

Our Life, Our Voice, Our Say

PROJECT REPORT:

*“Applying a Public Sector Equality and Human Rights Duty Approach
to the Human Rights and Equality Issues Identified by
Service Users of Opioid Treatment Services”*

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2018



Placing People at the
Heart of Change

*Service Users
Rights in Action*

Acknowledgements

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The views expressed in this report are the views of the Project Steering Committee, and do not necessarily represent those of the Irish Human Rights and Equality Commission.

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Executive Summary

This report represents the findings and recommendations of the project “Applying a Public Sector Equality and Human Rights Duty Approach to the Human Rights and Equality Issues Identified by Service Users of Opioid Treatment Services”. This project is directed by a steering group, comprising services users and service user representatives, health professionals and members of the Public Sector Duty Team of The Irish Human Rights and Equality Commission (IHREC). It is facilitated by Community Action Network (CAN), a social justice NGO working with drug service users since 2009. The project aims to support the active involvement and leadership of the service users as well as the willing collaboration of representatives of the drug treatment services, in order to address effectively human rights and equality issues identified by the service users themselves.

There are approximately 10,000 service users of opioid treatment in Ireland. Service users come from a diverse range of backgrounds in terms of socio-economic status, gender, age, disability, education level, income and in terms of pathways that lead to problems with addiction. Serious human rights and equality concerns in relation to the lived experience of service users have been expressed in a submission to the HSE commissioned review, documented in “The Introduction of the Opioid Treatment Protocol Report” (Farrell Report, 2010)¹, in the findings of two rounds of peer led research (2012 and 2017), during two dialogue events, (2015 and 2016) and are repeated yet again in this report. The concerns relate to four main aspects of the drugs services, namely

The practice and frequency of **supervised urine sampling**; (Chapter 5)

The **engagement with and participation of service users** in drug treatment service delivery; (Chapter 6)

Availability of information on and access to **treatment choices and care plans**; (Chapter 7)

Availability of information on and access to an effective, transparent and accountable **complaints mechanism**. (Chapter 8)

Service users have named and given evidence of

- Degrading, undignified, invasive, embarrassing, judgmental experiences that often leave them feeling shamed, inadequate, worthless, powerless and angry.
- The impact of language, attitudes and beliefs that underpin their experience of availing of services.
- The lack of privacy and control over the way their day-to-day time is structured, given the demands of attending clinics and pharmacies and how this impacts negatively on their ability to work, conduct family and social life.
- The lack of meaningful, engaged and active participation in care plans, the lack of choice of treatment and sense of possible progression to full health and well-being.
- The lack of an effective complaints system that they know how to use and can believe in.

The following figures provide an overview of the main findings of the research under the four key issues:

- Urine analysis;

¹ This is the first external review of the Methadone Treatment Protocol in Ireland, known as the Farrell Report. It sought to examine the regulatory process and oversight of methadone and opiate dependence treatment, focusing on both the 1998 protocol and the processes by which treatment is implemented and delivered. Available at http://www.drugs.ie/resourcesfiles/reports/Opioid_Treatment_Protocol.pdf

- 40% of service users expressed that they did not like giving urine samples (supervised or not), 50% described it as degrading and 26% described it as undignified.
- 95% of women in the survey expressed dissatisfaction with the process, in particular given that the sampling system does not show consideration for female health realities such as periods.
- Meaningful engagement and participation;
 - 26% of respondents reported having a good or very good relationship with their doctor, a slight dis-improvement on the 2012 survey.
 - 84% reported that they have had no participation, and have not been asked their opinion in relation to their treatment.
- Treatment choice
 - 70% of respondents viewed treatment as a barrier to employment, with the times of the clinic, the stigma of being on methadone and the impact of methadone cited as reasons.
 - While 75% of respondents stated that they wanted a care plan, 76% reported that they had not been offered a care plan.
- Complaints mechanism:
 - 59% of respondents reported that they did not know how to make a complaint.

The report notes with dismay that the 2017 user-led survey demonstrates a deterioration in almost all the issues previously identified by service users in the 2012 user-led survey.

In addition to documenting the lived experience of service users and their efforts (including methodologies used) to have their concerns addressed, this report outlines the relevant national and international human rights and equality legal and policy infrastructure. It grounds the issues and evidence in HSE policy and Section 42 of the Irish Human Rights and Equality Commission Act 2014. Known as the Public Sector Equality and Human Rights Duty, Section 42 requires public bodies to take steps to “eliminate discrimination, promote equality and protect the human rights” of both its staff, and the persons to whom it provides services.

The report sets out 28 recommendations which should inform HSE plans, policies and actions to address issues identified in line with its Public Sector Equality and Human Rights Duty. All are based on the lived experience of people availing of drug services and are informed by principles and values which they feel are critical to the provision of drug treatment services such as:

- Dignity and respect;
- Participation and autonomy;
- Equal treatment;
- Proportionality;
- Accountability and transparency;
- Privacy.

If implemented, the recommendations would see the end of the degrading and inhuman practice of supervised urine sampling and the cessation to the use of urine sampling as an evidence base for clinical decisions. Instead they would ensure the centrality of a positive and supportive relationship between people accessing drug treatment services and people providing them that has respect and dignity at its core. Holistic and integrated treatment would facilitate not only the progressive realisation of the right to health and wellbeing but also to employment, education and participation

in family and community life. Active, engaged and meaningful service user participation in care planning that has built in regular review and treatment choice would take account of the changing life cycle and diverse needs of service users. Proactively supporting an open, transparent environment and culture where information is accessible, targeted and relevant would address existing fears in relation to making and effectively dealing with complaints. The drugs services could value accountability and become a learning service that strives for excellence.

Report Recommendations

This report provides in-depth and valuable evidence of the experience of service users of drug treatment services in Ireland. The issues identified by service users in this report should form part of the assessment of equality and human rights issues that the HSE has a statutory duty to undertake in accordance with Section 42 of the *Irish Human Rights and Equality Commission Act 2014*, the Public Sector Equality and Human Rights Duty. The recommendations set out below should inform HSE plans, policies and actions to address issues identified in line with its Public Sector Equality and Human Rights Duty.

Recommendations

Supervised and frequent urine sampling (Chapter 5)

Based on the lived experience of people availing of drug services of urine sampling as degrading and inhuman; and

Highlighting that the HSE commissioned 'Farrell Report' and HSE 'Clinical Guidelines for Opioid Substitution Treatment' both recognise that urine analysis may be conducted in an inhuman and degrading manner, and with a frequency that is unnecessary;

The project steering committee:

1. Calls for an immediate cessation to the practice of supervised urine sampling by all drug treatment service providers
2. Calls for a cessation to the use of urine sampling as an evidence based approach for clinical decisions in relation to the service users, including as the basis for accessing treatment, withdrawing methadone or allocating "takeaway" doses to service users and contingency management
3. Recommends 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 accessing treatment
4. Recommends 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
5. Recommends 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, for example, women's refuges
6. Recommends 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 (Chapter 6)

Based on the lived experience of people availing of drug services of the key role that a positive and supportive relationship between people accessing drug treatment services and people providing drug treatment services (including doctors and staff in clinics and pharmacies) plays in terms of human dignity and drug treatment; and

Highlighting that the HSE 'Clinical Guidelines for Opioid Substitution Treatment' recognise the importance of dignity when engaging with service users, including building trust and adjusting the nature of interventions to suit individual service users;

Recognising the important role that integrating treatment with participation in employment, education and family and community life can have for recovery and recognising that the HSE commissioned 'Farrell Report' recommends that an integrated services approach should account for family, community and user groups as well as a service model outside of Dublin;

The project steering committee:

7. Calls for the HSE to ensure an end to the culture of blame, stigma and punishment that is reflected in the experiences of service users documented in this report.
8. Calls 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.
9. Calls for an immediate cessation to the partial or full suspension of medical treatment by service providers or by pharmacies as a reaction to anti-social behaviour. This includes restricting methadone takeaways as a form of punitive action.
10. Recommends 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.
11. Recommends, based on an assessment as outlined above, a redesign of current treatment and dispensing structures that better facilitate the participation of service users in living a more dignified and fulfilled life.
12. Recommends that that HSE design and promote dispensing and treatment structures that are person-centred 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.
13. Recommends that the HSE ensure greater flexibility in how services are delivered and a choice of services to accommodate the diversity of peoples' health needs and circumstances. This includes, for example, meeting gender specific needs; meeting the needs of people with disabilities; taking into account family or work commitments; and taking into account issues arising from the geographical distance between treatment services and where service users are living.
14. Recommends 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.
15. Calls for the findings of this 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-centred service delivery model.
16. Calls 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.
17. Calls for the HSE to recognise the value of consultation and that service users are diverse and are not represented by one umbrella organisation.
18. Recommends that the HSE put in place a multi-pronged approach to facilitate the participation of service users that draws on a range of engagement approaches. For example, consultation should include a number of opportunities for participation such as engagement with individual services 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 supports to service users.

Treatment choice and treatment plans (Chapter 7)

Based on the lived experience of people availing of drug treatment services of lack of information and engagement with their treatment plans;

Highlighting that the HSE commissioned 'Farrell Report' recommends the need to develop a more structured care planning process and care plans subject to regular review and update; and

Highlighting that the HSE 'Clinical Guidelines for Opioid Substitution Treatment' recognise that service users should be fully involved in the development of their care plans, setting appropriate treatment goals and reviewing their progress in treatment;

The project steering committee:

19. Recommends the HSE engage with service users to review the provision of information on treatment choice - including suboxone, subutex, 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.
20. Recommends 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 uniform approach to treatment.
21. Calls for the HSE to 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.
22. Recommends that the HSE conduct a review of methadone dispensing practices, taking into account that supervised daily doses runs entirely counter to a holistic approach to treatment with a significant impact on the overall wellbeing 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.
23. Recommends that the HSE ensures that all drug treatment services provide meaningful holistic care plans that are informed by service users' personal goals and are clearly documented in an accessible manner and are subject to regular review and update.
24. Recommends that physical copies of care plans are made available to services users, and not just available on computers.

An effective complaints mechanism (Chapter 8)

Based on the lived experience of people availing of drug services of the lack of information about how to make a complaint and the fears about making a complaint;

Highlighting that the HSE commissioned 'Farrell Report' recognises the need to review the lines of reporting and accountability in all of the services; and

Highlighting that the recommendations on how public hospitals could improve their complaints processes set out in the 2015 Ombudsman Office could inform improvement of complaints processes in drugs services;

The project steering committee:

25. Recommends 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.
26. Recommends 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.
27. Recommends that the HSE ensure that all service users are informed of their right to make a complaint. This may include holding meetings to ensure that service users know how to make a complaint and are introduced to their complaints officer. Care should be taken to avoid conflicts of interest between complaints officers and patient advocates (and review officers) so that there is an independent system of complaints.
28. Recommends 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 issues as part of their Public Sector Equality and Human Rights Duty under Section 42 of the *Irish Human Rights and Equality Commission Act 2014*.

1 Introduction and Background

There are approximately 10,000 service users of opioid treatment in Ireland. Service users come from a diverse range of backgrounds in terms of socio-economic status, gender, age, disability, education level, income and in terms of pathways that lead to problems with addiction. At the core of the evidence presented in this report are the findings of a survey of service users conducted in 2017. One hundred and thirty two service users participated in the user-led survey which sought to elaborate on four main issues identified in a previous 2012 user-led of service users experience of drug treatment services in Ireland.

The four main issues are;

- A. The practice and frequency of **supervised urine sampling**; (Chapter 6)
- B. The **engagement with and participation of service users** in drug treatment service delivery; (Chapter 7)
- C. Availability of information on and access to **treatment choices and care plans**; (Chapter 8)
- D. Availability of information on and access to an effective, transparent and accountable **complaints mechanism**. (Chapter 9)

The 2017 user-led survey demonstrates a deterioration in almost all the issues identified by service users in previous user-led survey and in other projects.

This report represents the findings and recommendations of the project “Applying a Public Sector Equality and Human Rights Duty Approach to the Human Rights and Equality Issues Identified by Service Users of Opioid Treatment Services”. The purpose of this project is two-fold.

The primary purpose of the project is to build on the evidence-base developed through previous user-led research conducted into the experiences of service users in opioid treatment services, and to link these issues with the human rights of the service users.

The project also seeks to elaborate and demonstrate the methodology and approach of how service users can utilise a human rights approach to campaigning on their issues, and represent their rights to a public body within the context of that public body’s statutory obligations under Section 42 of the Irish Human Rights and Equality Commission Act 2014.^{2 3} Known as the Public Sector Equality and Human Rights Duty. Section 42 requires public bodies to take steps to “eliminate discrimination, promote equality and protect the human rights” of both its staff, and the persons to whom it provides services. (see 1.1.3 for more on the Public Sector Equality and Human Rights Duty).

This project was coordinated by Community Action Network (CAN)⁴ with support by the Irish Human Rights and Equality Commission from 2015 to 2017.

CAN, a social justice NGO based in Dublin, has worked with service users and service user representatives in a process known as Service User Rights in Action for some time. In 2015 they assembled a Project Steering Committee which also included medical professionals and staff from

² <https://www.ihrec.ie/our-work/public-sector-duty/>

³ The methodology of engagement elaborated in this report seeks to break the silence of people experiencing oppressive structures in their lives, bring those lived experiences together as core issues, imagine a better future by identifying the changes that need to occur, and move together by identifying forms of action to make change happen.

⁴ http://canaction.ie/can_15/scripts/page/home.php?gi_sn=595caef215c27%7C0

the IHREC. The Project Steering Committee undertook extensive user-led research into the lived experiences of service users of drug treatment services. Other engagement activities included dialogue events to which a range of stakeholders were invited, and meetings with HSE and Department of Health officials.

Report structure

This report will describe the experiences of service users as captured through the user-led research and dialogue events which have been undertaken in the context of this project. Chapter 1 outlines the background to the project. Chapter 2 provides an overview of the approach and methodology used to facilitate service users as rights holders to express their experiences, to advocate for change and to engage with the Health Services Executive (HSE) to present these findings in the context of the HSE's Public Sector Equality and Human Rights Duty. An overview of human rights and equality legislative and policy frameworks relevant to the provision of health services in Ireland is provided in Chapter 3, with Chapter 4 providing an overview of relevant health policies in Ireland. Chapters 5-8 present the four main issues identified during the extensive user-led research. The report recommendations are presented at the start of the report, after the executive summary.

1.1.1 Early stages of identifying human rights and equality issues within drug treatment services

Set up in 2009, the Rialto Rights in Action Group (RRIAG) was established with the support of CAN to empower residents experiencing inequalities to adopt a human rights-based approach to issues of health and housing.⁵ RRIAG first became involved in the issue of methadone use and treatment protocols because of a community led audit on health needs in the Rialto area called "Community Health, Community Wealth."⁶ Serious concerns emerged about the lived experience of people who are on long-term medication in the context of opioid treatment services. The RRIAG went on to establish clear linkages between the issues identified and the human rights of service users affected, in particular their right to health.

In 2010, the RRIAG made a submission to the HSE-commissioned report "The Introduction of the Opioid Treatment Protocol report" (Farrell Report)⁷ in which they called for:

- An end to the current practice of urine sampling immediately;
- Compulsory and meaningful treatment plans;
- Real treatment choice.

The Farrell Report, produced by Professor Michael Farrell and Professor Joe Barry, contained an extensive list of recommendations, many of which, this report argues, have not been acted upon.

In 2012, the Service Users Rights in Action (SURIAG), which emerged from the work of the RRIAG was formed to campaign on the non-implementation of the recommendations of the Farrell Report. SURIAG are a coalition of Drug Service Users, service user representatives and community activists, facilitated by CAN.

⁵ http://canaction.ie/can_15/scripts/page/our_work_human_rights_housing.php?gi_sn=4fdb415fc4f75%7C0

⁶ Fatima Regeneration Board (2009) "Community Health, Community Wealth- Rialto's health and wellbeing: Local needs and community solutions." *Participatory Research and Action*.

⁷ This is the first external review of the Methadone Treatment Protocol in Ireland, known as the Farrell Report. It sought to examine the regulatory process and oversight of methadone and opiate dependence treatment, focusing on both the 1998 protocol and the processes by which treatment is implemented and delivered. Available at http://www.drugs.ie/resourcesfiles/reports/Opioid_Treatment_Protocol.pdf

In 2012 SURIAG interviewed 107 service users to establish their lived experience of the four issues identified above, and to establish what progress, if any, had been made in relation to the human rights and equality issues previously identified.⁸

On foot of this survey, SURIAG made submissions calling for a review of the protocol for opioid treatment services

In 2014, the group considered how to exert pressure on the drugs services and have the issues identified, recognised and addressed. All explorations of possible ways of engaging with “decision-makers” and “power-holders” identified in the power mapping exercises served to highlight the complete lack of power and societal supports of this particular group. (See Chapter 3 for an explanation of the process of power mapping). Analysis of the research results identified the internalised powerlessness of a group of service users whose experience is influenced at all levels by the criminalisation of drug use – a feature that individuals carry with them in all their experiences of trying to overcome their initial addiction. The group felt that there would be little public sympathy for their issues and to seek to change the prevailing attitudes and prejudices towards them would be at a huge additional cost to their sense of self-worth. The group sought instead to strengthen its power base and seek to build up the support of allies.

In 2014 the group approached President Michael D. Higgins for his support in calling the first “dialogue event” of a microcosm of the drugs services with the Office of the Ombudsman and the Irish Human Rights and Equality Commission in attendance. (an explanation of a “dialogue event” is provided in Chapter 3) The purpose of this dialogue event was to engage key actors in a collective inquiry into how the human rights and equality issues identified within drugs services can be addressed and who has the power to make this happen.

1.1.2 Initiating the project: “Applying a Public Sector Equality and Human Rights Duty Approach to the Human Rights and Equality Issues Identified by Service Users of Opioid Treatment Services”

In 2013 SURIAG made a submission to the Irish Human Rights and Equality Commission on what it called the “human rights violations in relation to how people who are on long term methadone are treated”.⁹

Since 2015, the Irish Human Rights and Equality Commission has supported CAN to enable service users to highlight and address the issues they experience with drug treatment services. From the outset it was decided that this work should be conducted within the context of the statutory obligations that public services in Ireland have to eliminate discrimination, promote equality and

⁸ 2013, Service Users Rights in Action. “Submission to the Irish Human Rights and Equality Commission, 2012”. On file with the Irish Human Rights and Equality Commission. Main findings included:

- 65.7% of interviewees found the practice of urine testing degrading.
- There was little consistency in the frequency of testing across the service, with 52.3% of respondents reporting being tested weekly, and 24.7% reported being tested every two weeks.
- There was little consistency in the methods used, with 20% reporting being supervised without mirrors, 21.9% reporting the use of heat bottles and 54.2% reporting being supervised with mirrors.
- 83% said they were not asked for their opinion in relation to a review of their treatment
- 62% reported never been given a care plan.
- 43% never felt they had a meaningful discussion with a doctor while a further 34% did not know this was an option.

⁹ 2013, Service Users Rights in Action. “Submission to the Irish Human Rights and Equality Commission, 2012”. On file with the Irish Human Rights and Equality Commission

protect the human rights of the people to whom they provide services and to their staff. Known as the “Public Sector Equality and Human Rights Duty” this statutory duty is contained in Section 42 of the Irish Human Rights and Equality Commission Act 2014.¹⁰

1.1.3 The Public Sector Equality and Human Rights Duty

Section 42 of the Irish Human Rights and Equality Commission Act 2014 places a positive duty on public sector bodies to have regard to the need to eliminate discrimination, promote equality, and protect human rights, in their daily work. This is an innovative development in Irish equality and human rights legislation and presents a valuable opportunity for public bodies to embed human rights and equality considerations into their functions, policies and practices.

Section 42 states that:

42. (1) A public body shall, in the performance of its functions, have regard to the need to:

1. eliminate discrimination,
2. promote equality of opportunity and treatment of its staff and the persons to whom it provides services, and
3. protect the human rights of its members, staff and the persons to whom it provides services.

Section 42 of the IHREC Act 2014 sets out three core steps to be taken by public bodies:

1. In preparing strategic plans, public sector bodies must assess and identify the human rights and equality issues that are relevant to their functions. These issues must relate to all of its functions as policy maker, employer and service provider.
2. Public bodies must then identify the policies and practices that they have in place or that they plan to put in place to address these issues.
3. Finally, in their annual reports, or equivalent documents, public bodies must report in a manner accessible to the public on their developments and achievement in that regard.

This project aims to support the active involvement and leadership of service users availing of opioid treatment services as well as the willing collaboration of representatives of the drug treatment services, in order to address effectively the human rights and equality issues identified by services-users.

As set out above, the HSE and the Department of Health are required under Section 42 of the IHREC Act 2014 to assess these issues within the context of their different functions, and to identify the policies and practices that they have in place or that they plan to put in place to address these issues. They must also report on progress in relation to the issues annually, in a manner that is accessible to the public.

IHREC’s support of this project comes within its own obligations under Section 42(3) of the IHREC Act to develop guidance and provide support to public bodies on implementing the Public Sector Equality and Human Rights Duty. This project therefore seeks to demonstrate how service users may identify and communicate issues they experience in terms of equality and human rights. It also seeks to facilitate and highlight the role of meaningful engagement between service users as rights holders, and public service providers within the context of the service provider’s Public Sector Equality and Human Rights Duty under Section 42 of the IHEC Act 2014.

¹⁰ <https://www.ihrec.ie/our-work/public-sector-duty/>

1.1.4 Overview of project activities - Dialogue events and engagement

In July 2015 a dialogue event was convened by CAN with a number of key institutional stakeholders working in drug treatment services. The event was attended by managers of drug treatment services, NGOs, service users, GPs, medical and administration staff, regional staff, national policy makers, Ombudsman and IHREC. This first dialogue was supported by President Michael D. Higgins.

Around the same time, a consultation with Service Users Rights in Action was also facilitated by CAN as part of the Irish Human Rights and Equality Commission's consultation process for the development of its statement of strategy in 2015.¹¹

A second dialogue event was held in November 2016. As with the previous dialogue event, CAN convened a microcosm of the drugs services, who together with representatives of the IHREC and the Office of the Ombudsman explored how best to ensure that the named issues could be addressed and services delivered in a manner that is in line with the Public Sector Equality and Human Rights Duty. This second dialogue event was attended by Catherine Byrne TD, Minister of State at the Department of Health with responsibility for Health Promotion and the National Drugs Strategy. Minister Byrne invited IHREC to write to her, to inform her of the issues being identified through the project.¹²

At both these dialogue events people who have lived with drugs services for many years have talked about their lived experiences. These experiences included:

- Degrading, undignified, invasive, embarrassing, judgmental experiences that have left them feeling shamed, inadequate, worthless, powerless and angry.
- The impact of the language, attitudes and beliefs that underpin their experience of availing of services.
- The lack of privacy and control over the way their day-to-day time is structured, given the demands of attending clinics and pharmacies and how this impacts negatively on their ability to work, conduct family and social life.
- The lack of meaningful, engaged and active participation in care plans, the lack of choice of treatment and sense of possible progression to full health and well-being.
- The lack of an effective complaints system that they know how to use and can believe in.

The Project Steering Committee subsequently met with officials from the Department of Health in February 2017. The Project Steering Committee presented the Department officials with a draft interim report on the project which included the preliminary findings of the user-led research. The project steering committee requested that they meet with the Steering Committee for the development of the new national Drugs Strategy to present these findings.

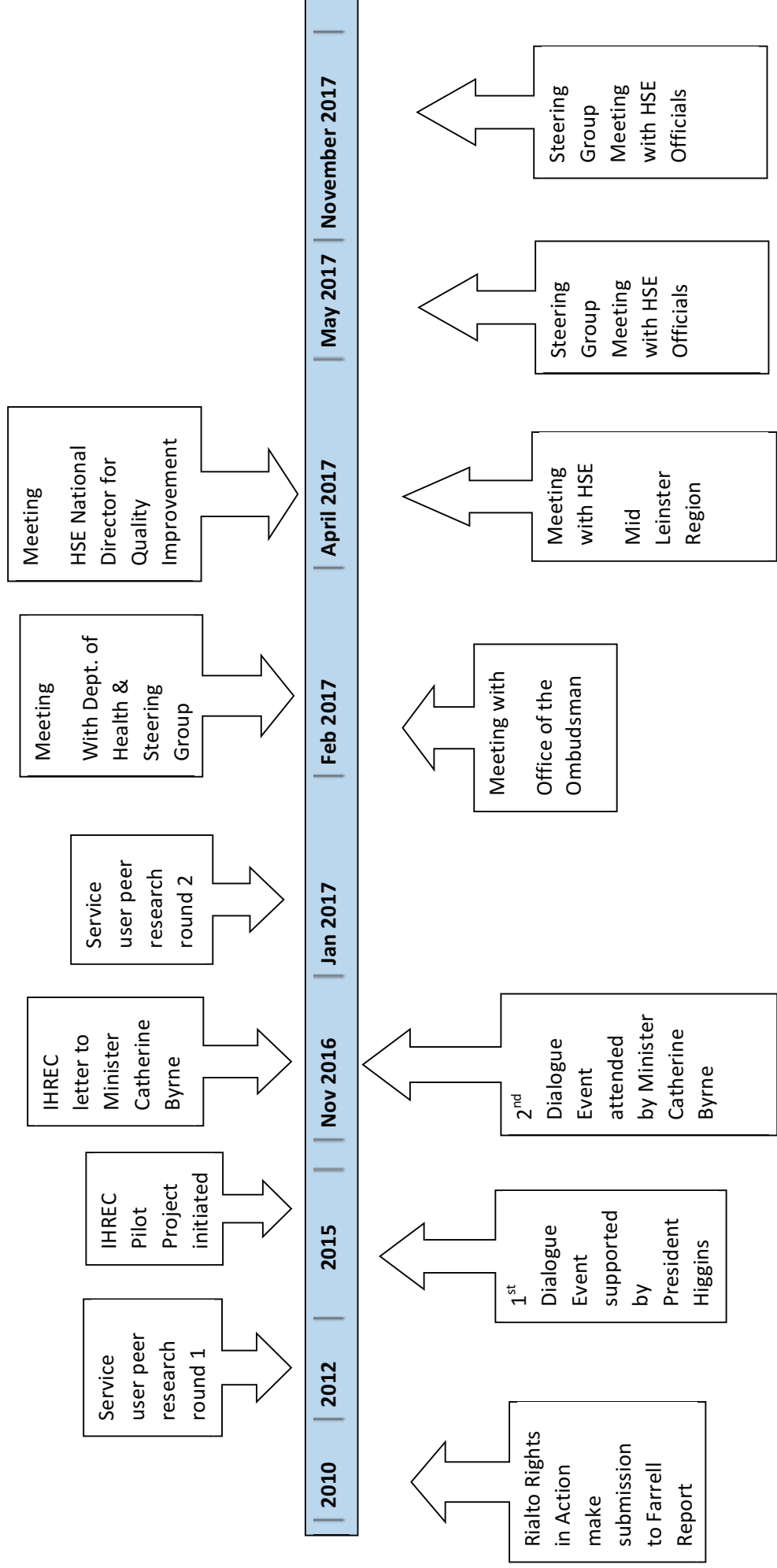
A meeting was also held between the Project Steering Committee and the Office of the Ombudsman on 12th January 2017 to discuss and seek advice on issues presented during the dialogue event specifically relating to the absence of an effective complaints process.

See Figure 1 for a timeline of the key project milestones.

¹¹ <https://www.ihrec.ie/download/pdf/strategystatement.pdf>

¹² A letter was issued by IHREC's Chief Commissioner Emily Logan to Minister Byrne on 15th December 2016

Figure 1: Key project milestones



1.1.5 Summary of research findings and key issues identified

Chapters 6-9 describe in detail the experiences of service users as captured through user-led research and dialogue events which have been undertaken in the context of this project.

As outlined above, in July 2015 and November 2016, “Dialogue events” were convened by CAN with service users active in SURIAG and a number of key institutional stakeholders working in drug treatment services. The “Dialogue” event inquired into how the lived experience of service users in opioid treatment services engage equality and human rights.

The Dialogue events have confirmed the importance of this project’s emphasis on peer-led support and empowerment, rooted in the real lived experiences of methadone users.

Service users became involved in the group because they wanted to see change, after many years of frustration about discrimination and poor services:

“I got involved in this because I really questioned how people were treated on methadone”;

Service users at the dialogue events spoke about the importance of the human rights based approach (HRBA) to addressing a wide range of issues, ranging from poor quality of services from doctors, poor access to services, a lack of an independent complaints system, and multiple incidences of discrimination and poor treatment and treatment choice.

“For me it is humiliating being tested and I wanted to see a change to all of this”;

“For me having a human rights focus on service users was very important, it was degrading how we are treated and with no one behind you to help you get clean”;

“I got involved at the beginning because of one of my experiences with a doctor, who treated me so badly, he made derogatory comments about my appearance and about me...I made a complaint against him, but that went nowhere”.

Most recently, members of the Project Steering Committee conducted a follow up survey to the 2012 SURIA user-led survey. The results of the 2017 survey are presented in detail in Sections 5-8 of this report under 4 thematic areas: urine analysis; meaningful engagement and participation; treatment choice and complaints mechanisms. The following figures provide an overview of the main findings of the research user the four key issues:

- Urine analysis;
 - 40% of service users expressed that they did not like giving urine samples (supervised or not), 50% described it as degrading and 26% described it as undignified.
 - 95% of women in the survey expressed dissatisfaction with the process, in particular given that the sampling system does not show consideration for female health realities such as periods.
- Meaningful engagement and participation;
 - 26% of respondents reported having a good or very good relationship with their doctor, a slight dis-improvement on the 2012 survey.
 - 84% reported that they have had no participation, and have not been asked their opinion in relation to their treatment.
- Treatment choice

- 70% of respondents viewed treatment as a barrier to employment, with the times of the clinic, the stigma of being on methadone and the impact of methadone cited as reasons.
 - While 75% of respondents stated that they wanted a care plan, 76% reported that they had not been offered a care plan.
- Complaints mechanism:
 - 59% of respondents reported that they did not know how to make a complaint.

The 2017 user-led survey demonstrates a deterioration in almost all the issues previously identified by service users in the 2012 user-led survey and in other projects.

2 Project Methodology

The project “Applying a Public Sector Equality and Human Rights Duty Approach to the Human Rights and Equality Issues Identified by Service Users of Opioid Treatment Services” used a mixed-methods approach to achieve its aims. The project was coordinated by CAN who convened a project Steering Committee comprised of CAN and IHREC staff, service users involved in SURIAG, GPs and representatives from community groups.

At the core of the project is what came to be called the “CAN Method” of engagement by the project Steering Committee. The “CAN Method” seeks to break the silence of people experiencing oppressive structures in their lives, bring those lived experiences together as core issues, imagine a better future by identifying the changes that need to occur, and move together by identifying forms of action to make change happen.

The user-led survey conducted in December 2016 and January 2017 used a semi-structured questionnaire designed and administered by service users from the project Steering Committee. Additional quotes from service users were provided by Steering Committee member Richard Healy, Irish Research Council Scholar at the Department of Sociology in the University of Maynooth who has conducted in-depth interviews with service users on their experiences using opioid treatment services in Ireland as part of his PhD research.

The “CAN Method”

Community Action Network is a social justice NGO that places people at the heart of change. A core feature of CAN’s work is to build the inherent leadership of people and communities to challenge and change unjust and inequitable policies and structures of decision-making. In so doing, it seeks to change the power relationship between people experiencing inequality, ‘service users,’ decision-makers, and ‘duty bearers,’ by using a human rights based approach. A human rights based approach is about empowering people to know and claim their rights and increasing the ability and accountability of individuals and institutions who are responsible for respecting, protecting and fulfilling rights. It is guided by principles of participation, social justice and equality.

CAN has developed many different tools, strategies, initiatives and templates to arrive at outcomes that deliver positive sustainable change in the life experience of those who face structural injustice and inequality. Over time, these various tools have merged and diverged, coalesced and grown, developed and changed, so that now there is a process that is recognisably the “CAN Method” - a structured and outcomes-driven template for intervention.

CAN has applied the following strands to its work with people who use drug treatment services to call for the protection of human rights in the delivery of drug treatment services:

- **Breaking the silence:** A range of techniques for eliciting the lived experience of those who have been affected by social injustice or inequality.
- **Inside out analysis:** Ways of questioning the systems, structures and processes that cause and perpetuate inequality, from the lived perspective of those affected by it.
- **Imagining a better future:** Strategies for imagining a better future founded on strong community leadership and capacity building, and focused on creating new structures to reflect change in action.
- **Moving together:** A range of strategies for engaging in positive collective action for change and for developing sustainable cross-issue partnerships.

2.1.1 Breaking the silence

From the beginning, this project has been grounded in the lived experience of drugs service users. They have broken the silence of living for many years with methadone treatment. They have done this in groups, on video, through the two rounds of surveys (2012 and 2017), through dialogue events (explained in more detail at para 2.2.5), in seminars, reports and meetings with service providers.

The first step is to facilitate the individual to speak out loud of their experience. When they do this with others in an atmosphere of respect and dignity, they can quickly begin to identify the patterns and similarities across their stories. This makes it possible for them to name the core issues that contribute to this collective experience of inequality and powerlessness.

‘Breaking the Silence’ has been an *ongoing feature* of the project as new people get involved and new ways of presenting the experience are required. As engagement with internal and external service providers and policy-makers has developed it is essential to revisit the impact of giving voice to this lived experience and to pay attention to the many ways in which service users can be silenced and experience unequal and degrading power relations. In this way it is core to the ongoing process of service users taking and exercising power.

2.1.2 Inside out analysis

Once issues are named, they can be inquired into. This begins with the lived experience as described above and moves to an understanding of the interconnected web of cultural, political and economic factors that keep the issues in place. This process is a key enabler of civic engagement, and represents *the shift from needs to rights* as people begin to understand the power dynamics that govern their lives.

The 2012 and 2017 surveys play a crucial role in getting the community and cultural perspectives of service users. Having analysed the issues, CAN and the service users linked them to the right to adequate health as enshrined in the International Convention of Economic, Social and Cultural Rights and the European Social Charter (Revised), both of which Ireland has ratified in international law.

Framing the named issues in human rights terms was a very empowering experience for the group of people who use drug treatment services. In so doing, it shifted the focus from them as individuals, who are ‘failures, inadequate, in need, powerless,’ to the systems and services that perpetuate the indignities they experience. The human rights based approach empowers users to hold the services to account and to demand to be active participants in the progressive realisation of their right to adequate health. **It restored a sense of dignity and pride in people** who now felt they had a voice and could take collective action.

2.1.3 Imagining a better future

Reawakening the belief that change is possible is often challenging to people and communities who have lived with inequality for generations. This was the case with the group of service users, many of whom have been using opioid treatment services for over 20 years. It was and continues to be critically important that those of us who lead this change initiative hold a powerful vision and help service users to deal with limiting assumptions about what is possible.

One of the strategies for envisioning a better future was focused on creating new structures to reflect change in action. This is a rights-holder led campaign that has the support, encouragement

and active engagement of many allies, all working together in an atmosphere of mutual respect and equality of participation. From the outset, this has been a significant feature in validating the negative impact of the lived experience of service users and the need for change in how services are delivered. Another strategy for imagining a better future has been the simple task of service users setting their own indicators for the progressive realisation of their right to health in relation to their named issues.

2.1.4 Moving Together

Moving together and acting with intention to change systems has taken many forms of action. But it has been characterised by an ongoing process of introducing new allies. While this can often be a delicate time as people from different backgrounds and life experiences find ways to create new structures and ways of working together that reflect change in action, this has not been the case in this project.

The core group now consists of a large collaboration of service users, ex-service users, service user representatives, community activists, general practitioners, a PHD student, representative of the IHREC and CAN. This group has the support of others working within and without the drugs services. Each member makes a different and valuable contribution, all of which are valued equally. Time and attention is paid to open communication, planning, equal representation and voice at meetings and ongoing reflection and shared learning.

The active participation of clinicians has enhanced the campaign, giving validation to the issues, how they are experienced and the need for change. This has been all the more significant in a system that is dominated by clinical decision-making, which is off limits for inquiry and complaint. The IHREC involvement has given external authority to the call for action and locating it within the Section 42 Public Sector Equality and Human Rights Duty has given direction to how change can be achieved. It also provides a statutory framework within which service users can press for change from HSE, HSE providers and Department of Health. Securing Pilot Project status within the IHREC has given urgency and authority to claim spaces for service user engagement around issues that can be formally named and validated as human rights and equality issues. The ongoing support of the Office of the Ombudsman has also had a significant impact on how the issues are perceived by service users and providers alike.

2.1.5 Project Dialogue events

Dialogue was chosen as a system change methodology for this project. As outlined earlier, to date we have held two dialogue events, bringing together service users, service user representatives, community activists, local and regional service providers (both administrative, and clinical personnel), policy makers, the Minister with responsibility for Drugs policy and services and key outside agencies such as the Office of the Ombudsman, the Prison Services, a representative of the Irish Medical Council Ethics Committee, and the IHREC. CAN facilitated both dialogues which have been an attempt to build ownership and engagement with the process of making the drugs services more human rights and equality compliant.

The invitation to dialogue is an invitation to sit in non-operational space and inquire into the diverse experience of the named issues. On both occasions (2015 and 2016), the process of dialogue has had a major impact on those participating. Each dialogue facilitated conversations that were more

open and honest, where differences were named but not defended and where challenges, constraints and opportunities were inquired into in a way that has helped build collective ownership of the current reality. They have also been disturbing experiences, raising feelings of vulnerability in those participating as they come to grips in a new way with the system within which they all operate.

The dialogues have been successful in generating significant meetings with power-holders and conversations about the need and focus of the required change.

CAN's understanding of Dialogue is primarily about creating the space for learning and listening differently to one another. It happens when people are prepared to sit, talk, think and feel together in a way that entertains the possibility that there is more than one valid experience, view point of perspective. It is different to discussion, debate, negotiation or decision-making. In those forms of meeting, people tend to plan strategies in advance, hold on to and defend their differences.

Dialogue is underpinned by four distinct practices:

- Speaking one's true voice and encouraging others to do the same.
- Deep, mindful, listening both within oneself and to others. Listening not just to what is said but to what is not said.
- Respecting others by listening to what they are saying, whether we agree with them or not. Acknowledging that each person has a legitimate reason for holding their point of view.
- Suspending one's own reactions, opinions and the certainties that lie behind them, so that we can listen without judgment to that of others. Being mindful of the limiting assumptions we make in relation to others.

When CAN engages in a process of dialogue, it uses these practices to understand how we act and behave in relationship with each other at the moment. CAN believes that when we all fully understand what the current culture of engagement is a different future can then be explored.

Alongside these practices Dialogue incorporates a 'whole systems' change methodology. The belief underpinning a Whole Systems Approach is that we only see the world from one perspective/experience/ expertise but when we see it as "a whole" we have so much more knowledge with which to work and plan for the future. This knowledge is generated by;

- Having a microcosm of the whole system present. Therefore those invited need to represent all the different perspectives, experiences and knowledge in relation to drugs services
- Facilitating an inquiry and dialogue into the experiences of service users, service providers and policy-makers of the named issues in a safe, non-judgmental environment. This safety is created through the invitation process, the introduction of basic dialogue skills and skilled facilitation.

2.1.5.1 Identifying principles and values relevant to the project

During the dialogue events, user-led research and project steering committee meetings, service users identified a range of principles and values which they felt are critical to the provision of drug treatment services. These values and principles were used by participants throughout the project to express their own lived experiences of treatment services. The principles and values identified were:

- Dignity and respect
- Participation and autonomy;

- Equal treatment;
- Proportionality;
- Accountability and transparency;
- Privacy.

2.1.6 Empowering leaders

Building the leadership and awareness and skills of service users has played a significant role in igniting the belief that change is possible as part of the work of this project. CAN has offered ongoing support and leadership development to participating service users outside the project meetings. This has consisted of one-to-one support and group training. Some of those participating have engaged in a leadership development programme facilitated by CAN and accredited at Level 8 by Maynooth University. This has included modules on leadership, strategies for change, understanding collaboration and complexity, all of which have been applied to the experience of being involved in and reflecting upon this project.

Methodology of service user led research

A small group of service users who are members of the Service Users Rights in Action (SURIAG) worked with CAN and IHREC to develop a questionnaire and prepare for carrying out the 2017 peer-led research. The work began on 27th of Sept 2016. The group was involved in the redesign of the 2012 questionnaire and tested it out on a small number of service users. With the feedback from the sample testing the group developed what they considered to be an informative and appropriate questionnaire. They discussed the experience of interviewing and being interviewed and drew upon previous training they had participated in regarding peer led research.

Four members of the group carried out the research between November 2016 and April 2017. They spoke to people on an individual basis who are attending the drug services within the Dublin and Kildare regions. The cohort reflects people in a variety of circumstances, all of whom are accessing the services.

Those leading the research shared initial findings with a large group (60+) of service users at the Talk Time meeting, held in the North Inner City on the 10th of March. They received feedback and confirmation that the findings were in line with the lived experience in the room.

Additional research data was provided by another SURIAG member Richard Healy, Irish Research Council Scholar at the Department of Sociology in the University of Maynooth who has conducted in-depth interviews with service users on their experiences using opioid treatment services in Ireland as part of his PhD research.

3 Legal Frameworks – Human Rights and Equality

Introduction

“For me having a human rights focus on service users was very important, it was degrading how we are treated and with no one behind you to help you get clean”¹³

This Chapter sets out the human rights laws and equality legislation relevant to this project. These include international and regional human rights instruments and Irish equality legislation.

3.1 International Human Rights Law

3.1.1 United Nations

3.1.1.1 *International Covenant on Economic, Social and Cultural Rights*

The right to the highest attainable standards of health is a right that must be enjoyed by all people living in Ireland.¹⁴

The right to health is protected by **Article 12 of the International Covenant on Social, Economic and Cultural Rights, (ICESCR)**,¹⁵ which defines the right as the

“Right of everyone to the enjoyment of the highest attainable standard of physical and mental health”.

The UN Committee on Economic, Social and Cultural Rights monitors the implementation of the ICESCR through country reviews of State parties to the Covenant, including Ireland.¹⁶ The UN Committee’s General Comment (No. 14)¹⁷ on Article 12 ICESCR explains that the right to health is inextricably linked to the enjoyment of other rights:

“The right to health is closely related to and dependent upon the realization of other human rights, as contained in the International Bill of Rights, including the rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement. These and other rights and freedoms address integral components of the right to health”.

¹³ Service user at a Community Action network dialogue event, 2016

¹⁴ The human right to health is recognised in numerous international instruments by which Ireland has agreed to be bound. Article 25.1 of the Universal Declaration of Human Rights affirms: “Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services”.

The International Covenant on Economic, Social and Cultural Rights provides the most comprehensive article on the right to health in international human rights law. In accordance with article 12.1 of the Covenant, States parties recognise “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”, while article 12.2 enumerates, by way of illustration, a number of “steps to be taken by the States parties ... to achieve the full realization of this right”.

¹⁵ United Nations (1966) *International Covenant on Economic, Social and Cultural Rights*.

<http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx>

¹⁶ UN Committee on Economic, Social and Cultural Rights

<http://www.ohchr.org/EN/HRBodies/CESCR/Pages/CESCRIndex.aspx>

¹⁷ UN Committee on Economic, Social and Cultural Rights (2000) *CESCR General Comment No.14: The Right to the Highest Attainable Standard of Health (Art. 12)*. <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G00/439/34/PDF/G0043934.pdf?OpenElement>

This general comment explains that the right to health is to be realised on a progressive basis:¹⁸

The realisation of the right depends on a number of conditions and principles:

1. **Non-discrimination:** including on the grounds of race; religion; gender; sexual orientation; disability.
2. **Availability:** A sufficient quantity of functioning facilities, goods and services, as well as programmes.
3. **Accessibility:** which also includes: non-discrimination; physical accessibility; affordability and information accessibility.
4. **Acceptability:** services must be respectful of medical ethics, and must be culturally appropriate as well as sensitive to gender and life-cycle requirements.
5. **Quality:** services must be scientifically and medically appropriate and of good quality.
6. **Accountability:** States and other duty-bearers are answerable for the observance of human rights.
7. **Universality:** Human rights are universal and inalienable.

In addition to the right to health ICESCR¹⁹ protects the following relevant human rights;

- Article 1- Right to self-determination
- Article 6- Right to work
- Article 9- Right to social security
- Article 11- Right to adequate standard of living (food, housing)
- Article 13- Right to education

3.1.1.2 Other UN Human Rights Treaties

The right to health is also protected by a number of other UN human rights treaties which have been ratified by Ireland.

Article 12 of the Convention on the Elimination of All Forms of Discrimination Against Women²⁰ states that *“States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.”*

Article 24 of the Convention on the Rights of the Child²¹ states that *“States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.”*

¹⁸ UN Committee on Economic, Social and Cultural Rights (2000) *CESCR General Comment No.14: The Right to the Highest Attainable Standard of Health (Art. 12)*. <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G00/439/34/PDF/G0043934.pdf?OpenElement>

¹⁹ United Nations (1966) *International Covenant on Economic, Social and Cultural Rights* <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx>

²⁰ United Nations (1979) *Convention on the Elimination of all forms of Discrimination against Women* <http://www.un.org/womenwatch/daw/cedaw/text/econvention.htm>

²¹ United Nations (1989) *Convention on the Rights of the Child* <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>

3.1.2 Regional Human Rights Law

3.1.2.1 European Convention on Human Rights

The European Convention on Human Rights (ECHR)²² is an international treaty concluded by the members of the Council of Europe which protects human rights and fundamental freedoms in Europe.

The ECHR has been incorporated directly into Irish domestic law by the *European Convention on Human Rights (ECHR) Act 2003*.²³ This means that people living in Ireland can vindicate their ECHR rights directly through the Irish courts system.

The ECHR Act 2003 incorporates a host of human rights into Irish domestic law, including;

- Article 2- Right to Life
- Article 3- Prohibition of Torture, Inhuman and Degrading Treatment
- Article 8- Right to Respect for Private and Family Life
- Article 13- Right to an Effective Remedy (in relation to ECHR rights violations)
- Article 14- Non-discrimination in enjoyment of ECHR rights

Health issues can be engaged by ECHR rights such as the right to life, prohibition on degrading treatment and right to privacy and family life.²⁴

3.1.2.2 Revised European Social Charter

The right to health is also protected at the Council of Europe by **Article 11 the Revised European Social Charter**, which provides that;

“Everyone has the right to benefit from any measures enabling him to enjoy the highest possible standard of health attainable.”²⁵

In addition to the right to health the European Social Charter protects the following relevant human rights;

European Revised Social Charter (Council of Europe)²⁶

- Article 1- Right to work
- Article 9/10- Right to vocational guidance and training
- Article 12- Right to social security
- Article 13- Right to social and medical assistance
- Article 14- Right to benefit from social welfare services
- Article 15- Right of persons with disabilities to independence, social integration and participation in the life of the community
- Article 30- Right to protection against poverty and social exclusion

3.2 European Union Law

At European Union level the right to health is included under **Article 35 of the Charter of Fundamental Rights of the European Union**. It provides that;

²² Council of Europe (1950) *European Convention on Human Rights*
http://www.echr.coe.int/Documents/Convention_ENG.pdf

²³ *European Convention on Human Rights Act 2003*
<http://www.irishstatutebook.ie/eli/2003/act/20/enacted/en/print.html>

²⁴ European Court of Human Rights (2017) *Factsheet on Health*
http://www.echr.coe.int/Documents/FS_Health_ENG.pdf

²⁵ Council of Europe (1996) *European Social Charter (Revised)* <https://rm.coe.int/168007cf93>

²⁶ Council of Europe (1996) *European Social Charter (Revised)* <https://rm.coe.int/168007cf93>

*Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all the Union's policies and activities.*²⁷

3.3 Irish Law

3.3.1 Bunreacht na hEireann

The Irish Constitution recognises and declares that people living in Ireland have certain fundamental rights. These constitutional rights include:

- Right to Life
- Right to Personal Liberty
- Right to Bodily Integrity
- Right to Privacy
- Right to Earn a Livelihood
- Freedom to Travel (within the State and abroad)
- Family rights

3.3.2 Equality Legislation

The Irish equality legislative framework provides for both for the promotion of equality and the prohibition of discrimination in relation to nine protected grounds through the *Employment Equality Acts 1998-2015* and *Equal Status Acts 2000-2015*.²⁸

The Equal Status Acts 2000-2015 bans discrimination by public and private bodies in the provision of goods and services, including health services, in relation to nine grounds;

- Gender
- Civil Status
- Family Status
- Sexual Orientation
- Religion
- Age
- Race
- Membership of Traveller Community
- Disability

Discrimination may be direct; when a person is treated less favourably than another person in the same situation under any of the nine grounds, or indirect; where an individual or group of people are placed at a disadvantage as a result of conditions or rules which they might find hard to satisfy and which cannot be reasonably justified.²⁹

²⁷ European Union (2009) *European Union Charter of Fundamental Rights* <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:12012P/TXT&from=EN>

²⁸ *Employment Equality Acts 1998-2015* <https://www.ihrec.ie/guides-and-tools/human-rights-and-equality-for-employers/what-does-the-law-say/the-employment-equality-acts-1998-2015-a-summary/>

Equality Status Acts 2000-2015 <https://www.ihrec.ie/guides-and-tools/human-rights-and-equality-in-the-provision-of-good-and-services/what-does-the-law-say/equal-status-acts/>

²⁹ https://www.ihrec.ie/download/pdf/ihrec_employment_equality_rights_explained.pdf

Under the Equal Status Acts 2000-2015 harassment, sexual harassment and victimisation are not allowed. Harassment is any form of unwanted conduct related to any of the nine grounds. Sexual harassment is any form on unwanted verbal, nonverbal or physical conduct of a sexual nature. Unwanted conduct can include acts, requests, spoken words and gestures. It can also include the production, display or circulation of written words, text messages, pictures or other material. A person who makes a complaint of discrimination, or is a witness to a case, taken under equality legislation cannot be treated adversely.³⁰

The Equal Status Acts 2000-2015 allows for positive action on any of the nine grounds to promote equality of opportunity for people who may be disadvantaged because of their circumstances, or to cater for their special needs. The Equality Status Acts 2000-2015 also requires reasonable accommodation for people with disabilities, subject to a nominal cost, whereby service providers are required to put supports in place so that people with disabilities can access and use services.³¹

3.3.3 The Public Sector Equality and Human Rights Duty – eliminating discrimination, promoting equality and protecting human rights

Section 42 of the Irish Human Rights and Equality Commission Act 2014 places a positive duty on public sector bodies to have regard to the need to eliminate discrimination, promote equality, and protect human rights, in their daily work.

Section 42(1) states that:

A public body shall, in the performance of its functions have regard to the need to:

(a) eliminate discrimination,

(b) promote equality of opportunity and treatment of its staff and the persons to whom it provides services, and

(c) protect the human rights of its members, staff and the persons to whom it provides services.

Section 42 (2) of the Irish Human Rights and Equality Commission Act 2014 set out what public bodies must do in this regard, including setting “out in a manner that is accessible to the public in its strategic plan (howsoever described) an assessment of the human rights and equality issues it believes to be relevant to the functions and purpose of the body”, as well as the “the policies, plans and actions in place or proposed to be put in place to address those issues”. A public body must also “report in a manner that is accessible to the public on developments and achievements in that regard in its annual report (howsoever described). “

The Irish Human Rights and Equality Commission has a specific role in providing guidance as well as monitoring the Public Sector Duty implementation. Under Section 42.3, the IHREC can give guidance to and encourage public bodies in developing plans and good practice in relation to human rights and equality, and issue guidelines or codes or practice in respect to implementing the Public Sector Equality and Human Rights Duty.

Under Section 42(5) of the Act, where the Commission considers that there are failures to fulfil the Public Sector Equality and Human Rights Duty obligations, it can invite a public body to carry out an

³⁰ <https://www.ihrec.ie/documents/ihrec-equal-status-rights-explained/>

³¹ https://www.ihrec.ie/download/pdf/equality_and_mental_health_what_advocates_need_to_know.pdf

equality and human rights review of the work of the organisation, and prepare and implement an action plan.

4 Relevant Health Policies and Guidelines

HSE and Department of Health Frameworks and Policies

This section identifies the major HSE policies and frameworks which form the landscape of current Irish healthcare policy. It highlights the key values, goals and policy commitments relevant to the issues raised in this report.

4.1.1 National Drugs Strategy: “Reducing Harm, Supporting Recovery (2017-2025)”³²

The new National Drugs Strategy identifies issues and includes some important commitments in relation to opioid treatment services. These commitments are relevant to the issues raised in the course of this report.

The National Drugs Strategy includes commitments relating to accessibility of treatment, treatment choice and treatment standards. It does not include discussion around urine sampling or complaints mechanisms.

The National Drugs Strategy recognises the following issues;

- *People report having to travel a significant distance to access more specialist treatments, especially in rural areas.*
- *The time involved, the cost of travel, the need for childcare or the absence of a support network can result in barriers to accessing treatment for some people, even when there are financial supports available.*
- *Difficulties in accessing OST also include a lack of local services and waiting times*
- *People who are dependent on opiates, are engaged in high risk drug use such as injecting, or who are using multiple substances can also experience barriers to accessing treatment, especially residential treatment.*
- *All the participants in a 2009 Irish study on sex work 32, had a history of injecting drug use and half reported recently injecting drugs. This highlights the need for an effective response for those with complex interlocking needs.*
- *Some residential services do not have the appropriate level of clinical governance to respond to those with more complex needs, and may have entry thresholds in place which exclude those who have more unstable patterns of drug use.*

The following commitments are made in the new National Drugs Strategy;

- *A range of options will therefore be explored to facilitate wider access to OST in the community. This includes measures to involve more GPs in prescribing OST, an examination of the feasibility of nurse-prescribing of OST and the provision of OST in a wider range of settings, such as community-based initiatives or homeless services.*
- *In conjunction with the Irish College of General Practitioners, the HSE is working to increase engagement of all GPs who are trained at Level 1 and Level 2 throughout the country.*
- *Ideally all stable methadone patients who are registered with a Level 1 GP should be transferred to their own GP, where appropriate, provided their own GP has Level 1 training.*
- *Standardising referral processes and lowering the entry criteria for accessing residential treatment services, while ensuring appropriate levels of clinical governance, would make it easier for people with more complex needs to access treatment. The development of residential services that can cater for the needs of those who use a variety of substances will be particularly important in this context.*

³² <http://health.gov.ie/wp-content/uploads/2017/07/Reducing-Harm-Supporting-Recovery-2017-2025.pdf>

- *It is also intended to improve treatment choices for people who are not clinically suited to methadone treatment, but require medication-assisted therapy to address dependence on opiates. There is a commitment in the 2017 HSE Service Plan to provide wider access to alternative OST products containing buprenorphine or buprenorphine/naloxone.*
- *The HSE has published national clinical guidelines for OST to ensure that the quality and safety of care to the patient is maintained and improved where necessary. The HSE will implement these guidelines until National Clinical Effectiveness Committee guidelines are in place.*
- *Finally, the National Drugs strategy also emphasises the importance of continuing to develop the capacity of services to respond to service users with more complex needs, including vulnerable groups, such as Travellers or those affected by homelessness, or those with more high-risk behaviours or patterns of use.*

The key actions to be taken in the Strategy in relation to opioid treatment services are as follows;

- *Developing a competency framework on key working, care planning and case management.*
- *Extending the training programme on the key processes of the National Drugs Rehabilitation Framework.*
- *Increasing the number of treatment episodes provided across the range of services available, including:*
 - *Low Threshold;*
 - *Stabilisation;*
 - *Detoxification;*
 - *Rehabilitation;*
 - *Step-down;*
 - *After-Care.*
- *Strengthening the capacity of services to address complex needs.*
- *Examining potential mechanisms to increase access to OSTs such as the expansion of GP prescribing, nurse-led prescribing and the provision of OSTs in community-based settings and homeless services.*
- *Implementing the HSE National Clinical Guidelines on OST and reviewing in line with National Clinical Effectiveness Committee processes.*

4.1.2 “Clinical guidelines for opioid substitution treatment.”³³

In Ireland, Opioid Substitution Treatment (OST) refers to the provision of both methadone and buprenorphine/ buprenorphine-naloxone. At the end of 2014, there were 9764 people in receipt of OST in HSE Addiction Clinics and GPs, compared with 9,116 in 2013.³⁴

According to the Health Research Board, these guidelines

“are based on the principles that people who use drugs have the same entitlement as other patients to the services provided by the HSE. Service users have a right to be heard, listened to and taken seriously and should be consulted and involved in all matters and decisions that may affect their lives. The Guidelines have been developed in order to outline evidence-based care to standardise and improve the quality and safety of care to the patient.”

³³ <http://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

³⁴ <http://www.drugsandalcohol.ie/26573/>

Chapters 6-9 refer to and critique specific aspects of the “Clinical guidelines for opioid substitution treatment” under each of the four issues identified. These critiques are not intended as clinical judgments, but rather aim to relate the issues and lived experience identified by service users with the relevant aspects of these new guidelines. Chapters 6-9 also refer to the 2010 HSE-commissioned report “The Introduction of the Opioid Treatment Protocol report”, or “Farrell Report”. This report contains specific recommendations in relation to the development of new clinic guidelines that are also relevant to the identified issues.

Other relevant HSE policy documents

4.1.3 HSE Corporate Plan for Health Services 2015-2017³⁵

“Building a High Quality Health Service for a Healthier Ireland- Health Service Executive Corporate Plan 2015-2017” illustrates that the work of the HSE should be guided by 5 key goals;

- Goal 1: Promote health and wellbeing as part of everything that we do so people will be healthier.
- Goal 2: Provide fair, equitable and timely access to quality, safe health services that people need.
- Goal 3: Foster a culture that is honest, compassionate, transparent and accountable.
- Goal 4: Engage, develop and value our workforce to deliver the best possible care and services to the people that depend on them.
- Goal 5: manage resources in a way that delivers best health outcomes, improves people’s experiences of using the service and demonstrates value for money.

Underpinning these goals in the corporate plan are the aims that everyone should live fulfilled lives, that the health service should positively impact people’s health and wellbeing, that the health service support people to be healthy, that services are made easy to access and that care, compassion, openness and honesty underpin service provision.

These goals are an excellent expression of human rights values, with an emphasis on transparency, dignity and respect informing the 5 goals. The four core issues, such as supervised urine sampling and lack of an effective complaints mechanism, identified in this report by service users demonstrate that the HSE should scrutinise the systems and structures around opioid treatment services in Ireland more closely. This report outlines serious service user identified issues that suggest that the 5 goals of the HSE corporate plan have not been delivered in the context of opioid treatment services over the 2015-2017 corporate plan cycle.

4.1.4 HSE National Service Plan 2017

The above outlined 5 goals informing the Corporate Plan for 2015-2017 also informs the work of the Service Plan for 2017.

Importantly, the service plan identifies “improved outcomes for the most vulnerable in society including those with addiction issues” (page 21) as priority for 2017. Actions such as establishing a pilot supervised injection facility in Dublin and the provision of 25 more addiction residential treatment beds and 142 additional treatment episodes demonstrates an openness to reform in the area of drugs treatment services in the HSE Service Plan for 2017.

The planning process for the next corporate plan cycle 2018-2020 provides a crucial opportunity to build upon beginnings of reform in the area, and conduct a full human rights and equality

³⁵ <http://www.hse.ie/eng/services/publications/corporate/corporateplan15-17.pdf>

assessment of the issues raised in this report in relation to the provision of opioid treatment services.

4.1.5 HSE Charter “You and Your Health Service”³⁶

The HSE Charter, “You and Your Health Service”, is a health service charter and a Statement of Commitment on healthcare expectations and responsibilities. Values of such services should be:

1. Access: HSE services are organised to ensure equality of access to public health and social care services.
2. Dignity and respect: HSE to treat people with dignity, respect and compassion.
3. Safe and Effective Services: HSE to provide services in a safe environment, delivered by competent, skilled and trusted professionals.
4. Communication and information: HSE to provide clear, comprehensive and understandable health information and advice.
5. Participation: HSE to involve people and their families and carers in shared decision making about their health care.
6. Privacy: HSE to ensure adequate personal space to ensure privacy in providing care and personal social services. We maintain strict confidentiality of personal information.
7. Improving Health: HSE services to promote health, prevent disease and support and empower those with chronic illness to self-care.
8. Accountability: HSE to accept complaints and feedback about care and services, investigate complaints and work to address concerns.

4.1.6 HSE Complaints Policy: “Your Service, Your Say”³⁷

The introduction to the “Your Service, Your Say” policy states the following;

“It is the policy of the HSE that the complaints management process implemented in the HSE will:

- Address the needs of the consumer.
- Demonstrate consumer satisfaction with the way their complaint was handled.
- Uphold the rights and protect the dignity of staff.
- Improve public confidence in the service.
- Prevent, where possible, complaints from further escalation, which can be very time consuming and costly to resolve.
- Enable information about complaints to contribute to quality improvement and organisational learning.”³⁸

The policy commits the HSE to a complaints management process that is fair, transparent, non-prejudiced, non-recriminatory and impartial. It further commits all staff of the HSE to be enabled and empowered to appropriately handle complaints. It states that each individual service provider is accountable to the patient/client and has a responsibility to respond to concerns that they raise in an appropriate manner.

It further states that information will be widely available to consumers on the Complaints Management Process.

³⁶ <http://www.hse.ie/eng/services/yourhealthservice/hcharter/>

³⁷ <http://www.hse.ie/eng/services/yourhealthservice/feedback/Complaints/Policy/complaintspolicy.pdf>

³⁸ HSE. “Your Service, Your Say”. Page

2. <http://www.hse.ie/eng/about/QAVD/Complaints/ysysguidance/ysys2017.pdf>

4.1.7 A Vision for Change³⁹

The Vision for Change Report of the Expert Group on Mental Health Policy published in 2006 commits the HSE to a human rights based approach (HRBA) to mental health services.

“All mental health policies and strategies should promote the following overarching human rights principles that apply also to service users and carers:

- the right to equality and non-discrimination
- the right to privacy and autonomy
- the right to physical and mental integrity
- the right to participation
- the right to reciprocity
- the right to information
- the right to the least restrictive alternative
- the right to freedom of association
- the right to proportionality in all restrictions imposed on rights.

But there are other international human rights that relate to these overarching principles such as:

- the right to freedom from inhumane and degrading treatment
- the right to respect for family life
- the right to education
- the right to procedural safeguards and accountability mechanisms.”⁴⁰

Given that mental health issues are frequently interrelated to addiction and the associated causes of addiction, the HSE commitments to the human rights approach as stated in “A Vision for Change” are highly relevant to service users of opioid treatment services in Ireland. The lived experiences of service users and evidence-gathered outlined in this report do not reflect the human rights approach as committed to in “A Vision for Change.”

4.1.8 Healthy Ireland⁴¹

Healthy Ireland is the government-led initiative that “aims to create an Irish society where everyone can enjoy physical and mental health, and where wellbeing is valued and supported at every level of society.” It is the primary policy document directing health

One of the four main stated goals of the “Healthy Ireland Framework” as launched in 2013 is to “reduce health inequalities.”

The lived experiences and health outcome inequalities described by service users of this project do not reflect the stated aim of “Healthy Ireland” of valuing wellbeing at every level of society in relation to the provision of opioid treatment services in Ireland.

³⁹ https://www.hse.ie/eng/services/publications/Mentalhealth/Mental_Health_-_A_Vision_for_Change.pdf

⁴⁰ Page 233 https://www.hse.ie/eng/services/publications/Mentalhealth/Mental_Health_-_A_Vision_for_Change.pdf

⁴¹ <http://www.healthyiireland.ie/about/>

4.1.9 Department of Health Statement of Strategy 2016-2019⁴²

The Department of Health has committed to meaningfully implementing Section 42 the Public Sector Equality and Human Rights Duty across the organisation in its Statement of Strategy for the period 2016-2019. The Department states the following;

“Human Rights & Equality: The Department is conscious of its responsibility in ensuring that the principles of the Public Sector Duty in relation to human rights and equality are embedded across the work of the Department. An example of this is the Department’s commitment to the creation of a more responsive, integrated and people-centred social care system which (amongst other things) supports the full and effective participation of people with disabilities in society on an equal basis with others, in accordance with the United Nations Convention on the Rights of Persons with Disabilities (see Independent Living section on page 7 under Objective 1).”⁴³

4.1.10 Additional strategies

In addition to the above cited policies, there are a host of issue or group specific policy documents and national strategies which inform the policy-making and service provision of the Department of Health and HSE. These strategies should be considered when considering how to apply a human rights based approach to reform of opioid treatment services in Ireland. These strategies will assist in understanding issues across the equality grounds, and how a one-size-fits all approach to drugs treatment services may not address the specific needs of different groups across grounds such as gender, disability, age etc.

- National Positive Ageing Strategy⁴⁴
- National Intercultural Health Strategy⁴⁵
- The National Women’s Strategy⁴⁶
- National Men’s Health Action Plan⁴⁷
- Connecting for Life Strategies⁴⁸
- National Sexual Health Strategy⁴⁹
- National Maternity Strategy⁵⁰
- National Strategy on Domestic, Sexual and Gender-based Violence⁵¹

Conclusion on policies and guidelines

This section has set out the policy landscape within which the delivery of health services takes place in Ireland. The values, principles, goals and objectives of the policy documents outlined form an important backdrop and context for considering and understanding the four key issues in this report as identified by service users.

⁴² <http://health.gov.ie/wp-content/uploads/2016/12/Statement-of-Strategy-2016-2019-English.pdf>

⁴³ Page 4 <http://health.gov.ie/wp-content/uploads/2016/12/Statement-of-Strategy-2016-2019-English.pdf>

⁴⁴ <http://health.gov.ie/healthy-ireland/national-positive-ageing-strategy/>

⁴⁵ https://www.hse.ie/eng/services/publications/SocialInclusion/HSE_National_Intercultural_Health_Strategy_.html

⁴⁶ http://www.merrionstreet.ie/MerrionStreet/en/ImageLibrary/20170503_National_Strategy_for_Women.pdf

⁴⁷ <http://www.lenus.ie/hse/bitstream/10147/621003/1/HealthyIrelandMen.pdf>

⁴⁸ <https://www.healthpromotion.ie/hp-files/docs/HME00945.pdf>

⁴⁹ <http://health.gov.ie/healthy-ireland/national-sexual-health-strategy-2015-2020/>

⁵⁰ <http://health.gov.ie/wp-content/uploads/2016/01/Final-version-27.01.16.pdf>

⁵¹ <http://www.cosc.ie/en/COSC/Second%20National%20Strategy.pdf/Files/Second%20National%20Strategy.pdf>

5 Supervised and Frequent Urine Sampling

5.1 Explaining the issue

“The urines were a big issue for me. I couldn't give a urine with people watching. . It wasn't that I wouldn't.... I couldn't, and they wouldn't wait around, my bladder used to be hurting me. I would try not go for five to six hours before, I thought I would be able to go, but I just couldn't do it with people observing. So, then a GA in the clinic said I'll give you a heat bottle and I gave the urine no problem. When I changed clinic, this new clinic wouldn't use the heat bottles, they wanted to supervise. They didn't trust me. For personal reasons I am unable, or find it extremely difficult, to urinate whilst being observed at close proximity. You would think people working in this area would be trained in things like this, that there could be underlying issues. There was certain GAs that would be looking right over your shoulder.”⁵²

Urine analysis has been the preferred screening method used by many drug treatment agencies for a considerable time now⁵³. However this particular screening method is viewed negatively by a majority of service users surveyed. Its effectiveness in reducing illicit drug use has also been questioned in several reports and articles.⁵⁴

Underlying all the issues that supervised urine sampling engages is the fundamental question over the medical efficacy and necessity of urine sampling. There are several pieces of medical research which question the excessive use of urine testing as the only parameter for drug addiction treatment:

“Results of numerous studies suggest that there is little to be gained by using urinalysis to monitor drug use, if the main purpose of the procedure is to deter patients from using illicit drugs. On the basis of the available evidence, it has to be concluded that there is no compelling evidence that the absence of urinalysis leads to an increase in illicit drug use”

Ward, Mattick & Hall. “Methadone maintenance treatment and other opioid replacement therapies”. 1998⁵⁵

The following sections present the findings of the user-led survey taken in 2017 of 132 service users, the methodology of which is described in Chapter 2 of this report. Comparisons are made with the results of the user-led survey conducted with 107 service users in 2012 in order to see changes in urine sampling practices and service user experiences over time.

⁵² Interviewee, age 46. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

⁵³ O’Heaire, Gary (2013) *Urine Analysis, an exploratory case study from the perspective of participants in a rehabilitation day programme*, Dublin: Bawnogue Youth and Family Support Group
<http://www.drugsandalcohol.ie/22061/>

⁵⁴ Farrell, Michael and Barry, Joe (2010) *The introduction of the Opioid Treatment Protocol*, Dublin: Health Service Executive, http://www.drugsandalcohol.ie/14458/1/Opioid_Treatment_Protocol%5B1%5D.pdf
Keane, Martin (2012) ‘The lived experience of those on methadone maintenance in Dublin North East’ *Drugnet Ireland*, Issue 41, Spring 2012 pp 19-20.

Ó’Súilliobháin, Cathal (2009) ‘Taking the piss: is HSE drug testing wasting millions?’ *Irish Medical Times*, 9th September 2009. <https://www.imt.ie/opinion/guest-posts/taking-the-piss-is-hse-drug-testing-wasting-millions-09-09-2009/>

⁵⁵ Ward, J., Mattick, RP., & Hall, W (1998) *Methadone maintenance treatment and other opioid replacement therapies*. Amsterdam: Harwood Academic.

5.1.1 Perceptions of supervised urine sampling

5.1.1.1 Frequency

The HSE commissioned Farrell Report (2010)⁵⁶ and the Review of the Dublin North City and County Addiction Service (2013)⁵⁷ recommend the cessation of frequent, regular urine testing. However, the user-led survey results from 2012 and 2017 demonstrate that there has been an increase in the amount of service users required to give samples weekly from 51% (2012) to 56% (2017). There has also been a substantial increase in the number of service users required to give samples 2-3 times per week from 6% (2012) to 22.7% (2017).

5.1.1.2 Feelings

In the user-led survey taken in 2012, 67% of service users expressed that they did not like undertaking supervised urine sampling.

The user-led survey in 2017 was expanded to get a more detailed breakdown of how service users felt about the complex experience of urine sampling. This resulted in many service users giving multiple responses, for example, responding that urine testing “keeps me on track” and that they have become “used to it” while at the same time reporting that it feels “degrading” and “undignified”. These complex and, at times seemingly contradicting, responses demonstrate the normalisation of practices that feel degrading and the internalisation of biases experienced by many service users. This process was reflected in the 2017 survey results where 40% of service users expressed that they did not like giving urine samples (supervised or not), 50% described it as degrading and 26% described it as undignified. 32% expressed the view that urine sampling kept them on track while 44% felt like they have no choice.

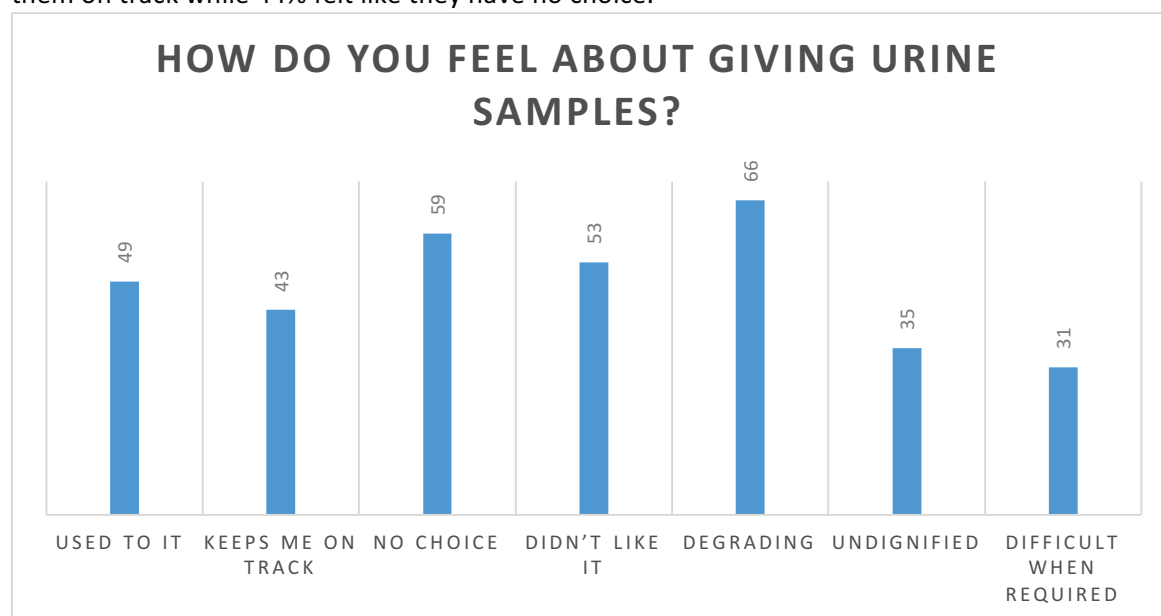


Fig. 2.

⁵⁶ Farrell, Michael and Barry, Joe (2010) *The introduction of the Opioid Treatment Protocol*, Dublin: Health Service Executive, http://www.drugsandalcohol.ie/14458/1/Opioid_Treatment_Protocol%5B1%5D.pdf

⁵⁷ Pilling, Stephen and Hardy, Roberty (2013) *Review of the Dublin North City and County Addiction Service*, Commissioned by HSE Dublin North City http://www.drugsandalcohol.ie/21143/1/Addiction_Service_Review_Document_FINAL_July_2013.pdf

The service users in this project have indicated that drug treatment services are permeated by a penal culture of stigma. The primary and even sole form of monitoring 'recovery' of this cohort of service users is driven uniquely by urine samples.

"It's extraordinary the amount of urines you have to give, especially when you think of how it's done in other countries. For me it's to make things easier. I mean any idiot, a monkey can check a test. You just dip it. Then they (the doctors) don't need to know anything about addiction. The whole of treatment is your urine and everything is based on it. Nobody would ask how you are or anything."⁵⁸

Service users at the dialogue events also reported that the perception that OST patients are 'chaotic' is often misleading and linked to a culture of bias and punishment expressed in the urine sampling based treatment. Terms such as 'unclean' or 'dirty' urine sampling have become part of a stigmatising language of bias, and not of a medical condition. Service users also reported that there is a general assumption that service users will cheat, hence the practice of supervision.

When I used, I held up and said it, before they got the result. I just thought it would be easier to tell the truth, I thought honesty was the best way. Giving urines with someone standing behind you, it was degrading, I didn't know there was other ways of testing.⁵⁹

This has, according to one service user, a counterproductive effect on his treatment:

There's nothing worse, I mean like you would be sitting down taking with your key worker, sometimes breaking down crying, next thing "can I get a urine off you?'. Rapport gone... makes you hate the place, hate the person, there's no empathy, no trust, you're getting emotional so you must have used, that's how it feels.⁶⁰

You'd be open with your doctor if there was no punishment. I mean you're trying to build up a relationship with your doctor or key worker. You've talking personal stuff to these people, next thing they're asking you for a urine, it's disheartening. Then it turns into a person of authority and I can't work with them. So the next time I talk to them there's a big change. I don't tell them as much so in a way the urine has got in the way of my treatment. Urines have damaged my treatment, it has played a big part in the way I open up, created issues for me... it has created 'us and then', it doesn't sit with me, it's degrading, it's not nice.⁶¹

⁵⁸ "Jazz", age 52. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

⁵⁹ "Jazz", age 52. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

⁶⁰ "Davie", age 38. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

⁶¹ "Davie", age 38. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

5.1.1.3 Method

In 2017, 65% of service users reported that urine sampling is supervised with mirrors. This an increase from 54% in 2012. This increase has occurred despite recommendation 4.2 from the Farrell report which states that “The supervision of urine testing should be eliminated except where there is a legal requirement for supervision and that oral fluid or temperature testing be used to indicate whether a fresh sample is being provided”.⁶²

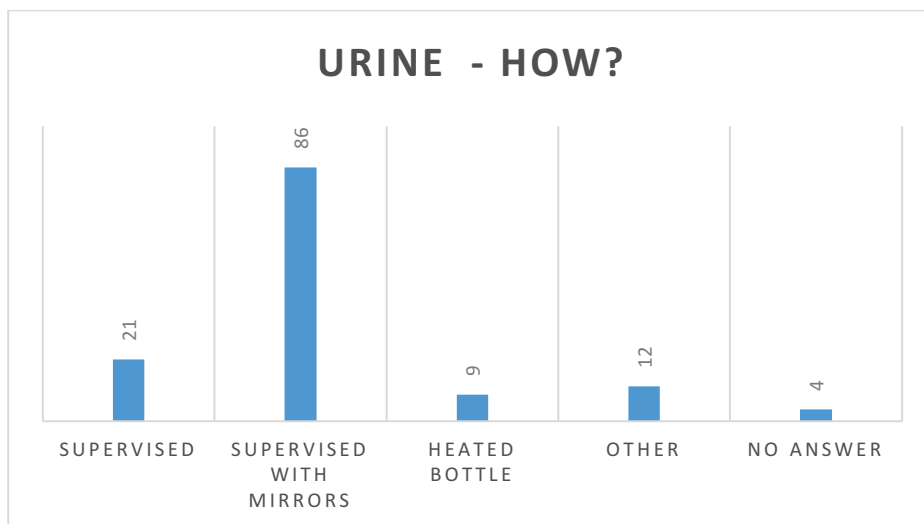


Fig. 3.

This practice of supervised sampling and the frequency of sampling have both increased since the 2012 survey.

2012	2017
20% supervised	16% supervised
54% supervised with mirrors	65% supervised with mirrors

Fig. 4.

2012	2017
51% Give samples weekly	56% give samples weekly
6% give samples 2 -3 times per week	22.7% give samples 2-3 times per week

Fig. 5.

⁶² Farrell, Michael and Barry, Joe (2010) *The introduction of the Opioid Treatment Protocol*, Dublin: Health Service Executive, http://www.drugsandalcohol.ie/14458/1/Opioid_Treatment_Protocol%5B1%5D.pdf

The issue of supervised versus unsupervised urine was reported as having an impact on service users experiences and perceptions.

I don't mind giving them where I am now, because they're not supervised. They use the heat strips so they can tell if they are legit. I can go in about 30 seconds, but when they were supervised it used to take me seven or eight minutes. Sometimes I would have to go for a walk, there's someone standing behind you with mirrors looking at you, it's degrading. My treatment is totally based on my urines...nothing else is discussed.⁶³

The act of urinating is often observed by a General Assistant and mirrors are often present on the walls. In addition to the indignity of urinating while being watched by another person, service users at the dialogue events reported gender-specific issues around the supervision of urine testing.

5.1.2 Gender perceptions

There are particular indignities for women being supervised urinating during certain times of their menstrual cycles, and people of both genders have expressed discomfort at the intimate act of urinating in the presence of a healthcare professional of the opposite (or same) gender.

81% of women in the survey expressed dissatisfaction with the process, in particular given that the practice of urinalysis does not show consideration for female health realities such as periods. This issue was previously reported to the Irish Human Rights and Equality commission during its consultation process for the Convention on the Elimination of all Forms of Discrimination against Women.⁶⁴

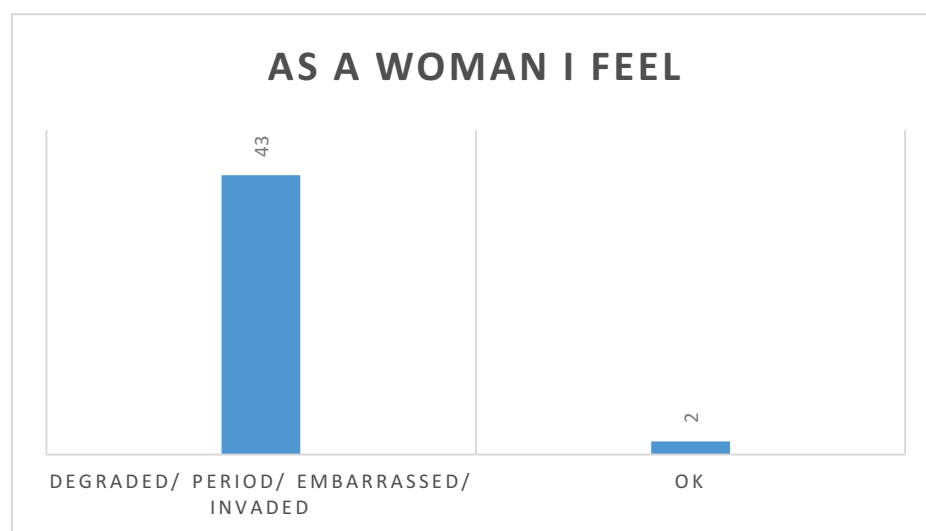


Fig. 6.

⁶³ "Joseph", age 36. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

⁶⁴ During the Irish Human Rights and Equality Commission consultation process for its report on the Convention on the Elimination of all Forms of Discrimination against Women, the IHREC conducted a consultation with service users of the SAOL project. Particular women's health issues were highlighted in the course of that consultation in relation to urine sampling. In particular, no consideration was given in the urine sampling process to the menstrual cycle and therefore the process can be especially degrading for women. <https://www.ihrec.ie/our-work/cedaw-2016/>

Service users reported that women who are methadone users (but might be on some kind of self-medication) can be refused entry with their children to women's refuges if they cannot provide a letter from a doctor saying that they have a 6 weeks record of "clean" urine sampling.

5.1.3 Withdrawal of Methadone on the basis of a positive sample

Service users reported being threatened with withdrawal of methadone treatment if they cannot comply with urine sampling within established times and modalities (for example, urinating in 5 minutes). Some service users have even reported that counselling offered may be conditional to providing urine sampling in degrading conditions. Service users felt that the lack of emergency support systems around the sudden reduction or suspension of methadone or other opiate-substitute treatment may and does lead to tragic consequences such as death by overdose, relapses and resorting to other drugs and multiple drug use.

Service users observed at the dialogue events that other patients who display aggressive, threatening or violent behaviour are rarely subjected to the suspension of medical treatment but are often referred to a different GP or clinic. Withdrawal of medication on the basis of the behaviour of the patient is an incongruent and disproportionate measure not known or used in any other medical conditions, or indeed addictions.

Service users have identified the issue of withdrawal of methadone on the basis of a positive urine test as requiring urgent attention.

5.2 Principles and values relevant to the practice of urine sampling

During the dialogue events, user-led research and project steering committee meetings, service users identified a range of principles and values which they felt are critical to the provision of drug treatment services. The following are some of the principles and values relevant to the practice of supervised urine sampling.

5.2.1 Proportionality

The practice of urine sampling is perceived as unnecessary, disproportionate and based on questionable medical evidence for the prescription of methadone by the majority of service users and General Practitioners in attendance at the dialogues events. As seen above, some service users report that they are threatened with withdrawal of methadone treatment if they cannot comply with urine sampling within times and modalities prescribed by the process. The withdrawal of methadone, an extreme medical action, on the basis of a positive result, would appear to be a disproportionate measure that impacts on the service users ability to access an adequate, appropriate and quality level of treatment. The removal of medical treatment with no corresponding *medical* justification counters the principle of progressive realisation of the right to health.

The dehumanising and degrading nature of supervised urine sampling, as expressed by service users, may also act as a psychological barrier for individuals to decide to access to medical treatment.

5.2.2 Dignity

Throughout the user-led research and the dialogue events, service users have repeatedly reported their lived experience of urine sampling as degrading and inhuman. One female service user stated, "As a woman I feel like I've been violated. I don't like the way my privacy is taken."⁶⁵ The key

⁶⁵ Interviewee "68". User-led survey, 2017.

causations of this sense of degradation are the supervision of the urination, the timeframe given to users to urinate, the lack of sanitary facilities in some rooms where urination is expected to take place, the linking of urination to receipt of medical treatment and the clear power imbalance created between service user and GP when one person has to urinate in front of the other. The process is thus felt to be fraught with indignity and humiliation.

Further degrading elements can exist in terms of gender, with opposite sex (or same-sex) GPs to service users increasing the discomfort of the supervised sampling process. Supervised urine sampling is particularly degrading for women when they are at a time in the menstrual cycle that makes it especially uncomfortable to have to urinate 'on command' in front of another person such as a GP.

In addition to gender issues, urine sampling may also be especially difficult and humiliating for those with reduced mobility and other disabilities. One service user reported:

“As a woman I feel it’s horrible invasive (when having) periods. For personal reasons my body is mutilated for a choice I had to make for myself and my children. Because of that I’m ashamed of the way my body looks and the reasons why it looks that way but yet they still won’t try swabs. It’s far too invasive and (I) wouldn’t do it but have no choice.”⁶⁶

These perceptions of degrading treatment have resulted in a belief by many of service users interviewed that drug treatment services are focused on punishing users, rather than helping them. One of the main values that underpinning the current National Drugs Strategy is compassion: “A humane, compassionate approach focused on harm reduction which recognises that substance misuse is a health care issue.”⁶⁷ However this research shows a lack of systemic compassion for service users.

5.2.3 Privacy

Service users have identified the supervision of an adult urinating (particularly in a non-criminal setting such as provision of medical treatment) by another adult as an affront to their privacy, particularly given the very intimate nature of the act being supervised. Dignity is fundamental principle of human rights, and the intrusion of privacy through supervision of urination is deeply felt by service users to be dehumanising, undignified and unnecessary.

Mirrors placed on walls and sometimes on ceilings of bathrooms exacerbates the lack of privacy and sense of humiliation.

5.3 Previous reports and current clinical guidelines

The findings of the user-led research (2012, 2017) demonstrate a deterioration of the situation reported in previous reviews and reports. Both a review of the HSE drug treatment services in Dublin North East, as well as the ‘Farrell Report’ (The Introduction of the Opioid Treatment Protocol, HSE, 2010) have highlighted repeatedly that urine analysis may be conducted in an inhuman and degrading manner, and with a frequency that is often unnecessary and disproportionate.

⁶⁶ Interviewee “110”. User-led Survey, 2017.

⁶⁷ Page 16, Department of Health (2017) *Reducing Harm, Supporting Recovery: A Health-Led Response to drug and alcohol use in Ireland 2017-2025* <http://health.gov.ie/wp-content/uploads/2017/07/Reducing-Harm-Supporting-Recovery-2017-2025.pdf>

The HSE-commissioned Farrell Report⁶⁸ made the following recommendations in 2010 related to urine sampling:

*Rec 4.1 **Frequent urine testing should be stopped.** It is not conducted often enough to be comprehensive and it mainly captures behaviour that is daily regular drug taking behaviour.*

*Rec 4.2 **The supervision of urine testing should be eliminated** except where there is a legal requirement for supervision and that oral fluid or temperature testing be used to indicate whether a fresh sample is being provided.*

*Rec 4.3 The Technology behind oral fluid testing has improved substantially and it **is now possible to undertake on site saliva testing.** With the ability to conduct such tests for immediate interpretation the utility and user friendliness of such an approach would be attractive to many service users and should be implemented as soon as possible.*

Rec 4.4 The Clinical Guidelines jointly developed by the ICGP and the College of Psychiatry of Ireland should include an implementation plan for the move to less urine testing and a greater clinical focus on the use of the results of drug testing samples. This overall change, which should result in a major reduction in the frequency of urine testing and the elimination of supervision, needs to be implemented by clinical team.

The “Review of the Dublin North City and County Addiction Service”⁶⁹, commissioned by the HSE in July 2013 made the following recommendations in relation to the Interim Drug Strategy and echoed the recommendations contained in the Farrell report of 2010 about the following:

- Cessation of frequent, regular urine testing
- Cessation of supervised urine testing except for where there is a legal requirement for supervision and that sample freshness requires verification.
- Consideration of saliva testing as an alternative.

This Review also emphasised that the voices of service users need to be strengthened and that a transparent appeals process should be put in place to allow service users to highlight any concerns about their treatment. The issue of patient treatment sanctions, around positive urine tests, was also raised in several submissions related to that review.

The current HSE “Clinical Guidelines for Opioid Substitution Treatment”⁷⁰ deal in detail with the rationale for and the practice of urine sampling.

The practice and frequency of urine sampling is a key concern of service users. The Clinical Guidelines state “The recommendations for frequency of testing are to be viewed as a minimum

⁶⁸ Farrell, Michael and Barry, Joe (2010) *The introduction of the Opioid Treatment Protocol*, Dublin: Health Service Executive, http://www.drugsandalcohol.ie/14458/1/Opioid_Treatment_Protocol%5B1%5D.pdf

⁶⁹ Pilling, Stephen and Hardy, Roberty (2013) *Review of the Dublin North City and County Addiction Service*, Commissioned by HSE Dublin North City http://www.drugsandalcohol.ie/21143/1/Addiction_Service_Review_Document_FINAL_July_2013.pdf

⁷⁰ Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment* <https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

standard”.⁷¹ The recommendation of testing at induction phase is that “at least one random drug test is taken per month”.⁷² There is no upper bound set in the Guidelines.

Beyond stating that “Drug testing should be viewed as an informative measure, and not as a reason for punitive action towards the service user”,⁷³ the Guidelines do not address the culture of urinalysis that has led to the current frequency of drug testing. Section 4.4.3 of the Guidelines recommend that “at least one random drug test is taken per month, used in conjunction with the above parameters.” This recommended minimum differs significantly from the equivalent UK guidelines. It has been the subject of serious and sustained reservations expressed by GPs on the project Steering Committee.⁷⁴ As per the experience of service users the current practice across the service is that urine sampling happens more frequently than this, outside and beyond the induction phase, and is generally used within what they perceive to be a punitive environment in which they are sanctioned for drug use. The Guidelines do not contain any upper bound for the frequency of urine sampling.

In relation to the supervision of urine sampling, Chapter 5 on “Drug testing” states that “Direct observation of urine specimen collection is not required in routine clinical practice.”⁷⁵ In light of the infringement of service users dignity and privacy reported above, this is a welcome statement. However the Clinical Guidelines do not go far enough in seeking to protect these rights of services users. For example, recommendations contained in the same chapter dealing with “urine sampling adulteration” seek to reduce the availability of hot water, soap and hand dryers. It recommends the use of “bathrooms within eyesight of staff to preclude use by more than one person at a time” and the checking of toilets before and after a urine sample is given.⁷⁶

As reported above, 95% of women in the survey expressed dissatisfaction with the practice of urine sampling, in particular given that the practice of urinalysis does not show consideration for female health realities such as periods. The Clinical Guidelines do not take account of the particular needs women may have when providing urine samples.

Chapter 5.7 on “Supervision of the provision of urine samples” does seek to restrict the overall practice of supervising urine testing, but not to eliminate it. It recommends that “Direct observation

⁷¹ Page 39, Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment* <https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

⁷² Page 33, Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment* <https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

⁷³ Page 39, Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment* <https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

⁷⁴ McGovern, Dr. Garrett and Ó Súilleabháin, Dr. Cathal (June 2017) “GPSSA rejects current opioid treatment clinical guidelines,” *Irish Medical Times*. <https://www.imt.ie/clinical/gpssa-rejects-current-opioid-treatment-clinical-guidelines-12-07-2017/>

Ó Súilleabháin, Dr. Cathal (2009) “Taking the Piss: Is HSE drug testing wasting millions?” *Irish Medical Times*. <https://www.imt.ie/opinion/guest-posts/taking-the-piss-is-hse-drug-testing-wasting-millions-09-09-2009/>

⁷⁵ Page 38, Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment* <https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

⁷⁶ Page 42, Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment* <https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

of urine specimen collection is *not required* in routine clinical practice.”⁷⁷ (emphasis added) However the experience of service users reported above is that supervision of urine sampling is still the widespread practice. The Clinical Guidelines do not implement the Farrell Report recommendation that “The supervision of urine testing should be eliminated”⁷⁸ except where there is a legal requirement. They do not address the equality and human rights issues that arise by this widespread practice.

⁷⁷ Page 42, Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment*
<https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

⁷⁸ Page 29, Farrell, Michael and Barry, Joe (2010) *The introduction of the Opioid Treatment Protocol*, Dublin: Health Service Executive, http://www.drugsandalcohol.ie/14458/1/Opioid_Treatment_Protocol%5B1%5D.pdf

6 Meaningful Engagement and Participation for Service users

As outlined in the introduction, underpinning this project's work are four key issues as identified by service users. These issues form the substantive four sections of this report;

- A. Supervised and frequent urine sampling
- B. Meaningful engagement and participation for service users
- C. Treatment choice and treatment plans
- D. An effective complaints mechanism

This section discusses the second issue- (B) meaningful engagement and participation for service users.

6.1 Explaining the issue

The survey results suggest that the doctor relationship and treatment of patients is a critical space of possibility. It can be positive, communicative and supportive; or negative, harmful and a possible block within the complaints system.

6.2 Perceptions of relationship with doctors

A lack of meaningful engagement, discussion and participation of service users with their GPs are some of the key findings from the service user led research and lived experiences of services-users as reported in the dialogue events in this project.

In the 2012 user-led survey, just 28% of respondents reported that they had a good or very good relationship with their doctor. Just 16% reported having regular meaningful discussions with their GP and 87% reported to having no participation in their treatment plan.

In the 2017 user-led research, 26% of survey respondents reported having a good or very good relationship with their doctor, a slight dis-improvement on the 2012 survey.

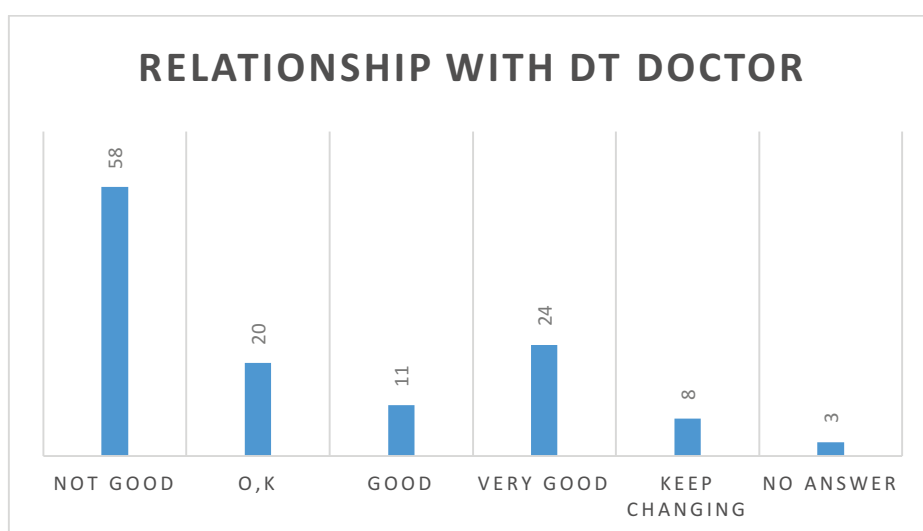


Fig. 7.

As in 2012, just 16% reported to regularly having meaningful discussion with their GP.

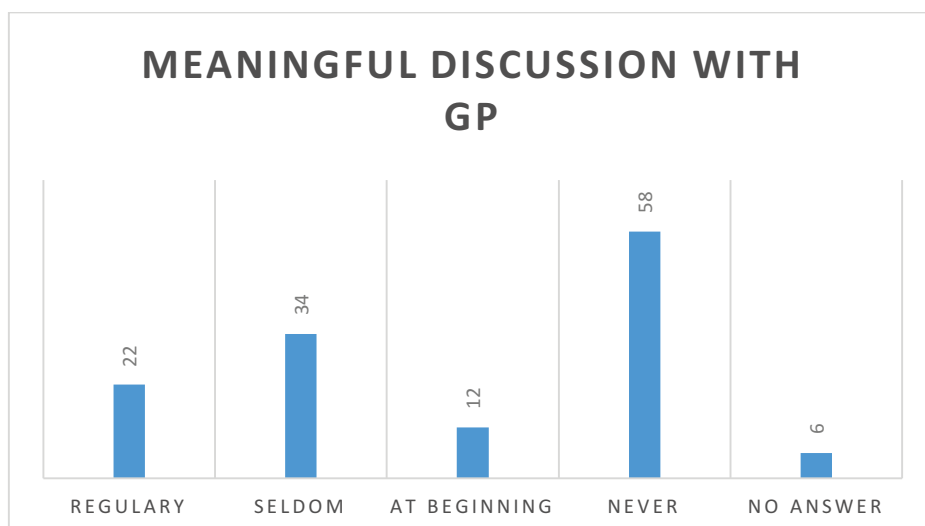


Fig. 8.

Service users who participated in the 2017 user-led survey reported relationships vary greatly depending on the individual doctor.

Many service users reported positive relationships, even if this takes time to develop:

*"I have a very good relationship with my doctor. There's trust there because I'm stable 9 years but it took a while to gain that trust. I'm with the same doctor 9 years."*⁷⁹

*"I have a good one with the doctor I have now had her 9 years but before that couldn't form a relationship with them"*⁸⁰

The context in which the service user sees a doctor also seems to be a factor in their experience:

*"Doctor at clinic (was) very rude, my doctor now (is) very compassionate."*⁸¹

*"Clinic-very negative, not trusted arrogant. Doctor- very good, listens, compassionate."*⁸²

Service users who reported having a good relationship with their doctor responded that trust, compassion, listening and being treated as an equal were characteristics of the relationship that made it positive.

*"Brilliant, speaks to me on human level."*⁸³

*"Very good he listens."*⁸⁴

Many service users reported that "there was no relationship" with their doctor and that they felt like "only a number". The need for and benefits of having a consistent relationship with the same doctor was brought up repeatedly. Lack of communication, negative and/or judgmental attitudes as well as uneven power dynamics were given as facets of relationships with doctors that were not good.

⁷⁹ Interviewee "18". User-led survey, 2017.

⁸⁰ Interviewee "38". User-led survey, 2017.

⁸¹ Interviewee "98". User-led survey, 2017.

⁸² Interviewee "112". User-led survey, 2017.

⁸³ Interviewee "85". User-led survey, 2017.

⁸⁴ Interviewee "105". User-led survey, 2017.

“None considering you get a new doctor every 6 months.”⁸⁵

“Well I’ve had many doctors that I haven’t got time to know them.”⁸⁶

“She’s a new doctor. (The relationship is) not very nice, feel like she looks down on you.”⁸⁷

“I’m just a number to him.”⁸⁸

“Don’t get to see him, he comes and goes.”⁸⁹

The doctor comes in, you hope she'll be there for 10, but it could be later. She gives you the script and you're out the door. There's no conversation. She knows my name but she doesn't know anything else about me. We don't talk.⁹⁰

The majority of service users reporting that the relationship with their doctor is “not good” is especially concerning in relation to an effective complaint system. Of those who said they know how to make a complaint, the most common response was to talk to the GP or to get a complaint form from the GP.

Many service users believe that complaints must be made through the GP but the lack of a positive, meaningful relationship with GP’s may result in service users not making complaints, particularly about treatment from GP’s and staff. This is critical because improved treatment by doctors, chemists and clinic staff was brought up consistently in the section of the survey that asked service users “What would you change?” about the opioid treatment services.

In the 2017 user-led research, 84% of participants reported that they have had no participation in their treatment plan, down slightly from 87% in the 2012 research.

⁸⁵ Interviewee “77”. User-led survey, 2017.

⁸⁶ Interviewee “70”. User-led survey, 2017.

⁸⁷ Interviewee “86”. User-led survey, 2017.

⁸⁸ Interviewee “25”. User-led survey, 2017.

⁸⁹ Interviewee “43”. User-led survey, 2017.

⁹⁰ “Jazz”, age 52. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

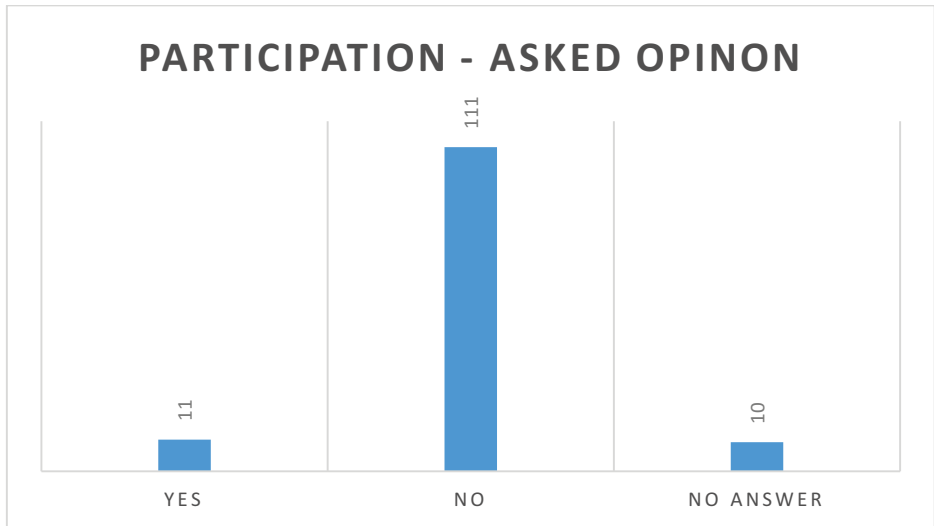


Fig. 9.

The survey results suggest that the doctor relationship and treatment of patients is a critical space of possibility, it can be positive, communicative and supportive; or negative, harmful and a possible block within the complaints system.

6.3 Service provision as a barrier to participation in daily life

Service users reported that the demands of attending GPs, clinics and pharmacies, and the restrictive practices of urine sampling, urinalysis, and methadone prescription and dispensing which can impact negatively on their ability to conduct a work, family and social life. For example, some service users who were in employment reported having to forgo employment to receive treatment.

This practice and its negative impacts runs counter to the concept of rehabilitation and can demoralise service users. In turn, substance use problems may be perpetuated and exacerbated.

For example, dispensing arrangements for methadone have no in-built flexibility and this often impedes on the opportunity to hold down jobs or to access employment and directly impact on the right to earn a livelihood.

Drug treatment services are even more difficult to access and more costly due to travel costs in rural areas. The frequent travel requirements endured by service users from rural areas therefore has an even greater disruptive impact on their lives.

The lives of the service users may revolve around urine sampling and prescription of methadone takeaways at the frequency and times set out by the drug treatment services. Service users report that failure to comply can lead to penalty through withdrawal or reduction of methadone. This punitive element of withdrawal of methadone is something which may be avoidable through engagement and participation of service users in their treatment- this ties into the issue of treatment plans which is outlined in section 7.

In the 2017 user-led research, 81% of respondents reported that they are not in employment. It also found that 70% of respondents viewed treatment as a barrier to employment, with the opening times of clinics, the stigma of being on methadone and the impact of methadone cited the main reasons.

“How you meant to get job going day after day to a clinic?”⁹¹

“Have to go to clinic everyday even though I haven’t used in 8 years.”⁹²

“Have to go to clinic at times most jobs would be.”⁹³

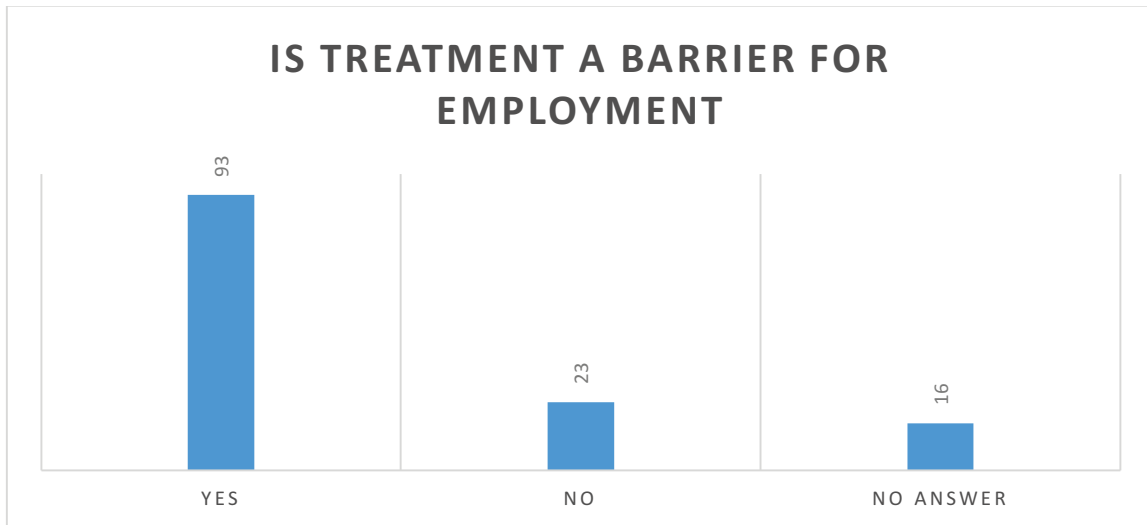


Fig. 10.

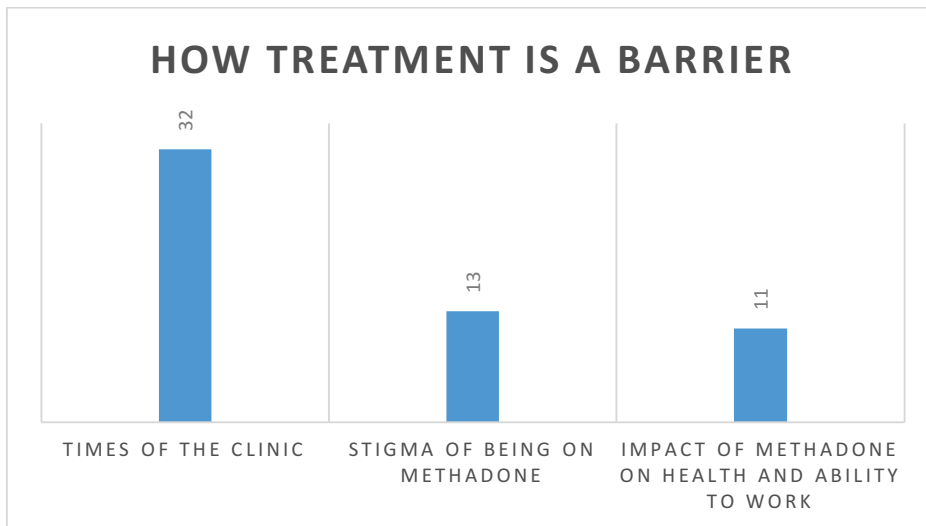


Fig. 11.

Service users outside of Dublin report their experiences of treatment as particularly disruptive and costly in their daily lives, and a barrier to work.

It was a small town I lived in, outside Dublin so methadone prescribing was uncommon so the doctor put me in contact with one that was very far away. It was two bus journeys, each one being one hour. Remember, I also had to get home from this place, so it was major hassle. I had to do this twice

⁹¹ Interviewee “103”. User-led survey, 2017.

⁹² Interviewee “82”. User-led survey, 2017.

⁹³ Interviewee “16”. User-led survey, 2017.

*a week and had to pay all the expenses myself. It was thirty euro twice a week, so sixty euro, and each day it was a full day to get there. So, the chances of a job were zilch, who was going to give me two days off?*⁹⁴

*The last time I went to see the counsellor, before they took me on, I was crying. I had a young baby, there was an eighteen month waiting list to get on in Y town (rural Irish town), so I had to go to X town, a two hour journey and two urines a week, otherwise they wouldn't take me, but I was happy because at least now I was getting some kind of help.*⁹⁵ Linda 36.

Another issue raised by service users which may be avoided through listening and engagement is that service users are often asked to take their dose supervised in local community services or pharmacies. Confidentiality issues arise when service users are required to get their liquid methadone in view of other customers, who may be neighbours, family, etc. Methadone tablets are seldom used or prescribed.

Service users reported instances of having to sign what they described as anti-social behaviour contracts in order for methadone to be dispensed in some pharmacies. Service users also reported being required by judges to sign document allowing their medical records to be shared with other institutions, without adequate knowledge of what the purpose of this was.

*Then I was given some contract to sign. You didn't have time to read it. It was about twenty pages. Nothing was explained. The place was mad busy, patients everywhere. Nobody explained the pros and cons of methadone to me. But I would have signed anything. I would have signed anything. Here, sign there and you're on it (methadone).*⁹⁶

*I had to sign a contract with the doctor. I have to be of good behaviour, not to turn up stoned, to be honest, to keep appointments, to be nice to all the staff. In the chemist, I have to be on my own. It's a bit embarrassing because everyone knows why I'm down there, it feels awful, you feel very small, they're OK down there but I had to sign a contract here as well. I couldn't have anyone with me, no shop-lifting, no walking around, don't go in with anyone, not even your mother, and they are very quick, they want you in and out. Totally different treatment than everyone else. I remember sitting one day in the chemist and I seen hand-warmers, I use them for poor circulation. I got up to look at them and I was told to stay sitting there.*⁹⁷

⁹⁴ "Lenny", age 37. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

⁹⁵ "Linda", age 36. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

⁹⁶ "Jazz", age 55. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

⁹⁷ "Joseph", age 36. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

6.4 What would service users change?

The 2017 user-led survey demonstrated that service users have clear opinions on how services can be improved in relation to treatment choice, respect, participation and urine sampling.

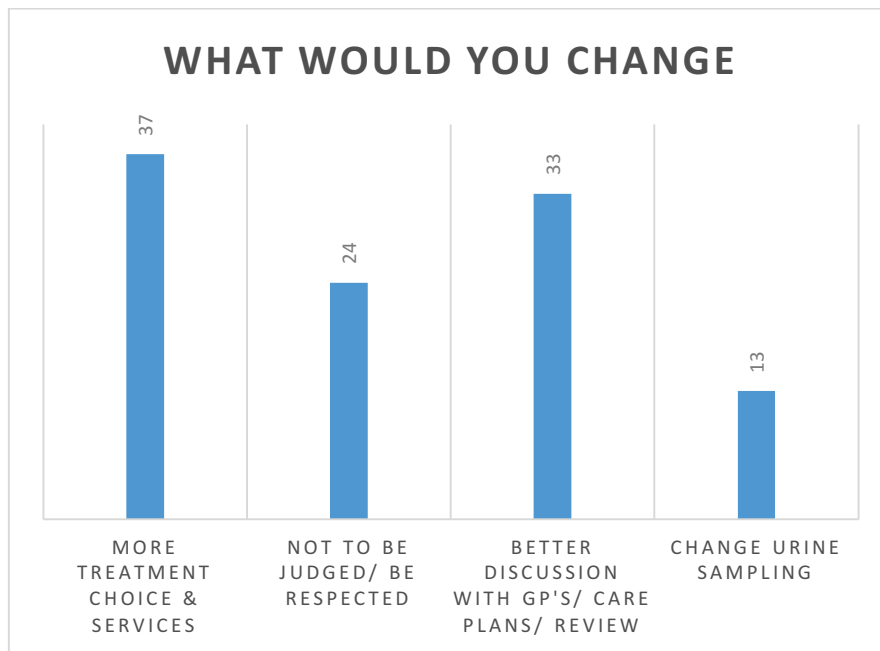


Fig. 12.

Suggestions for change were centred on treatment choice (focus on detoxification), treatment by doctors/staff and wanting more information about the long-term effects of methadone from the beginning of treatment.

“Change swabs instead of urine test and give people choices about their own treatment plan.”⁹⁸

“More choices, more treatment. Doc should be more encouraging on treatment not so quick to give methadone maintenance.”⁹⁹

“I say more detox outreach help also help line. Phy is not answer it ends up long term problem to short term solution.”¹⁰⁰

“(I) wouldn’t have people on methadone for so long plus we should be offered different types of treatment.”¹⁰¹

The most common response was about doctor/clinic treatment, with many respondents reporting they want to see a change in “the way they treat people” or to “treat people with respect”.

⁹⁸ Interviewee “46”. User-led survey, 2017.

⁹⁹ Interviewee “80”. User-led survey, 2017.

¹⁰⁰ Interviewee “90”. User-led survey, 2017.

¹⁰¹ Interviewee “108”. User-led survey, 2017.

“More compassion, belief in their patients. Long term use has destroyed my teeth and this has knocked my self confidence and self-esteem.”¹⁰²

“Being more open with doctor and being treated better. They left me on this Phy 8 years. I never intended to be on it this long. Would like a care plan.”¹⁰³

Service users identified reported feel excluded from the process of determining the appropriate treatment for them, and the specific needs which they have in their own lives are often not taken into account by the medical professionals who are providing the treatment.

“They had a meeting about me, I wasn’t at that meeting. I should have been there. They were talking about my life, no one else’s, my problems”.¹⁰⁴

Meaningful engagement and participation for service users in the delivery of treatment may allow for greater flexibility to accommodate any caring responsibilities, educational commitments or employment responsibilities they may have. Attendance at very important family occasions such as weddings may not be accommodated by the way in which a service is delivered. Engagement and participation should also improve the relationships which service users have with the medical professionals with whom they are interacting.

Consultation and participation are core human rights principles, and service users report that the current administration of opioid treatment services in Ireland does not allow for meaningful consultation.

Separately but linked to the issue of meaningful engagement is the issue of treatment choice and treatment plans, which will be discussed in further detail in section 7.

6.5 Issues particular to women

The Irish Human Rights and Equality Commission consultation with the SAOL project in relation to its reporting on the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) reported a lack of meaningful engagement has an impact on the lives of women in opioid treatment services.¹⁰⁵

The male –female ratio of addiction service users is 3:1, but a staff member indicated that reason for this may be slow uptake in services amongst women, because issues such as caring responsibilities make the commitments of daily supervised dosages extremely difficult or impossible to attend. Furthermore women talked about the stigma that is attached to accessing HSE methadone services- including whether it will lead to social services placing their children in care.

¹⁰² Interviewee “112”. User-led survey, 2017.

¹⁰³ Interviewee “89”. User-led survey, 2017.

¹⁰⁴ O’Reilly, Fiona; Reaper, Emily and Redmond, Tom. (June 2005) “We’re people too – Views of Drug users on health service Report” *Participation and Practice of Rights Project, UISCE, Mountjoy Street Family Practice* http://www.drugsandalcohol.ie/5989/1/2783-Were_people_too.pdf

¹⁰⁵ IHREC (January 2017) *What is life like for women in Ireland in 2016? IHREC’s Consultation on the CEDAW* <https://www.ihrec.ie/app/uploads/2017/02/What-is-life-like-for-women-in-Ireland-in-2016.pdf>

“The main thing that stops me from looking for help is my worry about what will happen to my baby.”¹⁰⁶

The consultation found that issues exist in relation to access to refuges for women with addiction, with very concerning reports that women on methadone cannot access women’s’ refuges.

“There isn’t that much awareness of how wrapped up in addiction domestic violence and trauma are.”¹⁰⁷

“The addiction is seen as the no1 issue. There’s no-one dealing with domestic violence.”¹⁰⁸

A key message from the CEDAW consultation was that, given the lack of meaningful participation and engagement;

“They don’t really understand the needs that women have.”¹⁰⁹

A further issue reported by female service users is that it is common for women who are methadone users (but might be on some kind of self-medication) to be refused entry with their children to women’s refuges if they cannot provide a letter from a doctor saying that they have a 6 weeks record of “clean” urine sampling. This issue has been raised with Women’s Aid.¹¹⁰

6.6 Principles and values related to user participation

During the dialogue events, user-led research and project steering committee meetings, service users identified a range of principles and values which they felt are critical to the provision of drug treatment services. The following are some of the principles and values relevant to issue of meaningful engagement.

6.6.1 Access to adequate and quality healthcare

The barriers posed by the current systems of administering opioid substitute treatment create a variety of difficulties for service users in accessing an adequate level of healthcare in relation to their drug addiction. Both the lack of meaningful engagement and participation with individuals to identify their own specific needs and the rigid and inflexible nature of treatment can lead to individuals being prevented from accessing treatment, or being deterred from remaining on a treatment programme.

There is no evidence to suggest the use of anti-social behaviour contracts for any other cohorts of patients. This forced pre-condition imposed upon service users of opioid addiction treatment

¹⁰⁶ IHREC (January 2017) *What is life like for women in Ireland in 2016? IHREC’s Consultation on the CEDAW* <https://www.ihrec.ie/app/uploads/2017/02/What-is-life-like-for-women-in-Ireland-in-2016.pdf>

¹⁰⁷ IHREC (January 2017) *What is life like for women in Ireland in 2016? IHREC’s Consultation on the CEDAW* <https://www.ihrec.ie/app/uploads/2017/02/What-is-life-like-for-women-in-Ireland-in-2016.pdf>

¹⁰⁸ IHREC (January 2017) *What is life like for women in Ireland in 2016? IHREC’s Consultation on the CEDAW* <https://www.ihrec.ie/app/uploads/2017/02/What-is-life-like-for-women-in-Ireland-in-2016.pdf>

¹⁰⁹ IHREC (January 2017) *What is life like for women in Ireland in 2016? IHREC’s Consultation on the CEDAW* <https://www.ihrec.ie/app/uploads/2017/02/What-is-life-like-for-women-in-Ireland-in-2016.pdf>

¹¹⁰ O’Connor, Monica (March 2006) *Housing Policy and Practice for Women Experiencing Domestic Violence; A Report to the Eastern Regional Planning Committee on Violence against Women incorporating a Survey of the six Local Authorities in the Region.* https://www.womensaid.ie/download/pdf/housing_policy_practice_women.pdf

services is also a barrier to their accessing an adequate level of healthcare and their differential treatment in comparison with other groups of patients.

6.6.2 Participation and autonomy

Failure to engage with service users on the unique and diverse needs of their private, professional, educational and family lives can impact on their ability to participate effectively in social and economic life. Dispensing arrangements for medication often impede the opportunity to hold down jobs or access employment or education.

Restrictive practices around methadone takeaways impact on service users' capacity to enjoy leisure events or to attend or access work or training.

The lack of participation of service users in how their treatment is delivered has led to a rigid and inflexible system which does not accommodate or facilitate their caring responsibilities or their private and family lives. Service users or potential service users may be parents or carers, and have commitments to collect children from school, mind their child, prepare meals, bring people in their care to appointments etc. Restrictive practices around methadone takeaways can be highly disruptive to family life. As reported by service users above, it has had an impact on their ability to attend key family events, such as funerals and weddings.

6.6.3 Equal treatment

There are an extensive number of areas where differential treatment of opioid treatment service users vis-à-vis other patient groups occur. Differential and discriminatory treatment of users of opioid treatment services in comparison with other users of health services in Ireland may amount to discrimination.

The suspension of methadone or other OST is a serious concern of service users. Suspension or reduction of treatment is generally a very extreme measure in health care, and is clearly regulated by medical protocols. Suspension of medical treatment as a reaction to anti-social behaviours does not occur in other contexts (such as failure to quit smoking, or failure to adhere to dietary requirements).

The restrictive practice of daily methadone collection, and frequent/weekly urine testing is highly disruptive to those with family and caring responsibilities, as reported by service users. The provision of medical treatment in this way may interfere with the family lives of those who have caring responsibilities, and therefore disproportionately impact their lives in comparison with those who do not have caring responsibilities.

Fears can pervade the decision by those with children to access opioid treatment services. Service users have reported fearing that their children may be taken into care if they access methadone treatment. This acts as an additional barrier to accessing treatment than for those who do not having children or caring responsibilities.

6.7 Previous reports and current clinical guidelines

The HSE-commissioned Farrell Report¹¹¹ made the following recommendations in 2010 which are relevant to the issue of meaningful engagement and participation:

¹¹¹ Farrell, Michael and Barry, Joe (2010) *The introduction of the Opioid Treatment Protocol*, Dublin: Health Service Executive, http://www.drugsandalcohol.ie/14458/1/Opioid_Treatment_Protocol%5B1%5D.pdf

Rec. 1.4 Services with a focus on key workers and multidisciplinary work should be promoted and developed in more settings.

Rec. 1.5 An integrated services approach should account for family, community and user groups and it is recommended that these voices get a more prominent place in the future planning and development of drug services

Rec. 1.6 There is a need for a service model outside of Dublin that has a clear focus on rural aspects of service delivery.

The current Clinical Guidelines initially capture the importance of dignity when engaging with the service user, recommending that staff engage “while demonstrating satisfactory levels of warmth”, ‘ability to build trust’, ‘ability to adjust the nature of the intervention according to the capacities of the service user’.¹¹²

The Clinical Guidelines positively highlight consultation as an element which informed the drafting. However, it is not clear what consultation process was used, what service users were consulted, what stakeholders were consulted and what experts were consulted.

The Guidelines also positively reflect the importance of partnership between statutory drug treatment services and community / voluntary sectors and involving families / carers.

Overall the general underlying assumption within the Guidelines seems to be that opioid substitution treatment is an end in itself rather than as part of a treatment plan. For example there may be insufficient emphasis on detoxification as an element of treatment.

The Guidelines positively emphasise the importance of involving service users in their care plans and in the design, planning, development and evaluation of services. However, the Guidelines do not specify how this should be done.

On issues such as frequency of attendance to clinics and frequency of drug tests, there appears to be little emphasis on choice or flexibility put forward in the Guidelines.

¹¹²Page 12, Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment*
<https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

7 Treatment Choice and Treatment Plans

7.1 Explaining the issue

Recovery to me, it's about getting clean, getting a job so you can get on with your life, without being held to ransom. None of this has really happened for me. The clinics and doctors don't help you get any of this, they get in the way, no empathy, no discussion. I've never been offered anything to do with recovery. I've no positive experiences of any drug services. When I made the transition from the clinic to the doctor, she hadn't got a clue. I had to tell her everything. She had no details, file on my history of being on the clinic, my medication.... she knew nothing about me.¹¹³

Service users have reported that they often do not have access to information on the types of treatment available, or have a choice in the treatment available to them. Most service users are not aware of or do not have established treatment plans. It may be acceptable for some service users that they stay on methadone or OST for a lifetime. While this may be a personal choice for many service users, it should be recognised that other alternatives are not widely available. Information or availability of detoxification programmes is not widely available. Counselling services are also not broadly available, not available at the appropriate time or might not be suitable to this cohort of service users.

While methadone is known to be an effective and safe medication that improves health, reduces crime and saves lives, it should form just part of a holistic treatment plan to help opiate dependent patients with complex bio-psycho social needs. As stated in Chapter 7, treatment plans should be the result of meaningful engagement and participation of service users.

7.2 Care plans

“At 17 years old, when I started to be on drugs I went to the doctor. He put me on methadone and said I would be clean in 6 months. I was failed by him. The dosage kept going up and was never reduced. Doctors have failed me for the past 21 years... All my babies were born with a methadone addiction. And later, when you're not healthy, you can't get up and do things with your children.”

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The lack of care plans offered to patients means that patients can end up on methadone for the course of their lifetimes. While this might be appropriate and preferred for some patients, it is not satisfactory that this situation should arise without proper thought, engagement, consent and planning in relation to the care and treatment of that service user.

Despite the importance of holistic care plans based on the needs of the service user, 76% of respondents in the 2017 user-led survey reported that they had not been offered a care plan, while 75% expressed that they wished to have a care plan. This is a deterioration from the 2012 survey, in which 62% of service users reported that they were never offered a care plan.

¹¹³ “Jazz”, age 52. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

¹¹⁴ Europe for Citizens Project (June 2017) *Irish Project participant: Our Voices Learnings for the Future of an Inclusive Social Europe* <http://www.atd-fourthworld.org/wp-content/uploads/sites/5/2017/06/OV2017-Final-Report-Web-1.pdf>

While 75% of respondents stated that they wanted a care plan, 76% reported that they had not been offered a care plan.

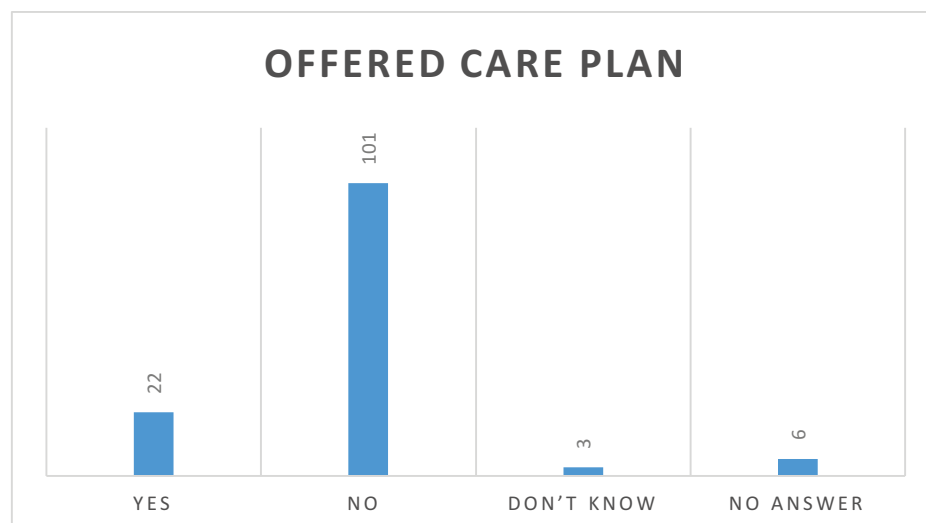


Fig. 13.

Interviews with service users in the 2011 study in the Dublin North East have also indicated a lack of clear information available about care plans and options.

“Most of the information I have learnt in clinics has not been off doctors, it’s been off clients, that’s where you find the information...there is a lack of information, its only if you go looking for something then you’re told about it other than that its just in and out, it’s like a revolving door you go in give your urine, you get your dose and then go unless the doctor wants to see you.”

Male aged 29-33 years¹¹⁵

More recently, interviews conducted by Steering Committee member Richard Healy, (Irish Research Council Scholar at the Department of Sociology in the University of Maynooth) also demonstrates that a lack of care plans is an issue, with treatment being equated with the prescribing of methadone;

The only time I have ever heard anything about detox is if I’ve mentioned it, so he has never asked me what I would like to do. There’s no treatment plan, it very much “wham bang, thank you ma’am, there’s your week’s script”.¹¹⁶

The evidence gathered by the 2017 Survey demonstrates that the Farrell Report recommendation 1.12 that “there is a need to develop a more structured care planning process” and that “the services need to develop to the stage where every individual has a clearly documented care plan that is subject to a regular review and update” has not been implemented for a significant proportion of service users.

¹¹⁵ Van Hout, Dr Marie Claire, Tim Bingham, Tim (2011); *Holding Pattern: An exploratory study of the lived experiences of those on methadone maintenance in Dublin North East*, Clients Forum of the Dublin North East Drugs Task Force,

¹¹⁶ “Mick”, age 37. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

The Clinical Guidelines on Opioid Substitution Treatment highlight as a ‘guiding principle of opioid substitution treatment’ that “service users should be fully involved in the development of their care plans, setting appropriate treatment goals and reviewing their progress in treatment.”¹¹⁷ This guiding principle is very welcome, as the evidence gathered in this report demonstrates that service users’ involvement in development of care plans is not currently a widespread practice.

7.3 Treatment choice and information availability

*No, I was never encouraged to detox, I was never told anything about treatment... I had to find it all out myself, I am in treatment for the past 4 months and I am still only finding out about places...Male aged 33 years*¹¹⁸

*“On the clinic, there's no choice or say in your treatment. Just feeling like a number, going to see a doctor once a week, I don't know why you'd bother. Threatening you with urine results, saying "you need to get a clean urine". Nobody would ask you why you can't get clean, or help you get clean. You're not made aware of anything. In all my time on Trinity Court, I never even seen the doctor I was supposed to be under. Just them stand-in doctors. One would give you a sleeper, the other would take it off you.” “Louise”, 35.*¹¹⁹

During the project’s dialogue events and steering group meetings service users pointed to poor accessibility to treatment option information, and if care plans exist, service users have no knowledge of or little consultation on them. This has led to a lack of meaningful reviews for patients in drug treatment services.

The lack of information available to service users is identified in the HSE Clinical Guidelines on Opioid Substitution Treatment as an issue. The Guidelines recommend as a key point in chapter 3 that “good communication between the patient, the prescriber, the pharmacist and other members of the interdisciplinary team is crucial in providing optimal treatment.” It states that “patients should be made fully aware of the risks of their medication.”¹²⁰

In the 2012 user-led survey, 89% of respondents reported not being offered any alternative to methadone, with just 26% reported as being aware of having care plans. While care plans may exist in many circumstances, they are not meaningful except where service users do not feel they are active participants in the care plan.

In the 2017 user-led survey, 93% of respondents reported that they had not been offered an alternative to methadone, an increase since 2012.

¹¹⁷ Page 11, Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment* <https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

¹¹⁸ Dr Marie Claire Van Hout, Mr Tim Bingham; *Holding Pattern: An exploratory study of the lived experiences of those on methadone maintenance in Dublin North East*, Clients Forum of the Dublin North East Drugs Task Force, 2011.

¹¹⁹ Van Hout, Dr Marie Claire, Tim Bingham, Tim (2011); *Holding Pattern: An exploratory study of the lived experiences of those on methadone maintenance in Dublin North East*, Clients Forum of the Dublin North East Drugs Task Force,

¹²⁰ Page 17, Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment* <https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

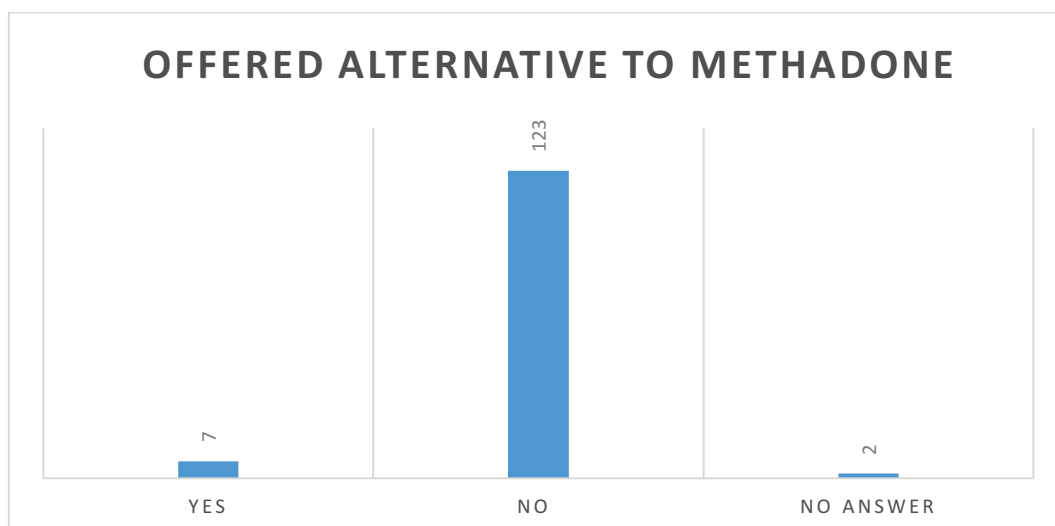


Fig. 14.

Service users report that they have not had the information provided to them so that they can make informed choices around their treatment. According to the Clinical Guidelines on Opioid Substitution Treatment it is “good practice to involve service users in the design, planning development and evaluation of services,”¹²¹ and it is the duty of healthcare professionals to provide the necessary information, in a manner that is accessible, to patients in relation to their treatment and choices. Given the length of time service users can be accessing opioid treatment services, information provision should be a repeated exercise, taking into account change circumstances as time passes. While this is standard practice in many other areas of healthcare provision in Ireland, the evidence from the research and engagement with service users in this project suggests it does not currently extend as a practice to the provision of opioid treatment services.

The Clinical Guidelines highlight as a guiding principle that “therapeutic alliance” is the model which should be pursued by service providers in developing care plans with service users. Key competencies for developing a therapeutic alliance include “the ability to engage a service user appropriate while demonstrating satisfactory levels of warmth,” “an ability to adjust the nature of the intervention according to the capacities of the service user” and the “ability to engage a service user appropriate while demonstrating satisfactory levels of understanding.”¹²²

The IHREC’s consultation for its report for the Convention on the Elimination of all forms of Discrimination Against Women with the Saol project¹²³ (outlined above) identified further issues relating to the lack of treatment choice. Concerns were expressed by service users at the overuse of methadone, lack of review of usage and tendency for medical staff to increase methadone dose when users raise problems related to anxiety and depression.

¹²¹ Page 11, Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment* <https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

¹²² Page 12, Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment* <https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

¹²³ IHREC (January 2017) *What is life like for women in Ireland in 2016? IHREC’s Consultation on the CEDAW* <https://www.ihrec.ie/app/uploads/2017/02/What-is-life-like-for-women-in-Ireland-in-2016.pdf>

The consultation demonstrated that care plans are not currently in place to address the wider health needs of service users, with a lack of linking up of treatment for mental health and addiction, and a lack of services dealing with dual diagnosis with mental health difficulties such as schizophrenia.

7.4 Duration of treatment

The lack of a treatment plans can lead to service users spending significant portions of their lives in opioid treatment services. Treatment plans and treatment choice should take account for the changing circumstances of service users' lives, given the long time-scales involved in treatment, however service users report little change in their treatment provision over the course of many years.

The 2017 survey demonstrated that service users spend very long periods of their lives in treatment. The lack of treatment plans and treatment review has been identified as a clear factor in the very long durations people spend in opioid treatment services in Ireland.

In the 2017 survey, the average age that people began treatment was 25. The average time people had spent on methadone was 14.6 years. The service users in the 2017 survey had spent an average of 36.7% of their entire lifetimes on methadone.

Recommendation 1.9 of the Farrell Report stated that "there is need to create a sense of progression within services either through the tiers of the services or alternatively through the detoxification and rehabilitation pathway, with movement within and between these pathways being actively promoted through a variety of mechanisms."¹²⁴

Clearly, the very long durations of service users' lifetimes spent in opioid treatment services without changes in treatment plans or review directly contradicts this Farrell Report recommendation.

It is therefore very welcome that the Clinical Guidelines recommend that;

*"A care plan should be fully drawn up within the first three months of treatment and should clearly document the patient's aims and goals for treatment and outline the range of treatments required to achieve the user's goals. A formal care plan review should be undertaken every 3 months and when a change in a service user's circumstances makes it necessary. The date of the next care plan review should be explicitly stated in the care plan at the end of the care planning session and at the end of each subsequent case review. Patients should be provided with a copy of their care plan."*¹²⁵

Implementation of the above recommendation would represent real change to the current circumstances faced by service users.

7.5 Principles and values relating to treatment choice and treatment plans

During the dialogue events, user-led research and project steering committee meetings, service users identified a range of principles and values which they felt are critical to the provision of drug treatment services. The following are some of the principles and values relevant to the issue of treatment choice and treatment plans.

¹²⁴ Farrell, Michael and Barry, Joe (2010) *The introduction of the Opioid Treatment Protocol*, Dublin: Health Service Executive, http://www.drugsandalcohol.ie/14458/1/Opioid_Treatment_Protocol%5B1%5D.pdf

¹²⁵ Page 13, Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment* <https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

7.5.1 Access to adequate and quality healthcare

Access to adequate and quality healthcare is engaged by the lack of treatment choice and adequate treatment plans in the provision of opioid treatment services in Ireland. The non-availability of complementary treatment, community-based programmes and addiction counselling impedes the service users' ability to access adequate healthcare.

The lack of care plans for all service users is perceived to further diminish access to healthcare for service users, as it makes it difficult for service users and care-providers to measure improvements and better outcomes in each service users' cases.

Meaningful access to healthcare requires a holistic approach to service-provision, where the broad set of health needs of patients are assessed and addressed through a care plan. The limited focus on methadone provision, without a structured care plan, does not offer such a holistic approach.

7.5.2 Access to information

Access to information about healthcare options is an important value which should be applied in the provision of healthcare services. Service users have repeatedly emphasised that in many instances information is not made available to them in relation to treatment choice, and that GPs do not consult with them in the formation of a treatment plan, if such a plan exists at all. The lived experiences of service users demonstrate that information is not accessibly provided to them on the treatment options available.

7.6 Previous reports and current clinical guidelines

The HSE-commissioned Farrell Report¹²⁶ made the following recommendations in 2010 which are relevant to the issue of treatment choice in treatment plans:

Rec. 1.2 There should be a mechanism to rapidly access treatment for the six months after detoxification to ensure support if relapse occurs.

Rec 1.8 The professional expertise of the adolescent services and the midwifery services should be used for developing an overall national strategy in these specific topics.

Rec 1.9 Implementation of a once yearly completion of a brief instrument, such as the Treatment Outcome Profile, would provide important information on the performance of individuals and on the overall performance of the service. There is need to create a sense of progression within services either through the tiers of the services or alternatively through the detoxification and rehabilitation pathway, with movement within and between these pathways being actively promoted through a variety of mechanisms.

Rec 1.10 Services should use the full range of skills of the multidisciplinary team to ensure that the mixture between health and social problems of the drug users is evenly addressed.

Rec 1.12 There is a need to develop a more structured care planning process... The services need to develop to the stage where every individual has a clearly documented care plan that is subject to a regular review and update. The care plan should be fully drawn up within the first three months of treatment and should clearly document the patient's aims and goals for treatment and outline the range of treatments required to achieve the users goals. This plan

¹²⁶ Farrell, Michael and Barry, Joe (2010) *The introduction of the Opioid Treatment Protocol*, Dublin: Health Service Executive, http://www.drugsandalcohol.ie/14458/1/Opioid_Treatment_Protocol%5B1%5D.pdf

should be fully reviewed and modified at twelve months and measured against whether the stated goals have been achieved.”

The evidence gathered in this report demonstrates that these recommendations have not been meaningfully implemented, although there has been some welcome incorporation of the recommendations in relation to treatment plans in the Clinical Guidelines.

The HSE Clinical Guidelines for Opioid Treatment Services state in their introduction that “OST plays an intrinsic role in supporting patients to recover from drug dependence. Assessment and recovery care-planning is an ongoing process and, once stabilised on OST, collaborative and active care planning to consider options across a wide range of personal recovery goals is an important part of recovery-orientated culture.”¹²⁷

The emphasis in the introduction Clinical Guidelines on active care-planning is very welcome. The key issue is implementation of this recommendation.

Chapter 2 of the Clinical Guidelines clearly states as a key point that “All drug users entering treatment and rehabilitation should have a care plan based on assessed need, which is regularly reviewed.” The Clinical Guidelines recommend the use of the “therapeutic alliance” model to interacting with and engaging service users. This model requires a “non-blaming, non-judgmental stance, use of motivational dialogue, being a good listener” etc.¹²⁸

The Clinical Guidelines recommend the development of a “holistic, documented care plan between the service user and service provider based on SMART objectives.”¹²⁹ The guidelines give details on what should be included in care plans i.e. Drugs and alcohol misuse, Health (physical and psychological) Offending and Social functioning (housing, employment, relationships). It further states that “care plans should be readily understood by all parties and should be a shared exercise between the service user and service provider.”¹³⁰

It is welcome that the clinical guidelines provide this guidance on how to engage in meaningful care planning with service users. Given the evidence gathered in this report that indicates that such active care-planning is not currently taking place, it is crucial that the guiding principles and recommendations of the Clinical Guidelines in the context of care planning are meaningfully implemented.

8 An effective complaints mechanism

¹²⁷ Page 4 Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment*
<https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

¹²⁸ Page 12 Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment*
<https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

¹²⁹ Page 16 Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment*
<https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

¹³⁰ Page 16 Health Service Executive, *Clinical Guidelines for Opioid Substitution Treatment*
<https://www.hse.ie/eng/services/publications/Primary/clinical-guidelines-for-opioid-substitution-treatment.pdf>

8.1 Explaining the issue

The current system of complaint-making available to service users has been found by service users to be inadequate, ineffective and difficult to access.

Service users have reported a lack of information about how to make a complaint, a perceived bias within the complaints procedure and a reluctance to complain within the HSE's internal structure for fear of penalty.

8.2 Awareness of complaints mechanism

I never knew there was a method of making complaints against drug services.... but you don't want that... it's intimidation isn't it, you don't want them having that on you. I mean they're condescending enough as it is. I wouldn't make a complaint, you'd be made pay, you just know it... and you don't want to be doing this. We are manipulated by the fear of our script being stopped. There was loads of times I wanted to say something, but you'd be afraid to open your mouth.¹³¹

The research of this project has found that a clear lack of awareness exists in relation to the procedures required to make a complaint. In the user-led survey taken in 2017 of 132 service users, 59% of respondents reported that they did not know how to make a complaint.

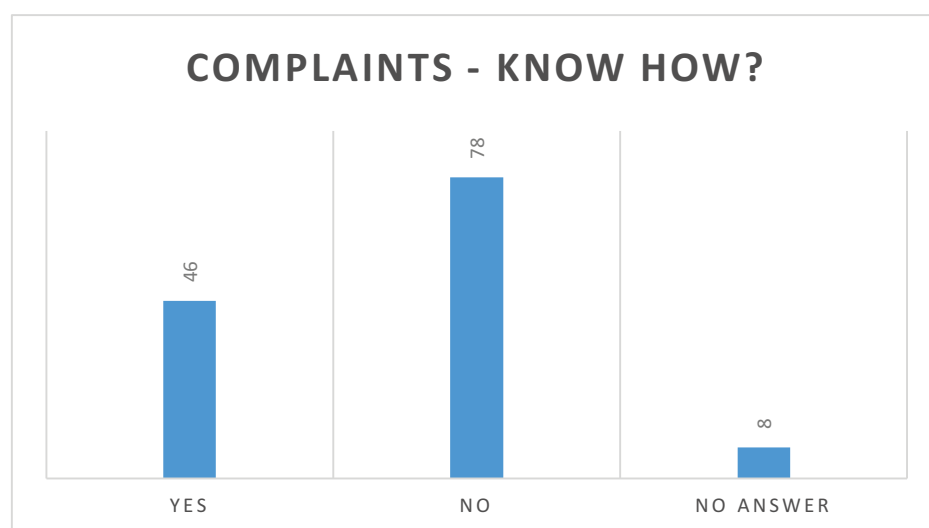


Fig. 15.

The availability of information on how to make a complaint was reported by one service user to be an issue:

It should be up on clinics, on the walls, the information service users need.¹³²

8.3 Effectiveness of complaints mechanism

In the 2017 user-led survey, 77% of respondents reported that they had not made a complaint.

¹³¹ "Jazz", age 52. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

¹³² "Louise", age 35. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

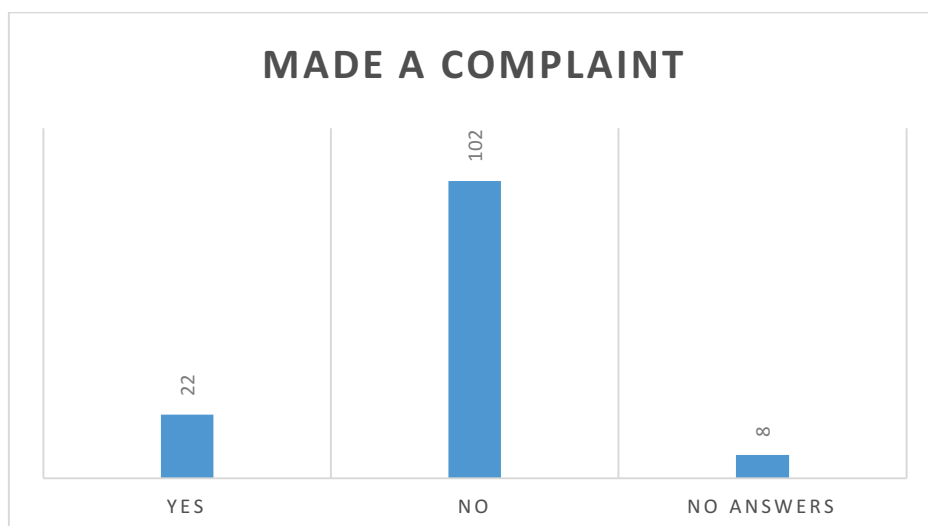


Fig. 16.

When asked why they had not made a complaint, the most common response was because of a fear of punishment and a belief that nothing would be done, with many service users responding “what’s the point.”

Reluctance and fear to make a complaint are issues which are particularly pertinent in relation to opioid treatment service users. One service user reported feeling “Afraid I’ll be punished” if they made a complaint.¹³³ Another reported that they would be “not listened to and I feel I’ll have to pay for it.”¹³⁴ As set out in Section 5.1.3 methadone can be suspended for service users on the basis of a positive urine test or anti-social behaviour. The suspension of medical treatment for behavioural reasons is almost unique to this cohort of patients within the HSE. Therefore the surrounding context of the potential threat of suspended methadone has a chilling effect on the confidence of service users to make complaints, even where they feel clear ill-treatment has occurred.

*Service users should know they can complain and not be afraid that if they do complain, they're not going to be sanctioned, or put off the clinic.*¹³⁵

*Service users now have got used to bad treatment. They almost expect to be treated bad. It's indoctrination. It's also shame. These people don't or won't complain. It's the shame, people feel they deserve bad treatment, it's like 'I got myself into this and I deserve it,' but it's not right. It perpetuates and exacerbates it. (bad treatment).*¹³⁶

*“I know people who made complaints but nothing ever came out of them.”*¹³⁷

Service users reported fearing victimisation and being afraid that satisfaction and feedback surveys are not really anonymous. This demonstrates the inter-related nature of the issues laid out in this

¹³³ Interviewee “1”. User-led survey, 2017.

¹³⁴ Interviewee “62”. User-led survey, 2017.

¹³⁵ “Louise”, age 35. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

¹³⁶ Interviewee, age 46. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

¹³⁷ Interviewee “16”. User-led survey, 2017.

report, which are borne out of deeply entrenched and systemic attitudes towards and stigma attached to users of opioid treatment services.

*If I was to make a complaint, I know my doctor would hear about it. I think I'd be put off the doctor's list and wouldn't get on with another one. No matter how bad it was I don't think I'd make any complaint.*¹³⁸

*"Nothing happened and I was disciplined."*¹³⁹

*"Just gets held against you and not taken seriously."*¹⁴⁰

The HSE feedback system known as 'Your Service, Your Say', is not perceived by service users as being independent or impartial, as the complaint is usually investigated by the HSE itself. There is a perception that it serves more as an internal risk management operation for the HSE.

*"They said they'd get back to me and never did."*¹⁴¹

A fundamental perception of inequality exists within the system for many service users in relation to accountability. While many doctors and pharmacists do not appear to be accountable to the system in relation to their behaviour and treatment of service users, service users themselves feel they are always made accountable in terms of their own behaviour.

*A few years ago, the last doctor I was on with, I was directed to the HSE complaints section. It's called "Your Service. Your Say", which I later found out to be a risk management operation. I had my complaint put through twice, by three different doctors, they all... their conclusion was that despite all the evidence refuting what the doctor said, they said that we believe that the Doctor involved behaved properly and was professional at all times. Even though I had people who had witnessed what he done. They found in favour of him, they either didn't look at the evidence or they disregard it. The people who are being complained about are dealing with the complaints. It's kind of like police brutality or something. There is no one watching the watcher. It should be impartial. I mean the doctor I was complaining about was an agent of the HSE, being investigated by other agents of the HSE. I mean they are hardly going to go against each other.*¹⁴²

*"I was told to write an A4 page letter to my own doctor to complain about him and hand it back to himself to look for a new doctor so the decision was in his hands."*¹⁴³

A further issue informing the perception that the complaint mechanism is ineffective is that service users report that complaints are not followed up and crucially that no clear time-line for addressing the complaint is provided to them.

¹³⁸ "Joseph", age 36. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

¹³⁹ Interviewee "90". User-led survey, 2017.

¹⁴⁰ Interviewee "78". User-led survey, 2017.

¹⁴¹ Interviewee "109". User-led survey, 2017.

¹⁴² Interviewee, age 46. Interview conducted by Steering Committee member Richard Healy, PhD Candidate, NUI Maynooth. 2017

¹⁴³ Interviewee "125". User-led survey, 2017.

8.4 Reasons for complaining

Urine sampling, lack of respect and participation, treatment choice and confidentiality were cited by service users as the main reasons making a complaint.

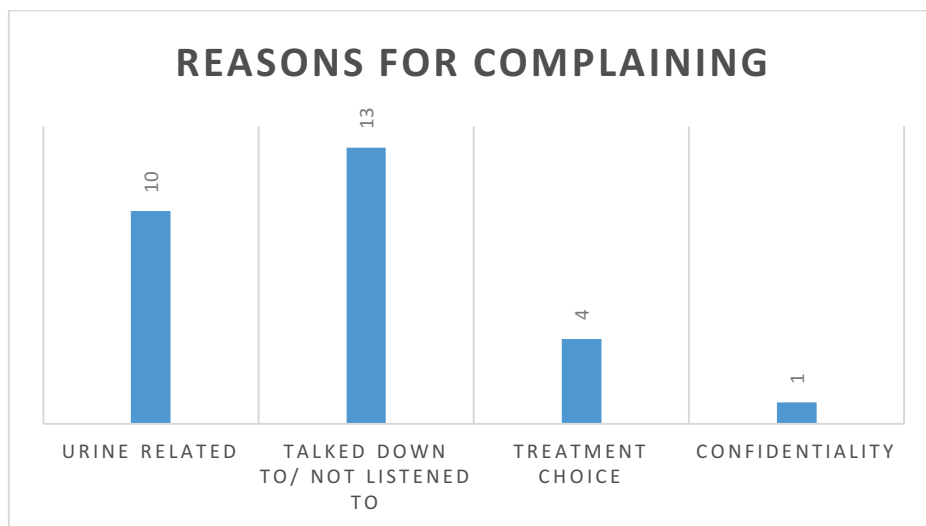


Fig. 17.

Service users in the 2017 Survey gave the following examples of reasons why they complained;

“When I had my leg broken had to go every day when I complained.”¹⁴⁴

“My take away was stopped because I couldn't give a urine at that time”¹⁴⁵

“The pharmacist is not very nice the way he treats addicts seeking help.”¹⁴⁶

“Times when I couldn't give urine I get my phy stopped.”¹⁴⁷

8.5 Principles and values related to an effective complaints mechanism

During the dialogue events, user-led research and project steering committee meetings, service users identified a range of principles and values which they felt are critical to the provision of drug treatment services. The following are some of the principles and values relevant to the issue of an effective complaints mechanism.

8.5.1 Accountability

Service users should be confident that they have the right to complain and to have this complaint investigated and responded to within a fixed period of time. A meaningful expression of the value of accountability in the provision of opioid treatment services requires a greater awareness of the complaints systems that are in place and confidence on the part of service users on the effectiveness, impartiality and fairness of that complaints system.

¹⁴⁴ Interviewee “85”. User-led survey, 2017.

¹⁴⁵ Interviewee “38”. User-led survey, 2017.

¹⁴⁶ Interviewee “8”. User-led survey, 2017.

¹⁴⁷ Interviewee “1”. User-led survey, 2017.

The lived experiences of service users indicate that there is no fixed period within which a response to a complaint is issued. Furthermore, the apprehension felt by service users towards making a complaint at all, given the penal nature of methadone-provision some have experienced, serves to undermine their willingness to make a complaint.

8.6 “Your Service Your Say”

The internal nature of the HSE feed-back system, “Your Service, Your Say”, means that there is a perception that it is not independent or impartial. As outlined earlier, there is a reluctance amongst service users to make complaints to the HSE, their service-provider, given the penal context of methadone suspension which occurs.

Moreover HSE service users’ surveys, are experienced as not being very accessible from a language, jargon and literacy points of view.

An effective complaints examiner should have no affiliation with the organisation, be impartial and have investigative powers.

8.7 Previous reports and current clinical guidelines

The HSE-commissioned Farrell Report¹⁴⁸ made the following recommendation in 2010 which is relevant to the issue of an effective complaints mechanism:

Rec. 2.2 The lines of reporting and accountability in all of the services requires review so that all professionals have their [sic] within service reporting lines clarified.¹⁴⁹

A May 2015 report by the Ombudsman office contains 36 recommendations on how public hospitals could improve their complaints processes.¹⁵⁰ Many of these recommendations resonate with the issues raised by service users and the related human rights and equality principles explained here. These include:

“1. Multiple methods of making a complaint should be available and easily understood,”

“3. A standard approach should be adopted by all hospitals in relation to the information available to the public when viewing their website.”

“8. Regulators and the Ombudsman should work more closely together to co-ordinate access for patients to the complaints system. In this regard, the online platform healthcomplaints.ie should be extended to provide a better publicised point of information and access for complainants.”

“11. A detailed complaints policy statement should be displayed in public areas within all hospitals, on the hospital website, and in, or near, the Complaints Officer’s office. Induction and other training for staff should include a reference to the policy. Staff should also be periodically reminded of the provisions of the policy.”

¹⁴⁸ Farrell, Michael and Barry, Joe (2010) *The introduction of the Opioid Treatment Protocol*, Dublin: Health Service Executive, http://www.drugsandalcohol.ie/14458/1/Opioid_Treatment_Protocol%5B1%5D.pdf

¹⁴⁹ Page 34 Farrell, Michael and Barry, Joe (2010) *The introduction of the Opioid Treatment Protocol*, Dublin: Health Service Executive, http://www.drugsandalcohol.ie/14458/1/Opioid_Treatment_Protocol%5B1%5D.pdf

¹⁵⁰ Office of the Ombudsman (2015) <http://m.ombudsman.gov.ie/en/Publications/Investigation-Reports/Health-Service-Executive/Learning-to-Get-Better/Recommendations.html>

The Clinical Guidelines do not address the issues raised in relation to awareness of the complaints mechanisms available, and effectiveness and appropriateness of the complaints mechanism available.