treatment and drug free, like my methadone free.

to go back to treatment and come off the rest of my methadone, I'm only on 30 mls now.

get clean and get my kids back.

Get off this phy and live a little.

Going to see someone to get off the methadone.

I'd like to go to treatment and be drug free.

Have goals to get drug free but haven't had a chance to discuss with doctor.

Like to become drug free, see my son. In time this will happen, I hope.

Returning to work / education

I would like to get off this methadone and go back to work (trauma because of losing family members).

to get completely off everything and maybe go to college.

to get off everything and maybe go to do a course.

I want to look for a course, to better my health and feel like the doctor connects with me more.

To get into detox, get a job and be in recovery.

To get back to having a job when I get off this methadone.

Start a CE scheme, maybe get a job.

I want to be methadone free and get back to work.

I want to do the detox and then deal with my traumas and abuse and deal with anxiety and go to further education and help other addicts when I'm clean.

Go to treatment then go to college.

I try get work; they won't talk about detox because I drink.

Come off phy, work with women and younger girls to spot signs of DV/ get proper access with kids.

I'd love to be able to work with traumatised women because I can understand them on a personal level.

To stay drug free and get into employment.

I want to be methadone free and back to work.

Children

I like to get my kids back, go get a nice place to live. It's a horrible life, I am very down today and no one asked how I am.

I like to get take aways. I have a child and I need to be on weeklies.

To get in treatment and get my kids back.

I like to get drug free. My son does not want to know me because of the phy.

To get to see my son and get off this methadone, I lost everything

I like detox but it is difficult to get treatment etc.

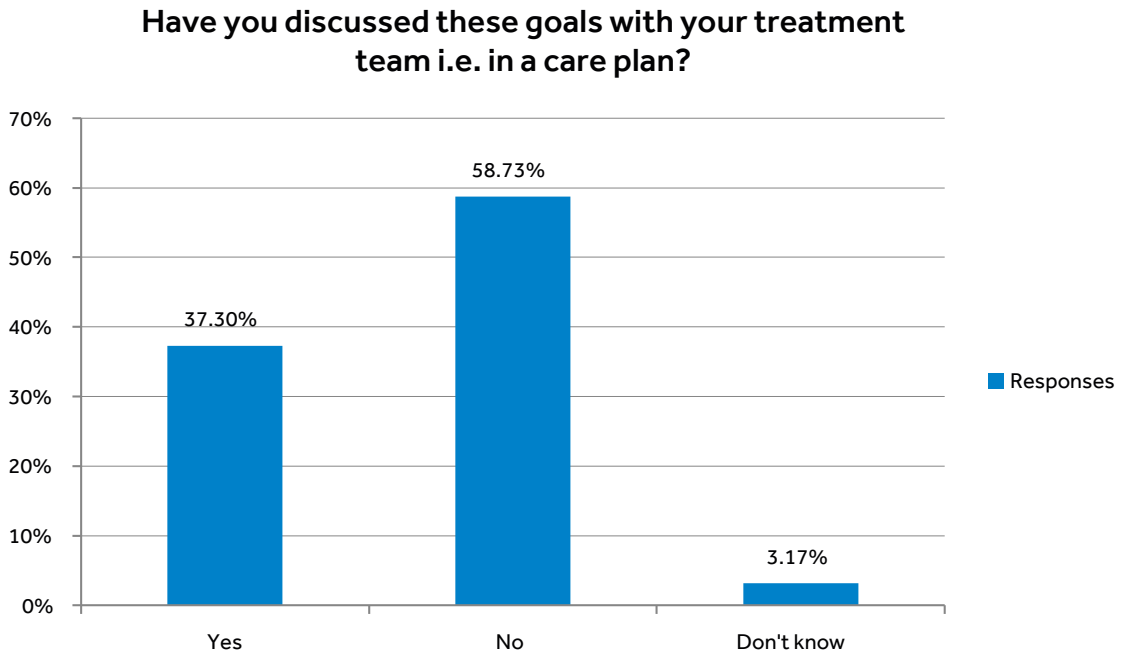
Want to start course so I can get back to work.

I keep asking them to help me and they won't put me in, I want to detox.

I want treatment detox and go back to work.

To cut down on methadone and get help for me and my child.

Question 28: Have you discussed these goals with your treatment team i.e. in a care plan?



Answers	Responses	
Yes	37.30%	47
No	58.73%	74
Don't know	3.17%	4
		101

Only 37% had discussed these goals with their treatment team, 59% had not discussed them and 3% did not know.

As mentioned earlier, the project team on reflection, questioned their use of language in the design of questions around care plans and personal goals. It is clear from the answers to the open ended ques-

tions that service users clearly have ambitions but are not understood in the terms of care plans and / or personal goals.

Hopelessness

I want a care plan but I'm too old to come off methadone now, I'm scared to do it at this stage, been on it so long.

To get off this phy and try to get a better life.

I haven't gotten much time without using so never really thought about it.

Spoke with my doctor about going into treatment.

I am on crutches and lost my leg (amputation) due to drugs, don't see a doctor.

I don't have treatment team; doctors change all the time.

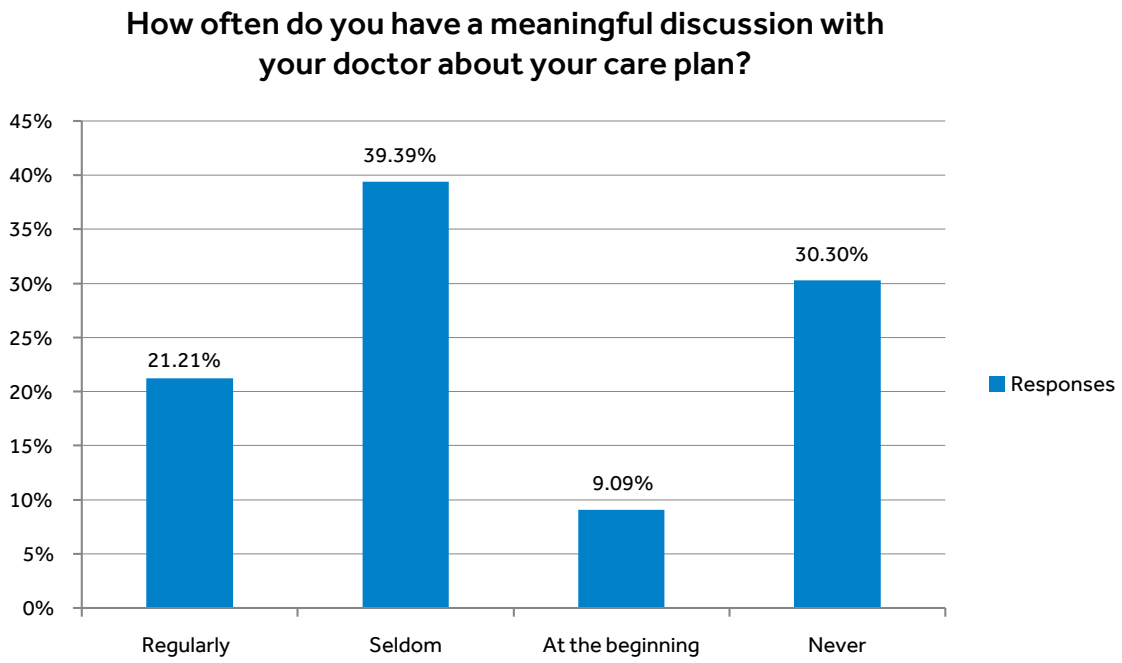
They don't ask me.

No treatment team.

The doctor does not really talk, maybe at times I talk to doctor.

The doctor says I am not ready.

Question 29: How often do you have a meaningful discussion with your doctor about your care plan?



Answers	Responses	
Regularly	21.21%	28
Seldom	39.39%	52
At the beginning	9.09%	12
Never	30.30%	40
Further comment		26
		132

Responses ranged from every few weeks, 'only when I request it', years and never. If at the beginning (9%), seldom (39%) and never (30%) are combined, 78% if respondents have limited engagement with their doctors about their care. The majority of the comments centered on lack of engagement from the doctor and the frequency with which doctors were changed.

I laugh at this cos she's not someone I can talk to without leaving.

I barely see my doctor cos I'm in the chemist.

Only when I request it, no encouragement.

Haven't seen him in 2 years.

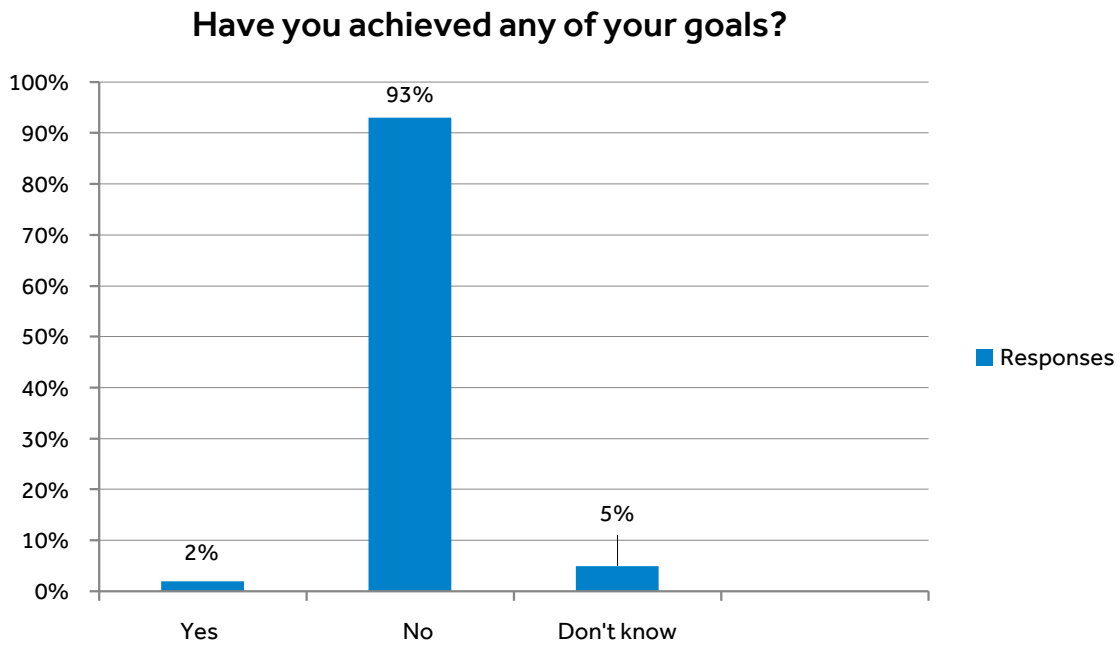
Every few weeks.

I barely see my doctor; I just get my molly and leave.

They don't care, look at me, woman crying, she wants to take her life.

There is always an excuse, new doctors all the time.

Question 30: Have you achieved any of your goals?



Answers	Responses	
Yes	2%	1
No	93%	60
Don't know	5%	3
		64

93% of service users stated that they had not achieved any of their goals, 2% had and 5% did not know. For some it was coming off tablets or street drugs and getting stabilized or starting the process of recovery, for others it was doing a course or working to become healthy.

I haven't fully achieved but I am only on my methadone and the tablets the doctor gives me.

Switched from phy to suboxone.

I've detoxed and given up street tablets.

I have cut down my methadone from 80 to 30 mls.

I am doing small courses and getting ready to restart my detox.

Starting the process of recovery.

I got off tablets and I am down to 4o mls.

I am in Coolmine which I accessed myself.

Roughly 6-7 weeks clean just prescribed meds.

Staying off drugs for 1 month going to a personal trainer and living healthy.

I'm no longer addicted to heroin or sleeping on the streets.

Staying off other drugs, quite happy with being on phy.

Reduced methadone by 50 mls but done it myself.

I'm just on methadone now, stopped smoking gear on top.

I went back to college and studied.

Doing great, don't have to rob or make money.

In education at SAOL. peer worker with probation and victims of domestic abuse.

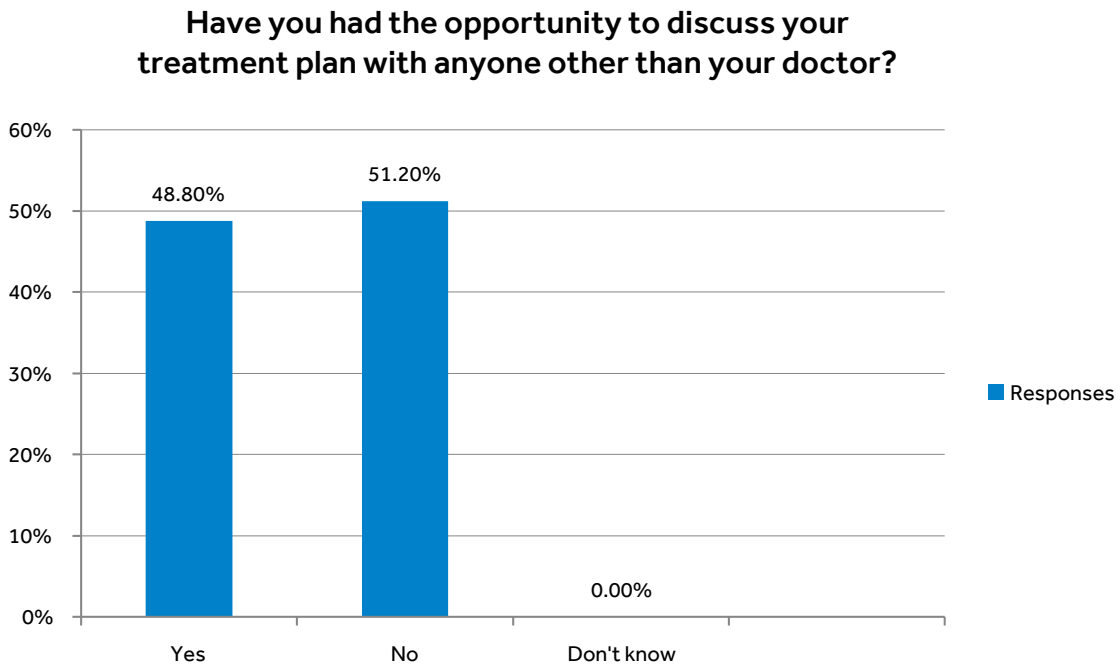
Keeping myself live and paying my rent at hostel.

Stayed away from gear for so long, very impressed with myself for that.

Not using drugs only my phy and I cutting down on tablets.

I am detoxing myself, I am down to 10mls, not giving up.

Question 31: Have you had the opportunity to discuss your treatment plan with anyone other than your doctor?



Answers	Responses	
Yes	48.8%	61
No	51.2%	64
Don't know	0%	0
		125

There were two very distinct answers to this question, 51% of respondents said they had not had the opportunity to discuss their treatment plans with anyone other than their doctors while 49% said that they had. Key workers or support workers within addiction projects were named most often as the other person they had discussed their treatment plans with, or friends or family.

My key worker in my course, nothing was offered but at least my name is on the list for treatment now.

Staff in the course I attend.

Keyworker, she's really supportive and is helping me get it together and keep on top of appointments.

Just my friend.

My key worker.

My key worker, my sponsor and at my day programme.

In SAOL, they help me, but I can't seem to go as much as I like.

In Ana Liffey, my key worker left so I need a new one.

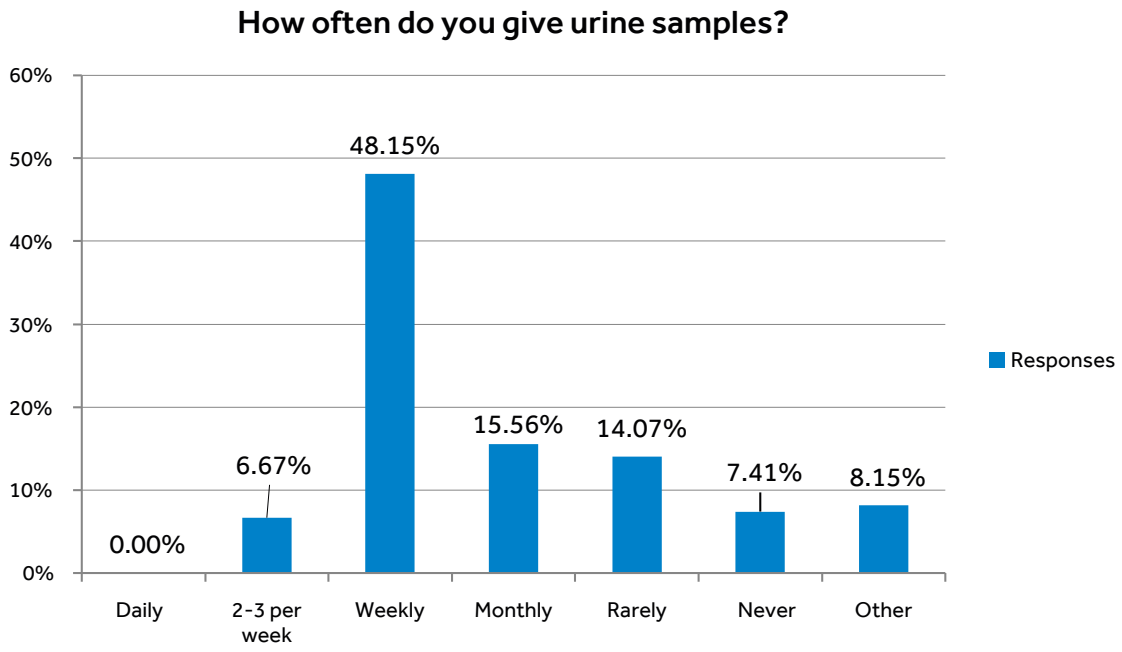
Key worker, she is helping me with a few things about my treatment and housing.

Key worker in hostel, they say to start community detox and then back to hostel.

Key worker, not ready for detox but I like speaking with the key worker.

Just my Dad, feel doctor does not care. I ask for detox but get ignored.

Question 32: How often do you give urine samples?



Answers	Responses	
Daily	0%	0
2-3 per week	6.67%	9
Weekly	48.15%	65
Monthly	15.56%	21
Rarely	15.56%	21
Never	7.41%	10
Other	8.15%	11
		135

The answers to this question covered a range from 2-3 per week to never, with the highest response being at 48% giving weekly samples. This is a significant improvement on earlier surveys where the

majority had to give them 2-3 times a week, this number had dropped to 7% but 48% are still required to give weekly urine samples.

Only when I collect my script

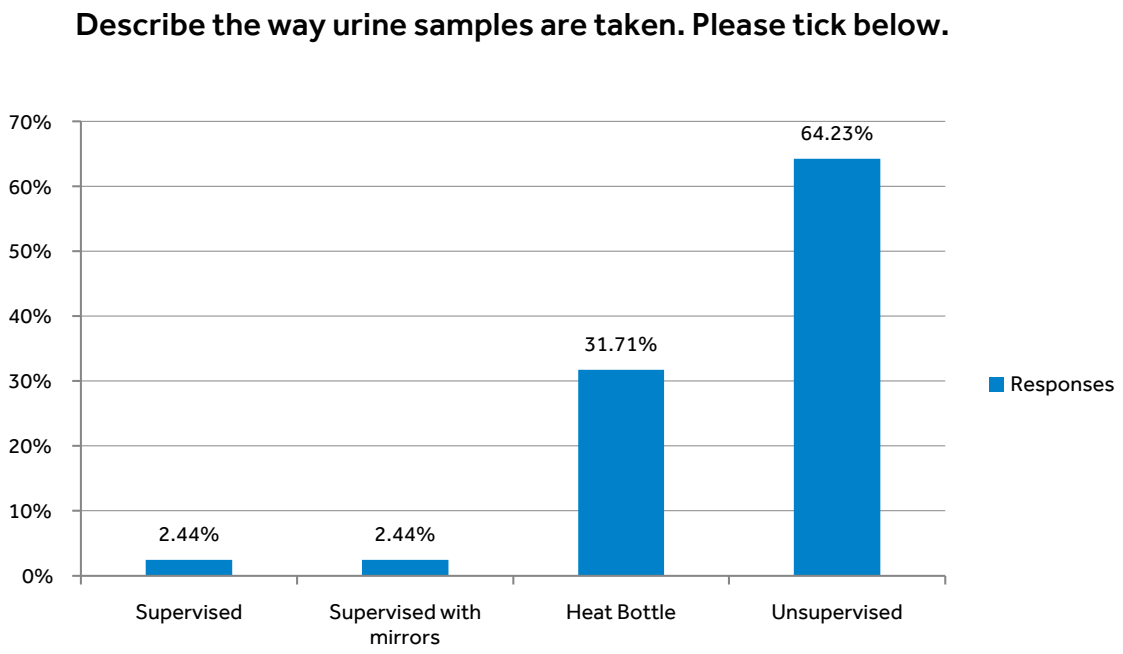
Random

Every 2 weeks

Rarely, when they ask

Weekly but sometimes monthly

Question 33 Describe the way urine samples are taken. Please tick below.

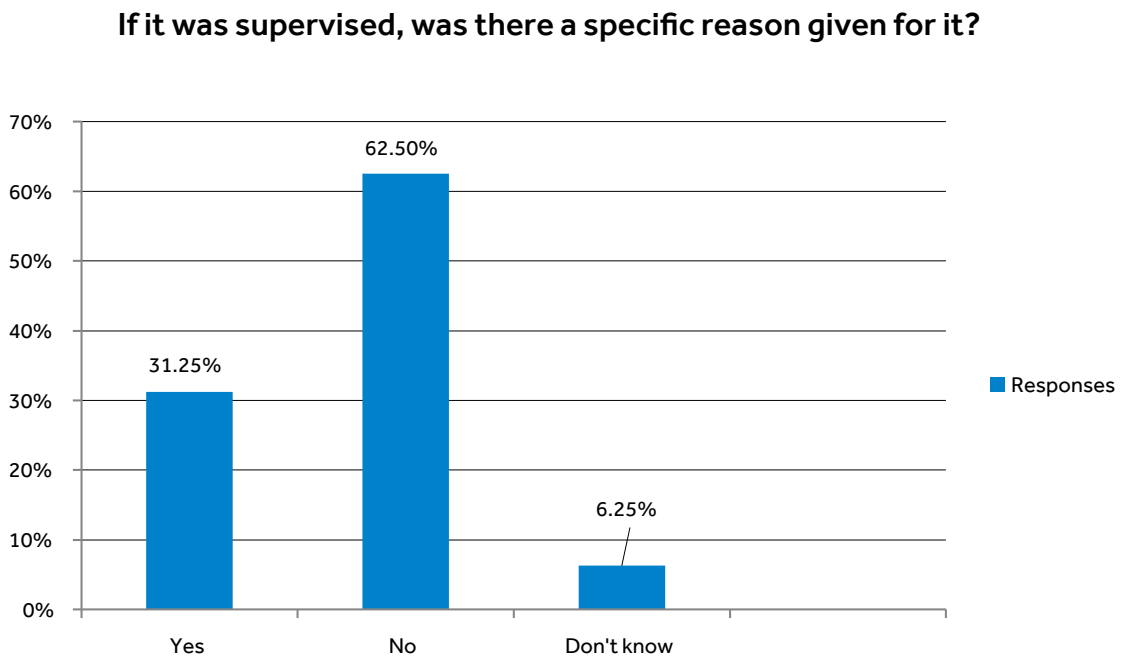


Answers	Responses	
Supervised	2.44%	3
Supervised with mirrors	2.44%	3
Heat Bottle	31.71%	39
Unsupervised	64.23%	79
Other		8
		122

Question 33 focuses on a key monitoring point in looking at improvements in opioid treatment services. Supervised urine samples were removed as part of the HSE response to the IHREC Equality Review. 96% of those surveyed gave urine samples unsupervised and 2% stating supervised and a further 2%

stated supervised with mirrors. This reduction in numbers from previous surveys is welcome, however 4 % still stated that they were subject to being supervised which is contrary to the Equality Review.

Question 34: If it was supervised, was there a specific reason given for it?



Answers	Responses	
Yes	31.25%	5
No	62.50%	10
Don't know	6.25%	1
		16

63% stated there was no reason given for the urine samples being supervised and 31% stated that there was a reason given, 6% did not know. One respondent states they have to give supervised urinalysis to a social worker which is also contrary to the Equality Review and involves an external state service. It is another example of using MMT as an instrument to control through children, very common in the narrative of women in treatment. People going to access "treatment", and they end up trapped.

Some examples of the reasons given are detailed below:

At one point, I had to give him urine in his office, a few years ago

They ask you to just go in there, there is a guy at the door.

So I don't give a bogie urine.

Asked to be supervised, my idea

I signed a form saying this as it is for my baby and a social worker is involved.

Question 35: In the last 2 years have you ever been refused treatment as a result of your urine analysis?

Answers	Responses	
Yes	5.74%	7
No	94.26%	115
Don't know	0%	0
		122

When asked if they had ever been refused treatment as a result of a urine analysis, 94% said no but 6% of those surveyed reported that they had been refused treatment as a result of a urine analysis. Some said they were refused treatment because of alcohol use, or they had missed days.

Couldn't give a urine so I couldn't get my prescription.

They refused to give me treatment, took me off my pills but then I got my usual dose of phy.

When I went back using it took weeks to get back on my script and the chemist. I had to go to doctor every day because of a slip.

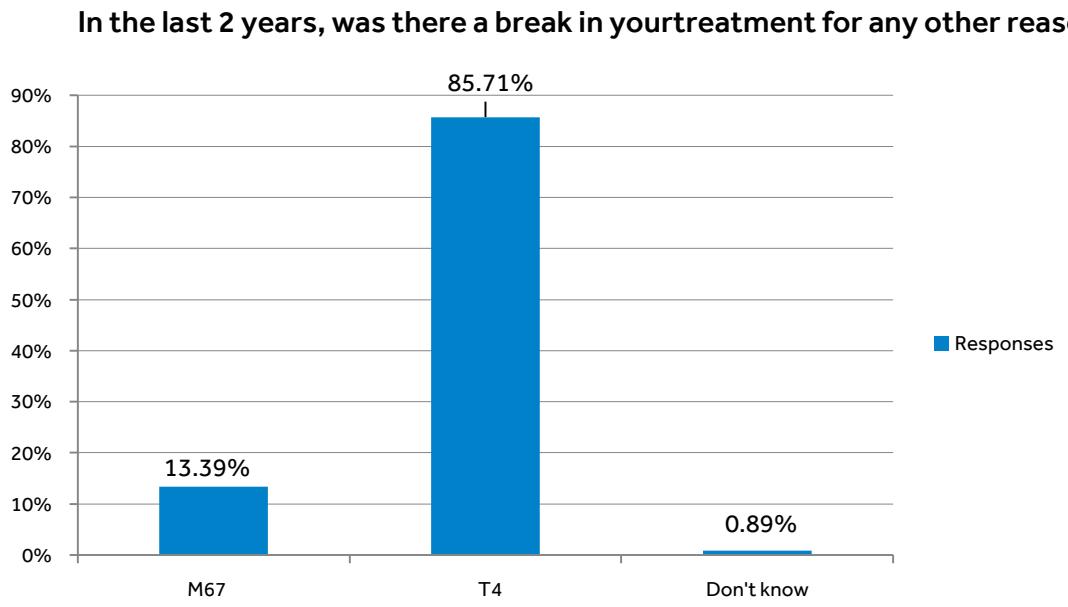
They stop my take aways because I take drink, real control.

Missed days and they would not give it, had to start all over again.

I dropped a bottle of phy and I was not believed by my doctor.

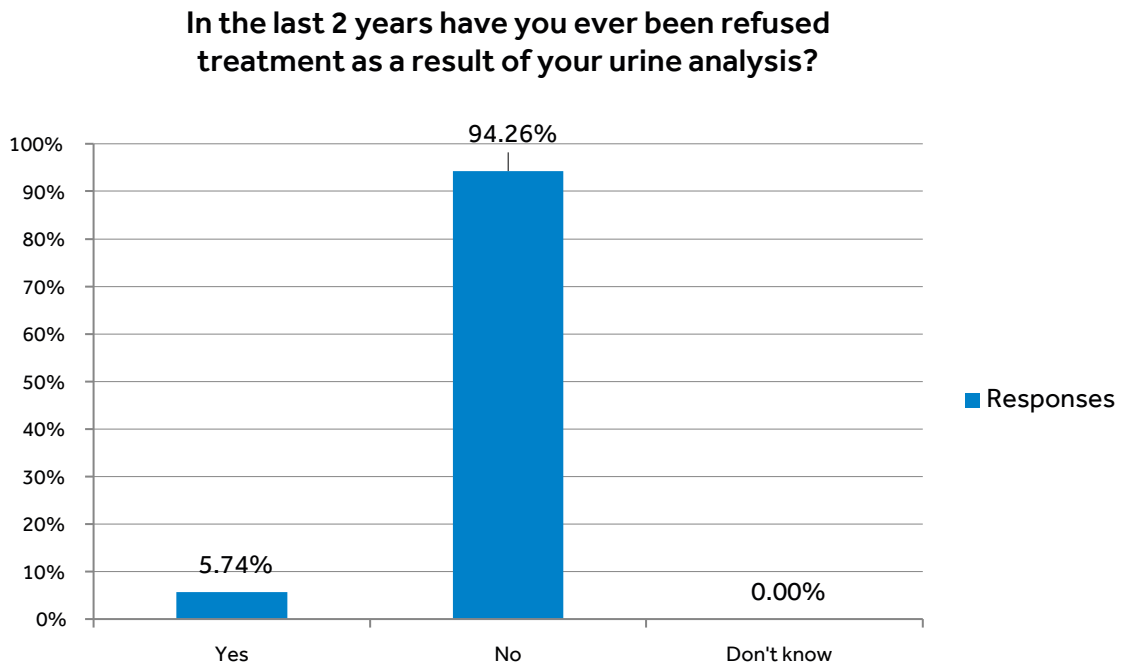
Because my urine been dirty, they stopped my treatment got Peter McVerry to call and they sorted it out.

Question 36: In the last 2 years, was there a break in your treatment for any other reason?

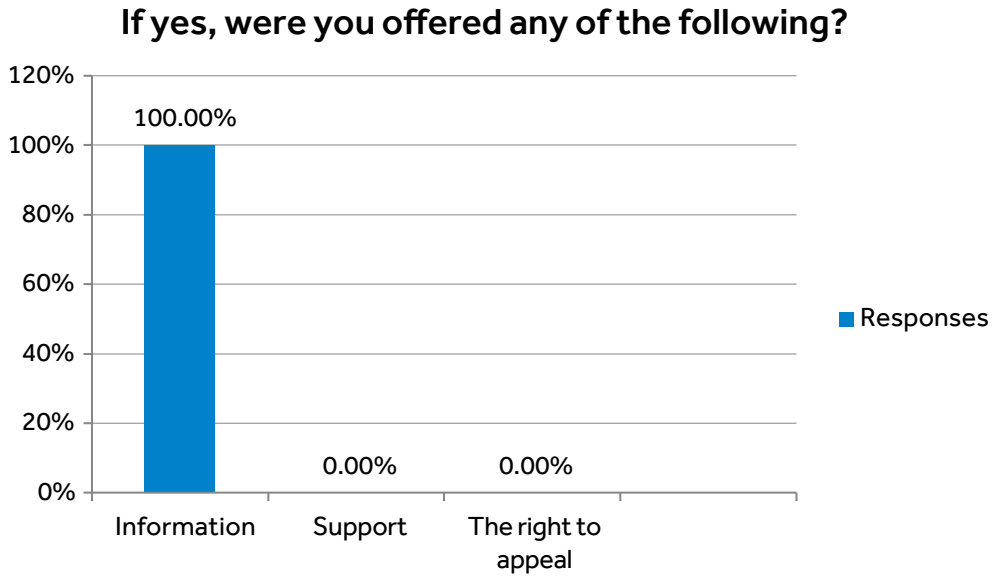


Answers	Responses	
Yes	13.39%	15
No	85.71%	96
Don't know	0.89%	1
		112

85% reported no break in their treatment for other reasons with 13% stating yes.



Question 37: If yes, were you offered any of the following?



Answers	Responses	
Information	100%	3
Support	0%	0
The right to appeal	0%	0
		3

There were only 3 responses to this question with all 3 stating that they were provided with information the follow up question, if you appealed, what was the outcome gave a range of answers:

Was in hospital for a broken jaw.

Got unwell from smoking crack, bad mental health.

Nothing I was told to piss off for a month and come back with a better attitude - their words not mine.

In prison but now I am back in the clinic.

Didn't appeal as the break was when I went to prison.

None of this, the GA can be cheeky.

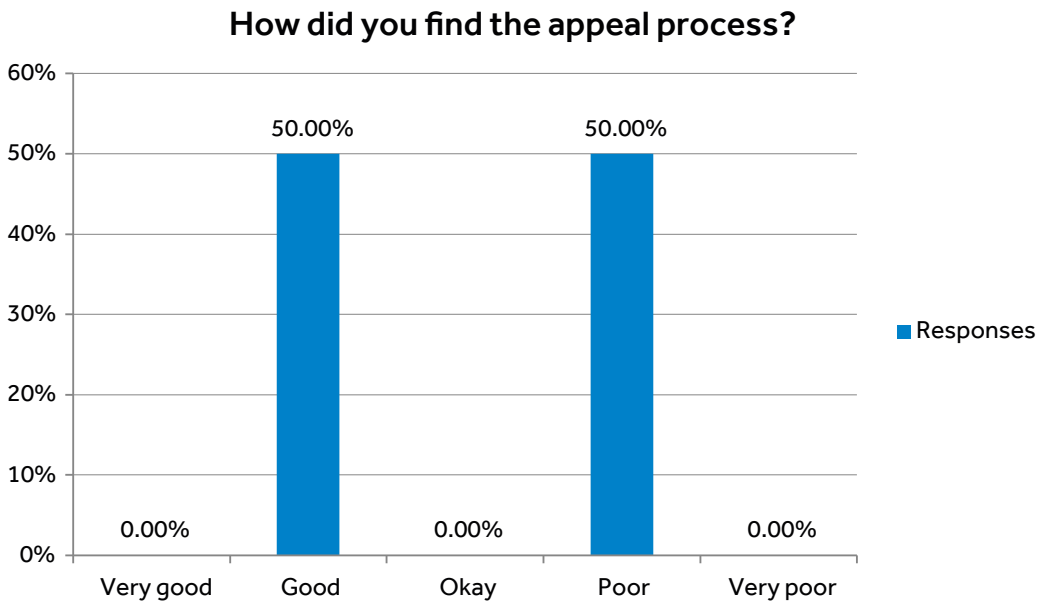
Kids taken into care by Tusla.

In prison and they didn't give me my dose till I got them to ring my doctor.

They stopped my take aways because of key worker. No chat, no talk, just done it. She was telling me to go to treatment.

Got unwell from smoking crack, bad mental health.

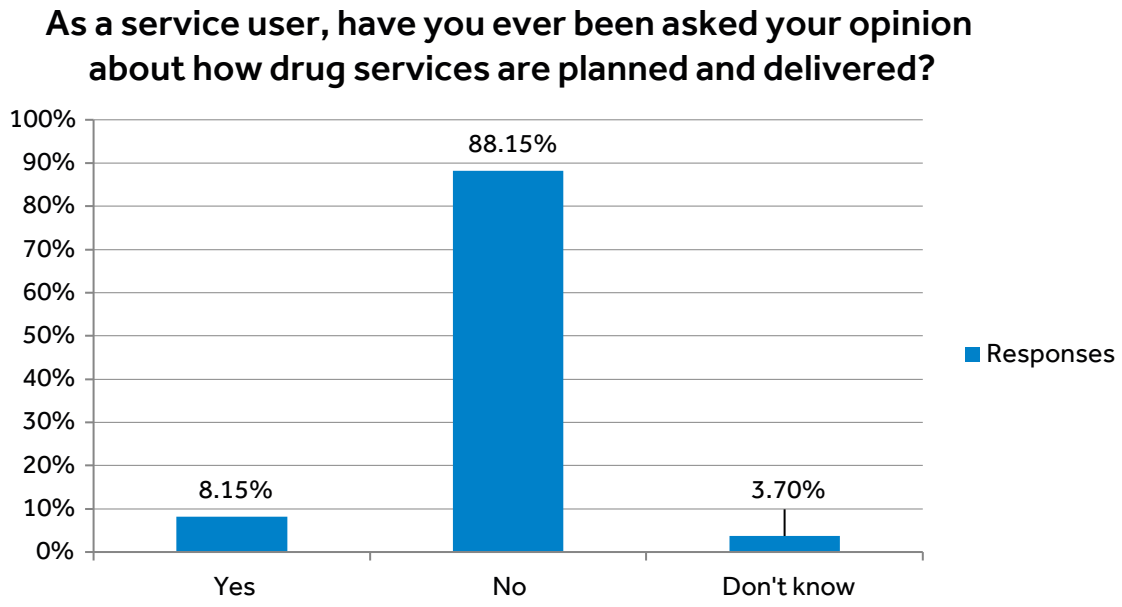
Question 38 How did you find the appeal process?



Answers	Responses	
Very good	0%	0
Good	50%	1
Okay	0%	0
Poor	50%	1
Very Poor	0%	0
		2

50% response that the appeal process was positive(good) and 50% stated that that it was negative (poor). It should be noted that this is based on 2 responses to this question.

Question 39: As a service user, have you ever been asked your opinion about how drug services are planned and delivered?



Answers	Responses	
Yes	8.15%	11
No	88.15%	119
Don't know	3.70%	5
		135

88% stated that they had never been asked their opinion about how drug services are planned and delivered; 8% had and 4% did not know.

Question 40: if yes, how did this happen?

The table below illustrates the ways in which people were asked to express their opinion and what the outcome was of the process.

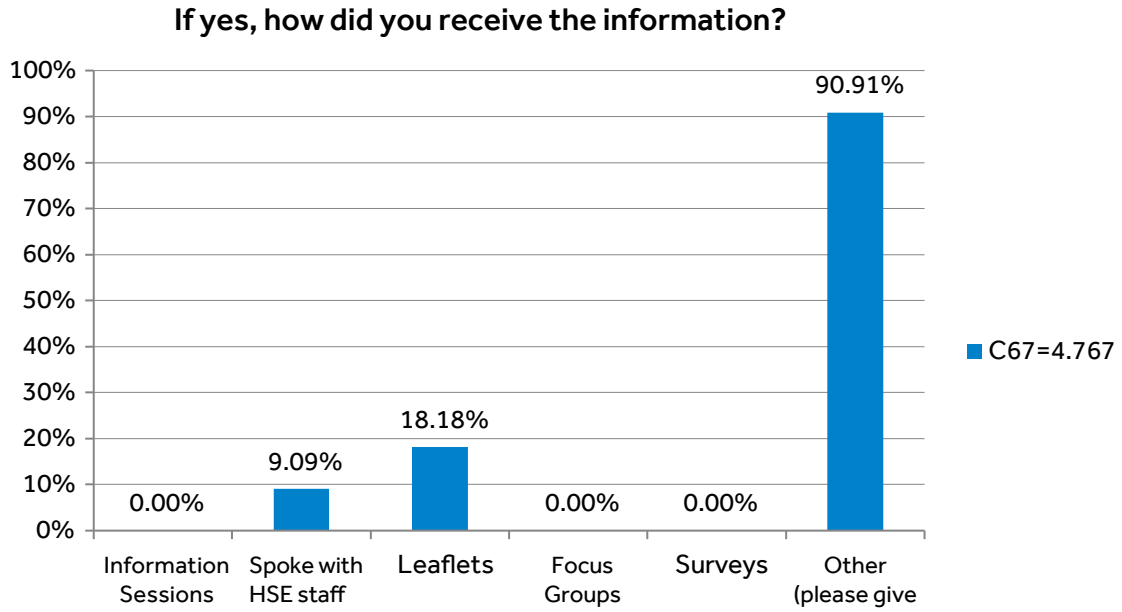
Which service?	How were you asked?	What happened?
Harm reduction	Meeting set by HSE	We were not told.
UISCE	Linking with the support worker	I am going to become a peer worker
Coolmine	They were very nice	Not sure what happened
Coolmine	Group setting	I left for personal reasons
UISCE	To help with research into safe injecting facilities	Still not opened yet
SAOL, the DAVINA project	Se work together as peers	Our voices and lived experience are heard
SAOL Project		Only programme where my opinion has mattered
	There's a sign saying we could comment but no box.	

Question 41: Have you ever received information on your rights in treatment services from the HSE?

Answers	Responses	
Yes	3.91%	5
No	91.41%	117
Don't know	4.69%	6
		128

91% have never received information on their rights in treatment services from the HSE, 4% stated that they had and 5% did not know. This is another area which is contrary to the Equality Review and that information should be available to service users through patient information leaflets, information in induction packs, informing clients when they start treatment and key workers or staff advising clients of the practice/ change in practice.

Question 42: If yes, how did you receive the information?



Answers	Responses	
Information Sessions	0%	0
Spoke with HSE Staff	9.09%	1
Leaflets	18.18%	2
Focus Groups	0%	0
Surveys	0%	0
Other	90.91%	10
		11

The responses to this question show a low level of engagement with service users, 9% of respondents spoke to HSE staff, 18% were given leaflets and 91% stated other. Further explanation on 'other' demonstrates how little service users are involved in in the development of services.

From time to time, leaflets only.

In and out, GA asks how you are, that's it.

It would be nice to be asked.

I asked for my contract, complaint to the clinical team was ignored. I wrote to the HSE.

Got my solicitor to approach them.

It would be nice to know my rights, they tell you those hostels, it's a horrible way to live.

Only when I was in treatment years ago.

Question 43: If you could change anything about the Opioid Substitution treatment programme, what would that be?

The answers to the changes that service users would like to see in the Opioid Substitution Treatment Programme focused on 4 key areas.

- Treatment Choice
- Engagement and Participation for Service Users
- Less Judgement and Stigma Placed on Service Users
- Improved Servies

Treatment Choice

We could choose what treatment we want and not have to wait.

We wouldn't be left on methadone for our lives, we'd get 6 months then into treatment to come off it.

They would encourage us to come off it quicker.

Not to be left on it for so long and not being offered a plan.

They give you a plan when you start there.

Don't like being on methadone so more help.

Not to be left on phy for so long and be offered treatment.

That I be given help to go to treatment, they just keep you on this phy.

People would have choices and autonomy.

Should have someone there with information on alternative treatments and someone to talk to always.

We would be able to make our choices about our treatment.

There would be no waiting list to go in somewhere to come off phy cos I wanted to do this before but by the time a bed was there I wasn't interested any more.

To have a choice of treatment, I have to take what they offer.

That there would be a limit to the amount of methadone you receive and a realistic timeframe to detox.

More freedom

Having to go to the clinic every day.

The way they treat me, control our time and left waiting at door in queue.

Engagement and Participation for Service Users

I believe they could help more; the chemist is a nightmare.

Maybe give you a cup of tea, make you feel welcome, general chat.

To be offered a bit more support.

More help, it's the worst clinic you could be in.

To be treated better, it's in and out to see the doctor.

Support mothers more.

More care focus on the problem not be left so long without detox.

More advertisement about recovery, more cafe that encourages drug free, more info on routes to recovery.

More helpful, GA are not nice, be listening too.

The way the doctors don't engage with me and see different doctors all the time. Bit more compassion where I am at.

Maybe just make place nice, GA not very welcoming.

The way they treat you left on queue for half an hour then you're in and out, they are not nice.

Need more support, other treatment, spend more time showing compassion.

Suboxone and other help, like doctor helping me more.

Bit more care, there's no connection from doctor to clinic, it very much in and out.

More interacting with doctor since been on this, super depressed.

To be offered detox, not to be left on it, better chat with doctor.

Doctor showed a bit more interest in my treatment.

I am on Doctor now. For the GA to be a bit more compassionate as they can be very difficult to deal with.

Doctors would listen when you say you want to change instead of them thinking they know you better than you know yourself.

I wish I never touch this phy, get offered detox, doctor to not to dismiss me.

That Doctors would talk to me more and offer treatment.

Less judgment and stigma placed on service users

Less judgemental

I think it's ok, it stops me from being sick but sometimes I don't like how some staff can talk to you.

Staff would be nicer.

I want to go to the chemist, it's a bit degrading going into the clinic, never knowing who will see you come out.

If the doctor treats us better also not be left on it for so long.

I am 50 and I want to be stable now and to be treated more human and for more of a connection. You are told what to do, get your phy and then leave.

I go to my own doctor for my script and most people don't know why I'm there, this should be for everyone.

Improved Services

It would be easier to get takeouts.

When people are giving clean urines, they should get takeaways easier.

I would like to be able to get take aways and not have to worry on weekends.

Weekend times should be later/ I have to come from Santry before 10.45 - should give take aways.

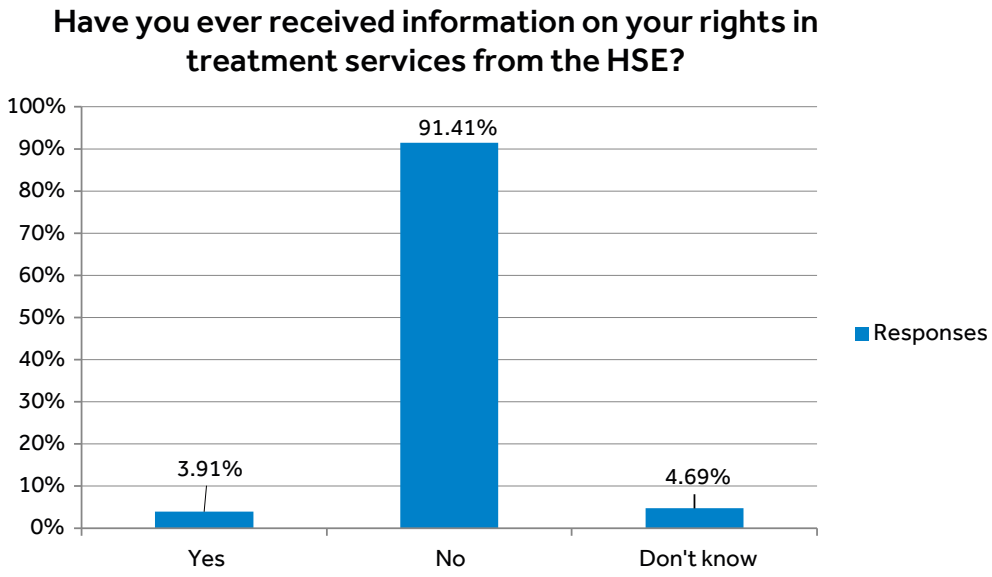
Make it easier to get weeklies, they make you jump through hoops.

That clinic nightmare, I hate it. I would like Take aways, I on it for years. Maybe to see same doctor every few months. At Gramby I was assaulted by a man following me, it was traumatic and there was no proper security.

To be given take aways and not have to go to the chemist 4 days a week.

Once a month to get take aways, everyone in chemist looks at me, they know I am an addict.

Question 44: Do you know how to make a complaint? If yes, explain how.



Answers	Responses	
Yes	41%	34
No	56.6%	47
Don't know	2.4%	2
		83

57% of service users do not know how to make a complaint, 41% do and 2.4% stated that they don't know. When asked how they could make a complaint, the answer centred on the main doctor or the boss. Some service users did not see the point or were not willing to make a complaint, some just didn't know that they could.

to the boss in the clinic

to the main doctor in charge of the clinic

I would just talk to a doctor when I get to see one.

Yes, to the doctor or staff in clinic.

Didn't know I could complain.

No, to who would I complain?

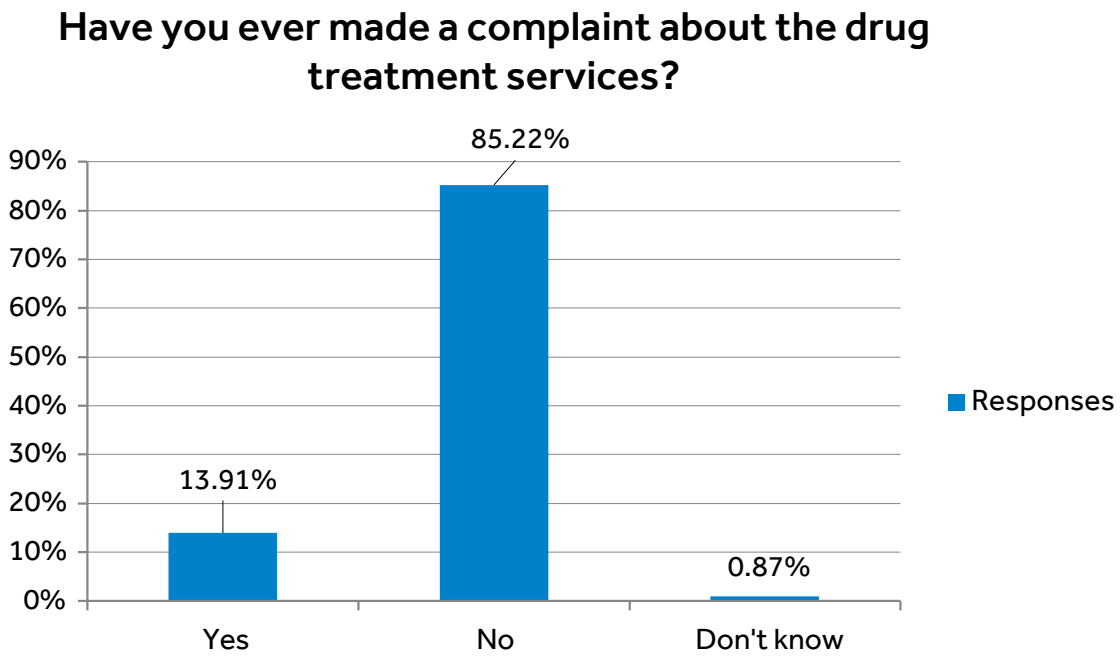
Yes, I do but I am not willing to.

Who do you complain to, the doctor? They kind of corner you.

Yes, write a formal letter to the doctor or head of clinic.

Yes, but I'm not willing to make one.

Question 45: Have you ever made a complaint about the drug treatment services?



Answers	Responses	
Yes	13.91%	16
No	85.22%	98
Don't know	0.87%	1
		115

Only 16 respondents or 14% have ever made a complaint about the drug treatment services, 85% or 98 said they had not made a complaint.

Question 46: If yes, what was it about?

Treatment by staff, doctors and GA's were the main reason given for making a complaint.

The way I was treated by staff, been left waiting on doctors, put on Valium.

I was denied services for 4 weeks.

GA putting people down.

To the doctor about the way I was treated by the GA. The way they speak to you.

It's this whole place. Clinic it's a joke, there is very little help offered.

They close the place early.

Just been asked if I want to buy drugs when I am at clinic.

They walked in which I was going to the toilet, GA thought I had drugs.

GA putting people down and about urine samples.

Question 47: What was the outcome?

The responses to the complaints were poor with little to no change being enacted on behalf of the service user which reinforces earlier comments on the state of the system and how practices involved in the treatment can sometime be worse than the treatment itself and how the system continues to internalise stigma.

Made a complaint before and nothing happened.

Doctor made agreement I be left with the same doctor.

I had to endure.

Just got put to hospital.

They said sorry but told me it best not to take it any further.

They did nothing for me, I will take treatment if they give it.

They didn't listen and fobbed me off.

Not listened to by doctor.

I just had to endure.

Question 48: If no, why not

The reasons offered for not making a complaint on services focused on three themes:

- They would not be believed
- There was no point
- Afraid of the consequences.

Would not believe/ listen to me

The boss in my clinic would not care.

Don't believe they would listen to me.

Don't believe they would listen.

They wouldn't listen. They are never there; doctors change all the time.

Tried but I was not listened to, the way a GA listened to me.

I don't believe they will listen to me, I won't complain because they look after their own back.

No don't believe, they listen, just you're there a long time, they don't stick to the time.

No point

Never bothered.

No point.

I've heard other people's stories and didn't think there was any point.

Just in addiction and not bothered.

Get the treatment, in and out, if one minute late, door shut, wouldn't complain.

Afraid of the Consequences

I am afraid I would be stopped attending the service.

I'm not making the complaint because I don't want to suffer the consequences for complaining.

I wouldn't probably be treated respectfully.

I was told not to complain, I'd be put to Pearse Street.

Question 49: Have you had experiences you would like to make a complaint about? If so, what were/are they?

- Treatment Choice
- Engagement and Participation for Service Users
- Less Judgement and Stigma Placed on Service Users

Treatment Choice

Yes, I should have a care plan.

I like to not have to go weekends 9 to 11.

When I ask for detox, they don't listen or care.

They took me off my night meds and its hard, the doctors won't listen. I need them to help me sleep, maybe have someone to talk for me.

Engagement and Participation for Service Users

I don't get to speak to my doctor as much as I would like.

Again, doctor not listening.

I don't feel listened to when I want to detox.

Yes, supervised urines are inhumane

Some of the staff think they're the boss

Staff are not very nice, don't trust them.

If you can't give a urine sample within 15 minutes, it goes down as a dirty urine

Less Judgement and Stigma Placed on Service Users

When I am at the chemist, I am treated differently e.g. pushed to the side.

The way the pharmacist treats me.

How the staff treat and talk to you. Doctor doesn't listen

I like if they try to make me feel a bit better, feel looked down on.

Withdrawing Treatment

Loads but what's the point, they're gonna back each other.

About the GA going to meetings about me and know my information.

Denial of services.

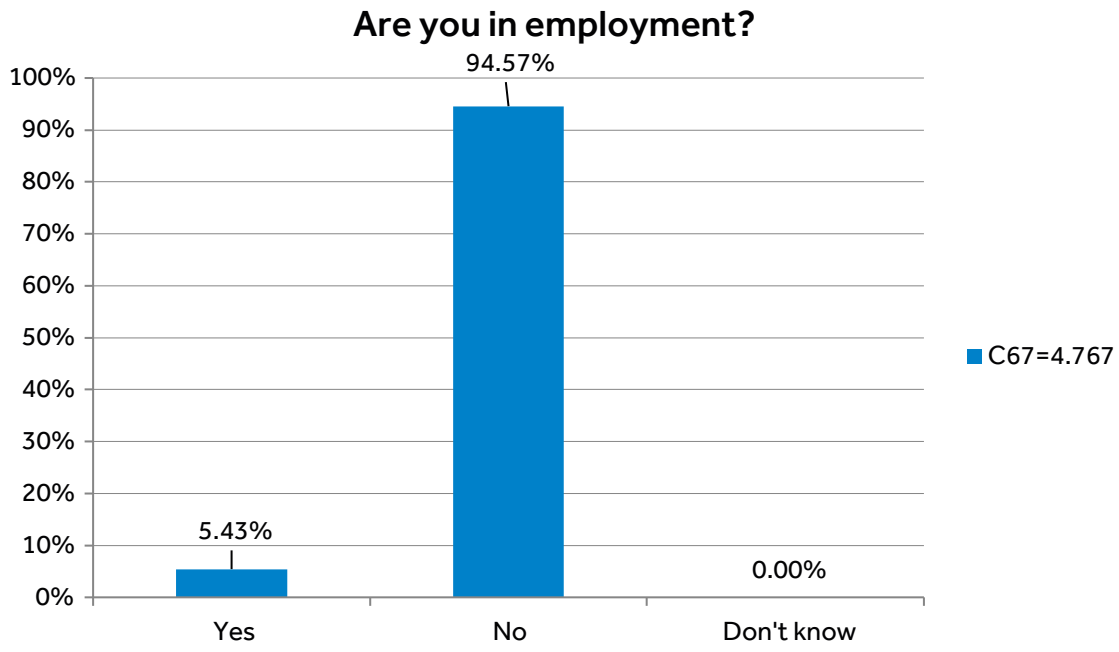
Been cut of my tablets, put me in withdrawal for a week.

No not to complain about because they have you over a barrel.

Sometimes they close early, been left one weekend sick, cant understand them, they have no compassion

My take aways were stopped because I took extra tablet for pain. They won't listen and I need them back

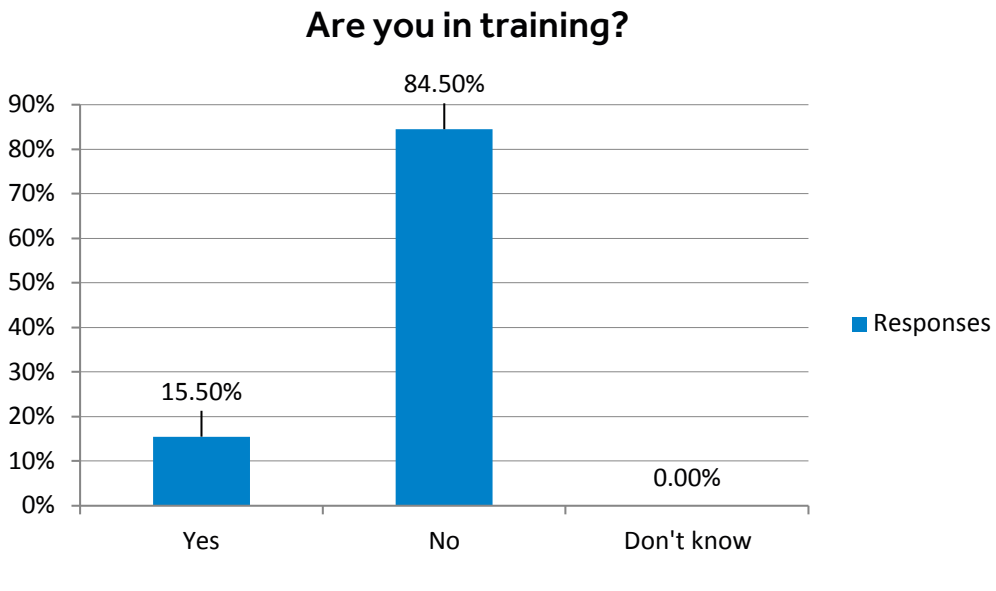
Question 50: Are you in employment?



Answers	Responses	
Yes	5.43%	7
No	94.57%	122
Don't know	0%	0
		129

95% of respondents are not in employment.

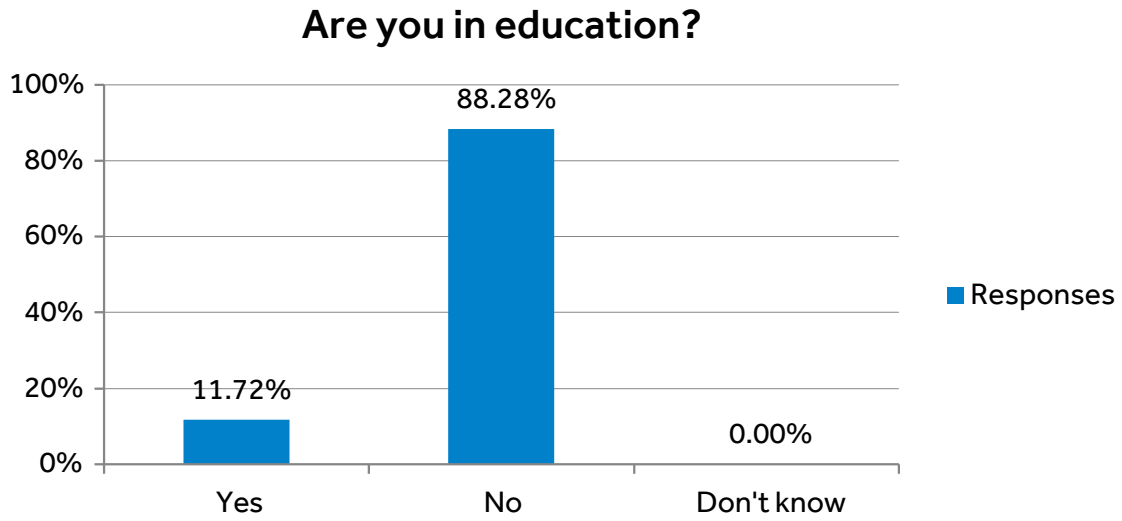
Question 51: Are you in training?



Answers	Responses	
Yes	15.50%	20
No	84.5%	109
Don't know	0%	0
		129

85% of respondents are not in training.

Question 52: Are you in education?



Answers	Responses	
Yes	11.72%	15
No	88.28%	113
Don't know	0%	0
		128

88% of respondents ae not in education.

Question 53: How does treatment affect your employment/education/training if at all?

Having to go to the clinic/chemist every day

Lying to my boss when I need to collect my methadone is hard cos he is nice so I feel bad.

I started a training course but had to miss classes because I had to go the clinic.

going to the chemist means it's hard to work but I'm also getting too old to start now.

It does because I go to the clinic.

I can't work as I go to the clinic every day.

Can't do nothing as I be at the clinic at different times

I want to study but having to go the clinic makes it hard.

Times of clinic does stop me accessing these.

Life revolves around the clinic.

Having to go to the clinic means I can't engage fully.

I hate not being able to be honest with my boss, I make excuses when I have to go for my treatment.

Impact of methadone

Phy can make me sleepy and uncomfortable so i get anxious about doing things face to face

Having to take this phy can't work.

A lot, being on methadone effects this.

Can't work while being on this phy.

I go to clinic every day.

Can't work because charges and been on drugs.

If I tried to get a job, can't because of my drug treatment.

If I went for job, I wouldn't let them know I am on phy.

Can't work, I hear people talking about me, the way I look, crack now?

Come on, who would employ me

I am on drugs, who would give me a job? I tried work but got judged for being on phy so what's the point?

Poor health/ mental health

No how could I work, ill health.

I am on disability.

It keeps you down being on phy, can't go to education or work.

More my addiction and I get down, I soke crack so I am not ready for anything else.

Have HIV and I drink so I can't work.

Can't seem to do anything, kids are in care so my head is not great.

Question 54: Final comments

It's good yous are doing this cos it will help people to know they have rights.

They don't give you enough time or attention, you go in and out that's it.

Feel trapped by the clinic. I would like my doctor to show interest, its in and out.

There's no detox for couples. Doctor asked my missus to supervise me.

In clinic don't feel they treat you nice and the doctor does not listen, it's next, next, no connection

I am going to end up taking phy for life. I have been in and out of jail most of my life.

I tried to get myself off and ended up back in the clinic.

In prison I asked for Suboxone but they just gave me phy.

I go to the doctor every few weeks, get my phy weekly, I am happy with my doctor, also work so getting take aways helps me.

Found a dead body in hostel, I never received counselling about this.

That Gramby, its so difficult to try get clean and stay in recovery in a hostel.

My mental health is not good.

I have turned my life around and have my forever home and I am free from domestic abuse and off the clinic. new doors are opening for me.

It's like wearing hand cuffs on this can't go anywhere.

Let people know we are not scum bags, we are nice people. I just go doctor and it maybe 7 words, he never really speaks.

SURIA COMMENTARY

The Service Users Rights in Action (SURIA) are a group of service users, former service users, researchers, doctors, and community group members that was established in 2012, as a result of the non-implementation of the Farrell Report (2011), a damning HSE funded evaluation of MMT/OST service provision in Ireland, (SURIA 2021, CAN and SURIA 2018).

For over a decade, SURIA have been collating data from service users and tracing the narrative of this cohort as they engage with this necessary public health service. We have published our findings five times in the intervening years, using four key principles as a frame of reference from which we seek accountability from stakeholders, monitor the realisation of, or lack thereof, of a number of key but basic human rights mechanisms. These include international instruments (The International Covenant of Economic, Social, Cultural Rights, European Pillar of Social Rights) and Irish rights. The Right to Health and Public Sector Duty both inform much of our analysis.

SURIA welcomes the opportunity to provide a brief commentary for this peer-led research report from ICON. While it is similar to our own broader research, ICON's report makes a number of key contributions that can help empower service users, improve service provision and further highlight and capture the persistent shortcomings that are regularly reported by service users regarding MMT (methadone maintenance treatment) and OST (Opioid Substitution Treatment) in Ireland, and in particular the North Inner City of Dublin, where ICON's research was conducted.

The North Inner City is roundly recognised and accepted as one of the first areas of the city in which life was described as "short, nasty and brutish" by the Rabbitte Report (1996) as a result of problematic heroin use in the early 1980s, (Bradshaw 1983). The academic literature also delineates the North Inner City as an area of deprivation, poverty, and gentrification, all of which combine to advance the conditions that often foster problem drug use, (Punch 2005). As such, it is of little surprise that this area has some of the earliest iterations of harm reductionist service provision.

Many of the findings of SURIA's own research, both in our current work and in previous iterations, are substantiated by ICON's impressive report, which is a thorough explication of the service user narrative of those engaging with MMT/OST in the North Inner City. The culture of blame, institutional stigma, the lack of autonomy and choice and the many unnecessary but mandatory obligations that underpin the narratives of service users are all re-iterated in this Report. ICON have succeeded in engaging with what are often termed a "hard to reach" population, in this case homeless service users. To this end, this Report is an impressive examination of the real-life experiences and the barriers to progression that service users are often forced to endure due to service providers inability to provide evidence-based harm reduction informed services. SURIA argue that this is a corollary of a reluctance to adhere to harm reduction practices that are recognised as best practice, alongside the challenge of using harm reduction in a landscape which is still dominated by prohibition, with abstinence considered to be the sole indicator of successful care, (Butler and Mayock 2004, Mayock 2021). This report demonstrates that

this contradiction has led to harm reduction services that frequently produce harm, are heavily linked to controlling a perceived difficult to govern population and routinely fail to improve the quality of life for the majority of service users.

The demographics, or profile of research participants in this report differs from that of SURIA's broader piece, therefore, it adds great value to the research as a collection of work. 36% of ICON's research sample identified as homeless, with clinics being the dominant way of accessing supports. ICON's work also draws attention to the long periods of time that many service users are engaged with MMT/OST, with almost one in three accessing this care for between 16 and 20 years. Considering many research participants reported feeling controlled, oppressed, and stigmatised, while having a poor quality of life, with service providers "working to incite, reinforce, control, monitor, optimize and organise" their lives, (Harris and McElrath 2012), 16 to 20 years is a long time to be living this life.

Drawing from the personal experiences of several of SURIA's members who have prolonged personal experiences of navigating an MMT system which is fraught with difficulty and challenges, and from over a decade of gathering both quantitative and qualitative data pertaining to MMT/OST, SURIA now employ four key principles when disaggregating the data we collect through peer led data gathering.

These principles are:

- supervised urinalysis
- meaningful review
- choice of treatment and
- an independent and robust avenue for complaint

Another fundamental difference between peer led research like ICON's and SURIA's is our normative practice of meeting service users as they negotiate the litany of obligations and duties that are part of life as a client of this unusual form of public health provision. To this end, this report and the Lives on Hold Report that is being launched at the same time, are informed by data from research participants on the street, outside clinics etc. The objective of this form of research is to get an authentic and real-life overview of this lifestyle. In furtherance of our aim to unpack this narrative, we have developed these key principles that precipitate a nuanced overview of the efficacy of Irish MMT/OST, and in this case, that of the urban, frequently homeless, service user.

When the four principles are applied across ICON's work, the stark similarities become clear and demand a response from service providers and stakeholders from the sector. ICON's report is very impressive in this regard, with both reports simultaneously reinforcing each other's findings. What was a hypoth-

esis that was an outcome of repeated monitoring by SURIA is amplified by ICON's work. Both reports are similar, with almost identical findings and all are reiterated by ICON's research.

Using the four principles, ICON have demonstrated that for the North Inner City, there has been some improvement regarding urinalysis. While this is welcomed by SURIA, it is done so with caution, considering it is a likely outcome of enforced action due to an Equality Review that emanated from previous SURIA research. This examined urinalysis as an overly invasive practice, while the Farrell Report (2011) critiqued the propensity of Irish MMT to use sampling to evaluate dosages, takeaways and one could argue all aspects of MMT/OST care.

Moreover, this report also highlights that meaningful review remains an aspiration for many service users. Instead, the propensity of providers to use urinalysis to dominate, control and survey the lives of clients through punitive practices remain the norm. All are predicated on the reward/punishment binary that are advanced by testing and sanction.

It's like I am chained to my clinic, I can't just go on a holiday because if I have had a slip, I can't get takeaways.

Research Respondent ICON

Choice of treatment is crucial to a human rights-based model of MMT/OST and ICON's exploration of this illustrates the difference between other forms of Public Health and Irish MMT/OST. Almost 75% of ICON's research sample allude to never being offered an alternative to methadone, a practice that would be deemed unacceptable in any other public health model. This is indicative of the disdain in which service users are held by many service providers. An unfortunate outcome of this is the internalisation and normalisation of poor, non-evidence-based treatment. The qualitative data that ICON has gathered helps the reader understand this by showing that service users are expectant of poor treatment, many of their goals of treatment are limited by the continuous stigmatisation they endure, combined with the lack of privacy and ever-present threat of sanction, (Healy et al. 2023). There is little evidence of the development of therapeutic alliances between service users and providers, an essential element of recovery. 'Recovery' is also determined by service providers and is often evaluated by abstinence. The simple underpinnings of harm reduction are lost in a space dominated by prohibitionist discourse. The fundamentals of harm reduction, or a health led response are usually lost behind explicit demands and power imbalances between service providers and those that use services, all of which are captured perfectly in this report.

With this in mind, it is little surprise that many have little idea of how to make a complaint, with many stating that they would be reluctant to do so even if they did know how. Again, many service users believe that making a complaint is counterproductive and will likely result in reprimand or amplified poor treatment. In short, MMT clients engage with services in fear, and ICON have highlighted this excellently in this Report. Furthermore, much like SURIA's research findings, detoxification is rarely a decision made by service users, which again expounds how little autonomy clients have in their own treatment.

The use of care plans has been identified by SURIA as key to effective MMT/OST and ICON have added further credence to this in this Report. Almost one half of respondents do not know what a care plan is,

with over 60% postulating that they would like a care plan to underpin their treatment. Meaningful review is part of employing care plans, and the lack of opportunity to avail of this basic service is also explored in detail in this report.

In conclusion, ICON's report is skillfully crafted with many of the key aspects of the real-life narrative of urban MMT/OST clients examined discussed in detail, facilitating a glimpse into the lives of one of the State's most vulnerable cohorts. It confirms many of SURIA's conclusions and adds evidence-based findings of its own. As a standalone piece, it shows the lack of progress in MMT/OST in Ireland. It asks questions of over-burdened services and poor practices that have been normalised in the sector yet would be deemed unacceptable in other area of Irish public health. As part of a collection of data, analysis, and research, it challenges stakeholders and uncovers the catastrophic failure of the State. Many service users are from areas in the urban which have become the "ideal" environment for problem drug use, due to lack of opportunity, socio-economic discrimination and deprivation. What is possibly more concerning, is that in seeking an escape from this lifestyle, they have been further penalised as individuals who have "chosen" a life fraught with risk, crime and deviance. While this is potentially excusable for the laymen, the fact that this rationale has permeated the treatment sector is inexcusable. This Report, alongside SURIA's exploration of MMT/OST seeks accountability, monitors service provision and challenges the sector to use evidence based practices to advance better outcomes for vulnerable people.

REPORT RECOMMENDATIONS

This report provides in-depth and valuable evidence of the experience of service users of drug treatment services in Dublin's NEIC. Our recommendations are in line with previous research. Our Lives, Our Voice, Our Say, detailed a large number of recommendations under the 4 key monitoring points. This research demonstrates that there has been little development on a substantial number of those recommendations which still require urgent redress.

Supervised and Frequent Urine Sampling

While we welcome the significant decrease in the use of supervised urinalysis, 48% of service users are still required to give weekly tests.

Reiterate the call for the cessation of the use of urine sampling by all drug treatment service providers and by other agencies coming into contact with service users such as TUSLA, Refuges, Homeless Services.

1. Reiterate the call for the cessation to the use of urine sampling as an evidence based approach for clinical decisions in relation to service users, including as the basis for accessing treatment, withdrawing methadone or allocating 'take away' doses to service users and contingency management.

2. Reiterate the recommendation that the HSE provides training and awareness for medical and administrative staff on more evidence based approaches to providing adequate levels of treatment and care to service users, including the limitations of urine sampling as a condition for service users treatment.

3. Reiterate the recommendation that the HSE provides training and awareness for medical and administrative staff on the diverse experience of people accessing drug services, including specific issues arising from urine sampling for particular groups – for example women, transgender people, people with disabilities or people who may have suffered abuse.

4. Reiterate the recommendation that the HSE provides training and awareness for service providers on the limitations of urine sampling and resulting barriers to accessing important supports when urine sampling is used as a criteria to determine access to services such as, women's refuges.

5. Reiterate the recommendation that the HSE actively promote a culture of dignity, respect, and equality of participation for service users in the development and delivery of care plans and treatment to service users.

Meaningful Engagement and Participation for Service Users

6. Reiterate the recommendation that the HSE ensure an end to the culture of blame, stigma and punishment that is reflected in the experiences of service users documented in this report.

7. Reiterate the call for the HSE to put a greater emphasis on building a positive relationship and open dialogue between service users and service providers and for deeper and more meaningful service user engagement.

8. Reiterate the call for an immediate cessation to the partial of full suspension of medical treatment by service users or by pharmacies as a reaction to anti-social behaviour. This includes restricting methadone takeaways as a form of punitive action.

9. Reiterate the recommendation that the HSE uses the evidence contained in this report as the basis for assessing how current treatment structures impact negatively on the lives of service users or potential service users.

10. Reiterate the recommendation for a redesign of current treatment and dispensing structures that better facilitate the participation of service users in living a more dignified and fulfilled life.

11. Reiterate the recommendation that the HSE design and promote dispensing and treatment structures that are person-centered and flexible, recognise the diversity of service users and aim to facilitate service users to engage in employment, training, education and carrying out family and caring duties.

12. Reiterate the recommendation that the HSE ensure greater flexibility in how services are delivered and a choice of services to accommodate the diversity of people's health needs and circumstances. This includes for example, meeting gender specific needs, age needs, living conditions, disabilities, family or work commitments or issues arising from geographical distance between treatment services and where service users are living.

13. Reiterate the recommendation for the provision of financial assistance for service users who have to travel to treatment clinics or dispensing pharmacies to avail of services that are not locally available.

14. Reiterate the call for the finding of this report and previous report to be widely disseminated to both medical and administrative staff in all drug treatment services in Ireland with a view to encouraging a service wide shift to a more client service delivery model.

15. Reiterate the call for the HSE to actively support and resource the empowerment of service users with a view to building and developing the leadership of service users to self advocate and support other service users to do the same.

16. Reiterate the call for the HSE to recognise the value of consultation and that service users are diverse and are not represented by one umbrella organisation.

17. Reiterate the recommendation that the HSE put in place a multi-pronged approach to facilitate the participation of service users that draws on a range of engagement approached. For exam-

ple, consultation should include a number of opportunities for participation such as engagement with individual service users across different services and geographical locations. , focus groups with service users accessing different services and focus groups with a range of organisations representing or providing support to service users.

Treatment Choice and Treatment Plans

18. Reiterate the recommendation that the HSE engage with service users to review the provision of information on treatment choice- including suboxone, Subutex, Buvidal, methadone maintenance, methadone detox, methadone tablets, residential and community detox – and ensure it is accessible and usable for all service users in all drug treatment services. Provide information cards to service users that explains in an accessible way the nature and impact on their treatment choice as is currently done for service users taking Buvidal.

19. Reiterate the recommendation that the HSE ensure that when people start drug treatment, and at regular intervals thereafter, the implications for the different treatment choices available are more thoroughly discussed with them and reviewed regularly as their individual needs and circumstances change, ending the unform approach to treatment.

20. Reiterate the call for the HSE to be offer more flexible treatment options at more regular intervals taking into account the changing life circumstances, opportunities and challenges that are present at different stages in a person's life, particularly given the length of time that a person can be in opiate treatment.

21. Reiterate the recommendation that the HSE conduct a review of methadone dispensing practices, taking into account that supervised daily doses runs entirely counter to holistic approach to treatment with a significant impact on the overall well-being of people using drug services and are a barrier to effective participation in employment, education, society and family life. This review should take into account that most people availing of methadone treatment are stable and should not be required to attend every day for their daily doses. It should also consider, in particular, if consultation rooms could be used when dispensing methadone or if this could be more easily managed if the tablet form of methadone was available, as is the case with many other European countries.

22. Reiterate the recommendation that the HSE ensures all drug treatment services provide meaningful holistic care plans that are informed by service users' personal goals and care clearly documented in an accessible manner and are subject to regular review and update.

23. Reiterate the recommendation that physical copies of care plans are made available to service users and not just available on computers.

Effective Complaints Mechanism

24. Reiterate the recommendation that the HSE engage with service users to develop and implement a positive action plan to ensure that information on a complaints system is available in an accessible manner.

25. Reiterate the recommendation that the HSE ensure that all drug services create a supportive, open, and transparent environment and culture to lessen fear and perceptions that there will be negative consequences/reprisals for making a complaint.

26. Reiterate the recommendation that the HSE ensure that all service users are informed of their right to make complaints. This may include holding meetings to ensure that service users know how to make a complaint and are introduced to the complaints officer and patient advocates (and review officer) so that there is an independent system of complaints.

27. Reiterate the recommendation that the HSE ensure that service providers publish statistics, case studies and audits of complaints made by service users and use this information to inform their assessment of equality and human rights as part of their Public Sector Equality and Human rights Duty under Section 42 of the Irish Human Rights and Equality Commission Act of 2014.

Other Recommendations

Recommend that the Equality Review is reviewed on an ongoing basis to ensure that the HSE drug services are required to abide by the terms of the Equality Review in the same manner that service users are required to abide by the rules/ obligations/ sanctions imposed on them.

Add the 10th Amendment: There are currently nine grounds of discrimination set out in equality legislation including gender, civil status, family status, sexual orientation, religion, age, disability, membership of the Traveller community and race. Those experiencing socio-discrimination currently have no way of seeking any form of legal redress and have no protection in the law. Socio- economic discrimination can occur in many forms and can be experienced both individually and collectively. For service users in treatment, the addition of discrimination on socio-economic grounds would assist in reporting and addressing incidences of discrimination and thus address the impact of stigma in drug treatment services.

The development of the new National Drugs Strategy should incorporate the recommendations outlined in this report and ensure the meaningful involvement of service users in its design.

Mandatory training should be provided to those engaging in service users across the HSE and other state services (social care, homeless, prison and probation) on trauma informed care and health and person led approaches to addiction and treatment.

The Oireachtas Joint Committee on Drugs Use that is being established with a view to implementing the recommendations of the Citizens Assembly on Drug Use should review the recommendations in this report as part of their work.

APPENDIX 1

In 2018, CAN and SURIA carried out a survey of 132 service users which sought to elaborate on four main issues identified in a previous 2012 user-led survey of service users experience of drug treatment services in Ireland. The publication of Our Life, Our Voice, Our Say, which was informed by peer-led research by SURIA, stated that "serious human rights and equality concerns based on the lived experience of service users have been expressed" (SURIA 2018:5).

The four main issues identified in those pieces of research were:

- The practice and frequency of supervised urine sampling
- The engagement and participation of service users in drug treatment and service delivery
- Availability of information and access to treatment choices and care plans
- Availability of information on and access to an effective and transparent and accountable complaints mechanism

SURIA carried out further research which provided the basis for Nothing About Us, Without Us. The evidence gathered was used to inform an Equality Review by IHREC into drug treatment services and the subsequent development of an Action Plan.

HSE Equality Action Plan

In preparing the Equality Action Plan, the Commission asked that as a starting point, the HSE address the following:

- Address and prioritise the elimination of direct supervision of urine samples across HSE services in Ireland providing OST.
- Confirm that the necessary systems are in place to ensure that OST service users are not refused treatment on the basis of unsatisfactory samples and that drug testing is not used as a punitive action towards a service user.
- Confirm that the necessary systems are in place to ensure that the supervision of samples is randomized and occurs with a frequency that is in line with the HSE Guidelines.
- Address organisational equality arrangements.
- Equal Status Policy and Training
- The Public Sector Equality and Human Rights Duty [12]

12 *The project team were unable to find a copy of the HSE's statement on the Public Sector Duty. An email request to the HSE stated that it was not finalised as of the 21.10.23 due to the impact of covid but that work would be commencing on it.*

In 2020 the HSE presented their Action Plan which included the following actions:

- Address and prioritise the elimination of direct supervision of urine samples across HSE services in Ireland providing OST.
- That the practice of direct supervision of urine samples ceases across all HSE services providing OST.
- That systems are in place to ensure that OST service users are not refused treatment on the basis of unsatisfactory samples.
- That systems are in place to ensure that sampling is randomized and reduced in line with the HSE Guidelines.
- That OST service users are not treated less favourable when compared to a person who does not have a disability or a person.
- POCT kits are provided.
- Non routine direct supervision is not encouraged and must only take place with service user's consent.
- All service users should be informed of this from January 2020 through leaflets, information sessions.
- The National Addiction Advisory Governance Group (NAAGG) should have urine analysis on the agenda at monthly meetings.

APPENDIX 2: QUESTIONNAIRE

Service Users Rights in Action Group Survey 2023

This questionnaire is designed to capture the lived experience of people on Opioid Substitution Treatment and in treatment for opiate use. The information you give will be treated confidentially and used anonymously to inform a human rights campaign. You have the right to withdraw from this process at any time.

What area do you live in? _____

Where do you get your treatment? _____

What is your age? 18-24 ☐ 25-35 ☐ 36-45 ☐ 46-55 ☐ 56-65 ☐ 65+ ☐

What is your gender? Male ☐ Female ☐ Nonbinary ☐ Don't want to say ☐

How long have you been in opioid substitution treatment (e.g., methadone)?

Less than one year ☐ 1-5 ☐ 6-10 ☐ 11-15 ☐ 16-20 ☐ 21-25 ☐ 26+ ☐

Have you ever been offered an alternative to methadone? Yes ☐ No ☐ Don't kno ☐

Have you ever asked for an alternative to methadone? Yes ☐ No ☐ Don't know ☐

If yes, what were you offered?

Suboxone ☐

Bufadol ☐

Other ☐ What was it? _____

Has methadone improved the quality of your life? Yes ☐ No ☐ Don't know ☐

In what way?

_____

_____

b) Do you feel like you have ever been treated differently because you take methadone/ are in addiction?

Yes ☐ No ☐ Don't know ☐

If yes, how were you treated differently?

_____

_____

c) Overall, how would you describe the experience of being on methadone on a scale of 1 to 5

Bad 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ Excellent ☐

Have other treatments been offered to you? Yes ☐ No ☐ Don't know ☐

Treatment	When offered	What was your experience?
Counselling		
Hepatitis C Treatment		
Rehabilitation		
Support Programmes e.g., personal development		
Other (alternative treatment) – what was this?		

b) Were there any barriers to you accepting these treatments?

Access ☐

Childcare ☐

Confidentiality Concerns ☐

Other, please describe

_____

_____

Have you discussed detoxification or ongoing methadone maintenance treatment with your treatment team?
Yes ☐ No ☐ Don't know ☐

If yes, with who? _____ When? _____

Who initiated the subject? _____

How often has detoxification been discussed? _____

How did you find that discussion?

Very good ☐ Good ☐ Okay ☐ Poor ☐ Very Poor ☐

Do you know what a care plan is? Yes ☐ No ☐ Don't know ☐

Do you want to have a care plan for your treatment? Yes ☐ No ☐ Don't know ☐

13 Do you have personal goals for your care? Yes ☐ No ☐ Don't know ☐

If yes, what are they?

_____

_____

_____

(b) Have you discussed these goals with your treatment team i.e. in a care plan?

Yes ☐ No ☐ Don't know ☐

(c) How often do you have a meaningful discussion with your doctor about your care plan?

Regularly ☐ Seldom ☐ At the beginning ☐ Never ☐

(d) Have you achieved any of your goals? Yes ☐ No ☐ Don't know ☐

If yes, what are they?

_____

_____

_____

(e) Have you had an opportunity to discuss your treatment plan with anyone other than your doctor?

Yes ☐ No ☐ Don't know ☐

If yes, with whom and what was offered.

_____

_____

_____

14. How often do you give urine samples?

Daily ☐ 2-3 per week ☐ Weekly ☐ Monthly ☐ Rarely ☐ Never ☐

Other: _____

(a) Describe the way urine samples are taken? Please tick below

Supervised ☐ Supervised with mirrors ☐ Heat bottle ☐

Other please specify _____

(b) If it was supervised, was there a specific reason given for it?

Yes ☐ No ☐ Don't know ☐

If yes, what was the reason?

(c) In the last 2 years have you ever been refused treatment as a result of your urine analysis?

Yes ☐ No ☐ Don't know ☐

If yes, please explain

(d) In the last 2 years, was there a break in your treatment for any other reason?

Yes ☐ No ☐ Don't know ☐

If yes, were you offered any of the following?

Information ☐

Support ☐

The right to appeal ☐

If you appealed, what was the outcome?

(e) How did you find the appeal process?

Very Good ☐ Good ☐ Okay ☐ Poor ☐ Very Poor ☐

As a service user, have you ever been asked your opinion about how drug services are planned and delivered?

Yes ☐ No ☐ Don't know ☐

If yes, how did this happen?

Which service?	How were you asked?	What happened?

Have you ever received information on your rights in treatment services from the HSE?

Yes ☐ No ☐ Don't know ☐

If yes, how did you receive the information?

Information Sessions ☐

Spoke with HSE Staff ☐

Leaflets ☐

Focus Groups ☐

Surveys ☐

Other, please give details

If you could change anything about the Opioid Substitution treatment programme what would that be?

Do you know how to make a complaint? If yes explain how?

Have you ever made a complaint about the drug treatment services?

Yes ☐ No ☐ Don't know ☐

If yes, what was it about?

What was the outcome?

If no, why not?

Have you had experiences you would like to make a complaint about? If so, what were/are they?

Are you in employment? Yes ☐ No ☐ Don't know ☐

Are you in training? Yes ☐ No ☐ Don't know ☐

Are you in education? Yes ☐ No ☐ Don't know ☐

How does treatment affect your employment/education/training if at all?

Thank you for your time.

Coimisiún na hÉireann um Chearta an Duine agus Comhionannas
Irish Human Rights and Equality Commission

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