HRB drug and alcohol evidence reviews

An integrative evidence review on service user participation in the design and delivery of drug treatment, recovery and harm reduction services

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Acknowledgements

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Pratschke J, Glanville J and Engling F (2022) An integrative evidence review on service user participation in the design and delivery of drug treatment, recovery and harm reduction services. HRB Drug and Alcohol Evidence Review 8. Dublin: Health Research Board

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Preface

This project was commissioned by the Health Research Board and carried out by Jonathan Pratschke, in collaboration with Julie Glanville and Feline Engling Cardoso. It aims to provide an overview of what user involvement entails within the context of drug treatment services in Ireland. The objective of the study is to provide policy-makers, practitioners, researchers and service users with a clearer understanding of the challenges associated with user involvement, a fundamental paradigm or principle when seeking to develop more effective and satisfactory services.

The study involved a lengthy and complex series of research tasks, including an extensive literature search, a service user consultation and discussions with a number of stakeholders. Julie Glanville was responsible for designing the literature search, Feline Engling Cardoso coordinated the stakeholder interviews and Jonathan Pratschke carried out the service user consultation, as well as analysing the interview transcripts and supervising the study. Brian Galvin from the Health Research Board provided oversight and guidance, the Royal College of Physicians of Ireland provided ethical approval for the service user consultation.

The authors would like to express their gratitude to all those who contributed to this project and above all to those who participated in interviews and other forms of data collection. In particular, we would like to thank the service users who generously shared their experiences and reflections on drug treatment services in Ireland. Their willingness to share their stories and insights with the researchers, and their determination to contribute to the improvement of services, was nothing short of inspiring. We are also very grateful to the managers, medical practitioners, staff members and experts who shared their knowledge of user involvement and empowerment initiatives across a wide range of organisations and contexts.

Finally, we would like to thank the advocacy groups – UISCE, SURIA and CityWide – which supported this study by helping us to interact with service users, by participating in stakeholder interviews and by providing advice. Their commitment to the well-being of service users and their belief in the possibility of greater involvement and empowerment within drug treatment services is exemplary and provides a stimulus for innovation and improvement across all aspects of service delivery. We are especially grateful to María Otero Vázquez, Community Development Officer at UISCE, for enabling us to interact with a much wider range of drug treatment service users than would otherwise have been possible.

Although the concept of service user involvement is multi-faceted, it is far from being an abstract or theoretical issue. It is likely to prove difficult to secure lasting improvements in services without consulting and involving the people who use them, and this is just as true of drug treatment services as it is in other areas of provision. Arguably the most challenging aspect of service user involvement is its dependence upon open-ended and far-reaching processes of change that transform the relationship between service users and providers.

Our aim when writing this report was to allow the perspectives of different individuals and groups to emerge, while concentrating on identifying the key themes. Because of the openness of the user involvement paradigm, it is difficult to identify programmatic steps for empowering and engaging users. The implications and consequences of service user involvement are likely to vary across settings, which means that policy-makers, service managers and practitioners have a crucial role to play in translating the general principles of user involvement into new forms of professional practice and innovative organisational solutions.

Executive summary

Introduction

The concept of service user involvement has gained traction in recent decades and many countries have introduced measures to promote the active participation of patients and clients. Current policy in Ireland treats service user involvement as crucial to improving drug treatment, recovery and harm reduction services. Not only should drug treatment service users have the opportunity to participate in decisions about their own care, it is argued, they should also be able to participate in the development and redesign of services at local, regional and national levels through appropriate forms of representation.

Pressure to enable users to have a greater say in their treatment has increased in recent years as a result of a series of interrelated processes, including the affirmation of the New Public Health and New Public Management models, grassroots movements promoting user empowerment and the influence of the recovery and harm reduction paradigms. A number of obstacles to involvement have also been identified, including social disadvantage, social isolation and stigmatisation.

International policy context

Drug treatment services in Ireland come under the auspices of a health strategy and a multi-sectoral drugs strategy, both of which set out aims regarding service user involvement. Service user involvement has come to be viewed as an important aspect of a wide range of health and social services. This development mirrors the situation in other countries, where user involvement is a central policy goal. For example, patient and public involvement is a well-established practice in health and social care policy in the UK. This approach focuses on improving services by building relationships between users and those in decision-making roles. In England and Wales, the providers of state-funded health care have a statutory requirement to involve users in their activities. In the USA, Canada and Australia, user involvement is often viewed as a means to enhance accountability, support freedom of choice and improve the quality of services.

The Portuguese National Drugs Strategy includes participation as one of its pillars, which is understood as referring to the involvement of the community in the definition of drug policy and interventions. Structures have been introduced to facilitate participation, including a National Council for Drug Addiction on which service users are represented. In Norway, the National Action Plan on Alcohol and Drugs emphasises the need to ensure genuine user influence through free treatment choice, more user-driven solutions and greater participation in the design of services.

User involvement in treatment decisions is mandatory under the Swedish Social Services

Act, which stipulates that treatment must be designed and implemented in collaboration with service users. The national substance abuse treatment guidelines include a chapter on individualised care, which specifies that treatment should be adapted to service users' needs, experiences and preferences, and that staff members should aim to establish a positive therapeutic alliance with service users. Empowerment has also become a key concept in Danish debates since the late 1990s, with ministerial guidelines and handbooks defining appropriate empowerment strategies.

Methodology for literature review

To be eligible for inclusion in our extensive review of the literature, studies had to meet a set of eligibility criteria. We followed 8 steps during the review, starting with the definition of the literature search and terminating with a narrative synthesis of eligible documents. We searched a range of bibliographical databases, including Embase.com, as well as the websites of relevant organisations. In total, we identified 10,024 records using research databases and we found a further 579 potentially eligible documents by searching websites. After carefully reading each eligible article and report, we identified themes and gathered together the empirical evidence. The themes were defined in an iterative fashion as we analysed the literature.

The main strength of our literature search is its impressive scope, covering not only academic journal articles, but also reports and unpublished dissertations. A wide coverage was ensured by using a number of databases and web-based resources. We screened a considerable number of records, ensuring that our literature search includes a wide range of relevant documents across a range of fields of study, services and geographical contexts. Our study has a much more extensive coverage of the literature than previous reviews.

Results of the extensive literature search

A total of 45 studies were included in our narrative synthesis, 38 of which have a qualitative design, 5 are quantitative and 2 use mixed methods. We constructed an evidence summary by extracting information from the eligible studies on location, research design, setting, aims, data collection, analysis and findings.

Narrative syntheses

In order to extend the scope of the evidence review, we also consulted 18 stakeholders from Ireland and other countries, including researchers, administrators, user representatives, and professionals. These consultations took the form of semi-structured online (Zoom) interviews lasting between 45 and 90 minutes each.

To ensure that the voices of service users were also included, we interviewed 24 service users from around Ireland. In the first stage of the sampling process, we contacted service providers, practitioners, and voluntary groups in different parts of the country in order to identify service users who were willing to participate. The interviews were conducted between December 2021 and March 2022.

In the following sections we summarise the results of the integrative evidence review for each of the main themes, presenting findings from the literature, from our interviews with stakeholders and with service users.

Theme 1a. Building and maintaining trust

Literature

Empirical studies based on interviews with service users and practitioners have yielded rich descriptions of collaborative relationships. Being treated with respect and being valued as a person are of primary importance to service users, who would like clinicians to take the time to talk to them and to get to know them before proposing treatments. They do not want practitioners to try to fix them or to judge them, but instead to meet them, to 'walk alongisde' them and to treat them as individuals. User involvement in defining an individual treatment plan ensures that this matches the needs and preferences of the patient, but the process itself is also important, generating motivation to make progress and building trust.

Once they have established trust, service users can open up to staff members by disclosing sensitive information, which is often of fundamental importance to their health and recovery. There are, however, structural factors rooted within the organisational context and professional culture of treatment which can obstruct service user involvement. Viewed from the perspective of a trusting therapeutic alliance between service user and clinician, asymmetries in power and punitive regulations represent formidable obstacles.

Stakeholders

All of the practitioners we interviewed emphasised the importance of building equal and honest relationships with service users. A number of risks and challenges must be addressed in this context. These include fear, power differentials and legal responsibilities. Descriptions of supportive relationships stand in marked contrast to the situation at the large drug treatment clinics, which our stakeholders described as oppressive institutions that keep service users isolated and in a position of subordination. By contrast, stakeholders described positive examples of service redesign and user involvement that could potentially be extended and replicated. Collaborative and trusting relationships were frequently described as the foundation of user involvement.

Service users

The people we interviewed believe that relationships between service users and practitioners should be based on trust. Being open and honest with practitioners about drug use, sharing thoughts, discussing traumatic experiences, tackling housing and legal problems, and seeking to understand the drivers of problem drug use are key aspects of the treatment encounter that can only be addressed within the context of trusting relationships. In the absence of trust, powerlessness, fatalism, and despair can take hold among clients. Service users generally find that there is greater openness to involvement and engagement among staff members who are at lower levels of the organisational hierarchy and among non-medical staff. One reason why more open and trusting relationships do not develop between service users and physicians is

that the latter typically dictate the terms on which interactions take place, and often have little time for direct contact and interaction with service users.

Theme 1b. Showing empathy

Literature

One of the reasons why trust and empathy are so important within the treatment setting is that they facilitate authentic communication, where people reveal their vulnerabilities, express their emotions and articulate their needs and hopes. Staff at treatment clinics, in particular, need to acknowledge how their fears can influence the way they treat service users. This means genuinely listening, confronting one's own uncertainties, avoiding defensive routines and refusing to fall back on institutional authority. When practitioners are honest about their own feelings, this provides service users with an opportunity to understand their difficulties and to empathise with them. Empathy is the basic emotion that grounds user involvement, and this can be developed by pursuing the conditions for free and equal communication.

Stakeholders

Empathising – being aware of and sensitive to the feelings and experiences of others – is an important aspect of building supportive relationships with service users. In our interviews with stakeholders we collected a considerable amount of information on this issue, including several accounts of the difficulties that arise when practitioners fail to empathise or erect defensive barriers to insulate them from service users. One way of building empathy and promoting service user involvement is to focus on the value of lived experience and to place service users at the centre of the services they attend.

Service users

Our interviews provide examples of practitioners who empathise with service users and help them to overcome their difficulties. Problems with housing are often a key testing ground for the development of empathy and trust. Expressing empathy can be challenging for practitioners, as it implies crossing boundaries and exposing oneself to the risk of failure. At the same time, closer relationships can offer rewards to both service users and practitioners. Influential practitioners influence their colleagues, and user involvement can help organisations to identify problems and risks. Involving peers within the process of service delivery is not only a cost-effective way of transforming services, it also opens up career pathways for service users who are in recovery. Peer workers and advocacy organisations can contribute in different ways to service development, by promoting service user involvement, by acting as role models for people in recovery, and by teaching practitioners how to engage more effectively with their clients.

Theme 1c. Creating a space for effective communication

Literature

Another important aspect of the relationship between service users and providers is communication, and the possibility of creating a space where effective and authentic communication can occur is linked with the distribution of power. Research suggests that most service users accept the communicative dominance of clinicians and tend to adopt a passive role within the therapeutic relationship. At the same time, patients would generally like to be more involved in decision-making and to have a voice in relation to treatment and services. With training and facilitation, service providers who are committed to user involvement can create a space for effective communication within their services.

The participation of people who use drugs in discussions and decision-making bodies is often compromised by challenging life conditions. However, the research suggests that it is possible to create conditions that are conducive to the empowerment of service users within this setting, by challenging assumptions, relating to all participants in the same way, unmasking power, adopting flexible practices, using skilled facilitators, acknowledging cultural and social differences and accepting different perspectives and styles of communication.

Stakeholders

All of the stakeholders we interviewed argued that communication is important within drug treatment, recovery and harm reduction services because patients have different needs and experiences, but also because feeling listened to and understood is an essential element of effective treatment. Our interviewees underlined the need to create mechanisms whereby people can express themselves freely and without fear, so that complex issues in relation to medication, substance use, trauma, family relationships, mental health and living conditions can be addressed in an open way. This simple concept – that you can only know what service users need if you listen to them – has far-reaching consequences for services and practitioners. Even when patients are experiencing adverse symptoms or struggling with the effects of detoxification, communication is an essential part of treatment. Stakeholders emphasised the need for training and support in order to prepare practitioners for the challenges involved in overcoming stereotypes and communicating effectively with service users.

Service users

Most of the service users who we talked to in the course of this project had very little contact with their doctors, and this limited their ability to communicate effectively with them. Many feel that the risks and implications of their treatment are not adequately explained to them, describing how they are often pushed to take higher and higher doses of medication without adequate plans being made for managing this aspect of their treatment in the future.

Theme 2a. Stigmatisation

Literature

It is fundamental to understand the nature of the stigma which attaches to people who use drugs, as this plays an important role in their social marginalisation as well as their disempowerment within treatment systems. People who use drugs tend to internalise the negative social meanings that are implicit in imposed identities, coming to view themselves as less deserving. The 'addict identity' can function as a master status, leading drug treatment service users to be penalised across different spheres. People using services often feel more comfortable interacting with peer workers, whom they feel they can trust, and with whom they can establish a more equitable and less intimidating relationship. Service user involvement thus demands a new kind of expertise on the part of professionals, but can also enable practitioners to identify more effective therapeutic approaches.

Stakeholders

Several stakeholders addressed the question of stigmatisation during our discussions. One GP emphasised the need for practitioners to reflect critically on their assumptions, suggesting that they may need support and encouragement to overcome the negative impact of societal stigmatisation. Practitioners need more training to prepare them for working in drug treatment, recovery and harm reduction services. An effective way of pursuing this goal is to provide opportunities for trainees to interact with people who use drugs and with service users so that they can learn from their lived experience.

Service users

In their interactions with drug treatment services, housing authorities, social services, and mainstream health care services, our interviewees had experienced many different forms of discrimination and disqualification. Managing health problems and tackling issues such as homelessness and poor living conditions is often a precondition for making progress in relation to substance use and mental health. This is also a crucial testing ground where service users find out whether service providers care enough about them to help them improve their lives. Because they are likely to face stigmatisation in these other areas, it is crucial that drug treatment service users feel respected as people when attending clinics and programmes.

Theme 2b. Policing moral and social boundaries

Literature

Published research documents the ways in which degrading and undignified experiences have become ubiquitous within the Irish drug treatment system, against the backdrop of a generalised sense of service user disempowerment. Researchers have shown that many service users receiving opiate agonist therapy were never informed of the health-related issues and addictive nature of the medication they were being prescribed. Within this context, there is a

risk of treating user involvement as an institutional fix that can be added to existing services without changing them. Without a corresponding empowerment of service users, there is a risk that such forms become a tokenistic gesture.

Stakeholders

Service providers are often exposed to social pressures which lead them to distance themselves from people who use drugs. This can prevent them from expressing empathy and from developing collaborative relationships with service users. Boundaries are often erected within the system of drug treatment services, where they tend to isolate and penalise service users. One key challenge that practitioners and service providers face when seeking to promote service user involvement is identifying and dismantling these boundaries and building trusting relationships with the people who rely on their services.

Service users

One way in which moral and social boundaries are maintained within the treatment setting is through urine testing, associated with disciplinary measures such as exclusion from services, forced transfers, elimination of privileges, and reductions in medication. These practices often come to define the relationship between service users and practitioners, and are closely linked with wider processes such as the medicalisation of treatment, the stigmatisation of people who use drugs, and lack of trust between service users and providers.

Theme 2c. Shifting the balance of power

Literature

Encouraging participation and empowering service users appear to be two sides of the same coin, and both require a change in attitudes, relationships, rules and behaviour. Only service users fully understand what it is like to engage with treatment services for problem drug use, and their experience should be considered valuable in itself. Because of the complex problems they often present with, there is a tendency to perceive service users as "citizens in need of help" rather than "self-managing citizens who can make their own decisions". Many service users view user involvement as a necessary component of treatment systems and an essential prerequisite for successful outcomes. In Sweden, the possibility of choosing a clinic marked a decisive change which shifted power in favour of patients, leading to improved staff–patient relations.

Stakeholders

Stakeholders identified five key sources of social power that need to be considered in relation to service user involvement in drug treatment and harm reduction services: (1) access to resources, (2) collective participation, (3) direct involvement in service provision, (4) professional corporatism, and (5) public policy. Starting with the first of these, our interviewees noted the importance of providing public funding for advocacy organisations as well as increasing staffing levels so that practitioners have the opportunity to build better relationships with

clients. Where service users formulate shared demands and organise to develop services, this can shift the balance of power in their favour. It is easy to overlook the challenge that service user involvement poses to established occupational groups, whose prestige, influence and power are sometimes reflected in specific ways of organising services. There is thus a need to develop and unify professional practice in order to embrace this challenge by creating material and occupational incentives that reward innovation. Finally, it is necessary to strengthen the entitlements and rights of service users by means of policy, creating effective and impartial procedures for registering complaints, requests and suggestions.

Service users

One of the ways that service users can shift the balance of power within drug treatment services is by changing treatment provider. In most cases, however, once a service user in Ireland has been assigned to a clinic, they have little chance of moving to another. While it is relatively straightforward to choose between different community drug projects or counsellors, it is much harder for service users to move from one doctor or treatment centre to another. This lack of alternatives can lead service users to make extreme decisions, such as refusing to take prescribed medicines, deliberately getting arrested, or dropping out of treatment completely. Another way of shifting the balance of power between practitioners and service users is via the complaints system. When managed correctly, this system can play a role in defusing conflict.

Theme 3a. The organisation of drug treatment services

Literature

When analysing the organisation of drug treatment services, it is important to bear in mind the different ways in which legislation and formal regulations influence decision-making and relationships. Involving service users has ramifications in terms of resource requirements because staff members need more time to support service users and to respond to their requests and needs. In terms of overall service delivery, the fragmentation of service provision in Ireland between a medical and a psycho-social component is problematic. If the different practitioners involved in providing treatment work in different organisational settings, maintaining an integrated approach and involving service users in all aspects of their treatment becomes difficult or impossible.

Stakeholders

The organisation of drug treatment services is an important factor in relation to service user involvement. Some services have found that online meetings facilitates a collaborative approach by allowing regular meetings where each participant – practitioner or service user – is treated as an equal. There is, however, a risk that more inclusive services can become niche services – islands in a sea of indifference – which lets other services off the hook. What is needed is greater commitment across the system to generalise the insights and experience of exceptional practitioners who have found ways of encouraging marginalised service users to get involved in treatment decisions and service development.

Service users

One of the striking issues to emerge from our interviews with service users relates to the lack of integration between services. If service users are to be empowered and given a voice, then providers must listen to what they have to say, and all practitioners involved must work together. Many of the people attending drug treatment clinics have difficulty identifying a doctor who can take overall responsibility for coordinating their treatment. There is little contact between services and little teamwork across organisational and sectoral boundaries. The barriers between mainstream health, mental health, social services, homelessness, and drug treatment services make it difficult for service users to access these in the integrated ways that they need. Service user involvement should be viewed as a collective aim and resource for the interdisciplinary, intersectoral, and interorganisational team that participates in providing treatment.

Theme 3b. Procedures for making decisions

Literature

The role of patients in making choices about treatment is increasingly recognised as an important aspect of patient-centred care. Policies have been introduced in many countries to promote the active involvement of patients in treatment-related decision-making by means of shared decision-making. This is a process whereby treatment providers engage patients in evidence-based decisions that support their preferences. The service user and provider cooperate during the decision-making process by expressing their preferences, discussing options, and jointly agreeing a treatment plan. Shared decision-making may be contrasted with the 'paternalistic' model where the service user has no autonomy and the practitioner is assumed to know what is best for him or her. An interesting extension of shared decision-making involves personal health budgets. As a result of the introduction of personal budgets as part of a pilot study in the UK, service users had higher well-being and accepted greater responsibility for their own care.

Stakeholders

Systemic factors such as legislation, liability, and professional responsibility can influence the way practitioners manage decision-making in the context of drug treatment, recovery and harm reduction services. Some stakeholders argued that concerted efforts at these different levels are needed in order to enable physicians and patients to work collaboratively towards recovery. Due to the complexity of the challenges that many service users face in their daily lives, it can be difficult for them to get involved in discussions about services. Informal processes of involvement have the potential to provide these service users with a voice, even where they are unable to participate in committees, fora or conferences. Advocacy groups also use informal interactions to consult people about key issues. Their networks of peers, volunteers, and service users could play a supporting role during the transition to more inclusive services. It is important for service providers to be aware that even relatively simple forms of consultation require them to address issues such as organisational culture, professional practice, and managerial commitment.

Service users

Service users often have difficulty determining who has authority to make decisions about their treatment, as the doctors they meet are sometimes implementing decisions taken by people higher up the organisational hierarchy. Another issue that was brought up during our interviews relates to the heterogeneity of prescribing practices: there appear to be few protocols in place to guide medical decision-making in this area of treatment. We were struck by the knowledge and depth of understanding that service users have of the treatment process, in both its pharmacological and non-pharmacological dimensions. Due to their experential knowledge, service users are often able to provide information regarding what is effective for them in terms of pain relief, reducing symptoms, and avoiding withdrawal. However, many service users are frustrated with the reluctance of their doctors to support them through the process of detoxification and tapering of opiate agonist therapy.

Theme 3c. The importance of (small) innovations

Academic literature

Initiatives to promote user involvement are often described as changing the feel of a service in a positive way. This helps to explain why service users and staff members typically provide positive assessments of these initiatives, pointing to improvements in the organisational climate and relationships. User involvement in the design of services can be promoted using co-production, an approach in which researchers, practitioners and the public work together for the generation of knowledge. In one service, removing security guards from a clinic represented a key change, and small things like encouraging service users to stay after receiving their treatment had symbolic significance. Having a cup of tea in the treatment centre gave service users a way to interact with staff on a more equal footing, disrupting formal and unequal relationships.

Stakeholders

Service user involvement is motivated not only by the principle of inclusion but also by its potential to generate innovations in policy and services. Having an influence on innovations in service design and delivery – including small improvements – encourages service users to get more involved and is functional to their recovery. To be effective and sustainable, this process needs the support of policy-makers, managers, and practitioners and extra resources may be needed to implement change. A creative approach is required, with an emphasis on inter-sectoral collaboration and identifying ways of satisfying emergent needs by accessing resources from other organisations and sectors.

Service users

One innovation that our interview volunteers often appreciated was the use of new technologies to provide support at more regular intervals and to reduce the social distance between practitioners and service users. Against the backdrop of the COVID-19 pandemic, some services used online platforms to link up with service users, identifying effective and innovative ways of using video conferencing to provide them with support. At the same time, it is important to ensure that online services do not exclude people who do not have access to digital devices or internet.

Theme 3d. Patient-centred care

Academic literature

A patient-centred approach to the provision of care is often viewed as a way of tackling the notable history of paternalism in the field of drug treatment, as well as reducing the systemic stigma and disempowerment experienced by service users. Patients appreciate a personalised approach to treatment that is responsive to their needs and flexible even if substance occurs. In one study, use of a model that emphasised continuity of individual care over the course of a year by a social worker and a psychiatrist led to the development of more supportive relationships. This and similar studies suggest that the first step towards service user involvement is the provision of flexible, non-judgemental, continuous and individualised support with a view to establishing trust and building up empathy. It is then possible to listen to the voices of service users and to achieve a better understanding of their needs. Service user involvement can develop as they address these needs in a holistic manner, with appropriate organisational support.

Stakeholders

Patient-centred care seeks to make providers more sensitive to the needs and preferences of their clients. Practitioners talked about crucial moments in their professional development in which they learned out how to give service users a voice and how to actively listen to what they were saying. They described how this enabled them to match treatment and other supports more closely to what service users actually needed, rather than making assumptions or adopting a standardised model of care.

Service users

Nearly all of the service users we spoke to emphasised the role of emotions within treatment and recovery services. They emphasised the close link between their emotions and their substance use, and their need for emotional support during treatment. Their ability to choose counsellors is seen as contributing to the effectiveness of this service, as it enables service users to try out different kinds of relationships until they find what works for them.

Theme 3e. Outcomes

Literature

Demonstrating the impact of user involvement remains a challenge in the health and social services as well as in relation to drug treatment, recovery and harm reduction. In recent years, researchers have sought to integrate the perspectives of service users by developing patient-generated outcome measures which enable service users to build a personalised questionnaire, where the items are defined by the patient themselves. A similar tool, known as patient-reported experience measures, ask service users to reflect on what happened during their encounters with service providers, focusing on factual information rather than subjective

assessments. When discussing outcome measures, researchers have argued that it is not realistic to expect people recovering from problem drug use to be free of anxiety, depression and loneliness, although measures which capture improvements in well-being should be included.

Service users

The rules and regulations regarding access to treatment can generate formidable obstacles. At the beginning, service users may be left in the contradictory situation of having to continue using illicit drugs in order to be admitted to treatment, a difficulty that could potentially be overcome through service user involvement. Service user involvement should be viewed in relation to services themselves, and the scope they provide for listening, providing information, and enabling people to make choices about their treatment. When thinking about outcomes, and ways of measuring and evaluating services, it is important to include personal growth, improved self-esteem, and better subjective well-being.

Theme 3f. Representing service users

Literature

We did not analyse this theme in relation to the literature.

Stakeholders

The stakeholders we interviewed described the complexities involved in ensuring the representation of service users. In the 1990s, public meetings in Dublin enabled service users to express their grievances for the first time: they weren't being listened to and felt angry and upset about how they were treated by practitioners in large treatment centres. This process influenced the development of the Drug Task Forces, but formal commitment to service user representation was not matched by practical efforts to empower service users within treatment. Advocacy groups played an important role in making the voices of service users heard, but service providers have been slow to adopt new methods of service delivery that embrace informal as well as formal engagement and promote service user involvement. A key issue is that service users cannot provide critical feedback on services – which is essential to service user involvement – unless they feel secure, safe and respected when attending services.

Service users

The service users we interviewed had little contact with advocacy groups and little or no experience of user representatives. Formal representation and complaint procedures are unlikely to be attractive to service users until certain basic features of treatment have been addressed. The only examples we came across of assertive service users, who were willing to get involved as service user representatives, were attending services that promote service user involvement within the treatment setting.

1
Introduction

The theme of service user involvement emerged in debates about the design and delivery of health and social services in the 1980s, and has attracted increasing attention since the 1990s. Against the backdrop of widespread criticism of standardised forms of care and increasing awareness of the need to take individual differences into account, service providers and stakeholders looked to user involvement as a counterbalance to bureaucratic forms of provision. By involving users in the design and delivery of services, it was argued, providers could achieve a closer fit between services and users. In Scandinavia, politicians called into question the patronising assumption that 'professionals know best', proposing that service users should be moved to the centre of the decision-making process (**Bjerge _et al._, 2014**[1]). In the context of mental health care in Ireland, the Health Service Executive (HSE) argues that:

> _Collaborative partnerships are required to move from what has been viewed as a traditional 'paternalistic' model of care to one that is person-centred and rooted in the values of empowerment and recovery, which should aid the personal journey to empowerment, while also assisting those involved with the major challenge of influencing the agenda, policies and services of statutory service providers._
> (HSE Mental Health Division, 2016)

In a similar vein, the national drugs strategy, entitled _Reducing Harm, Supporting Recovery: A health-led response to drug and alcohol use in Ireland 2017-2025,_ states that "Service users, because of their direct experiences of services, have unique insights which are a valuable resource to those involved in developing services and interventions. Facilitating their involvement in the development and design of services is therefore a core objective of drugs policy" (Department of Health, 2017, p. 66). All publicly funded addiction services in Ireland are expected to follow the _National Standards for Safer Better Health Care_, which emphasise the need for person-centred care. Drug treatment service users should have the opportunity to make informed decisions about their care and treatment, in partnership with healthcare professionals and key workers. They should also be enabled to participate in the development of local services and to influence policy at local, regional and national levels via representative organisations.

Goodhew _et al._ (2019) link the demand for greater user involvement in drug treatment services to the rise of new social movements in the 1960s and 1970s, demanding respect, recognition and empowerment for social groups which were experiencing discrimination. This highlights the role of ethical and political considerations in the growing 'grassroots' pressure for user involvement

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1   Publications included in the narrative synthesis of the literature presented later in this report are highlighted using bold type.

across the public services as a whole (**Frank and Bjerge, 2011; Laitila *et al.,* 2011**).[2] The concept of service user involvement has gained momentum in recent decades and many countries have introduced measures to promote the active participation of patients and clients in decision-making (see, for example, **King, 2011; Van Hout and McElrath, 2012**). Since the mid-1980s, health policy at international level has been influenced by the 'New Public Health' model, as promoted by the World Health Organization (1978, 1986). Service user involvement has come to be seen as an important element of this model, and a growing body of research treats user involvement as an integral part of evidence-based health policy (see, for example, Institute of Medicine, 2001).

As a result of these trends, patients attending general health care services increasingly expect to have an active role in making decisions about their treatment (Chewning *et al.*, 2012). In mental health services, shared decision-making is described as yielding higher levels of satisfaction, higher retention rates, better adherence to treatment and improved clinical outcomes (Lindhiem *et al.,* 2014). The 'recovery movement' campaigns for the users of these services to have greater control over treatment and the possibility of living full and independent lives (Tomes, 2006). A study of user involvement in mental health care in the United Kingdom (UK) shows that users typically want to be involved in their treatment, although there is a risk of unrepresentative involvement or tokenistic participation (El Enany, Currie and Lockett 2013).

In the field of drug treatment services, pressure to allow users to have a greater say in their treatment has come from a related paradigm shift, which involves a movement away from medically focused and abstinence-oriented policies and towards the harm reduction paradigm (**King, 2011**). The harm reduction paradigm emerged from the activities of people with HIV and AIDS who, in the 1980s and 1990s, demanded an end to stigmatisation and greater attention to identifying and tackling risks. As **King (2011)** observes, there is an affinity between the harm reduction and New Public Health models, as both seek to identify risk factors and to improve public health in a coordinated way. People who use drugs and who come from less privileged social groups tend to have high drug-related morbidity and mortality (Galea and Vlahov, 2002), implying that their empowerment could contribute to a reduction in social inequalities in health. However, there is a contrast between the value-neutral stance of these paradigms and the more abstinence-oriented policies which previously dominated the treatment landscape. Harm reduction embraces an unashamedly rational, non-coercive and non-punitive philosophy (Stimson, 2007) which clashes with the puritanism of the *status quo ante*, which treated drug use as immoral and drug users as deviant (Butler and Mayock, 2005).

Under the influence of another policy framework – known as New Public Management – policy-makers and administrators began in the 1980s to emphasise the importance of allowing users to choose between service providers and to have a say in relation to their treatment. As **Bjerge *et al.* (2014)** and **Storbjörk *et al.* (2016)** observe, this model was highly influential in Denmark and Sweden during the 1990s. Although the UK is sometimes viewed as a pioneer in relation to user involvement in drug treatment services (**Goodhew, 2019**; Hinton, 2010), Scandinavian countries began addressing this issue much earlier than Anglo-Saxon countries. Legislation on user involvement was introduced in Norway, Sweden and Denmark during the 1990s and pilot projects involving ambitious forms of user involvement had been undertaken by the beginning of the new Millennium (**Bjerge *et al.,* 2014; Storbjork *et al.,* 2016**). Indeed, the issue of user empowerment was already being discussed in Sweden in the 1960s (Börjesson and Karlsson, 2011, cited by **Billsten and Benderix, 2019**).

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2   The ethical case for meaningful peer involvement, as a good thing in itself, was stated authoritatively in 2007 in the influential report Nothing About Us Without Us, published by the Canadian HIV/AIDS Legal Network.

Roughly half of a sample of service users from four treatment units in Sweden interviewed as part of a study by **Storbjörk *et al.* (2016)** were described as having high levels of user involvement. **Billsten and Benderix (2019)** report that 10 out of 14 regional user representative bodies are participating in regional user committees, eight have regular meetings with managers from regional mental health and substance use treatment services and four have regular contact with social service units that provide support to relatives of people with substance use disorders. Twelve maintain contact with users in active treatment and provide them with support and information.

The evaluation studies which reflect on these experiences provide the best knowledge currently available on the challenges and opportunities involved in promoting user involvement. Studies carried out in Scandinavian countries account for roughly one third of the publications included in the literature review presented in this report (**Andersson *et al.,* 2017; Andersson and Johnson, 2020; Bakkeli and Grønningsæter, 2020; Bjerge *et al.,* 2014; Bjerge and Nielsen, 2014; Franke and Bjerge, 2011; Laitila *et al.,* 2011; Larsen and Sagvaag, 2018; Larsen *et al.,* 2020; Ness *et al.,* 2014; Storbjörk *et al.,* 2016; Wenaas *et al.,* 2021**). Many of the key dilemmas posed by user involvement have been described in research from these countries and important lessons can be learnt from their experiences.

The issue of service user involvement is often framed in terms of rights. A number of countries have enacted legislation that defines the rights of service users and citizens (Tritter, 2009). This approach appeals to broad definitions of human rights, as established by treaties, constitutional laws or other sources, and seeks to extend or apply these principles to the treatment setting.

Regardless of the context and approach adopted, a number of obstacles to involvement have been identified. Problem drug use is associated with social disadvantage, health problems and social isolation, and these factors simultaneously generate barriers to participation (Healy, 2019). For people who use illegal drugs, vulnerability to adverse health outcomes is associated with criminalisation, stigma, discrimination and social exclusion (Rhodes, *et al.,* 2005; Room, 2005). These factors can reduce the effectiveness of harm reduction programmes and impede the implementation of health promotion initiatives (**Belle-Isle, 2016**). People who use drugs are further stigmatised when they experience poverty, homelessness, mental illness or infection with HIV/AIDS or hepatitis C (Room, 2005). Drug users in Ireland typically elicit social disapproval (Mac Gréil, 1996); Room (2005) observes that drug addiction is rated highest in terms of social disapproval and stigma by people in 14 different countries.

People who use drugs frequently report negative experiences in their interactions with health and social services (Laitila *et al.,* 2018). Stigmatisation is associated with the criminalisation of drug use, fear of arrest and the predominance of enforcement-based policies rather than harm reduction. To counter this stigma, people who use drugs have mobilised locally, regionally, nationally and internationally (Jürgens, 2005). In common with people living with HIV, people who use drugs have difficulty expressing a positive collective identity, tending instead to emphasise a shared experience of marginalisation, discrimination and criminalisation as a basis for collective action.

The stigmatisation of problem drug users increased in Ireland during the 1970s and 1980s, as this phenomenon came to be identified with deprived communities. As **Van Hout and McElrath (2012)** observe, "Services traditionally view drug users as being manipulative, resistant and difficult to engage with…" (p. 7). Rance and Treloar (2014) argue that the users of drug treatment services frequently find themselves at the crossroads between medicalisation and criminalisation, "embroiled in a treatment system more concerned with controlling their

behaviour than treating their drug dependence" (p. 453).

In the United States of America (USA), an alternative tradition of user involvement in residential drug treatment services emerged from the post-war 'social model'. This form of treatment provided 12-step houses ('sober living' houses) where residents could recover from alcoholism by following the abstinence-based principles of Alcoholics Anonymous (Polcin *et al.,* 2014). These residential programmes emphasised the experiential knowledge of residents and encouraged them to help each other. Indeed, recovery was seen as taking place primarily as a result of the relationship between residents, rather than due to professional interventions. In the USA and in some European countries, residential treatment programmes run by religious or charitable organisations continue to be inspired by similar principles, emphasising the importance of the involvement of residents in their own treatment. We will discuss this model of treatment wherever appropriate, although our main focus in this report is on specialist outpatient drug treatment services provided by statutory services.

The evidence suggests that the implementation of policies for user involvement has been slower in the field of drug treatment than in other areas of service provision (on the situation in Ireland, see **Harris and McElrath, 2012; Healy, 2019; Kavanagh, 2012; King, 2011; Van Hout and McElrath, 2012**). We will discuss this issue in the following chapters and summarise the international research on user involvement in drug treatment, recovery and harm reduction services – including policy documents, briefing papers, commissioned reports, dissertations and articles in academic journals – published since 2011. This study also draws on interviews with stakeholders and service users, with a view to understanding the challenges posed by user involvement in drug treatment, recovery and harm reduction services.

1.1   Concepts and definitions

It is useful to clarify exactly what is meant by user involvement, as a number of different terms have been used in the literature, including "patient participation", "patient and public involvement", "consumer participation",[3] "client-centred care", "user empowerment"[4] and "user consultation". In recent years, a consensus has emerged among policy-makers and researchers that the term "service user" is preferable to terms like "patient", "client" or "consumer", as the latter tend to emphasise the active role of professionals within the treatment process, implying that the recipients of services play a relatively passive role (**Billsten and Benderix, 2019**).

The "people first" philosophy that developed in North America in the 1970s promoted the use of terms like "people with disabilities", "people who live on the street" or "people with lived experience of problem drug use", with the aim of focusing attention on the attributes of the person, rather than characterising the person as disabled, homeless or a drug addict. The service user concept reflects an awareness of the dangers of labelling and stereotyping, and has been widely adopted, although it has some shortcomings, as Beresford (2005) observes. Expressions like "people who use drugs", "people with lived experience of drug use" and "experts by experience" are also in line with the "people first" approach, and emphasise resilience in the face of adversity.

In a similar vein, the term "involvement" is generally preferred over "participation",

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3   This term is frequently used in Australian research.

4   This term is more frequently encountered in Scandinavian research.

"empowerment", "engagement" or "consultation", as it covers a wider range of practices and implies that service users play an active role in this process. It is less ambiguous than terms like "participation" and "engagement", which are sometimes used to describe enrolment in drug treatment services. Although other terms are also used, including "patient-centred care", "individualised treatment", "shared decision-making" and "user representation", these refer to more specific aspects of service user involvement, as we will show later in this report.

In the field of social psychology, service user involvement is often motivated by appealing to self-determination theory, which holds that experiences of mastery are essential to psychological well-being (Deci and Ryan, 2000, p. 259), while feeling fatalistically ruled by others is deleterious. Experiences of mastery convince the individual that he or she possesses the necessary skills, attributes and knowledge to deal with the challenges of life, and these perceptions of control are mutually reinforcing, boosting intrinsic motivation (Greenwood and Manning, 2017, pp. 1051-2).

Involvement can assume radically different forms based on the context, raising the issue of how relationships between service users and staff are shaped by institutional, legal, cultural and social factors. Most observers agree that service user involvement is not just an element that can be bolted onto existing systems of treatment provision, as it implies a far-reaching redesign of treatment, recovery and harm reduction services (Rise and Steinsbekk, 2015). Moreover, service user involvement is an open-ended and dynamic process which is often associated with a problematisation of existing procedures, relationships and rules. There is no single blueprint for integrating user involvement within drug treatment services, as it requires a context-sensitive, innovative and relational approach which is likely to vary with the context.

User involvement is a foundational principle or paradigm rather than an institutional mechanism or organisational form. The implementation of user involvement entails change across a number of dimensions which are difficult to identify in advance. A simple but effective definition of service user involvement, which emphasises these aspects of the concept, is provided by Millar *et al*. (2015) in relation to mental health care:

> *An active partnership between service users and mental health professionals in decision making regarding the planning, implementation, and evaluation of mental health policy, services, education, training and research. This partnership employs a person-centred approach, with bidirectional information flow, power sharing and access to advocacy at a personal, service and/or societal level.* (Millar *et al*., 2015, p. 216)

As Laitila *et al*. (2018) explain, service user involvement means that service users "are respected and appreciated, that they are listened to and can act in co-operation with professionals so than they feel that they can influence their own care and treatment" (p. 3). Having an influence over one's own treatment means that service users can mobilise their own resources and their own knowledge during the process of treatment and recovery.

A common way of analysing measures to promote user involvement is to situate them on a scale which ranges from weak to strong. One approach uses Arnstein's "ladder of involvement": weak forms of involvement might entail consulting users about their preferences, setting up procedures for complaints or assessing satisfaction with services, while stronger forms might accord a role to service users in making decisions about policy and the design of services (Arnstein, 1969). Bryant *et al*. (2008a, b) describe information exchange as the weakest form of user involvement in drug treatment services and systematic involvement in service planning and recruitment as the strongest form.

Other researchers have referred to Pretty's (1995) typology, which ranges from 'passive' forms of involvement to 'functional' participation, with higher levels of involvement including participation in debates and self-organisation. Laitila *et al.* (2018) provide the following overview:

> *Service user involvement is often described as a continuum or as a linear model, depending on how much power the service user has ... Involvement can occur on many levels. Peck et al. (2002) proposed four levels of participation: (i) interaction between service users, (ii) interactions between users and health care professionals, (iii) local service management opportunities and (iv) service planning. Tambuyzer et al. (2014) stated that involvement occurs on individual (micro-level), health-care service level (meso-level), policy level (macro-level) and on a level including involvement in research and education (meta-level). ... involvement is realised on the one hand when service users participate in their own care and treatment, and on the other hand when they participate in decisions concerning mental health services."* (Laitila *et al.,* 2018, p. 2)

Strong forms of user involvement may entail the selection of representatives and their inclusion within management committees or other decision-making bodies, which has been studied in several countries, as we will see. User involvement may therefore mean that representative organisations and advocacy groups acquire a role in policy development, service design and the delivery of treatment.

Grip (2006), as quoted by **Storbjörk *et al.* (2016)**, distinguishes between the individual, collective and representative levels of involvement, the first of which concerns individual contacts with care providers in terms of day-to-day care, the second relates to joint action by service users and the third refers to discussions about policy and service provision more generally. These three levels of user involvement are widely cited and represent a useful starting point, together with the distinction between formal and informal regulation, collective versus individual involvement and bottom-up and top-down initiatives. Tritter (2009) provides another typology which distinguishes between direct/indirect, individual/collective, and proactive/reactive forms of service user involvement.

In bottom-up involvement, service users develop their own proposals, carry out their own research and lobby the state for recognition. For example, advocacy groups often mobilise people with lived experience of drug use to campaign for changes in the nature and availability of drug treatment, recovery and harm reduction services or for greater involvement. In contrast with this kind of bottom-up mobilisation, user involvement may also involve top-down initiatives such as shared decision-making or patient-centred care. In these cases, user involvement takes a more individualistic form within the treatment process.

As Mold and Berridge (2010) observe, advocacy groups are more likely than local user groups to tackle broad issues relating to rights, identities and empowerment, which may be important in motivating service users to get involved. Advocacy groups are able to create a milieu where service users can improve their skills, receive organisational support and tap into regional, national and international networks, implying that supporting advocacy groups could be a necessary step towards promoting meaningful service user involvement.

Another form of involvement that has been discussed in the literature relates to the families of service users, with some scholars arguing that services which include family members are more likely to retain service users in treatment and to achieve positive outcomes **(Ness *et al.,* 2016).** Family members can provide support and participate in discussions and decision-

making. Research further suggests that relationships between carers[5] and service providers are frequently conflictual, with the former accusing professionals of not listening to them and not providing them with sufficient information. This reinforces the view that an important dimension of user involvement relates to the ways in which carers and other advocates influence the treatment process at various levels.

In this report, we study the interactions between service users and practitioners within the treatment setting, as well as forms of joint action involving service users and their participation in discussions about policy and service provision. We will show that many of the distinctions that have been made in the literature – between weak and strong, passive and functional, bottom-up and top-down involvement – are rather unhelpful when it comes to understanding the changes that are needed in order to give service users a meaningful voice and role. This is because service user involvement appears to require coordinated movement along several dimensions, driven by service providers as well as users. The participation of service users in wider, policy-related discussions about services is largely dependent upon their empowerment within the treatment setting, which means that different facets of user involvement are relevant to different institutional forms and organisational settings. An overly schematic approach can prevent these links from being appreciated, and hierarchical or schematic approaches often fail to capture the complexity of involvement (Tritter, 2009).

1.2 Drug treatment services

This study focuses on drug treatment, recovery and harm reduction services. Drug treatment services are provided by either public or private organisations, with public or private funding, and are provided on an inpatient or outpatient basis. Inpatient drug treatment services include medical detoxification units,[6] hospital-based treatment units, residential drug treatment centres, therapeutic communities[7] and drug treatment units in prisons. Outpatient drug treatment services are typically provided by specialist organisations, including both pharmacotherapy (such as opiate agonist therapy) and/or socio-psychological services (counselling, therapy, training, practical assistance). These services may be oriented towards harm reduction, control of withdrawal symptoms, recovery or complete abstinence, depending on the orientation of the treatment provider.

As Stein *et al*. (2015) observe, individual pathways through treatment services can be complex, involving a combination of services such as detoxification, opioid agonist therapy, psychotherapy, psycho-social counselling and participation in self-help groups. In treatment systems where it is difficult to access long-term treatment due to limited places, conditions or high costs, people who use drugs are likely to experience multiple episodes of detoxification (Stein *et al.,* 2015). In the context of drug treatment, 'recovery' is generally understood

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5   Carers' are those who have primary responsibility for the welfare of those experiencing problem drug use.

6   Detoxification is a medically supervised intervention to manage withdrawal symptoms which is mostly carried out in general or psychiatric hospitals in an inpatient setting

7   Therapeutic communities are typically a drug-free environment in which drug-dependent individuals can live together in an organised and structured way, in order to promote social and psychological change among the participants. The philosophy often includes the idea that residents are active participants in their own and each other's treatment, and that responsibility for the daily running of the community is shared among residents and staff members.

as rebuilding relationships (with family and friends), recovering social roles (employment, volunteering) and achieving a higher level of individual functioning, health and well-being.

Harm reduction services seek to prevent risks to the health and well-being of people who use drugs. To encourage people who use drugs to avail of these services, they typically impose few conditions for access, are free of charge and are often staffed, at least in part, by peer support workers with lived experience of using drugs. One type of harm reduction service – supervised injecting facilities – was introduced in Europe in response to the HIV epidemic and opioid-related deaths in the 1990s (Schatz and Nougier, 2012). In 2016, there were 92 supervised injecting facilities in 11 countries (Belackova *et al.,* 2019), and additional facilities subsequently opened in Melbourne, Canada and Luxembourg, with discussions about these services continuing in Ireland and the USA.

Many service users seek treatment with the aim of improving their health or ending their dependence on illegal drugs (Benyamina and Stöver, 2012). The Irish service users interviewed by **King (2011)** saw treatment as a way of normalising and stabilising their lives. Research shows that most people who use drugs associate recovery with having a meaningful life, participating in social activities, having hope for the future, re-establishing social ties, and maintaining relationships **(Ness *et al.,* 2014)**. This implies that service users are likely to have treatment goals that go beyond the reduction of drug-related harms and embrace issues such as housing, improvements in personal and family relationships, volunteering and paid employment.

A substantial proportion of patients discontinue opioid agonist treatment within the first year (Timko *et al.,* 2016), often due to disagreements over rules or as a result of conflicts with practitioners (Dunlap *et al.,* 2018). Those who leave treatment face greater risks of relapse and overdose (Dale-Perera, Goulão and Stöver, 2012: 35), and a large research literature has analysed these risks:

> *...a careful balance must be struck between the need for appropriate monitoring and controls, for example, to limit safety risks associated with initiation onto opioid medication and harms related to misuse (injecting or snorting) or diversion (selling, swapping or giving away) of prescribed OMT medications, and the potential negative impact that strategies such as supervised dosing can have on patients. The way in which supervised dosing is managed and implemented, such as requirements for daily attendance at certain times, may present barriers to patients accessing or remaining in treatment, and may also interfere with efforts to reintegrate into society and obtain employment.* (Dale-Perera, Goulão and Stöver, 2012: 24)

These authors argue that there is considerable scope for improving the quality of drug treatment services by ensuring that providers discuss treatment options with their patients, that there is a balance between control and freedom, and that appropriate psychosocial interventions are provided. The question of service user involvement plays an important role in this picture, as involvement can encourage service users to remain in treatment (**Davis *et al.,* 2020a**; Dunlap *et al.,* 2018).

1.3 Research questions

This study addresses the following four research questions:

1. What are the characteristics of service user involvement in drug treatment services as understood in official guidelines, research literature and advocacy documents?

2. What are service users' experiences of the consultative process and what aspects of service user involvement have been shown to facilitate or impede successful participation?

3. What are service providers' experiences of the consultative process and in what ways does their understanding of the goals of participation differ from that of service users?

4. What outcomes are associated with service user consultation in drug treatment and recovery services?

To address the first question, we draw on an extensive search of the academic literature and of official reports, unpublished research and advocacy documents. The aim is to identify different forms of involvement, to describe how they have been implemented in different contexts, and to analyse the issues they raise. The second and third research questions inquire about the experiences of service users and providers with respect to user involvement, including any tensions and conflicts that may emerge between these two groups. To address these two questions, we will draw on interviews with stakeholders and service users, which were carried out specifically for this purpose.

The final research question relates to outcomes, and this integrative evidence review aims to provide policy-relevant findings on the impact of user involvement on the likelihood of remaining in treatment and achieving specific treatment goals, including both substance-related and other objectives. In answering all four questions, we compare Ireland with other countries, with a particular focus on Europe, North America and Australia.

1.4 Structure of the report

Our first aim in this study is to carry out an extensive review of the literature on service user involvement in drug treatment, recovery and harm reduction services since 2011. Our review of the literature is informed by database searches, citation searching and analysis of a substantial number of websites of relevant organisations.

This study was implemented in collaboration with stakeholders and advocacy groups which seek to give a voice to people with lived experience of drug use. Thanks to the support provided by these groups, we were able to discuss the issue of involvement directly with stakeholders and service users and to integrate their views into this report. We carried out qualitative interviews with a total of 24 service users in Ireland, whose willingness to share their valuable experience has made a great contribution to this study as well as representing a concrete demonstration that service user involvement is useful when seeking to improve services and outcomes for people who use harm reduction services, those who enter drug treatment or are making the journey towards recovery.

In the next chapter, we review policies for service user involvement in Ireland and other

countries, and in Chapter 3 we describe the methods we used to carry out the literature review. In Chapter 4, we present the results, and in Chapter 5 we describe different forms of user involvement by means of a narrative synthesis of the literature. Chapters 6 and 7 address the experiences of service providers and users, respectively. We conclude the report by summarising the key themes and triangulating across the different forms of data collection, which enables us to provide further insights into the issue of service user involvement. This study is an "integrative evidence review" because it draws on several different sources of information on service user involvement, including different kinds of publications and interviews with a range of different actors.

Summary

The concept of service user involvement has gained traction in recent decades and many countries have introduced measures to promote the active participation of patients and clients in decision-making and policy making. Current policies in Ireland treat service user involvement as crucial to improving drug treatment, recovery and harm reduction services. Not only should drug treatment service users have the opportunity to participate in decisions about their own care, they should also be able to participate in the development and redesign of services at local, regional and national levels through appropriate forms of representation.

Pressure to enable users to have a greater say in their treatment has increased in recent years as a result of a series of interrelated processes, including the affirmation of the New Public Health and New Public Management models, grassroots movements promoting user empowerment and the influence of the recovery and harm reduction paradigms. A number of obstacles to involvement have also been identified, including social disadvantage, social isolation and stigmatisation.

This study addresses research questions regarding the different forms of service user involvement, the experiences of service users and providers and the relationship between involvement and the outcomes of treatment, recovery and harm reduction services. Our first step is to carry out an extensive review of the literature on service user involvement in drug treatment, recovery and harm reduction services since 2011. This study was implemented in collaboration with stakeholders and advocacy groups and seeks to give a voice to people with lived experience of drug use. Thanks to the support provided by these groups, we were able to discuss the issue of involvement directly with service users and we have integrated their views into this report.

2

Policies for service user involvement in drug treatment, recovery and harm reduction services

In this chapter we provide a concise overview of policies relating to service user involvement in drug treatment and harm reduction in Ireland and other countries, namely the UK, USA, Australia, Canada, Portugal, Norway, Sweden and Denmark. These countries were selected for inclusion in because they illustrate different approaches to promoting user involvement.

The evidence used in this chapter was gathered in parallel with the evidence review described in Chapter 4, drawing on the publications that were identified following title and abstract screening. Information on policies for service user involvement is not readily available, and the way in which policies are implemented varies between countries. A number of countries have national drug strategies, which set out policy objectives for a specific period of time, often accompanied by action plans. To the extent that these strategies mention user involvement, they typically limit themselves to general statements. In federalised or highly decentralised administrations, responsibility for the provision of drug treatment services may rest with regions or provinces, creating additional difficulties when seeking to identify policies.

As we will see in later chapters of this report, the relationship between policies for user involvement and practice on the ground is often complex and difficult to decypher within drug treatment services. The evidence base remains incomplete, which means that policy-makers cannot draw on established models or theoretical frameworks when defining interventions. Another problem is that it is difficult to legislate for service user involvement, as this is a complex process which cuts across different aspects of treatment and raises questions about how this is organised and delivered. Our aim in this chapter is simply to provide some institutional context for the subsequent review of evidence on the nature, forms and consequences of user involvement within drug treatment, recovery and harm reduction services.

Ireland

Current policies for drug treatment took shape in Ireland against the backdrop of a dramatic increase in intravenous heroin use in the 1980s, concentrated in deprived urban areas. This heroin epidemic coincided with rising rates of crime and HIV infection (EMCDDA, 2014). An important feature of drug policy in Ireland is the central role accorded to the network of Local and Regional Task Forces. The first Task Forces were established in 1996 with a view to bringing together government departments, state agencies and the community and voluntary sectors to provide a collective and coordinated local response to problem substance use. In 1996–1997, Local Drugs Task Forces were established in 13 areas, twelve of which were in Dublin and one in Cork, with a fourteenth Task Force being established in Bray in 2000. Ten Regional Drug and Alcohol Task Forces were introduced between 2001 and 2006 under the auspices of the National Drugs Strategy (2001–2008).

The Task Forces typically operate as a committee comprising representatives from statutory agencies, the voluntary sector, representatives of the local community and local public representatives. This committee meets on a regular basis with a view to coordinating the provision of services. Following a central evaluation, funding for specific projects and initiatives can be transferred from the Task Force to mainstream Government Departments or a state agency. Most such projects are designed to be ongoing initiatives and the process of mainstreaming has led to an expansion in initiatives to tackle problem drug use at local level.

Drug treatment services in Ireland come under the auspices of a health strategy and a multi-sectoral drugs strategy, both of which set out aims regarding service user involvement. As **King (2011)** observes, the 2001 strategy is rather equivocal on the subject of service user involvement, merely inviting Drug Task Forces to "enable user groups … to play a role in the generation of greater societal awareness of drug misusers and drug misuse issues" (Department of Tourism, Sport and Recreation, 2001, p. 123). The handbook provided to Task Forces during the early stages of their implementation was a little more specific in its guidance: "There is also scope for drug users to make a valuable contribution through, for example, the use of drug user fora, which can act as a mechanism for consultation between Task Forces and local drug users" (National Drug Strategy Team, 1997, p. 16).

Over time, service user involvement has come to be viewed as an important aspect of a wide range of health and social services in Ireland (HSE Mental Health Division, 2016, p. 11). The HSE-commissioned *Opiate Methadone Review* (Farrell and Barry, 2010) called for greater service user input and the *Clinical Guidelines for Opioid Substitution Treatment* (HSE, 2016) called for service user participation and the development of collaborative relationships with service users. Subsequent National Drug Strategies advocated more strongly for service users to be consulted in relation to the development of policy and service provision, once again indicating service user forums as one way of achieving this (see, in particular, the 2014 *Strategy Update*).

A key aim of the Drugs Initiative of the 1990s and the National Drugs Strategies was to improve access to opioid agonist therapy using a range of channels, including GPs. Although methadone had been officially available since 1992, the Methadone Treatment Protocol of 1998 provided a framework for an expansion in access to opiate agonist therapy (Butler, 2002). The Protocol sought to expand the number of people in methadone maintenance by encouraging community-based treatment through the network of primary care services, although this aspect of the protocol has had limited success. There are approximately 10,000 clients receiving methadone in Ireland, out of a population of more than 21,000 problem opioid users, with

roughly one third being cared for in general practice (EMCDDA, 2014; EMCDDA, 2019; **O'Reilly et al., 2011**). Opiate agonist therapy is provided primarily by specialist treatment centres, addiction clinics and satellite community clinics. In 2016, there were 80 HSE specialist methadone centres in operation in Ireland, treating 5,438 clients (Moran *et al.*, 2018). By the end of that year, only 117 of these patients had been appropriately stabilised and transferred to the community setting – just 2.2% (*ibid.*, pp. 2–3).

National treatment data reveal an increase in recent years in both prevalence and incidence rates of treated opiate dependency among Irish adults, with the majority of people being treated as outpatients, more than half receiving counselling, half commencing opioid agonist therapy, one quarter undergoing brief interventions and a small minority receiving medically assisted detoxification. Methadone maintenance treatment remains the most common form of treatment for opiate dependency in Ireland and is generally provided by specialised clinics under medical supervision. For example, the National Drug Treatment Centre in Dublin has approximately 550 clients, with methadone being dispensed on-site (O'Carroll *et al.,* 2020).

General practitioners are required to complete just one training course (minimum 3 hours) before they can prescribe methadone. The low level of addiction training and experience with treating people who use drugs have discouraged the diffusion of opioid agonist therapy within primary care settings (Griffiths *et al.*, 2016). A Level 1 GP prescriber can treat up to 15 stabilised opiate-dependent individuals in their practice. Patients may be referred from HSE Drug Treatment Centres, satellite clinics or Level 2 GPs (who are more highly trained and are permitted to treat up to 35 patients during initiation and maintenance on opioid agonists):

> Under the Irish MMTP, the 'ideal' journey through an Irish HSE Methadone Specialist Centre ... would have a client engage appropriately with all relevant services available to them inclusive of counselling, outreach support, nursing and psychology. Simultaneously, they should properly engage with their prescribing doctor and adhere to their methadone-dosing regimen, which is typically increased incrementally until a level is reached where clients' OUD is stabilised to allow them to function optimally in society. At this point, a client should be transferred to the care of a GP in the community who should provide the totality of their medical care including OATM [opioid agonist therapy with methadone]. (Moran ***et al.,*** 2018, pp. 2–3)

Alongside the Methadone Treatment Protocol, Irish policies for drug treatment, recovery and harm reduction accord a key role to community projects, which receive public funding:

> Community Drug Projects are usually Community Employment Schemes for recovering drug users. The standard model operates from Monday to Friday and is a confluence of recovery, counselling employment skills and education. Although Community Drugs Projects do not prescribe methadone, many of their clientele are also MMT patients and therefore these Projects could be termed an adjunct service to MMT. Ancillary services, services in which the client can discuss issues and problems, for example, counselling and the use of care plans, can be integral to recovery for some clients. (**Healy, 2019**, p. 159)

Some relevant changes to existing protocols and regulations were introduced in response to the COVID-19 epidemic:

> This policy briefing highlights three changes to practice during the COVID-19 crisis. Two of those changes (the removal of barriers to rapid access to methadone and

the expanded distribution of Naloxone) were such that they resulted in the removal of barriers to the implementation of national policy. The question remains as to why the barriers existed prior to the crisis. The epidemic created an overwhelming public health argument for the facilitation of immediate access to OST and Naloxone. However, a strong public health argument for having no waiting lists for OST and improved Naloxone distribution to PWUD existed prior to and independent of COVID-19. (O'Carroll *et al.,* 2020, p. 5)

United Kingdom

In the UK, policy debates about drug treatment have moved recently towards a greater focus on health-based, recovery-oriented initiatives which focus on well-being as the ultimate outcome of policy (Neale *et al.,* 2011). Shortly after the 2010 Drug Strategy was approved, it was announced that the National Treatment Agency would be incorporated into Public Health England, reinforcing this shift. Local authorities were to be given more control over how much they spent on services and how these were designed through the commissioning process. These developments have had the effect of focusing greater attention on service user involvement and its relationship with treatment effectiveness.

Treatment is provided free of cost by the NHS, with the GP typically acting as gatekeeper to specialist treatment. However, only one person in seven on opioid agonist therapy obtain their prescription from a GP, with the others attending specialist services (**Alves *et al.,* 2021,** p. 2):

> *In primary care, people in OST can also engage with other allied health professionals, such as key workers. Key workers are trained health and social care professionals who deliver psychosocial interventions and support people who use drugs making positive changes and work towards recovery. They also liaise with GPs to manage prescriptions, as well as collaborating in assessments and clinical reviews.* (**Alves *et al.,* 2021,** p. 2)

Patient and public involvement (PPI) is a well-established practice in health and social care policy in the UK. This instrument focuses on improving services by building strong relationships between users and those in decision-making roles, fostering openness, accountability and support at all levels. In England and Wales, the providers of state-funded health care have a statutory requirement to involve users in their activities (Patterson *et al.,* 2009). NHS organisations are required to involve service users and the public in the planning and provision of services, in the development of proposals for change and in decisions affecting the operation of services. The UK is sometimes described as being the first country to legislate for user involvement in drug treatment (Goodhew *et al.,* 2019; Hinton, 2010), although the Scandinavian countries appear to have been the first to have implemented formal policies to promote user involvement.

Service user and carer involvement were central to the National Treatment Agency's effectiveness agenda, and drug and alcohol treatment services are required to provide evidence of service user and carer involvement in their annual plans. In response to concerns about the low level of user involvement in drug treatment services, the agency provided guidance and financial support to services in an effort to stimulate greater user involvement (National Treatment Agency, 2006). The NTA's (2002) guidance to Drug Action Teams on commissioning treatment services recommended involving users in the development of treatment services, drawing on the "unique expertise and experience of users" in order to improve retention rates

and in recognition of their right to become involved in decisions that affect their health and well-being (Patterson *et al.,* 2009).

In terms of practice guidelines, the influential National Institute for Health and Clinical Excellence (NICE) recommends that "the decision about which drug to use should be made on a case-by-case basis, taking into account a number of factors, including the person's history of opioid dependence, their commitment to a particular long-term management strategy, and an estimate of the risks and benefits of each treatment made by the responsible clinician in consultation with the person" (NICE, 2006).

United States of America

Drug policy in the US has historically been of a prohibitionist nature, focusing on abstention and largely rejecting the principles of harm reduction. There are few needle exchanges, widespread drug testing and harsh penalties are generally applied for drug offences. In this respect, there are some historical similarities with Sweden (see below).

In the USA, opioid agonist treatment is mainly provided through specially-regulated Methadone Treatment Programs (MTPs) that are required to provide counselling. These programmes are allowed to discharge service users who fail to pay their fees, who do not attend counselling, who have repeated positive drug tests or loiter outside the centre. In many programmes, the counsellor functions as the disciplinarian, creating a potential for role conflict (Schwartz *et al.,* 2017).

The Drug Addiction Treatment Act of 2000 allows doctors to prescribe medications for opioid dependence if the Food and Drug Administration (FDA) has specifically approved them for this purpose. Pharmacological treatments have historically been viewed as a specialist service within the health care system, due primarily to the reluctance of primary care physicians to provide this service (Gryczynski *et al.,* 2013). Following its approval in 2002 by the Food and Drug Administration, buprenorphine has been widely used by people with health insurance.

In the USA, user involvement is often presented as a means to enhance accountability and to improve the quality of services in the context of a system where service users can choose between different service providers. Service users are also seen as having a responsibility to contribute to the greater good through active participation in their own care (Patterson *et al.,* 2009). Personalised care and patient-centred care are prominent themes in US health and social care services, and are used by providers to promote their services to prospective clients (Tompkins *et al.,* 2019). In some areas, personal budgets are also used to promote self-directed care plans, giving service users greater choice. Due to this reliance on individual choice and private forms of treatment provision, formal policies to promote user involvement have not played such an important role in the USA as in Europe.

Australia

Drug treatment services in Australia consist primarily of rehabilitation, detoxification facilities and harm reduction services (AIHW, 2018). Counselling, case management, withdrawal management, rehabilitation and pharmacotherapy are the main therapies used. Opioid agonist therapy is typically provided in large, single-purpose clinics, with an average of roughly 150 clients per service; more than 46,000 people are currently receiving this form of treatment (Rance and Treloar, 2014). There is one medically supervised injecting centre in Australia, which is situated in Sydney (**Goodhew, 2019**).

As in the Canadian case, user involvement in the broad area of health care is guided by policies and guidelines at the national, state and local levels, and is typically referred to as 'consumer participation'. At national level, the Australian Charter of Health Care Rights declares that all service users have the right to be involved in decisions and choices about their care (Australian Commission on Safety and Quality in Health Care, 2008). Furthermore, Standard 2 of the National Safety and Quality Health Service Standards requires that consumers be able to participate in the organisational and strategic procedures that drive the planning and design of health services (**Goodhew, 2019**).

Examples of lower-level policies for user involvement include Victoria's *Doing it with us not for us* (State Government Victoria Department of Health, 2011); the NSW Department of Health's Consumer and Community Representative Guidelines (NSW Department of Health, 2005, 2015); the NSW clinical excellence commission's consumer engagement programme (NSW Health Clinical Excellence Commission, 2016) and the *Strong Voices* guidelines that outline consumer health service representation in the Northern Territory (Northern Territory Government, 2015). Some local health districts in NSW have also developed consumer participation guidelines (Sydney Local Health District, 2016).

Consumer participation has increased in recent years in areas including cancer care, diabetes management and disability services, as well as in mental health (**Goodhew, 2019**). By contrast, there is little evidence of specific policies to support user involvement in drug treatment services (**Brener et al.,** 2019, p. 7; **Treloar et al.,** 2011, p. 970). **Rance and Treloar (2015)** observe that the introduction of user involvement initiatives in drug treatment services has lagged conspicuously behind progress in other spheres (Hinton, 2010; **Treloar et al.,** 2011). Nevertheless, the National Drug Strategy (Ministerial Council on Drug Strategy, 2011) advocates "consumer participation in governance" (p. 3) as part of its broad commitment to harm minimisation.

Recent studies by Australian research teams (Bryant *et al.,* 2008a, b) report that while consumer participation activities in drug treatment settings are not uncommon in this country, they are generally restricted to local initiatives involving low levels of involvement, due to the lack of formal policies and targeted funding at national level (cf. **Brener et al.,** 2019).

Canada

As in several other countries, reponsibility for providing treatment in Canada is distributed across different levels of government, with the federal government providing direction and funding (including a national strategy) and municipalities playing the main role in delivering treatment and harm reduction programmes. Drug treatment is provided as part of the public health care system, which is the responsibility of provinces and territories. As well as publicly-funded services – which often have lengthy waiting lists – there are private providers which are not regulated by the state and are often too expensive for deprived drug users. A key feature of the Canadian case is the high level of fragmentation across the provincial health authorities in terms of policies and services. Drug treatment services are provided by a varying configuration of clinics, hospitals, community agencies and private service providers, under a range of different policies.

The Canadian province of British Columbia has experienced high rates of overdose deaths in recent years and harm reduction strategies have been implemented in order to address this issue, particularly in Vancouver's Downtown Eastside, a deprived area of the city (Kennedy *et al.*, 2019). Interventions in this area have involved peers in programmes that have been delivered as part of the public health system or autonomously by peer-based drug user organisations (Jozaghi *et al.*, 2018; Kerr *et al.*, 2017). In December 2016, the BC Minister of Health issued a ministerial order to support the implementation of low-threshold drug consumption rooms (Collins *et al.*, 2019). Several unsanctioned peer-run SCFs were allowed to operate (Boyd *et al.*, 2018), although there have been clashes between the federal and state governments on the role of harm reduction facilities and other aspects of drug policy (Watson *et al.*, 2013, p. 161).

Following the publication of the influential report entitled *Nothing About Us Without Us* by the Canadian HIV/AIDS Legal Network (Jürgens, 2008), the BC Harm Reduction Services and Strategies committee acknowledged that "people who use illegal drugs should be engaged in all aspects of harm reduction supply distribution program development, implementation, and evaluation"[8]. In recent years, this committee has contributed to several peer-run events and provided financial support for a conference organised by the Vancouver Area Network of Drug Users (VANDU). Efforts to expand meaningful peer engagement have increased and discussions of user involvement in British Columbia tend to focus on the role of peer workers and volunteers in facilitating the active engagement of people who use drugs.

Portugal

Portuguese drug policy developed against the backdrop of one of Europe's most dramatic heroin and HIV epidemics in the 1980s and 1990s. At its peak, approximately one percent of the population was using heroin, leading to the establishment of a Commission to develop a National Strategy in 1998. This commission included experts from various fields of intervention as well as representatives of people who use drugs, their families and neighbourhoods. The National Strategy adopted in 1999 advocated for drug addiction to be viewed as a disease and viewed drug users as citizens in need of treatment rather than criminals (SICAD, 1999).

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8   Best Practices for British Columbia's Harm Reduction Supply Distribution Program. Vancouver: BC Center for Disease Control 2008. http://www.bccdc.ca/resource-gallery/Documents/Guidelines%20and%20Forms/Guidelines%20and%20Manuals/Epid/Other/BestPractices.pdf

Law 30/2000 was implemented in July 2001, decriminalising the acquisition and possession of drugs for personal consumption. Possession for personal use under this law is treated as an administrative offence and the individual concerned is transferred from the police or justice system to a local 'Dissuasion Commission', comprising two professionals (doctors, psychologists, sociologists or social workers) and one legal expert. Sanctions can be applied, but the main objective is to explore treatment options and to promote recovery (SICAD, 2000).

The realisation that criminalisation plays a role in aggravating stigma and discrimination was one of the main reasons for implementing these policies. Drug consumption rooms have also been introduced and there is a mobile drug consumption room which is part of a larger initiative by the city government and harm reduction NGOs to open 3 consumption rooms – two fixed and one mobile – in Lisbon. The team responsible for implementation is committed to an integrated and participatory approach to the health and social needs of people who inject drugs in Lisbon. Trained peer workers are part of the staff of the drug consumption rooms.

In Portugal, drug treatment is primarily organised and funded under the auspices of the Ministry of Health. Services for people who use drugs were reorganised in 2013-14 and are mainly provided by a referral network within the public health care system. In addition to public services, protocols between certified NGOs and other public and private treatment services ensure wide access to services. Many services are provided free of charge and are accessible to all people who use drugs, primarily on an outpatient basis. There are 73 specialised facilities (public and certified private therapeutic communities), 14 detoxification units and 13 accredited day centres.

Opioid agonist therapy can be initiated in treatment centres and buprenorphine treatment can be initiated by any medical doctor. Methadone is provided free of charge, whilst buprenorphine-based medications are available at a subsidised price, with the National Health Service covering 40% of the cost (EMCDDA 2019, p. 19).

The National Drugs Strategy includes participation as one of its pillars, which is understood as referring to the involvement of the community in the definition of drug policy and interventions. Structures have been introduced to facilitate participation, including a National Council for Drug Addiction on which service users are represented. At the same time, there is little evidence on institutional practices that encourage user involvement. Treatment focuses primarily on the needs of the individual as defined by professionals and aims to reintegrate service users into society by providing services and supports.

Historically, Portugal has a strong network of civil society organisations, many of which are involved in providing harm reduction services under agreement with SICAD, the body responsible for national interventions to tackle addiction. Explicit policies to encourage user involvement are evident only in relation to certain interventions, such as the introduction of a mobile drug consumption room (MDCR) in Lisbon. A needs assessment was undertaken involving people who use drugs as well as local community members (Taylor *et al.,* 2019). A participatory and peer-led process was adopted at all stages of data gathering and planning of the intervention and peers were included as members of staff.

The main advocacy groups in Portugal (CASO, R33) criticise the absence of a culture of user involvement in Portugal, identifying a number of obstacles to this, including resistance to civil society involvement, budgetary restrictions, bureaucratic barriers and a highly centralised administration. They have called for the creation of a civil society forum to promote user involvement in shaping policies and practices:

In Portugal, while relationships between civil society and the state tend to be good and a lot can be achieved in this context, the lack of a formal structure for civil society organisations and their involvement in national policy issues means that if there are key items which need to be worked out or progressed, there is no singular place for this to happen, which can in turn lead to uncertainty and a sense of powerlessness for civil society actors. (Queiroz, 2018, p. 18).

Norway

In Norway, there is a distinction between drug treatment services that are provided as part of the health care system and those provided by municipal social services. These two forms of service delivery cover a variety of disciplines and are governed by different laws and regulations. Four regional health authorities are responsible for providing specialist treatment, while municipalities are mainly responsible for outreach services, community teams and follow-up services. The primary tasks of municipal services include helping with issues such as work, housing, finances and leisure activities. There are significant variations in how municipal welfare services are organised, with the most common configuration involving a specialised unit providing both drug treatment and mental health services (**Bakkeli and Grønningsæter, 2020, p. 92**).

Opioid agonist therapy is provided in Norway by interdisciplinary teams, where pharmacotherapy is just one part of the treatment process. According to prevailing legislation, specialised mental health and substance abuse services are responsible for initiating as well as maintaining or tapering medication, with guidelines stating that the risk of relapse and overdose are so high that termination of pharmacotherapy should not be recommended unless there is good reason to believe that the patient will manage (**Larsen and Sagvaag, 2018,** p. 90):

In Norway, multidisciplinary specialised drug treatment focuses comprehensively on patients' health problems and social situations (Norwegian Directorate of Health, 2009). Although reduction or cessation of drug use is the primary goal of substance use treatment, treatment should aim at improving individuals' life circumstances in areas that are important for recovery and community adaptation. ... Comprehensive treatment should provide ancillary services related to domains such as housing, financial issues, and employment, as these are all areas of concern for recovery and reintegration into the community... (Andersson et al., 2017, p. 376)

User involvement is a central policy goal in Norway, with the National Action Plan on Alcohol and Drugs emphasising the need "to ensure genuine user influence through free treatment choice, more user-driven solutions and greater participation in the design of services" (Norwegian Ministry of Health and Care Services, 2015, p. 6). Under this Plan, increased funding is provided to municipalities to promote user involvement. Increasing involvement has been a policy aim in Norway since 1988 (**Larsen and Sagvaag, 2018**), with a view to upgrading public services in successive national action plans on mental health and substance abuse services (Norwegian Ministry OHACS, 2008).

Since 2004, people with substance use disorders in Norway have the right, by law, to receive specialist treatment and to be involved in treatment decisions. Treatment and recovery

programmes seek to provide a comprehensive response to the needs of service users through a combination of group and individual therapy as well as support with housing, financial difficulties and employment (Andersson *et al.*, 2017, p. 376). The patient's right to participate and to play an active role in decision-making is included in the Norwegian Patients' Rights Act (Norwegian Ministry of Health and Care Services, 2016).

Sweden

Sweden has relatively low overall levels of illicit drug use, although prevalence increased rapidly during the 1990s, mirroring the experience of many other European countries. Until the 1980s, there was a strong consensus in official circles that life-long abstinence was the only acceptable goal of treatment and the aim of achieving a drug-free society is often mentioned. Hallam (2010) argues that "in its treatment interventions, Sweden is untypical in its determination to enforce abstinence upon the recalcitrant drug user" (p. 2), and drug use is considered a criminal offence.

As in many other countries, opioid agonist therapy has gained acceptance in Sweden only recently, with an emphasis on reintegrating people who use drugs within society (Blomqvist *et al.*, 2009; **Storbjörk *et al.*, 2016,** p. 39). There are a number of restrictions on access to pharmacotherapy, and those who are prescribed opioid agonists must follow strict rules (Hallam, 2010). Drug treatment services expanded in Sweden in the late 1980s, but this growth slowed down with economic recession in the early 1990s and drug treatment services are described as having 'imploded' into the alcohol treatment system (Bergmark, 1998). Specialised services for problem substance use are provided by a range of actors, including municipalities (social services), regions (health care), the state (treatment systems within the criminal justice system, for example), non-governmental organisations and private care providers (generally funded by social services) (**Storbjörk *et al.*, 2016,** p. 39). Social services and health care services constitute the two main components of the drug treatment system, providing services that are free of charge or have low co-payments.

Responsibility for (long-term) treatment lies with social services and is regulated by the Social Services Act of 1982, which states that society has to promote every citizen's right to economic and social safety, equality in living circumstances and active social participation. It further establishes that municipal social services should provide substance misusers with the help and care they need in order to recover. Problem substance users may present themselves, be referred by someone near to them or by various other authorities. In many cases, they are provided with care directly by local social services or referred to private services, which are paid for by social services (including residential care, outpatient treatment and various forms of housing) (**Storbjörk *et al.*, 2016,** p. 40).

User involvement in treatment decisions is mandatory under the Swedish Social Services Act (SFS, 2001, p. 453), which stipulates that treatment must be designed and implemented in collaboration with service users and, if necessary, other community agencies, organisations and associations (**Billsten and Benderix, 2019**). Swedish laws emphasise the principles of self-determination and individual responsibility. By law, the social services and substance users collaborate when planning the type of care and other interventions that are required, and treatment is designed, chosen and implemented in agreement with the service user:

> *During the 1970s, demands were formulated on the rights of the service users. These became institutionalized in the Social Services Act and the Health and Medical Services*

Act, issuing the individual's right to participation and integrity. With the growing critique of the welfare state in the 1980s, the idea of service user involvement took a somewhat different form. Within the framework of New Public Management (NPM), concepts such as user participation or involvement have been used to legitimize rationalization and cut-backs in care (Karlsson & Börjeson 2011). Thus, on the one hand, there is a democratic tradition where concepts such as empowerment and social inclusion are influential, and on the other hand an economic tradition emphasizing efficiency and results... (**Storbjörk *et al.,* 2016**, p. 21)

Within the health care system, the Health and Medical Services Act (1982) specifies which kinds of drug treatment services shall be made available, including detoxification and other emergency services, medical and psychiatric care for alcohol- and drug-related disorders and pharmacological treatment, including opioid maintenance treatment. These medical treatments are usually provided by outpatient units, but detoxification and emergency care often start in inpatient wards (**Storbjörk *et al.,* 2016,** p. 41). Once again, care and treatment are expected to be designed and implemented in consultation with the patient:

...the individual patient cannot, according to law, require a specific treatment or a certain length or magnitude of intervention. It is the medically responsible doctor who makes the decisions. If, however, several alternative and equally good (judged by scientific evidence and proven experience) treatments exist, the patient shall be given the possibility to choose the alternative which he or she prefers. (**Storbjörk *et al.,* 2016,** pp. 41-42)

The National Guidelines for Substance Abuse Treatment are an updated set of recommendations for the integration of the user perspective within treatment (Socialstyrelsen, 2007). The National Board of Health and Welfare (NBHW) also publishes recommendations on how substance abuse treatment should be provided. The regulations in relation to opioid agonist therapy stipulate that treatment must respect individual self-determination and be based on the needs of the service user.

The national substance abuse treatment guidelines (Socialstyrelsen, 2015) also include a chapter on individualised care, which specifies that treatment should be adapted to the individual service user's needs, experiences and preferences, and that staff members should aim to establish a positive therapeutic alliance with service users. The service user can therefore expect good, respectful, competent and empathetic encounters with staff. To facilitate user involvement, the service user should receive information about his or her condition, available treatment options and the possibility to choose a care provider (**Storbjörk *et al.,* 2016,** p. 43). Other documents explain what is meant by individualised care, user involvement and which indicators should be used for monitoring progress in relation to these aspects of treatment provision. Regular evaluations are carried out by the Health and Social Care Inspectorate to ensure that service providers follow guidelines correctly.

From 2009 to 2014, the Swedish National Board of Health and Welfare (SNBHW) supported and financed the development of regional service user representative bodies. The aim was to overcome the traditional view of the service user as a 'passive consumer' of care by promoting a collaborative approach where the service user is empowered as an active citizen (SKL, 2010). This programme of support aimed to improve evidence-based practice in care for people with substance use disorders.

In 2009, only five out of twenty-one regions had an active user organisation in the area of

problem substance use. Over the next five years, under the aforementioned programme, an increase in the number of user organisations was achieved, with interventions to show these groups how to conduct user audits in health and social services using a questionnaire to record patients' experiences. By the time national financial support ceased in 2014, there were regional user organisations in 20 of the 21 Swedish regions (**Billsten and Benderix,** 2019).

Several structural and organisational factors continue to obstruct user involvement in Sweden, including strict budgets, negative attitudes among service providers and failure to respond effectively to the needs and wishes of service users (**Storbjörk *et al.,* 2016,** p. 9). Observers have also emphasised the contradictory nature of service user involvement, which can be used differently by various actors.

SKL (the Swedish Association of Local Authorities and Regions) argues that the traditional view of the service user as a passive recipient of health and social care should be replaced by a more modern view where the user is considered as an active partner and co-producer of treatment and treatment planning. This co-production should include the systematic collection and use of data on the experiences of service users and user organisations, a change in power relations between service users and professionals, a focus on boosting the resources available to individuals instead of viewing them as passive recipients of services, and greater collaboration between service providers (SKL, 2010, 2014, 2015a, b). To achieve long-term recovery from substance-related problems, it is argued that individuals need support from staff as well as peers from service user organisations who have had similar life conditions and experienced substance use disorders:

> During the years of national support being provided, one person with lived experience was appointed to support the total number of new user organisations. This person was presumed to have extensive knowledge in the field of substance use treatment and services. This 'change agent', sometimes called a 'key person', could also help to identify and solve any problems that arose (Couros 2013). A defined task of this agent was to remain informed about local user organisations, in order to establish contacts between these entities and treatment centres. The role included providing initial and ongoing support to user organisations while they defined their position and explored their opportunities to influence substance use treatment in their regions. The long-term goal was to routinise these efforts, thus eliminating the need for continuing dependence on a change agent. (**Billsten and Benderix,** 2019, p. 2-3)

Denmark

Medically assisted therapy is the most prevalent form of treatment for problem substance use in Denmark, in common with most other European countries (Bjerge and Nielsen, 2014). Out of approximately 15,000 drug users at national level, more than 7,000 are enrolled in opioid agonist therapy. Treatment is subject to a legal framework that regulates the prescription of addictive drugs (Sundhedsstyrelsen, 2003) and methadone is provided in the form of weekly take-home doses or daily consumption directly at clinics or pharmacies. Outpatient clinics enrol between 30 and 150 users. The employees of these clinics include doctors, social workers, nurses and psychologists and they generally open for just a few hours a day so that service users can pick up their methadone. People attending treatment for problem drug use receive psychosocial interventions from social workers or psychologists, usually by appointment.

Empowerment has become a key concept in Danish public discourse and debates since the late 1990s (Andersen, 2003; Krogstrup, 1997; Socialministeriet 1998, 2006b), with ministerial guidelines and handbooks defining appropriate empowerment strategies (**Bjerge and Nielsen, 2014**). In line with these policies, responsibility for change is increasingly placed on the individual service user, rather than on the helping professions:

> *Written into the Act on Social Services is the obligation for social institutions to ensure empowerment of their users. Similar to any citizen in the social security system, drug users are to be self-managing and active participants in their own treatment. Staff-members have to act on the individual users' preferences and needs and also have to ensure that users are included in decisions regarding the everyday practices in social interventions. Medically assisted drug treatment is thus subjected to two different sets of policy: health regulations, which contain a strong focus on control and regulation of prescriptive medicine, and social service regulations, which have a strong focus on self-management and user influence.* (**Frank and Bjerge, 2011,** p. 203)

Prior to the recent emphasis on empowerment, citizens were more likely to be portrayed as passive clients who were subject to welfare professionals' expert opinions and judgements. Empowerment is now applied to a range of groups, including elderly people, children in kindergartens and the users of drug treatment services (Bjerge and Nielsen, 2014), with the Danish Act on Social Services providing the following overview:

> *The aim of help [...] is to improve the individual's possibility to become self-managing [...] or to improve his/her quality of life [...]. Help is based upon the individual's own responsibility for him/herself and his/her family. Help is based upon the individual's need and ability, and help takes place in cooperation with the individual user. (Houborg & Bjerge, 2011, p. 22)*

As free and self-managing individuals – experts on their own lives – service users are expected to make rational and responsible choices (**Bjerge *et al.,* 2014,** p. 59). Social workers typically require that users be involved in formulating their own action plan, a written document that sets out the goals of intervention (**Bjerge *et al.,* 2014,** pp. 66-67). Clients are thus expected to participate in meetings on the organisation of treatment and service providers encourage service users to take the lead in these meetings.

Summary

In this chapter we provided some institutional context for this review of evidence on the nature, forms and consequences of service user involvement in Ireland and other countries. Drug treatment services in Ireland come under the auspices of a health strategy and a multi-sectoral drugs strategy, both of which set out aims regarding service user involvement. Service user involvement has come to be viewed as an important aspect of a wide range of health and social services. This development mirrors the situation in other countries, where user involvement is a central policy goal. For example, patient and public involvement (PPI) is a well-established practice in health and social care policy in the UK. This approach focuses on improving services by building strong relationships between users and those in decision-making roles. In England and Wales, the providers of state-funded health care have a statutory requirement to involve users in their activities. In the USA, Canada and Australia, user involvement is often viewed as a means to enhance accountability, support freedom of choice and improve the quality of

services.

The Portuguese National Drugs Strategy includes participation as one of its pillars, which is understood as referring to the involvement of the community in the definition of drug policy and interventions. Structures have been introduced to facilitate participation, including a National Council for Drug Addiction on which service users are represented. In Norway, the National Action Plan on Alcohol and Drugs emphasises the need to ensure genuine user influence through free treatment choice, more user-driven solutions and greater participation in the design of services.

User involvement in treatment decisions is mandatory under the Swedish Social Services Act, which stipulates that treatment must be designed and implemented in collaboration with service users. The national substance abuse treatment guidelines include a chapter on individualised care, which specifies that treatment should be adapted to the individual service user's needs, experiences and preferences, and that staff members should aim to establish a positive therapeutic alliance with service users. Empowerment has also become a key concept in Danish debates since the late 1990s, with ministerial guidelines and handbooks defining appropriate empowerment strategies.

3
Methodology for the literature review

In this chapter we describe how our review of the literature was carried out, starting with the objectives, moving on to the eligibility criteria and concluding by describing how the search protocol was implemented.

3.1 Objectives

This part of the evidence review addressed the following two questions:

1. *What are the characteristics of service user involvement in drug treatment services as understood in official guidelines, research literature and advocacy documents?*

2. *What outcomes are associated with service user consultation in drug treatment, harm reduction and recovery services?*

The review of evidence on user involvement in relation to drug treatment, harm reduction and recovery services included qualitative, quantitative and mixed methods research. This was not a pure review of the scientific literature, as we included research reports, dissertations and other documents, as well as peer-reviewed academic articles. We combined these different sources of evidence to provide a powerful overview of the issues raised by service user involvement.

3.2 Eligible documents

To be eligible for inclusion in this review, studies had to meet a set of eligibility criteria. We carried out our main literature search using the Embase.com database, which is owned by Elsevier and contains more than 37 million records (including the entire MEDLINE database). It provides researchers with a sophisticated search interface, where all records are indexed using the Emtree thesaurus. This allows complex searches to be carried out using words in the title, abstract and author fields, in conjunction with proximity operators. The development of large bibliographical databases such as this, together with powerful search environments, enables researchers to implement complex search algorithms in the health domain. This is particularly important when researching topics such as this where there are multiple search terms with a

low level of standardisation within the scientific literature, necessitating the use of synonyms and proximity operators.

As the research questions that guide this study do not follow the standard PICO (Population, Intervention, Comparison, Outcome) structure, we will set out the eligibility criteria using the headings below.

A   Population

The research questions refer to adult users of drug treatment services and service providers. We also included studies which are confined to subpopulations defined by the service used, characteristics of the service user or service provider or by geographical area. This choice is based on the awareness that the situation and needs of young people may be different from those of adult service users.

B   Setting

Eligible settings included drug treatment, recovery and harm reduction services. Treatment for any form of problem drug use, including illicit and prescription drugs, but excluding alcohol, was eligible, in line with the terms of reference provided by the Health Research Board.

C   Focal issues

Again following the terms of reference, studies that reported the following issues of interest were eligible for inclusion in the review:

» The involvement of service users in the design and delivery of drug treatment and recovery services in both an inpatient and outpatient setting

» Where, when, how and how often users were involved

» The experiences of users in relation to involvement

» Identifying factors which facilitate or impede participation

» Experiences of service providers in relation to user involvement

» How service providers' goals, priorities and experiences differ from those of service users

» Measures for assessing the impact of involvement on users (e.g. treatment retention, individual well-being), their families (e.g. support, relationships) and services (e.g. efficiency, staff satisfaction).

D   Study design

Qualitative, quantitative and mixed methods research designs were eligible. Case reports restricted to a single person, non-systematic reviews and commentaries were not eligible, in line with standard practices when reviewing the scientific literature.

E   Year of publication

Studies published in the period after 2010 (2011–2021) were eligible for inclusion, as we are primarily interested in recent research on service user involvement.

F   Countries and languages

Only documents published in English were considered in the database searches, although publications in French, German, Italian, Portuguese and Spanish could be included in our policy review. Studies carried out in the European Union (EU), USA, Canada and Australia were included, with the aim of limiting the heterogeneity of treatment settings and contexts.

G   Publication types

Editorials, conference presentations and news stories were not eligible, again in line with conventions when reviewing the scientific literature.

3.3 Review process

Our review comprised the following steps, which are described in detail below and are summarised in Figure 1.

Step 1 Define and implement the literature search

Step 2 Export records to EndNote[9] for de-duplication and preliminary screening

Step 3 Export the records to Covidence[10] for double independent screening of titles and abstracts

Step 4 Double independent full-text screening in Covidence

Step 5 Citation searching for eligible documents

Step 6 De-duplication and double independent screening of additional records

Step 7 Risk of bias assessment using standardised tools

Step 8 Narrative synthesis

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9   EndNote (The EndNote Team, 2013) is a standalone software programme for managing and analysing bibliographical references.

10 Covidence is a collaborative, web-based tool for the management of literature review projects, see https://www.covidence.org.

Figure 1 PRISMA flow diagram for literature search

Identification	Records identified through database searching (n=10,024) → Records identified through other searches (n=579) → Total records identified (n=10,603) → Duplicate removed (n=633)
Checking	Records screened rapidly on title/abstract by one reviewer (n=9,970) → Records excluded (n=8,300); Records imported into Covidence
Full Screening	Records screened on title and abstract by two reviewers (n=1,568) → Records excluded (n=1,448); Records screened on full text by 2 reviewers (n=120) → Records excluded (n=61); Records included (n=52) → Systematic reviews (n=7)
Extraction	Qualitative studies (n=38 plus 5 mixed methods). 5 exluded due to risk of bias; 38 included in synthesis; Quantative studies (n=9 plus 5 mixed methods). 7 exluded due to risk of bias; 7 included in synthesis

Step 1: Define and implement the literature search

We searched a range of bibliographical databases, including Embase.com, Google Scholar and websites of key organisations in order to identify eligible studies. Searches were conducted between 27 September 2020 and 6 January 2021 and are described in Appendix 2. The main search strategy was designed and implemented using **Embase.com**, which comprises both Embase and MEDLINE. This database was chosen as it has excellent coverage of health-related studies and facilitates the use of complex queries incorporating proximity operators. This was important as a three-concept search strategy was required, with the following structure:

Drug use AND Treatment AND participation

A large number of synonyms had to be specified for each concept, as they are not adequately captured by the Emtree thesaurus. The final Embase search strategy, which yielded 6,514 records, is shown in Appendix 2. The algorithm we used was developed in an iterative way by identifying potentially relevant articles and then analysing how they were indexed in **Embase. com**. We carried out textual, semantic and logical analysis on the different terms used to denote user involvement, as well as consulting relevant taxonomies and typologies (in relation to drugs, services, types of treatment and providers). In total, we identified 10,024 records using research databases and we found a further 579 potentially eligible documents by searching websites that relate to drug treatment services and the representation of people who use drugs.

Step 2: De-duplication and preliminary screening of records

The records identified during the searches described above were loaded into EndNote for de-duplication and rapid screening. The aim of this initial screening process was to exclude publications which were obviously ineligible because of their study design, subject area or another characteristic.

Step 3: Double independent screening of titles and abstracts

Following de-duplication and preliminary screening, two reviewers independently screened each record using information from the title and abstract fields. The reviewers then agreed on a list of documents to be included in the subsequent stage of the review. Any differences were resolved through discussion, against the backdrop of the eligibility criteria described earlier.

Step 4: Double independent full-text screening of publications

The full electronic text of each potentially eligible document identified during the title/abstract screening was acquired and uploaded to Covidence for the next stage in the screening process. During this step, two reviewers independently read and assessed the eligibility of each document, again resolving any differences through discussion. A reason for rejection was recorded for each publication excluded during this phase (68 in total). Of these, 53 were

excluded because they contained no empirical evidence on user involvement, 4 because they did not refer specifically to drug treatment services, 4 because they were actually published before 2011, 3 because they did not refer specifically to people who use drugs, 2 because they were invalid publication types, and 2 for another reason.

Step 5: Citation searches

At this stage, we carried out citation searches based on the list of eligible documents defined during the previous stage. As well as inspecting the publications referenced in each document, we also used Harzing's Publish or Perish (Harzing, 2021) to identify publications which cite them. This is an effective way of identifying recent publications and saturating coverage of specific strands of research.

Step 6: De-duplication and screening of additional records

An additional 46 publications which cited a study in our provisional list of eligible publications were incorporated into the EndNote database and again de-duplicated to avoid unnecessary screening. The basic Google Scholar records were augmented within EndNote and then exported to Covidence for screening of titles and abstracts, as before, with two reviewers working independently. Any documents identified as potentially relevant were uploaded to Covidence and the full text was subjected to a final round of screening, using the same procedures described above. A list of records excluded following the full-text assessment, together with the reason for exclusion, is included in Appendix 3.

Step 7: Risk of bias assessment

All publications identified as eligible were assessed for risk of bias. This step involved evaluating the quality and reliability of each study using a standardised tool with a view to highlighting and, if necessary, excluding studies that have a high risk of bias due to the way in which they were designed or implemented. We used three tools to carry out this assessment: CASP (for qualitative studies),[11] ROBINS-I[12] (for quantitative observational studies) and RoB 2[13] (for randomised controlled trials). A total of 52 documents were evaluated in this way, and 7 were excluded, leaving a total of 45 (38 academic papers and 7 publications which would be considered 'grey' literature, such as PhD theses, research reports, and working papers).

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11 The Critical Appraisal Skills Programme (2018) is a 10-item checklist for assessing whether there is any risk of bias when summarising the results of qualitative research. The Critical Appraisal Skills Programme (CASP) covers research design, methodology, recruitment, reflexivity, ethical issues and data analysis techniques.

12 ROBINS-I is a tool for evaluating risk of bias in quantitative research that does not rely on randomisation to allocate units to comparison groups (Sterne *et al.*, 2016).

13 RoB 2 is the revised version of the Cochrane risk of bias tool for randomised trials, and was published in 2019 (Sterne *et al.*, 2019). This tool is designed for the assessment of individually randomised, parallel-group and cluster-randomised trials and covers five domains of potential bias.

Reasons for exclusion at this stage varied, with some commissioned research reports providing no details on recruitment, data collection or analysis, and some of the quantitative studies relying on convenience samples or having design flaws that were likely to lead to confounding. In fact, four of the nine quantitative studies were excluded due to weaknesses in design or methods, and the quantitative part of the mixed methods studies was considered too weak for consideration in three out of five cases, although the qualitative part could still be used.

A total of 38 of the studies included in the narrative synthesis have a qualitative design, 5 are quantitative and 2 are based on a mixed methods design (see Table 1[14]). To construct the evidence summary shown in Table 1, we extracted information from the eligible studies on location, research design, setting, aims, data collection, analysis and findings. This table is a valuable intermediate output of this study and was used extensively when conducting the narrative synthesis.

Step 8: Narrative synthesis

Once we had identified the definitive list of eligible studies, we carried out a narrative synthesis of their findings. After carefully reading each publication, we identified a number of themes and gathered together the empirical evidence on each theme. The themes were defined in an iterative fashion as we analysed the eligible studies. We continued compiling and organising the evidence until we had achieved a satisfactory degree of saturation of the publications (i.e. all relevant findings could be assigned to a theme) and until we had obtained a restricted number of relatively homogeneous themes. We then summarised each theme, including references to the individual publications and to any other studies we deemed relevant in order to provide a comprehensive overview of the literature.

Methodological strengths and limitations

The main strength of our literature search is its impressive scope, covering not only academic journal articles, but also reports and unpublished dissertations. A wide coverage was ensured by using a number of databases and web-based resources. Although it was necessary to screen a considerable number of records, this ensured that our literature search was extensive enough to identify a wide range of relevant documents across a range of fields of study, services and geogrpahical contexts.

The first limitation of our literature search derives from the need to undertake a three-concept search involving terms which have a low level of both standardisation and specificity. In order to make this search feasible, we used the powerful Embase.com database and related search tools as our main source of records, integrating this with targeted searches using other databases and websites. The methods employed go beyond those typically used when carrying out a systematic review of the scientific literature.

Another potential limitation of this study is that it is based mainly on qualitative research carried out in different countries and settings, often with small samples. These studies aim to identify

14 For the sake of completeness, the table contains summary data on all studies, including those excluded due to risk of bias.

important features of service user involvement by analysing interview transcripts or by drawing on observations of treatment settings or decision-making bodies. Although they are generally of high quality, and most were assessed as having low risk of bias, this body of research is rather heterogeneous.

In light of these considerations, we adopted a research strategy that relies on thematic analysis and narrative synthesis. The themes which emerged from a careful study of the eligible documents are wide-ranging, which necessitates a meticulous narrative synthesis in order to provide a summary of the research findings in relation to each theme. The main difficulty with this kind of analysis is that it can be challenging to provide a coherent presentation of the research findings due to the large number of themes and the heterogeneity of the studies concerned.

Summary

In this chapter we described the methodology of our extensive review of the literature on service user involvement in drug treatment, recovery and harm reduction services. To be eligible for inclusion, studies had to meet a set of eligibility criteria. We followed 8 steps starting with the definition of the literature search and terminating with a narrative synthesis of eligible documents.

We searched a range of bibliographical databases, including Embase.com, as well as the websites of relevant organisations. In total, we identified 10,024 records using research databases and we found a further 579 potentially eligible documents by searching websites. After carefully reading each publication, we identified themes and gathered together the empirical evidence. The themes were defined in an iterative fashion as we analysed the eligible studies.

The main strength of our literature search is its impressive scope, covering not only academic journal articles, but also reports and unpublished dissertations. A wide coverage was ensured by using a number of databases and web-based resources. Although it was necessary to screen a considerable number of records, this ensured that our literature search included a wide range of relevant documents across a range of fields of study, services and geographical contexts.

4

Results of the literature review

We will start this chapter by summarising the contents of 7 existing systematic reviews which touch on the issue of user involvement in drug treatment, recovery and harm reduction services. These were identified during the research and provide a useful overview of existing knowledge on this theme. We will then describe the publications that were included in the narrative synthesis, the results of which are presented in Chapter 5.

4.1 Existing systematic literature reviews

During our literature search, we identified seven systematic reviews relating to the theme of user involvement (Davis *et al.,* 2020b; Fisher *et al.,* 2021; Friedrichs *et al.,* 2016; Goodhew *et al.*, 2019; Marchand *et al.,* 2019; Marshall *et al.*, 2015; Ti *et al.,* 2012).[15] For example, Davis *et al.* (2020b) review quantitative studies of patient-centred care and identify 25 publications. The most common measure of patient-centred care used in these papers is satisfaction with treatment, with studies generally reporting a positive association between this variable and improved substance use outcomes (frequency of use, abstinence). However, the authors point out that user satisfaction with treatment is not a fully satisfactory measure of patient-centred care. They conclude that "overall, these findings are consistent with previous systematic reviews in which it seems that a patient centered approach shows some association with patient health benefits alongside a tendency toward unclear results".

The review by Fisher *et al.* (2021) summarises the evidence on shared decision-making in the context of dual diagnosis (involving problematic alcohol or other drug use and a co-occurring mental health condition).[16] As the authors note, shared decision-making "involves clinicians and patients (and potentially others, e.g. family) partnering together to share information and their respective clinical and lived expertise on available treatment options and outcomes. Parties then deliberate on preferences and reach agreement on a treatment choice" (p. 307). This enables the clinician to take the patient's preferences into account in situations where multiple

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15   In order to provide a single, authoritative review of the recent literature on user involvement, we decided to include all relevant publications in this study, even if they appeared already in one of these existing reviews (this applies to only a small number of publications). When presenting our findings, we will be careful to point out any areas of overlap in order to avoid bias.

16   For a systematic review of shared decision-making in general health services, see Hauser *et al.* (2015).

treatment options exist and there is uncertainty regarding effectiveness. Shared decision-making (SDM) can thus be justified in ethical terms (as it enables patients to make informed choices), in political terms (as a response to requests for active involvement[17]) and in clinical terms (as it can yield better treatment compliance while boosting self-esteem and autonomy [18]). Fisher *et al.* (2021) identify just 10 studies (four of which were conducted by the same group of researchers), and reach the following conclusions:

> *SDM-based interventions led to improvements in reported SDM levels, patient involvement in decision-making and autonomy, patient-centred approaches to care, clinician-patient agreement and attention given to patient concerns and goals in treatment decision-making, therapeutic alliance, and patient knowledge of treatment. These improvements were seen across a number of studies comprising a range of designs (RCT and non-RCT, qualitative) and outcome measures (validated and non-validated, self-report), patient populations (primary AOD [alcohol and other drug] use/mental health disorder vs. co-occurring subclinical symptoms), intervention types (clinician-based, decision-support resources) and treatment/service delivery settings (primary-care, outpatient, inpatient). Of note too, SDM-related improvements in decision-making quality were reported not only by patients themselves, but also by their managing clinicians (who often delivered the intervention) and independent observations of consultations.* (Fisher et al., 2021, p. 321)

Friedrichs *et al.* (2016) review patient preferences and, like Fisher *et al.*, study shared decision-making in relation to treatment for substance use disorders. They conclude that user involvement is likely to lead to better relationships, better support, better therapeutic alliance, higher self-esteem, new skills and a reduction of stigma in the context of drug treatment services. They note that a decrease in psychiatric symptoms and drug consumption has been reported for patients with substance use disorders who have the opportunity to participate in shared decision-making in relation to treatment options (Joosten *et al.,* 2009). The authors identify 25 eligible studies, and conclude that patients who are matched to their preferred treatment have better outcomes (including substance use over the previous 90 days) as well as lower drug use severity. If shared decision-making leads to patients receiving all required vocational, housing, family or medical services, then treatment retention tends to improve. They advise other researchers to consider different kinds of outcomes in future studies, including substance-related behaviour, social situation and psychiatric symptoms.

Goodhew *et al.* (2019) study user involvement in drug treatment services, and this review is the closest to ours in terms of thematic coverage. The authors identify 16 eligible studies and describe a range of improvements in service quality following inclusion of users in committees or forums, leading to an expansion in the range of services available and a stronger emphasis on harm reduction (Goodhew *et al.,* 2019, p. 101). Service providers are found to be reluctant to involve service users in decisions, as the latter are perceived to lack the required skills and are not considered trustworthy. However, harm reduction services show less paternalistic attitudes (p. 104) and the review finds that supportive attitudes on the part of professionals can encourage consumers to get involved:

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17 Fisher *et al.* (2021) cite a number of studies of the preferences of patients with substance use disorders, which confirm this point (see Friedrichs *et al.,* 2016).

18 Research on health conditions more generally indicates that patients who receive their preferred treatment tend to have higher treatment adherence, to feel more satisfied with treatment, although the evidence on treatment outcomes is inconclusive (see Friedrichs *et al.,* 2016, for a summary).

> *Therefore, CP [consumer participation] was facilitated by an organisational culture that embodied optimistic views and an appreciation of consumer contributions (Van Hout and McElrath, 2012), and mutual respect (Patterson et al., 2009) that allowed consumers and staff to work towards a collaborative ethos (Rance and Treloar, 2015).* (Goodhew *et al.,* 2019, p. 105)

Marchand *et al.* (2019) present a scoping review of patient-centred care in the context of drug and alcohol treatment services. Their review describes different forms of patient-centred care, including how this has been measured and assessed. A total of 149 papers published between 1960 and 2018 are identified, with almost three quarters mentioning therapeutic alliance, more than one third describing shared decision-making, less than one third discussing individualised care and just under one quarter emphasising holistic care. The authors emphasise that a number of enabling factors of a systemic nature must be in place in order for more specific initiatives to be effective. Although patient-centred care is typically defined as embracing all four, most of the studies mentioned just one or two:

> *Thus, individualized needs assessment and treatment delivery overlapped with holistic, trauma-informed and culturally competent, responsive, and appropriate care with respect to their common goal to provide comprehensive and flexible care, adapted to client-identified needs and values. Under ideal circumstances, such consideration would be facilitated by an assessment of clients' bio-psycho-social needs, which are often inextricable from their cultural context and the pervasive impacts of structural and interpersonal trauma.* (Marchand *et al.,* 2019, p. 10)

Marchand *et al.* (2019) also note the lack of agreement in the literature on how to measure the outcomes of patient-centred care. Examples include treatment satisfaction, health and other outcomes reported by the patient, with an emphasis on substance use and treatment engagement, which are the most common outcomes used in research on drug treatment services. As the authors observe, however, "continued emphasis on substance use outcomes neglects that the stated goal of patient-centred care is to improve the treatment process. It is also not congruent with prior research demonstrating that clients' goals extend to other domains (e.g., health, housing, family relationships) and emerging recommendations to integrate patient-centered or patient-reported measures in substance use disorder treatment" (Marchand *et al.,* 2019, p. 11).

Marshall *et al.* (2015) conducted a systematic review of the peer involvement literature, emphasising that people with lived experience of drug use may be involved as peer workers or volunteers in drug treatment or harm reduction services. A total of 164 documents were included in the review, and the authors identify 36 different peer roles within drug treatment services. Systemic factors were the most frequently cited obstacles (in 69 documents), involving criminalisation of drug use, policies that emphasise enforcement rather than harm reduction and the stigmatisation of people who use drugs. Marshall *et al.* (2015) also identify a number of facilitators at the systemic, organisational and individual levels, such as recognising the role of peer influence, providing training and support and building relationships between peer support workers and other staff based on mutual (cf. Billsten and Benderix, 2019).

Several of the factors identified by Marshall *et al.* (2015) in their systematic review of the literature on peer support workers in harm reduction initiatives are also relevant to the broader question of service user involvement in drug treatment services. They conclude that service providers need to base relationships with peer workers on mutual respect as well as suspending judgement, accepting peer workers for who they are, reorienting services and/or schedules to

meet their needs, enhancing consideration of confidentiality and providing training and skills to further build capacity. These are crucial ingredients of inclusive work practices in any area of service provision, and could usefully form part of staff training programmes.

Ti *et al.* (2012) assess the available evidence in relation to the engagement of people who use drugs in policy and programme development. This study includes research on peer engagement, which means that it has a relatively broad remit. In this context, peers are defined as people with lived experience of using drugs. The well-known "Nothing About Us Without Us" manifesto (Jürgens, 2008) argues that people who use drugs should be invited to participate wherever policies, interventions or services concerning them are planned, discussed, or researched. Similarly, the 6th EXASS Net[19] meeting in Amsterdam in 2009 concluded that there is great value in engaging people who use drugs when seeking to develop policies and strategies. Ti *et al.* (2012) identify 19 eligible publications which shed light on barriers and enabling factors in relation to the inclusion of people who use drugs in policy and programme development.

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19 Formed by the Pompidou Group of the Council of Europe, EXASS Net is a European network of frontline workers in the health, social and law enforcement sectors that aim to address policy issues relating to substance use.

The main barrier they identify is stigmatisation, which leads to negative stereotypes and undermines the self-confidence of people who use drugs. Resources can also limit the ability of organisations to involve people who use drugs, along with power imbalances between service users and professionals. Ti *et al.* (2012) also emphasise the role of advocacy groups and the employment of peer support workers within drug treatment, recovery and harm reduction services. They describe how these broader forms of peer engagement have impacted on policies, improving service delivery and facilitating user participation.

4.2 Eligible studies

A full list of the eligible studies, together with some summary information on each, is provided in Table 1.

Table 1 Summary of eligible publications

Author/year/ country/ type/quality	Research design	Data collection	Data analysis		Aims	Findings	Risk of bias
1. Alves *et al.,* 2021 (UK) – academic paper	Observational study following the critical incidents technique	Qualitative – semi-structured interviews with 24 people in OST	Interviews were transcribed and subjected to thematic analysis.		To understand the most significant aspects of care experienced by people in OST in primary care settings	People who use drugs value receiving treatment in humanised and destigmatised environments, with a good relationship with primary care professionals and flexible, individualised and collaboratively designed treatment plans	Medium
2. Andersen, 2014 (Denmark) – academic paper	Ethnographic study based on a dramaturgical approach informed by Goffman	Qualitative – participant observation at the two centres, semi-structured interviews with 15 professionals and 24 service users	Audiotaped sessions and interviews were transcribed verbatim.		This article investigates how everyday interaction organises clients' experiences in ways that alternately support and contradict the view of clients as "agents of change".	Talk and arrangements "backstage" make professionals, not clients, appear as the real agents of change. Clients are increasingly encouraged to participate in the meetings where treatment is organised, but, contrary to intentions, they may experience participation as debasing rather than empowering.	Low
3. Andersson and Johnson, 2020 (Skåne, Sweden) – academic paper	The original design focused on patients who had changed clinics, but since few had switched, those who had chosen to stay were also included.	Qualitative – semi-structured interviews with 33 patients in substitution treatment	Digital recordings of interviews were transcribed verbatim. The authors analysed the transcribed interviews in three steps using manual qualitative text analysis based on reading/manual coding.		The article is primarily an empirical study concerning patients' views and experiences of the introduction of patient choice in substitution treatment.	Problematic drug use is often accompanied by social, economic and emotional problems, and impedes organised action. The possibility to choose one's clinic is a decisive change – as patients have become customers, mutual dependence has emerged between them and the clinics. Competition forced clinics to improve the staff-patient relationship, and services provided.	Low

Author/year/ country/ type/quality	Research design	Data collection	Data analysis		Aims	Findings	Risk of bias
4. Bakkeli and Grønningsæter, 2020 (Southern Norway) – academic paper	Cross-sectional observational study	Qualitative – notes from four focus group discussions lasting 2–3 hours	Thematic analysis of researchers' notes based on inductive coding and subsequent refinement		To develop new ideas about how technology can be used to create improved drug treatment services at local level	Participants were concerned about developing meaningful relationships and struggled with loneliness. Having access to peers was a necessary prerequisite for empowerment. Technology can facilitate three-way cooperation involving users, skilled peers and professional social workers, and can be used to extend support.	Low
5. Belle-Isle, 2016 (Ontario and BC, Canada) – PhD thesis	Community-based participatory ethnographic research	Qualitative – observation of meetings (field notes) and 40 interviews with participants	Thematic analysis of field notes and interview transcripts based on inductive coding following by refinement		This study aims to understand how power inequities are transformed in committees where people who use drugs are at the table.	Large social inequalities between people who use drugs and others, alongside inconsistent attempts to alleviate barriers. Committee members underestimated people who use drugs (PWUD). Local organisations of PWUD ensured more democratic selection of representatives. Safe spaces entailed building trust, relationships, relational and reflective dialogue, facilitation.	Low
6. Billsten and Benderix, 2019 (Sweden) – academic paper	Observational study of user organisations	Mixed methods – a self-response survey was completed by 14 representatives of user organisations.	Descriptive analysis of open (content analysis) and closed (statistical analysis) items from questionnaire		To evaluate whether user organisations continued to exist once national support ended, and whether their influence was significant	14 out of 20 user organisations still existed and exerted an influence on treatment services at both the organisational and individual levels. National support was perceived as necessary for their ongoing development.	Low
7. Bjerge et al., 2014 (Denmark) – academic paper	Observational study based on ethnographic fieldwork and qualitative interviews	Qualitative – participant observation and semi-structured interviews with 26 staff and 37 users	Interviews were transcribed and coded, with field notes, coded in NVivo.		To understand how the political framing of institutional practices is articulated in everyday encounters between social workers and clients	The authors show that social workers' encounters with drug users are not based on the presumption of individual choice. The life situations of drug users conflict with the idea that drug users should be "empowered", and that treatment tends to be about improving the overall situation of drug users rather than individual choice.	Low
8. Bjerge and Nielsen, 2014 (Denmark) – academic paper	Participatory ethnographic research	Qualitative – 4 months of observation and interviews with 10 users (out of 17)	Thematic coding of ethnographic field notes and interview transcripts		The authors aim to assess whether an institutional commitment to user empowerment was reflected in practices.	The authors show that staff and users constantly produce, construct and negotiate institutional practices that differ from governmental intentions in relation to user involvement.	Low
9. Davis et al., 2020a (NSW, Australia) – unpublished paper	Observational study of clients and staff	Qualitative – 4 focus groups with 18 clients, semi-structured interviews with 8 staff	Interviews were transcribed and analysed using NVivo. Thematic analysis was performed in six phases.		To explore client and staff perspectives of a new client-centred model of care in a residential treatment service	Clients and staff shared predominantly positive views on the client-centred model, with an emphasis on the satisfaction in providing and receiving what felt like more authentic and comprehensive care. The main tensions related to striking a balance between flexibility and structure and managing comprehensive and individualised care within existing knowledge, skills and resources.	Low
10. Duke et al., 2020 (Denmark, Italy, Poland and UK) – academic paper	Comparative ethnographic research involving different groups in each country (EU EPPIC project)	Qualitative – semi-structured interviews with 160 people and 66 practitioners	Thematic coding of interview transcripts using NVivo		To explore processes of involving young people in drug treatment in the context of the criminal justice system	Despite institutional and policy differences, remarkable similarities across countries and between participants in what constitutes effective engagement – trusting, collaborative relationships – 'children and young people first', but some interventions relied on a constraining 'offender management' framework	Low

Author/year/ country/ type/quality	Research design	Data collection	Data analysis		Aims	Findings	Risk of bias
11. Foreman-Mackey *et al.,* 2019 (Ontario, Canada) – academic paper	Cross-sectional observational study	Qualitative – 30 semi-structured interviews with service users, volunteers, organisers	Interviews were recorded, transcribed verbatim, verified and coded inductively in NVivo using the applied thematic analysis approach.		To assess whether the overdose prevention site (OPS) alters the risk environment to reduce the risk of overdose by exploring service user experiences	Participants stressed that having peer workers on-site helped them feel more comfortable. The experience of the OPS shows that harm reduction models can be adapted. The OPS improved access to harm reduction supplies and other supports, such as access to services. Rules were generally seen as 'common sense' and shared.	Low
12. Frank and Bjerge, 2011 (Denmark) – academic paper	Cross-sectional observational study	Qualitative – interviews with 26 staff members and 37 service users, participant observation and focus groups	Interviews were transcribed and analysed in NVivo with field notes. Thematic coding was carried out using empirical themes and key policy concepts.		The authors' aim is to analyse how attempts to implement empowerment as a welfare policy in medically assisted drug treatment plays out through everyday practices.	Differentiation as a strategy to selectively promote empowerment. Resource constraints and individual characteristics – not everyone can achieve the same level of involvement. Structural features of drug treatment pose constraints. Staff focus on users' preferences and needs, but substitution drugs are subject to regulations – dilemma between individual and mass-based services.	Low
13. Goodhew, 2019 (Sydney, Australia) – PhD thesis	Participatory action research – the lead researcher mobilises the co-researchers to take action.	Qualitative – semi-structured interviews with 20 users and 10 staff. The small ad hoc survey is not considered.	Thematic coding (template analysis) of staff brainstorming exercise, recordings of meetings and interviews		This study aimed to investigate how the process of forming a consumer action group influenced participation at a harm reduction service.	Consumers' drug use and lifestyles can constrain participation. Staff focus on users' strengths counteracts this. Participation not only empowered consumers, but also increased their social capital and prompted them to make positive lifestyle changes. Highly marginalised consumers can successfully contribute to service delivery when a strength-based approach is adopted.	Low
14. Harris and McElrath, 2012 (Ireland) – academic paper	The authors pooled data from four studies in Northern Ireland and the Republic of Ireland.	Qualitative – a large number of semi-structured interviews were carried out with service users.	Thematic analysis based on reading the interview transcripts several times		To explore the experience of methadone maintenance from the perspective of clients in two jurisdictions	The potential of OAT is undermined by the nature of treatment provision in Ireland, which is inconsistent with contemporary models and principles, being characterised by highly regulated social control mechanisms and institutional stigma that reduce trust between providers and clients, (b) reinforce 'spoiled', 'addict' identities of clients and (c) view clients as passive recipients.	Low
15. Hawkins *et al.,* 2017 (US) – academic paper	Pre/post evaluation study	Qualitative – semi-structured interviews with 6 patients at 1 month and 4 at 3 months	Interviews were recorded and transcribed verbatim before being coded in ATLAS.ti using template analysis.		The authors assess a new Care Management Model by consulting patients. The model was designed to enhance engagement by delivering flexible and efficient care.	Familiarity with, and trust in, providers is a key factor, due to stigma, marginalisation, and previous negative experiences. Patients want to feel listened to, understood and cared for. Therapeutic alliance and provider empathy should be monitored during treatment. Individual encounters with therapists, flexible forms of care, a team-based approach and patient-centred care are important.	Low
16. Healy, 2019 (Ireland) – PhD thesis	Participatory Action Research and narrative analysis over a four-year period	Qualitative – participant observation and semi-structured interviews with 42 users, 5 providers	Narratives were constructed through recordings of semi-structured interviews with OAT service users and service providers.		Explores service user narrative and examines allegations that human rights violations are widespread within Irish OAT	A number of themes emerged, including how OAT is perceived by clients as a mechanism of social control, the strategic deployment of constrained user agency to achieve specific objectives, how OAT produces rather than reduces harm and the broader sociopolitical and economic context of OAT.	Low

Author/year/ country/ type/quality	Research design	Data collection	Data analysis		Aims	Findings	Risk of bias
17. Hussey *et al.*, 2019 (UK) – academic paper	Co-production project with observational research component	Qualitative – 2 focus groups with users, stakeholder meetings, consultations, workshops	No formal analytical procedures were used.		To support the uptake and use of low dead space syringes by co-designing harm reduction materials with people who inject drugs (PWID)	Drug users recommended avoiding stereotypical portrayals of PWID in posters, avoiding language that "tells people what to do", humour, inappropriate language, standard healthcare logos (due to the possibility of poor prior experiences) and showing body parts.	Medium
18. Jozaghi, 2014 (Vancouver, Canada) – academic paper	Cross-sectional observational study	Qualitative – 16 semi-structured interviews	Interviews were transcribed verbatim and analysed thematically using NVivo, following an open coding/inductive approach.		To determine the role of heroin-assisted treatment in the lives of drug users in SALOME, focusing on their activism and involvement in shaping drug treatment services	In SALOME, by contrast with NAOMI, relationships with social workers, nurses and doctors were characterised by kindness, provision of harm reduction, assistance in relation to housing and financial issues. Social activism by drug users in the randomised trials showed what can be achieved if services are reoriented towards the treatment needs identified collectively.	Low
19. Kavanagh, 2012 (Ireland) – BA dissertation	Cross-sectional observational study of key frontline workers	Qualitative – semi-structured interviews with 9 frontline staff members	Interviews were transcribed and a thematic approach was applied to analyse the transcripts using NVivo.		To investigate the effectiveness of methadone maintenance provision in the context of service users' objectives	As many as 8 out of 10 service users at the projects have the goal of being drug free. The majority of respondents expressed quite negative views in relation to enquiries about how much or to what degree service users "had ownership" of the treatment they were receiving.	Medium
20. King, 2011 (Ireland) – academic paper	Cross-sectional observational study	Qualitative – semi-structured interviews with 20 users and providers, 1 focus group	Interviews were recorded and transcribed verbatim, and thematic analysis was carried out.		This study seeks to improve knowledge of service user involvement in drug treatment, including meanings, mechanisms and limits to involvement.	Participants acknowledged that services could and should learn from the experiences of service users. Users were passive players in planning, developing, evaluating and delivering services. In order to change the rhetoric of policy into reality, a much more committed approach is required, including education and training.	Low
21. Laitila *et al.*, 2011 (Finland) – academic paper	Cross-sectional observational study	Qualitative – semi-structured interviews with 27 service users	Phenomenographic approach, reading the data, identifying meanings and then forming themes		To explore the perspectives of service users on service user involvement in mental health and substance abuse treatment	Organisational culture can hinder or facilitate involvement. Users of services can encounter prejudices, paternalistic or punitive attitudes and professional protectionism. Organisations are often hierarchical and inflexible. Services users need information to participate. SUI changes role of professional expertise.	Low
22. Larsen and Sagvaag, 2018 (Norway) – academic paper	Action research case study involving cooperative inquiry – patient co-researchers collaborated	Qualitative – participant observation, focus groups, interviews and co-researcher-led seminars (109 participants)	Qualitative data were "member-checked" by contributors and coded thematically using NVivo.		To explore obstacles to user involvement in mental health and substance abuse services and to develop a user participation method	Although empowerment was perceived as a goal by all, some leaders and staff were concerned that pathology could motivate patients; patients feared being "pathologised". Underlying assumption that patients "were allowed" to be involved, within limits. Need for empowerment of all – staff and patients.	Low
23. Larsen *et al.*, 2020 (Norway) – academic paper	Action research with patients, leaders and staff as co-researchers. Conceptualising the problem – several interventions	Qualitative –participant observation, 6 stages of focus groups, 10 individual interviews and 4 dialogue seminars	Member-checked field notes, journal notes, minutes, etc. were analysed in NVivo using an abductive approach combining inductive and deductive elements.		To unlock the potential of co-production in settings where staff have no prior experience involving patients systematically in service development	Direct communication between patients and staff was challenging for both, and several encounters were needed to prepare for meetings. Power sharing was subject to a risk of paternalistic or avoidance approaches by professionals. Facilitating service co-production may be served by mediation and support, including professional development and purpose-designed spaces.	Low

Author/year/ country/ type/quality	Research design	Data collection	Data analysis		Aims	Findings	Risk of bias
24. Latham, 2012 (Ireland) – academic paper	GPs were asked to nominate service users.	Qualitative – 25 service users were interviewed	Interview transcripts were analysed using a phenomenological thematic coding approach.		To fill a gap in research on methadone treatment in Ireland, where little qualitative work has been done on the experience of service users attending general practice	Most interviewees described their relationship with their doctors in positive terms, feeling that they were listened to and valued.

There were also negative experiences, where GPs were described as "phy doctors", in a rush to hand over a prescription and get rid of the patient. One difficulty is that GPs cannot meet patients' needs for counselling and psychosocial support. | Medium |
25. Marchand et al., 2020 (Canada) – academic paper	Observational, cross-sectional study	Qualitative – 30 in-depth interviews (14 females; 16 males) were conducted with people receiving injectable opioid agonist treatment.	Interview transcripts were coded using a grounded theory approach, which involved alternating between inductive and deductive approaches.		To explore participants' experiences of injectable opioid agonist treatment, with reference to patient-centred care and treatment outcomes	The core concept that emerged related to the relationship between service users and providers, as the data suggested that therapeutic relationships were fundamental to experiences of patient-centred care in this context. When relationships were respectful and understanding, participants received individualised and holistic care which was more likely to respond to their needs.	Low
26. Moore et al., 2019 (Ireland), research report	Ethnographic study	Qualitative – non-participant observation, interviews and focus groups with staff and service users	Field notes and interview/ focus group transcripts were analysed (no information on how).		To identify factors that users and staff experience as central to engagement and retention, and explore whether there are key skills or environmental elements that facilitate involvement	The person-centred care approach promotes the development of a partnership. The non-punitive and non-judgemental approach to relapses results in reduced shame. Trauma Informed Care allows service users to seek treatment for underlying issues. This philosophy influences therapeutic alliance, group cohesion and perceived safety of environment, contributing to stronger social bonds.	Medium
27. Ness et al., 2014 (Norway) – academic paper	Longitudinal action research with a cooperative inquiry/ participatory perspective	Qualitative – multistage focus group discussions with 10 practitioners	The transcribed focus group material was subjected to thematic analysis, by coding, leading to the identification of seven themes.		To provide practitioners' perspectives on working together with young adults with co-occurring mental health and substance use problems and their families	Three overarching themes: (1) walking alongside through negotiated dialogues; (2) manoeuvring relationships and services and (3) maintaining human relationships. The practitioners identified obstacles, such as inflexible work conditions, huge caseloads, putting aside one's own prescriptive ideas, manoeuvring complex bureaucracies, difficulties in getting families involved and dedicating time to patients.	Low
28. Ness et al., 2016 (Norway) – academic paper	Observational study which focuses on the families of young adults (see Ness et al., 2014)	Qualitative – multistage focus groups were carried out with 10 parents of young adults (7 females; 3 males).	The focus group discussions were transcribed and subjected to thematic analysis.		To explore the practical implications of user involvement from the perspective of the parents of young adults	Parents want to be invited to contribute with their experiences and knowledge, being a collaborative partner in service provision. But it is important to understand the complex situation of each family and parent, as the latter support their children while living lives of their own.	Low
29. O'Reilly et al. (2011) – academic paper	Observational study of opioid agonist therapy in a primary care setting	Qualitative – structured interviews with 41 service users (out of 47)	Data were coded by labelling individual units of meaning, and then re-categorising these according to emerging themes.		To assess views of service users, including the degree to which the patients were 'involved in decisions about their treatment'	Most patients felt listened to and had a say in deciding their methadone dose, but did not have an opportunity to engage in more structured forms of involvement. Service users who have become stabilised and wish to eventually stop taking methadone do not feel involved in their treatment.	Medium

Author/year/ country/ type/quality	Research design	Data collection	Data analysis		Aims	Findings	Risk of bias
30. Pascoe and Robson, 2015 (UK) – research report	Action research project	Qualitative – but no information is provided on how data were collected	No information		To evaluate the Whole Person Recovery model as it was implemented in West Kent by CFI, with support from the Royal Society for Arts, Manufactures and Commerce (RSA)	Lack of understanding of recovery capital and co-production. Importance of "embedded partnerships", "peer support", "co-production", "recovery capital", "local communities", but we need a better understanding of how these relate to recovery	High (exclude)
31. Rance and Treloar, 2015 (NSW, Australia) – academic paper	Longitudinal observational study with data collection at baseline and after 6 months	Qualitative – semi-structured interviews with staff (27) and service users (30) at three treatment facilities	Interviews were recorded and transcribed; then key themes were identified and coded in NVivo.		The authors aim to elucidate the conditions under which small shifts in relationships can occur through involvement.	Service users from the residential rehabilitation service crafted a 'welcome diary', consumers from the regional pharmacotherapy service-initiated initiated CPR and naloxone training, and consumers from the metropolitan service began attending local community 'law and order' forums. Through involvement in these initiatives, a possibility for change was created in the services.	Low
32. Storbjörk et al., 2016 (Stockholm County, Sweden) – research report	Longitudinal study of user/provider pairs	Qualitative – semi-structured interviews with 23 providers and 36 service users at two timepoints	Interviews were used to write summary reports, and then inductive and deductive coding techniques were used, following something like the "framework method".		To analyse perceptions of user involvement and the extent to which service users can influence interventions and treatment	About one-half of service users were satisfied with involvement, and about one-half were categorised by interviewers as having high involvement. Women and users in the health care system had higher levels of involvement, as did those with a more stable social situation, alcohol only service users and those with less severe substance use. All participants stressed the importance of service user involvement for a well-functioning service.	Low
33. Treloar et al., 2011 (NSW, Victoria and WA, Australia) – academic paper	Evaluation study based on realist framework – impact of interventions depends on context	Qualitative – semi-structured interviews with 33 staff and 25 service users	Interviews were recorded and transcribed, then themes were identified, focusing on organisational and structural factors.		To evaluate consumer participation projects conducted in five drug user treatment services, with a focus on the organisational level	None of the projects achieved their goals within the time-frame. There were delays and disruptions due to lack of resources. Staff underestimated the amount of work involved. A key finding was the shift in relation to the concept of "stability." In baseline interviews, staff focused on the need for consumers to be "stable", but this was replaced by a focus on whether the services themselves had the stability required.	Low
34. Treloar et al., 2016 (Sydney, Australia) – academic paper	Observational study	Qualitative – semi-structured interviews with 31 service users and 12 service providers	Interviews were recorded and transcribed, then coded using a coding frame, allowing for emergent themes.		To understand the relationship between trust, stigmatised identity and legitimacy with regard to people who use drugs and their experience	Trust should be recognised as a valuable resource for delivery of effective care for PWID. Client participants reported feeling like "any other person" when accessing NSPs – this was an exceptional experience. In other services there was mistrust, particularly in drug treatment. The collective experience of PWID participants was underpinned by the stigmatised identity of drug users.	Low

Author/year/ country/ type/quality	Research design	Data collection	Data analysis		Aims	Findings	Risk of bias
35. Van Hout and McElrath, 2012 (West of Ireland) – academic paper	Observational study	Qualitative – semi-structured individual interviews with 12 service users and 30 providers	Interviews, field notes, memos, etc. were transcribed and the researchers identified themes and coding schemes.		This study was undertaken in a rural area and aimed to investigate user and treatment provider perspectives on the nature and extent of service user involvement.	For service providers, user involvement offered the potential to enhance engagement and amplify the voice of service users. However, there was poor awareness of the service users support team and its intended service user forums. Some providers suggested that the concept of service user involvement needed to be explained to professionals and that encouraging clients to engage with service user forums was beyond their remit.	Low
36. Welch et al., 2017 (England) – academic paper	Evaluation study with a pre/post design	Qualitative – semi-structured interviews with 10 organisational representatives at two points in time	Interviews were recorded and transcribed, and then analysed using an inductive approach.		The overall aim of the evaluation was to explore if personal budgets can have an impact on outcomes in drug treatment, and to identify effective models.	Benefits include greater self-confidence, self-esteem and a 'sense of purpose'. The offer of 'choice' meant a wider range of options and a more 'person-centred' approach. Alternative and more appropriate providers could be selected, and clients took greater responsibility for their own care. Some issues need to be managed carefully (needs/wants of clients, relapse, control over budget, etc.)	Low
37. Wenaas et al., 2021 (Norway) – academic paper	The first author attended team meetings in various units and conducted participatory observation.	Qualitative – participant observation and semi-structured interviews with 5 service users	An ethnographic approach was adopted to study communication in team meetings using transcripts from interviews and field notes.		This article examines the usefulness of interprofessional team meetings for service users and how they can be involved in and influence such meetings.	Although an unmet need for information was one of the users' main motives for attending, insufficient information made it difficult for them to have an influence. Three obstacles to user involvement were identified: (i) unclear role responsibilities and unclear professional role functions, (ii) unclear practices regarding rules and routines and (iii) absence of user knowledge.	Low
38. White and Paloheimo, 2019 (Dublin, Ireland) – research report	Cross-sectional observational study	Qualitative – 62 semi-structured interviews with service providers, users, stakeholders	No information		To contribute to the development of a strategy for service user participation in the Finglas/Cabra and Blanchardstown LDATFs	Service providers lack an overarching structure which collects, collates and synthesises the service user experience to inform the policy and programmes of the DATFs. Many services and users were not satisfied with their current approach.	High (exclude)
39. Andersson et al., 2017 (Central Norway) – academic paper	Cross-sectional questionnaire survey	Quantitative – questionnaire survey based on self-completion, shortly before discharge	Descriptive statistics were used as well as correlation coefficients and multivariate linear regression.		To assess treatment satisfaction among patients who have completed an inpatient substance abuse treatment programme	A significant proportion of patients were dissatisfied with the support provided for housing, financial issues and employment. Confidence in staff competence was the domain of treatment satisfaction most strongly associated with the outcome score, and patients were more likely to report a positive outcome when they were involved in their treatment.	Medium
40. Guille et al., 2019 (US) – academic paper	Observational study based on a questionnaire survey which was administered after shared decision-making	Quantitative – questionnaire survey covering information, outcomes, personal values, guidance and conflict	Descriptive statistics (just N and %) were used to summarise the responses to the questionnaire and the characteristics of the sample.		The purpose of this study was to gather feedback from pregnant women with opiate use disorder who engaged in shared decision-making.	95% of women made a clear choice to either continue (64%) or taper (36%) buprenorphine or methadone, agreed or strongly agreed that they were provided with sufficient medical information (96%), understood the information (91%), that they were provided with evidence and risk probabilities and that their chosen treatment was in line with their values and preferences.	Medium

Author/year/ country/ type/quality	Research design	Data collection	Data analysis		Aims	Findings	Risk of bias
41. Joosten *et al.*, 2011b (IJSP) (Netherlands) – academic paper	Observational study with a longitudinal study comprising multiple measurements of treatment goals	Quantitative – measurement at four timepoints to assess change in treatment goals, as indicated by user-clinician pairs	Descriptive and inferential statistics to explore differences between completers and dropouts and to look at changes in priorities of patients and clinicians		To evaluate the perspectives of patients and clinicians with regard to the goals of treatment in problem areas using shared decision-making	Important treatment goals for patients were daytime activities,alcohol (abstinence or reduction), Psychological distress and drugs (abstinence or reduction). Clinicians indicated psychological distress, daytime activities, alcohol and drugs as the most important treatment goals. Strong correlations between treatment goals were identified by patients and clinicians. Treatment goals became more closely aligned during treatment.	Medium
42. Joosten *et al.*, 2011a (Netherlands) – academic paper	Longitudinal study comprising multiple measurements of treatment goals and interpersonal behaviour	Quantitative – measurement at baseline, end of treatment and three-month follow-up to assess change	Differences were tested using statistical tests. Difference scores between clinicians and patients were computed. Regression analysis was used to explain change.		To examine the mechanisms and correlates of shared decision-making (interpersonal relationships)	Patients who participated felt more able to make their own decisions, more in control and less submissive. At the end of treatment and three months later, these patients had moved significantly further towards the autonomy/control end of this dimension and remained towards the 'friendly and cooperative' end of the other major personality dimension while treatment-as-usual patients were assessed as relatively more silent and reserved.	Medium
43. McKay *et al.*, 2015 (US) – academic paper	Sequential multiple assignment randomised trial design, where non-responders are randomised	Quantitative – data on self-reported alcohol and cocaine use, urine toxicology, treatment participation	Differences between conditions were evaluated using statistical tests and GEE models.		To test the hypothesis that patients who enter addiction care, but fail to engage, will have better outcomes if given a choice of treatments	No apparent benefits of choice with regard to substance use outcomes for participants not engaged at 2 weeks, those who were initially engaged but dropped out between weeks 3 and 8, or for those disengaged at both week 2 and week 8. Providing choice to those not engaged at 2 weeks did not produce better treatment attendance.	Medium
44. Park *et al.*, 2020a (US) – academic paper	Secondary statistical data analysis of a representative sample of clinics	Quantitative – data from 2017 National Drug Abuse Treatment System Survey of substance use treatment clinics	Regression analyses examined whether clinics invited patients into decision-making processes and supervisors supported patient-centred care.		This study examines factors associated with patient-centred care practices in the substance use disorder treatment field, with an organisational lens.	About 23% of substance use disorder treatment clinics invited patients to participate in clinical decision-making processes. Clinicians were more likely to engage patients in decision-making processes when working in residential clinics or in clinics serving fewer alcohol-use disorder and opioid-use disorder patients. Clinicians tended to involve patients in decisions if supervisors attributed importance to patient-centred care.	High (exclude)
45. Park *et al.*, 2020b (US) – academic paper	Secondary statistical data analysis of a representative sample of clinics at a single point in time	Quantitative – data from the 2017 National Drug Abuse Treatment System Survey of substance use treatment clinics	The authors examined the associations between patient-centred care practices and utilisation of a range of core and ancillary services.		This study aims to examine the association between treatment clinics' practices and utilisation of various treatment and support services by patients.	After controlling for multiple environmental and organisational factors, greater proportions of patients utilised behavioural treatment, routine medical care, HIV tests and suicide prevention counselling in clinics that regularly invite patients into the clinical decision-making process and whose clinical supervisor valued patient-centred care. Patient-centred care variables accounted for between 11% and 27% of variation explained by these models.	High (exclude)

Author/year/ country/ type/quality	Research design	Data collection	Data analysis		Aims	Findings	Risk of bias
46. Trujols *et al.,* 2017a (La Rioja, Spain) – academic paper	Statistical data analysis of a representative sample of service users at a single point in time	Quantitative – survey of satisfaction with MMT, participation, satisfaction with methadone and dose	Regression analyses were performed to identify variables associated with satisfaction with MMT.		The main objective of the study is to identify independent factors that contribute significantly to satisfaction with MMT.	The results suggest that patients are, in general, 'mildly satisfied'. 74% of patients received frequent information about changes in methadone dose and 55% believed that their opinions influenced these changes a great deal or quite a lot. Multivariate binary logistic regression showed that education, number of patients per centre, perceived frequency of receiving information, and social dysfunction were associated with satisfaction.	High (exclude)
47. Trujols *et al.,* 2017b (La Rioja, Spain) – academic paper	Statistical data analysis of a representative sample of service users at a single point in time	Quantitative – perceived adequacy of methadone dose, satisfaction with MMT, perceived participation, psychological adjustment	Statistical tests and regression analysis were conducted to test for differences between patient groups according to perceived adequacy of methadone dose.		The main objective of the study is to identify independent factors that contribute to perceived adequacy of methadone dose.	58.2% of participants perceived their methadone dose as inadequate (too low [4.1%] or too high [54.1%]). Patients who perceived the dose to be adequate (i) were significantly older at onset of heroin use; (ii) had a more positive opinion of methadone; (iii) had greater participation in dosage decisions; (iv) attended smaller clinics; (v) had been on MMT for longer; (vi) presented lower levels of distress. Regression results show that only patient-perceived participation is significant.	High (exclude)
48. Brener *et al.,* 2019 (NSW, Australia) – academic paper	Observational study – evaluation of NADA consumer participation project by the Centre for Social Research in Health	Mixed methods – quantitative data via staff survey, qualitative via interviews pre/post with staff and stakeholders	Descriptive and statistical analysis of survey responses; interviews were transcribed coded.		This research aimed to evaluate NADA's consumer participation project and engaged in a consultative process to assess the effectiveness of processes, training provided, audit tools and outcomes.	The majority of participants agreed that consumers should be actively involved in identifying the goals of their treatment and diagnosis of their problems. There were significant relationships between staff attitudes towards involvement, consumer participation in their services, and beliefs about consumer participation. Uptake by individual staff was highly variable. Training activities seem to foster changes within services. Staff and consumers reported being overburdened.	Low for qualitative research, high for quantitative (exclude quantitative)
49. Community Action Network (CAN), 2018 (Ireland) – research report	Observational study, involving engagement of service users in the research	Mixed methods – quantitative data are from a user-led consultation, whilst qualitative data come from interviews with service users.	During dialogue events, user-led research and project steering committee meetings, service users identified principles which they felt were critical to the provision of drug treatment services.		To support the active involvement and leadership of service users, and the willing collaboration of drug treatment services, in addressing human rights concerns	Framing issues in terms of human rights can be empowering for participants. In 2017, 84% of respondents reported that they had no participation in their treatment plan. The demands of attending GPs, clinics and pharmacies had negative impacts on their life. Most wanted to see changes in how doctors and clinics treat them. Lack of care plans means that patients often end up on methadone for the rest of their lives, and they are fearful of making complaints.	High for both qualitative and quantitative (exclude)
50. Mooney *et al.,* 2020 (California) – academic paper	Development and pilot testing of decision aid using comparative analysis methods with a treatment and control group	Mixed methods – quantitative data were collected using scales and clinical records, qualitative via focus groups with 19 users and 16 staff	Statistical tests of differences between cases and controls		To develop and test a patient decision aid for medication treatment for opioid use disorder that assists individuals in making informed decisions about treatment at the time of first consultation	16 out of 19 participants provided feedback on the decision-making aid and most "agreed" or "strongly agreed" that they knew which treatment options were available (88%), the benefits (88%), the risks (75%), were clear about best choice for them (81%), made an informed choice (94%) and were satisfied (88%). A greater number of individuals who used the tool (37%) were inducted on methadone than controls (11%) and they received methadone for more days (M=14.0, SD=24.7) than controls (M=8.4; SD=22.5).	Low for qualitative, Medium for quantitative

Author/year/ country/ type/quality	Research design	Data collection	Data analysis		Aims	Findings	Risk of bias
51. Roussy *et al.*, 2015 (Victoria, Australia) – academic paper	A controlled before-and-after study design with four waves of quantitative data collection across two sites	Mixed methods – quantitative data from multiple-wave survey of 41 staff, qualitative data from 4 focus groups	Statistical tests were used to compare the mean scores over time and between sites. Focus groups were audio-recorded, transcribed and coded thematically.		To evaluate the effectiveness of consumer-led training by people with dual diagnosis in improving the knowledge, understanding and role adequacy of staff	Consumer-led training was associated with a significant increase in understanding. Clinician-led and consumer-led training was associated with a positive change in role adequacy. Consumer-led training can address stigma and judgemental attitudes by health workers. Change in understanding can be sustained over time if training enhances empathy through contact and interaction.	Low for qualitative, high for quantitative research (exclude quantitative)
52. Vanderplasschen *et al.*, 2015 (Belgium) – academic paper	Observational cross-sectional mixed methods study	Mixed methods – quantitative data on satisfaction and characteristics, qualitative via semi-structured interviews with service users	Sample characteristics were described using summary statistics. All interviews were recorded and transcribed verbatim, and coded.		To assess satisfaction with substitution treatment, client relationship with staff, client expectations, availability of psychosocial support, and treatment satisfaction	Being involved in determining substitute dose is very important to most respondents, but this depends on the programme and prescribing doctor. Limited involvement makes clients feel that they are chained to their substitute drug. Almost all respondents expressed the desire to decrease dose and dependence. Respondents reported stories of stigmatisation. OST clients do not want to be passive recipients of care.	Low for qualitative, medium for quantitative research

5

Service user involvement in drug treatment, recovery and harm reduction services

In this chapter, we present a narrative synthesis and discussion of the findings of the studies we deemed eligible for inclusion in our literature review. This synthesis is based not on the themes identified in the original studies but on the evidence and insights they contain. As we stated in Chapter 3, we first carried out a thematic analysis and then synthesised the material present in the studies using these themes.

In nearly all of the studies, a key issue is the nature of **relationships between service users and practitioners**. Another recurrent theme hinges around **social power**, including the stigmatisation of drug users, the ethos of drug treatment services and the nature of professional ideologies. A third dimension relates to **organisational practices**, including rules, regulations, principles and resources. Having identified these three dimensions, we developed them into sub-themes, with a view to highlighting specific aspects of service user involvement.

These themes are closely interrelated and it is only possible to distinguish between them analytically. In practice, initiatives to promote user involvement are likely to operate simultaneously across all three dimensions by intensifying and equalising relationships, empowering service users and modifying rules, regulations and therapeutic practice. Nevertheless, an awareness of the different facets of user involvement can help practitioners, service users, advocacy groups and researchers to make progress in the direction of more effective and satisfactory services. In the narrative synthesis that follows, eligible publications from our literature review are highlighted in bold type. Other documents are cited only where this is necessary in order to provide a more complete description of the themes.

Theme 1.
The relationship between service users and practitioners

This theme embraces what is arguably the most important set of issues regarding user involvement in drug treatment services. The literature we reviewed suggests that user involvement should be treated as a relational concept and that understanding the relationship between service users and staff members is crucial to any initiative that aims to empower service users. It is helpful to break this theme down into three sub-themes: (1a) building and maintaining trust, (1b) showing empathy, (1c) creating a space for effective communication. The first two sub-themes are of direct relevance to the involvement of service users in making decisions about their own treatment, whilst being indirectly related to the involvement of service users in the redesign of organisational practices or the development of new and existing services. Sub-theme 1c is also of great relevance to the involvement of service users in a representative capacity.

Theme 1a. Building and maintaining trust

Ness *et al*. (2014) provide the following overview of collaborative practice between service users and providers:

> *Combining such a relationship with a recovery orientation further involves a reorientation from the professional being an expert on other peoples' lives towards supporting individuals in their own ways of managing problems and struggles.* (**Ness et al.,** 2014: 2)

Empirical studies based on interviews with service users and practitioners have yielded rich descriptions of these kinds of relationships. For example, Ness *et al.* (2017) suggest that user involvement is about collaboration between service users and providers, which requires trust. They explore the perspectives of young adult service users in the Norwegian treatment system (two women and five men) with co-occurring mental health and substance use problems. They report that being treated with respect and being valued as a person are of primary importance to service users, who want clinicians to take the time to talk to them and to get to know them before proposing plans or treatments. They do not want practitioners to try to 'fix' them or to judge them, but instead to meet them and to treat them as individuals. The authors emphasise the importance of the 'little things', like tone of voice and body language, active listening, eye contact and making time for people.

The practitioners studied by **Ness *et al.* (2014)** described the value of (metaphorically) 'walking alongside' service users, the importance of not giving up on them and always seeing the service user as a unique and valuable person. This kind of relationship requires time and continuity, as practitioners must listen to the insights and knowledge that other actors bring to the treatment process:

> *They jointly develop expertise and knowledge that is an inter-subjectively shared form*

of knowing from their respective perspectives. In this way, they can negotiate dialogues and relationships forward. The focus, however, is on identifying and nurturing the service user's expertise and strengthening his or her ability to handle everyday life. (**Ness** *et al.,* **2014**, p. 6)

As **Moore** *et al.* **(2019)** observe, what is crucial to the relationship between service users and providers is the formation of a bond that is based on trust and respect. In order for the service user to trust the practitioner, the latter must also show trust (Cook and Kramer, 2004), which involves emotional labour (Larson and Yao, 2005). A good therapeutic relationship leads to better outcomes (abstinence, substance use, retention) across a range of different modalities of treatment (Horvath *et al.,* 2011) and a deeper and stronger connection between the therapist and the service user (Sexton *et al.,* 2005).

The relationship between service users and practitioners is often referred to as 'therapeutic alliance', comprising a number of dimensions, including the shared identification of goals and interventions and the bond between practitioner and service user (**Moore** *et al.,* **2019**). The goals of treatment are the primary focus and should be mutually agreed. Treatment interventions should be chosen by service user and practitioner in order to achieve those goals, and the bond between service user and practitioner is an active ingredient in this process. This implies that treatment plans should not be treated as a bureaucratic procedure. What is important about collaboratively drafting a treatment plan and securing the agreement of both the service user and the provider is the process itself, together with the trust and motivation that are needed in order to make progress towards the goals that are indicated in the plan.

Treloar *et al.* **(2016)** carried out interviews with 12 staff and 31 service users at a needle and syringe programme in Australia. Describing their previous interactions with health service practitioners, service users recounted how the demeanour of staff would change as soon as they found out about the patient's drug use. Participants were made to feel inherently untrustworthy and infectious and they experienced unfair exclusion from services. However, the needle and syringe programme was different, and staff worked hard to build trust by making clients feel like the legitimate, normal clients of a service:

> *Client trust in NSPs was perceived to be based chiefly on the non-judgemental and confidential nature of the service, the practical assistance offered, and the consistency and stability of staffing personnel.* (Treloar *et al.,* 2016, p. 142)

Whenever a practitioner treated them well, service users found this a remarkable and unusual event. Once they had established trust, service users could open up to staff members by disclosing sensitive information. This was often of fundamental importance to their health and recovery. If they did not trust staff, they could not risk sharing sensitive information, as this made them vulnerable. As a consequence, staff had to continuously demonstrate their commitment to the service user and to the relationship by maintaining confidentiality and demonstrating reliability. This sustained the trust that was essential in order to deliver treatment to this marginalised group:

> *Understanding global trust as the interplay between identity, stigma and legitimacy within a given social context, provides an important means by which to develop this theoretical concept, understand the decision-making of marginalised people, and broaden the possible responses of health systems to better engage these groups.* (**Treloar** *et al.,* **2016**, p. 144)

This issue is also raised by **Duke *et al.* (2020)**, who explore the perspectives of practitioners and young people in relation to user involvement in the context of drug treatment in the criminal justice systems of the UK, Denmark, Poland and Italy. This study is based on semi-structured interviews with 160 young people and focus groups with 66 practitioners. This context is particularly interesting, as user involvement is thought to be more difficult to achieve among 'involuntary' clients, due to external pressures from the criminal justice system.

Relationships were identified by most participants as the most important aspect of user involvement, with young people placing value not on programmes, but on caring, trusting and supportive relationships with practitioners who they hoped would be non-judgemental. It was particularly important for young people being held in secure settings to be able to talk freely with a practitioner without fear of sanctions.

For some of the young people interviewed in the course of the research, stopping all drugs except cannabis was considered to be an acceptable and achievable goal, and they appreciated it when therapists (in line with the principles of harm reduction) did not force them to stop using cannabis. In custodial settings, however, prison staff were less liberal when implementing the rules. For this reason, the prison environment is not considered conducive to providing drug treatment to young people:

> *Factors that improve engagement include: a focus on resilience rather than vulnerabilities; a welcoming and non-judgmental environment; use staff with life experiences similar to the targeted youth; participating youth work directly with targeted youth; flexibility in terms of eligibility (e.g. age), hours of operation, and mandatory requirements of youth; and offers of participation must be genuine, not simply tokenism.* (**Duke *et al.,* 2020**, p. 2)

There is a paradox in many drug treatment services, which is evident within the literature. Most practitioners are aware that collaborative relationships with service users are more effective than oppressive relationships, but their professional practice "often reveals the contrary" (**Ness *et al.,* 2014**, p. 2). This paradox suggests that there are structural factors rooted within the organisational context and professional culture of treatment which obstruct service user involvement. One way of thinking about this is in terms of vicious and virtuous cycles. Because of the interdependence between relationships, power and rules, it can be extremely difficult for service users and practitioners to break out of the vicious cycle of oppressive relationships, moral distance, suspicion and punitive rules and regulations. However, the benefits of doing so are considerable.

Because it is founded on trust, the relationship between service users and providers can involve quite a delicate balance. As Safran and Muran (2000) point out, interruptions and ruptures within this relationship are a normal occurrence during the treatment process. It can then require considerable effort on the part of both actors to restore trust. In drug treatment services, placing the clinician in the role of disciplinarian, with the power to withhold or administer methadone, can endanger the relationship, as Schwartz *et al.* (2017) observe. Crawford (2013) also notes that maintaining an effective therapeutic relationship becomes more difficult in the presence of buzzing doors and bulletproof glass (which have been reported in relation to drug treatment centres in some countries).

The Irish service users interviewed by **Healy (2019)** argue that constant demands for supervised urine samples (where the service user is observed by a staff member while they provide a sample, often surrounded by mirrors) disrupt the relationship between clinicians and service

users, creating a climate of mistrust. This reveals the interdependence between organisational practices, social power and collaborative relationships.

Adverse childhood experiences and trauma can also explain negative reactions to punitive and coercive forms of treatment, which can "re-traumatise" the patient or trigger resistance (Brown *et al.,* 2013, p. 387). For individuals who have experienced trauma, Brown *et al.* (2013) argue, it is essential to provide treatment in a safe environment, where trust can be developed by degrees. Treating service users with respect is itself part of the recovery process for people who have experienced stigmatisation, discrimination or abuse and may not be accustomed to trusting others.

Viewed from the perspective of a trusting therapeutic alliance between service user and clinician, asymmetries in power and punitive regulations represent obstacles to user involvement. In order to protect therapeutic relationships, disciplinary roles should be reduced to a minimum, while simultaneously increasing trust and involvement in order to compensate. This strategy has been documented in Scandinavian research and has the support of many researchers and clinicians in this context. In Sweden, for example, compulsory supervised urine tests have been scaled down (**Frank and Bjerge, 2011**), against the backdrop of a stronger focus on harm reduction and user involvement.

Rance and Treloar (2015) observe that drug treatment services often impose a rigid separation between service users and staff – both socially and physically – which (against the backdrop of stigmatisation) encourages service providers to keep their distance and to maintain a boundary between themselves and service users. These dynamics resonate with broader social inequalities, making it even harder to break through the barrier between 'us' and 'them'. This highlights the importance of studying user involvement through the prism of organisational, social and relational factors. One of the main reasons for the existence of a social and moral boundary between service users and practitioners is the stigmatisation of people who use drugs, which is discussed below (Theme 2a). This suggests that challenging stereotypes and building collaborative relationships with service users may be two sides of the same coin.

Individuals with less secure interpersonal styles, perhaps as a result of prior experiences of marginalisation, discrimination or abuse, tend to experience greater difficulties in forming and maintaining strong and trusting relationships. This is why it can be difficult and why it is so important for service providers to prioritise this aspect of treatment. Precisely because they are one of the most marginalised and stigmatised social groups, drug treatment service users tend to encounter more difficulties than other groups in establishing a trusting relationship with practitioners. This is perhaps why the implementation of the user involvement paradigm has tended to lag behind in this sector, as compared with general health and mental health services.

Bakkeli and Grønningsæter (2020) organised four group sessions with a total of 14 participants, all of whom were users of drug treatment services in four municipalities in Southern Norway. Because of the impact of substance use on their friendships and family relationships – and their need to distance themselves from substance-using peers – service users' participation in social services was very important to them, and they were critical of inflexible, distant, and bureaucratised services. At the same time, they were sceptical about the ability of new technologies to facilitate the provision of support (using an app to chat with staff or other service users, for example) and were more interested in opportunities for connecting with peers on a face-to-face basis:

> *Many of the participants seemed to think in terms of a three-way cooperative*

structure, where users, skilled peers and professional social workers were equal partners. This framework exhibited clear aspects of co-production, with the aim of developing stronger interactive relationships by connecting service practitioners, skilled peers and service users in new ways. (**Bakkeli and Grønningsæter, 2020**, p. 100)

The importance of creating a space for supportive interactions involving service users, peers and professionals has been mentioned by other authors, suggesting that this kind of 'triangular' configuration of relationships may be particularly effective in facilitating involvement. Collins *et al*. (2019) studied 118 hospital patients with substance use disorders (SUDs) who were assisted by peer mentors. Service users generally had a positive experience with mentors, describing them as honest, caring, authentic and supportive, although they described other hospital staff as generally intrusive and suspicious. This difference was evident in the "small, humanising gestures" whereby peer mentors showed service users that they viewed them as 'normal' patients, just by chatting with them or helping them to do something. One interesting aspect of this study is the way in which peer mentors were able to transfer their credibility to physicians and social workers:

> *Respondents described PMs [peer mentors] as "cultural brokers" who have the potential to 'transfer' the trust that they have earned with patients to providers who may otherwise be viewed as not trustworthy. Effects of hospital PMs included increasing patients' ability to tolerate hospitalization, accepting recommended care, de-escalating crises, and reducing staff stigma towards people with SUD.* (Collins *et al.*, 2019)

This important finding suggests that one way of enhancing user involvement within drug treatment, recovery and harm reduction services might be to integrate peer workers and professionals with experience of user involvement, while encouraging doctors and other occupational groups with less experience of user involvement to engage with harm reduction services and community drug projects where there is a tradition of more equal relationships. With sufficient managerial support, training and organisational resources, this has the potential to lead to a diffusion of skills across the workforce, exploiting peer effects within multidisciplinary care teams.

Summary

Empirical studies based on interviews with service users and practitioners have yielded rich descriptions of collaborative relationships. Being treated with respect and being valued as a person are of primary importance to service users, who want clinicians to take the time to talk to them and to get to know them before proposing plans or treatments. They do not want practitioners to try to 'fix' them or to judge them, but instead to meet them, to 'walk alongisde' them and to treat them as individuals. What is important about collaboratively drafting a treatment plan is the process itself, together with the trust and motivation that are needed in order to make progress towards shared treatment goals.

Once they have established trust, service users can open up to staff members by disclosing sensitive information, which is often of fundamental importance to their health and recovery. There are, however, structural factors rooted within the organisational context and professional culture of treatment which obstruct service user involvement. Viewed from the perspective of a trusting therapeutic alliance between service user and clinician, asymmetries in power

and punitive regulations represent formidable obstacles. In order to protect therapeutic relationships, disciplinary roles should be reduced to a minimum, while simultaneously increasing trust and involvement in order to compensate.

Theme 1b. Showing empathy

This theme draws attention to the emotional aspects of the relationship between service users and providers. One of the reasons why trust is so important within the treatment setting is that it facilitates authentic communication, where people reveal their vulnerabilities, express their emotions and articulate their needs and hopes. The research on user involvement reveals that emotions play a fundamental role in treatment and in building the therapeutic alliance.

Larsen *et al.* **(2020)** argue that professionals need to improve their communication and relational skills, suggesting that "in organisations where defensive routines prevent professionals from experiencing threat or embarrassment, they may be over-protected against self-inquiry about what caused specific emotions…" (**Larsen** *et al.,* 2020, p. 4). It is therefore important to consider the role of emotions and emotional labour within the treatment setting, as the suppression of affect due to fear, for example, can close down the therapeutic alliance. Staff at treatment clinics, in particular, need to acknowledge how their fears influence the way they treat service users, leading to an excessive reliance on rules and sanctions:

> *Emotional receptiveness between parties can evoke understanding, as the feelings of the other resonate within oneself. "'In the presence of the other' refers to a willingness to take the other inside oneself, to be affected by what they represent, to acknowledge both the validity of that experience and one's own emotional response to it" (Newton & Goodman, 2009, p. 296). This can be difficult, but facilitators can promote this capacity among participants in dialogue.* (**Larsen** *et al.,* 2020, p. 4)

Larsen *et al.* **(2020)** use these ideas to guide their research, which involves co-researchers and multistage focus groups led by service users and staff members. During the course of one research project, staff members reported feeling threatened by the way that service users, as co-researchers, were 'questioning everything' in an aggressive way. It was necessary for the researchers to hold several encounters with both groups in order to work through these conflicts and to defuse the risk of involuntary discharge of the service users who had been most critical. This leads to the following crucial insight:

> *…as the power balance tilts in favour of professionals who are more securely positioned than service users, they have greater responsibility to promote inclusion through equal and authentic communication.* (**Larsen** *et al.,* 2020, p. 12)

For staff, this means genuinely listening, confronting their own uncertainties, avoiding defensive routines and refusing to fall back on institutional authority. When practitioners are honest about their own feelings, this provides service users with an opportunity to understand their difficulties and to empathise with them. In turn, this means that service users can be more open about their feelings. In this sense, empathy is the basic emotion that grounds user involvement, and this can be developed by pursuing the conditions for free and equal communication, with another triangular configuration involving trust, communication and empathy.

Larsen *et al.* **(2020)** set out the following key operational steps, which are worth quoting in full:

(1) reach formal and mutual agreement on how to handle issues of power and decision-making; (2) convene regular meetings where participants can feel safe and empathy can be cultivated; (3) use the experience of a leader who is trained in facilitating dialogue; (4) provide training to encourage affective reflexivity and dialogue; (5) use role-playing and other tools to get around confidentiality issues; (6) encourage self-reflection by providing spaces and moments where this is possible, for both staff and service users (**Larsen *et al.,* 2020**).

In a similar vein, and drawing on 18 papers they published over almost 15 years, Sundet *et al*. (2020) develop a useful model which describes the different aspects of collaborative relationships between service users and providers in Norway. These are broken down into interactive, participatory and supportive processes, the first of which involves such themes as 'walking alongside' and 'taking the perspective of the other', the second involves 'accommodating user participation' and 'addressing the tension between help and control' and the third involves 'advocating' and 'coordinating'.

Summary

One of the reasons why trust and empathy are so important within the treatment setting is that they facilitate authentic communication, where people reveal their vulnerabilities, express their emotions and articulate their needs and hopes. Staff at treatment clinics, in particular, need to acknowledge how their fears influence the way they treat service users. This means genuinely listening, confronting one's own uncertainties, avoiding defensive routines and refusing to fall back on institutional authority. When practitioners are honest about their own feelings, this provides service users with an opportunity to understand their difficulties and to empathise with them. Empathy is the basic emotion that grounds user involvement, and this can be developed by pursuing the conditions for free and equal communication.

Theme 1c. Creating a space for effective communication

Another important aspect of the relationship between service users and providers is communication, and the possibility of creating a space where effective and authentic communication can occur is often linked, in Habermasian fashion, with the distribution of power. This interesting nexus emerges repeatedly in the studies included in our review. **Andersen (2014)** carried out participant observation for five months in two outpatient treatment services in Denmark, taking part in everyday routines, meetings and recreational activities. Both structures provided outpatient services and she interviewed 15 treatment providers and 24 young adults. She observed that during meetings, professionals would often talk to each other about the service user (using the first person plural) as if he or she was not actually present, creating the impression that the service user was a passive object of treatment. In the services that Andersen studied, meeting rooms were set up more to accommodate professionals than to make service users feel comfortable and engaged. She concludes that it is not enough to make rhetorical appeals to the agency and involvement of service users, as everyday practices and interactions must also change so that the latter can feel involved.

Similar observations emerge from other studies. In her PhD thesis, (University of Victoria), Belle-Isle (2016) studies what happens when people who use drugs are given a 'seat at the table'. This represents a key response to the demand to have a voice in relation to decisions about drug

treatment services. She explores the role of power in social interactions within four committees in Ontario and British Columbia, including a policy committee where people who use drugs were not members and were consulted once a year, two service provider committees which included two representatives of people who use drugs, and one research committee primarily comprised of people who use drugs.

The first committee was ostensibly committed to including people who use drugs on an ongoing basis, but members were unsure about how best to make that happen. The role of the second and third committees was limited to providing input on harm reduction policies and services, drawn from members' experiences. This led to frustration, as the committees were dominated by the local public health authority, which used it mainly as a source of information without delegating authority. In the last committee, people who use drugs were the majority. Although decision-making authority ultimately rested with an executive committee, considerable efforts were made to distribute decision-making power. Researchers were aware of the need to drop their role as leaders and to share power and ownership of the project. There was a feeling of meaningful representation among people who use drugs on this committee, as their input had a direct impact on decisions. The researchers commented that in this kind of project, a large amount of resources and time need to be dedicated to supporting people to participate, particularly where they are truly representative of the target group (and consequently experience marginalisation, hardship and discrimination themselves).

As well as observing meetings (one for each of the four committees), Belle-Isle interviewed 40 committee members and reviewed relevant documents. Her starting point is that simply bringing representatives of marginalised groups to the table does not automatically transform power relations and guarantee more effective and inclusive services. She observes that other committee members tend to underestimate people who use drugs. The latter are penalised as a result of criminalisation and stigmatisation, but also by a failure of committee members to build trust, establish authentic relationships and to engage in reflexive dialogue. Where a negotiated and consensus-based approach to decision-making was adopted, more meaningful forms of participation and involvement were possible.

Another issue that emerged relates to the practical difficulties involved in ensuring that representatives of people who use drugs actually attend meetings, due to practical difficulties, lack of time and resources. The participation of people who use drugs was frequently compromised by the challenging life conditions and socioeconomic situations they faced, particularly where they were not remunerated. Some organisations had hired people who use drugs and grappled with how to remunerate them and how to provide education and professional accreditation. The promising side of Belle-Isle's research is that it suggests that once people who use drugs have been included in decision-making bodies, there are ways of creating conditions that are conducive to their empowerment, such as challenging assumptions (including preconceptions about expertise and competence), relating to all committee members in the same way (normalisation), unmasking power, adopting flexible practices, using skilled facilitators, acknowledging cultural and social differences, accepting different styles of communication, encouraging openness to new and different perspectives, and facilitating the democratic selection of representatives.

Larsen *et al.* (2020) offer an interesting description of the role of communication in facilitating user involvement:

> *Communicative space in action research "refers to the social arenas for constructive dialogue and creative problem-solving among stakeholders on issues of common*

concern" (Bodorkós & Pataki, 2009, p. 314). Developing uncoercive spaces for communication may result in common ground for action, transformed power relationships, more equal participation and greater democracy (Bodorkós & Pataki, 2009). Here, power is regarded as relational as it is rooted in ties of mutual dependence; balancing this dependence may equalise an imbalanced relationship, within which the parties can more equally influence one other (Emerson, 1962). (**Larsen et al.,** 2020, pp. 3-4)

Interestingly, similar power imbalances are encountered in other contexts, including local planning and public consultations (but also in universities and voluntary organisations), where more powerful actors must 'equalise' the relationship if they want to facilitate involvement. This suggests that with training and facilitation, service providers who are committed to the user involvement paradigm can play a role in creating a space for effective communication within existing services.

In Canada, service users from various regions have participated at ever-higher levels of policy-making about drug treatment services, in part due to the leadership provided by peer-run organisations such as SOLID and VANDU (Greer *et al.,* 2016). Where service users are invited to speak at a conference, or to participate in a national decision-making body, however, it is necessary to make appropriate arrangements, such as paying tickets in advance, setting up local forms of support and direct links with local peers, creating a welcoming environment (avoiding practices that are typical of professional work meetings, for example) and facilitating local methadone prescriptions. It is preferable to invite two or more service users to participate, so that individuals feel more at their ease in meetings.

As Street (1991) and others have observed, most patients accept the 'communicative dominance' of the clinician and tend to adopt a passive role within therapeutic relationships (cf. **Joosten *et al.,* 2011a**). At the same time, however, the literature suggests that patients would generally like to be more involved in decision-making. **Joosten *et al.* (2011a)** argue that communication between service user and provider serves three main purposes: transmitting information, shaping the relationship between them, and facilitating user involvement in decision-making. They carried out a randomised controlled trial in three addiction treatment centres in the Netherlands, where the control condition was reaching and evaluating a treatment agreement as usual, and the treatment involved a structured intervention to systematically and frequently discuss and evaluate a wide range of problem areas and treatment goals to reach agreement. Treatment programmes covered relapse prevention and social skills, and were provided by clinicians with a background in nursing science or social work. Patients allocated to the shared decision-making intervention were found to be more open and sociable than those in the control group, and they also experienced a significant increase in feelings of autonomy and control.

In an Australian PhD thesis, **Goodhew (2019)** investigates how the process of forming a consumer action group (CAG) influenced user involvement (referred to as 'consumer participation') at the Uniting Sydney Medically Supervised Injecting Centre (MSIC), a service designed to reduce the negative impacts of injecting drug use. Qualitative data were collected via a brainstorming exercise with 36 staff, 36 structured interviews with service users and 22 interviews with providers. At the beginning, the new CAG had difficulties getting accepted by both service users and staff, although it provided service users with a voice and an opportunity to influence the service. There were difficulties with attendance, often associated with individual difficulties, life circumstances and health status, but those who participated reported greater self-esteem and social support. Another problem involved service users attending

group meetings in a state of intoxication, although Goodhew indicates that this was effectively managed by the group. Thus, even in the relatively difficult context of an MSIC, user involvement is possible and helpful, particularly if staff members participate and provide support.

Summary

Another important aspect of the relationship between service users and providers is communication, and the possibility of creating a space where effective and authentic communication can occur is often linked with the distribution of power. Research suggests that most service users accept the communicative dominance of clinicians and tend to adopt a passive role within therapeutic relationships. At the same time, however, patients would generally like to be more involved in decision-making and to have a voice in relation to treatment and services. With training and facilitation, service providers who are committed to user involvement can play a role in creating a space for effective communication within their services.

The participation of people who use drugs in discussions and decision-making bodies is often compromised by challenging life conditions. However, the research suggests that it is possible to create conditions that are conducive to the empowerment of service users within this setting, such as challenging assumptions, relating to all participants in the same way, unmasking power, adopting flexible practices, using skilled facilitators, acknowledging cultural and social differences and accepting different perspectives and styles of communication.

Theme 2. Social power

This theme relates to power and asymmetries in influence, status and the ability to make decisions. It therefore includes professional ideologies, forms of control, organisational culture, stereotypes and social hierarchies. This theme, like the previous one, can be broken down into three sub-themes: (2a) stigmatisation; (2b) policing moral and social boundaries; and (2c) shifting the balance of power. Each of these sub-themes is analysed below, drawing on the results of our study of the literature. The first two sub-themes are of direct relevance to the involvement of service users in making decisions about their own treatment, whilst their relationship with the involvement of service users in the redesign of organisational practices and the development of new and existing services is more indirect. The third sub-theme, however, is relevant to both forms of user involvement.

Theme 2a. Stigmatisation

A puritanical culture permeated drug treatment systems for most of the 20th century, particularly in Anglo-Saxon countries. As Duncan *et al.* (2010) observe, "[t]raditional addiction treatment in the United States has usually required a commitment to abstinence as a condition for treatment and has often discharged clients for recurrence of substance use while in treatment" (p. 410). Treatment systems thus tended to stigmatise clients at the same time as providing them with assistance. As Butler (2002, p. 122) points out, drug users have traditionally been viewed by treatment providers as behaviourally difficult and devious, morally suspect and socially pathological. In Ireland, this culture placed great pressure on practitioners to separate themselves from clients – to distance themselves from this stigmatised group – and to develop the organisational tools needed in order to maintain them in a subordinate position.

It is fundamental to understand the nature of the stigma which attaches to people who use drugs, as this plays an important role in their marginalisation within society and their disempowerment within treatment systems. **Rance and Treloar (2015)** provide a good overview which explores the relationship between stigmatisation and user involvement:

> *The deleterious impact of stigma, discrimination and unequal service user-staff relations has been highlighted repeatedly (Fischer & Neale, 2008; Hinton, 2010; Patterson et al., 2008, 2009; Patterson, Weaver, & Crawford, 2010; Ti et al., 2012; Treloar et al., 2011). Patterson et al. (2008) describe the drug treatment setting as a 'complex cultural context imbued with stigma' (p. 60); one where power imbalances and prejudices are 'invidious' and 'a pervasive influence' on user involvement (p. 59). Many service staff continue to hold 'deep stereotypes' (Zibbell, 2004, p. 62) about people who inject drugs, leading to discriminatory practices in service provision. Underpinning this stereotype is what Treloar and Holt (2006) describe as a 'deficit model': 'The perception of a person seeking drug treatment . . . as deficient, defective or lacking' (p. 377). Or, as Crawford (2013) puts it from the perspective of consumers: '[r]egardless of whether we are seen as immoral or sick we are understood as a problem to be solved' (p. e15). The potential of the therapeutic alliance is all-too-frequently reduced to an 'us and them' scenario, characterised by 'mutual antagonism' (McDermott, 2002, p. 18) and exacerbated by the structural inequalities underpinning the relationship between users and services (Patterson et al., 2008; Treloar et al., 2011; Zibbell, 2004).* (**Rance and Treloar, 2015**, p. 31)

Link and Phelan (2006, p. 528) suggest that stigmatisation should be conceptualised as a multistage process that begins with the labelling and stereotyping of disadvantaged groups. Drawing on the literature on mental illness, they distinguish between 'institutional' stigma and 'internalised' stigma, which occurs when individuals accept the social meanings linked with the penalising representation of the group they belong to. In a similar vein, a key theme mentioned by **Harris and McElrath (2012)** is the possibility that the 'addict identity' can function as a master status, leading drug treatment service users to be penalised across a variety of spheres. For example, one person interviewed by these authors described going to the pharmacy: "They would literally watch you and follow you to the door, like you've just been caught shoplifting. That's how you would feel, which I think is just damn right rude" (**Harris and McElrath, 2012**, p. 814).

As Gartner *et al*. (2018) observe, with reference to Vancouver (Canada), one important aspect of stigmatisation is the way in which service users with lived experience of problem drug use are automatically considered to be bad parents, increasing the risk that a baby born to a person in drug treatment could be taken into care. Research on self-organised harm reduction services for people who use drugs, such as the overdose prevention site in Toronto described by **Foreman-Mackey *et al*. (2019)**, sheds light on this issue. These services are characterised by a different organisational culture, due to their reliance on volunteers and their solid commitment to harm reduction. In both services, health care providers worked alongside peer workers and other volunteers, providing nursing care and informal links to other services.

When interviewed by **Foreman-Mackey *et al*.,** service users described the site as an inclusive space that offered a sense of community and a place of refuge from the everyday violence they faced. Because they experienced a sense of community at the site, they also took collective responsibility for its operation. This study demonstrates what a democratised service actually looks and feels like. Research by Kennedy *et al*. (2019) provides supporting evidence in relation to this point, again with reference to peer workers in harm reduction services in Canada. People using these services felt more comfortable interacting with peer workers, whom they felt they could trust, and with whom they could establish a more equitable and less intimidating relationship, compared with professionals in other organisations. The challenge is thus to migrate this kind of organisational culture – infused with humanity, inclusivity and respect for the service user – from the margins of drug treatment systems to their very core.

Treloar *et al*. (2016) link the issue of trust between service users and providers with questions of identity and power (being recognised as a 'legitimate' service user, for example):

> *Notions of identity and legitimacy are inextricably bound up with the illegality of, and stigma attached to, injecting drug use. Previous literature has noted that the stigma associated with drug use produces a discrediting or de-legitimising identity: a "master status" ... imposed upon and threatening to define all aspects of an individual's identity ... particularly as "undeserving and unworthy citizens". (Treloar et al., 2016, p. 139)*

These authors suggest that people who use drugs tend to internalise the negative social meanings that are implicit in imposed identities, coming to view themselves as less deserving than other people. This has the effect of eroding their trust in service providers, in the state and in wider society, and is linked with an initial lack of trust on the part of the service providers, accompanied by fear of sanctions or of interventions by child welfare services.

The role of gender in relation to user involvement in drug treatment services is often mentioned but rarely analysed in a systematic fashion. In the Irish context, Geaney (2016) argue that women

often experience greater difficulties than men in accessing treatment itself, and many of the barriers they describe are likely to reduce their ability to get involved. These include lack of childcare, concerns about being labelled bad parents, and health issues due to poor diet, infections, lack of exercise and an unhealthy lifestyle. The relationship between gender and user involvement has not been addressed adequately in the research literature, and deserves further consideration.

Another Canadian study provides further evidence in relation to the role of organisational culture in relation to user involvement (**Jozaghi, 2014**). The Study to Assess Long-term Opioid Medication Effectiveness (SALOME) aimed to determine whether specific people affected by chronic opioid addiction could benefit from hydromorphone. A previous study (NAOMI) had provided heroin to 251 chronic opiate users in Montreal and Vancouver for a year, but many participants experienced difficulties as there were no provisions for ongoing treatment at the end of the intervention. By setting up an advocacy organisation and lobbying for recognition, service users pushed the team running the SALOME project to adopt a new approach modelled on the principles of service user involvement:

> *The staff has been able to establish trust amongst the participants that has ultimately helped participants get much needed medical help for their undiagnosed medical conditions such as mental illness or endocarditis. The close bond and the relationship that exists between the staff and patients at SALOME has increased nursing, counseling care, and harm reduction education. The social workers at SALOME have also been able to improve the housing and financial situations of participants through social housing and income assistance...* (**Jozaghi, 2014**)

An important question that we must address when discussing professional power and beliefs is whether there are differences between occupational groups. This is very difficult to determine, as most researchers do not make careful comparisons. For example, **King (2011)** draws on interviews with an outreach worker, a nurse, a doctor, a counsellor, a pharmacist, a general assistant, an education officer and an administrator, but does not identify their occupation when she cites these different practitioners.

Laitila *et al*. (2011) also emphasise the role of power in relation to service user involvement:

> *Listening and valuing service users' expertise required time and giving up paternalistic thoughts about service users. According to the participants, service users in mental health and substance abuse services still encountered negative attitudes and bias. Their ability to be involved, to participate and express their opinions was questioned. SUI [service user involvement] entailed a division of power; those in power were not willing to share it.* (**Laitila *et al.,* 2011,** p. 4)

These authors argue that service user involvement changes how professional expertise is viewed; it requires "a new kind of expertise on the part of professionals" (**Laitila *et al.,* 2011**, p. 6). Service users have a distinct perspective on treatment, and to the extent that professionals share power with them, their own role must evolve. For example, they must explain their suggestions and articulate their doubts and uncertainties without closing down the discussion with service users and without relying on paternalism or institutional authority. In other words, they must relinquish some of the cultural and organisational power that derives from their professional status and base their role on scientific evidence and practical experience.

There are likely to be benefits in this new configuration for service providers as well as users,

as both groups are typically critical of existing arrangements. For at least some practitioners, user involvement is a welcome development as it enables them to develop their own practice in new directions and to identify more effective therapeutic approaches. For example, **Davis et al. (2020a)** report that "[s]taff described there being a greater spirit of authenticity to care by acknowledging the client from a whole person perspective with consideration to the family and community systems that they ultimately need to re-integrate into" (p. 10).

Summary

It is fundamental to understand the nature of the stigma which attaches to people who use drugs, as this plays an important role in their social marginalisation as well as their disempowerment within treatment systems. People who use drugs tend to internalise the negative social meanings that are implicit in imposed identities, coming to view themselves as less deserving. The 'addict identity' can function as a master status, leading drug treatment service users to be penalised across different spheres. People using services often feel more comfortable interacting with peer workers, whom they feel they can trust, and with whom they can establish a more equitable and less intimidating relationship. Service user involvement thus demands a new kind of expertise on the part of professionals, but also enables practitioners to develop their practice in new directions and to identify more effective therapeutic approaches.

Theme 2b. Policing moral and social boundaries

Roughly a decade ago, **King (2011)** reported that service users in Irish drug treatment services were not routinely involved in making choices about their treatment, in shaping the treatment system as a whole, or in determining policy. None of the services and Drugs Task Forces she studied had any user representatives and she described a range of mechanisms which kept service users locked into a subordinate position. These included refusal by practitioners to countenance dose reductions, withdrawal of take-away doses of methadone and expulsion from treatment as a punishment for breaking (or at times even questioning) the rules. Service providers expressed fears of being compromised, damaged, exposed or made vulnerable if they interacted with service users or participated in peer initiatives. They were highly critical of their own services, describing them as 'restrictive', 'punitive', 'dictatorial', 'judgemental' and 'controlling'.

In his PhD thesis, **Healy (2019)** provides a detailed account of the practices employed within Irish drug treatment services to keep service users in a situation of powerlessness (p. 6). These include not only the threat of withdrawing methadone, but also frequent urine tests and an obligation to attend treatment centres at a specific time in order to receive a prescription or dose. **Harris and McElrath (2012)** document similar forms of social control within Irish drug treatment services, building on earlier work by Cox and Lawless (2003), who were perhaps the first researchers in Ireland to argue that the way methadone is dispensed under the Methadone Treatment Protocol has the effect of further stigmatising an already marginalised population.

Healy (2019) provides the following summary of the role of power in this context:

> As opposed to liberating the drug user, the strategies propagated by contemporary Irish MMT [methadone maintenance treatment] services often coerce service users

into oppressed, docile bodies. The instrument of regulation and oppression is fear: fear of sanctions, dose reduction and other forms of discipline elicited through biopolitical strategies buttressed by the monitoring of the client and facilitated by the practice of urinalysis… (**Healy, 2019**, p. 6)

Healy uses a Foucauldian approach to describe the dehumanising aspects of current treatment modalities, and a human rights approach to advocate for change. He argues that user involvement represents a tool for achieving human rights: "A human rights-based framework should be informed by empowerment, accountability, an avenue for complaint, equality and opportunities for service users and NGOs to participate in the development and implementation of policy and law" (**Healy, 2019**, p. 33).

He points out that the Farrell Report (Farrell and Barry, 2010) and the HSE Clinical Guidelines for Opioid Substitution Treatment (2016b) mark a shift in the direction of user involvement and harm reduction, although they were not followed by change at ground level. **Harris and McElrath (2012)** re-analyse data from several previously published studies in Ireland and Northern Ireland, focusing on the organisational culture of opioid agonist therapy. They discuss the different aspects of treatment systems, emphasising the especially punitive character of service provision in the Republic of Ireland. They discuss the negative aspects of treatment systems, focusing on stigmatisation. The key issue, they conclude, is that service users are tarred by the 'addict identity':

A woman respondent indicated that her current daily dosage of methadone (i.e., 50mg) was insufficient, and had reported this problem to addiction services on several occasions. At the time of interview, her dosage level still had not been increased. As a result, she was "topping up" with heroin periodically to avoid withdrawal and cravings. In the same locale, adjustments to dosage levels and withholding methadone altogether were at times used as punishment: "I was three minutes late one time—three minutes, and they took me down five mg [decreased the methadone dosage level]." Another client reported, "Some chemists in town—if you're late, they'll pour methadone down the sink. Pour it down, I swear. There's you—using heroin again. (**Harris and McElrath, 2012**, p. 815)

These reports – together with those by **Van Hout and McElrath (2012)** and **Kavanagh (2012)** – provide evidence of the ways in which degrading and undignified experiences have become ubiquitous within the Irish drug treatment system, despite the existence of legislation, strategies and recommendations which protect human rights and promote respect and involvement (see Chapter 2). These accounts of opioid agonist therapy in Ireland resonate with Crawford's (2013) account of medically oriented drug treatment services in Australia and Klingemann's (2017) description of addiction treatment in Poland, where patients are frequently insulted by staff, are asked to undress so that doctors can check for needle marks and are expelled from treatment if they are found positive for illegal drugs in three consecutive, supervised urine tests. In this way, rather than being inspired by harm reduction, opiate agonist therapy can become a contradictory mixture of punitive practices. **Healy (2019)** argues that this rigid version of opioid agonist therapy is in conflict with many of the central tenets of the original treatment model, as well as contrasting with harm reduction philosophy.

Drawing on data from the ETHOS project, including 76 in-depth interviews, Rance and Treloar (2014) highlight the culture of minimal engagement and limited care that characterises opioid agonist therapy in Australia. Many staff members were critical of this form of treatment, observing that existing forms of provision bordered on neglect: "It's just, you know, dosing

people, dosing people and getting them out". Staff came to feel trapped within this model of service provision and welcomed the possibility of responding more effectively to the needs of service users.

Both **King (2011)** and **Healy (2019)** note that Irish service providers often question whether service users deserve to be involved in making decisions in the first place, arguing that their history of drug use suggests that they are incapable of making good decisions. Conversely, many of the service users these authors interviewed were not interested in getting involved, having become accustomed to being powerless.

As mentioned above, Ireland's National Drugs Strategy (2009–2016) highlighted the need for greater service user involvement and the development of local and regional service user forums. The role of these organisations was never made clear and few were established. This experience can shed light on the risk of treating user involvement as an institutional form to be added to existing services without really changing them. The justification is that a forum can provide service users with a voice, enabling them to articulate their needs and preferences, so that service providers can then make the required changes to drug treatment systems. However, without a corresponding empowerment of service users, targeted funding and a clear mandate, there is a risk that such forums remain a tokenistic gesture (Patterson *et al.*, 2010).

Van Hout and McElrath (2012) note that existing research "underscores the need for initial and ongoing consultation processes to be combined with other participation modalities to ensure that user concerns and opinions are taken into consideration … These processes would help avoid the interpretation that service user forums are tokenistic or reflect an element of 'window dressing'" (p. 7). For example, a shift to truly patient-centred care within treatment services and enabling advocacy groups to support service users and to influence policy at the systemic level would help to make user forums more relevant and sustainable.

A number of respondents in the study by **Kavanagh (2012)** described a generalised sense of disempowerment, a situation which **King (2011)** explains in the following terms:

> *It appears that the main obstacles [to the implementation of user involvement in the health services generally] pivot on the discrepancy in power between the providers and users of services and the challenge to conventional institutional and professional powers, that user involvement brings … For user involvement processes to be successful, a change in the inter-relationships and particularly, the power balance between the users and providers of services is necessary.* (**King, 2011**, p. 276)

Van Hout and Bingham (2012) focus specifically on opiate agonist therapy, reporting that a majority of the participants in their study were never advised of health-related issues and the addictive nature of methadone, and were never informed that this form of treatment would be long-term, in some cases lasting over 10 years (p. 65). Participants reported a lack of doctor-client dialogue, with one service user arguing that "[i]t's just to keep people quiet. I have been on the opposite side of a doctor's biro [pen] and the power they have over you…". Although many service users were initially satisfied with opiate agonist therapy, over time the medical emphasis on retention appeared at odds with requests by service users to reduce or come off this type of treatment. The authors found that most service users were increasingly frustrated with the effects that medication had on their daily lives, including a lack of control, compromised personal freedoms and a lack of progression.

Summary

Numerous research reports document the ways in which degrading and undignified experiences have become ubiquitous within the Irish drug treatment system, against the backdrop of a generalised sense of service user disempowerment. Researchers have shown that many service users receiving opiate agonist therapy were never informed of the health-related issues and addictive nature of the medication they were being prescribed. Within this kind of context, there is a risk of treating user involvement as an institutional fix that can be added to existing services without changing them. Without a corresponding empowerment of service users, there is a risk that such forums remain a tokenistic gesture.

Theme 2c. Shifting the balance of power

The third sub-theme relates to change and describes how the balance of power can be changed within drug treatment services. As well as shedding light on the role of relationships, stigmatisation and control, existing research provides insights into different ways of bringing about change in order to facilitate user involvement. We touched on this issue above, where we cited projects which aim to change the relationship between service users and providers, to improve communication or shared decision-making. It is necessary, however, to address the balance of power and how this can be affected by policies and interventions.

Encouraging participation and empowering service users are two sides of the same coin, and both require a change in attitudes, relationships, rules and behaviour. People within treatment services must embody the change by calling into question the policies, resourcing, legislation, stigma and power relations that prevent them from extending their involvement. Successful examples of this process typically draw on the experience of peers, advocacy groups and professionals in harm reduction services and they start by addressing relatively small but significant aspects of treatment, providing staff with training and opportunities for reflection and ensuring that the necessary resources are available.

A study by **Andersson and Johnson (2020)** discusses freedom of choice between drug treatment service providers in Sweden. Skåne Regional Council introduced this measure for the provision of OST in April 2014, with the result that all treatment providers which meet accreditation requirements have the right to provide treatment and to receive public funding, while all residents who require this service can choose between providers and receive treatment without delay. The main motives for this step were to promote choice and to expand the provision of health care:

> *From a Swedish perspective (and probably also from an international perspective), such freedom of choice is unique. No other public health authority has previously tried out publicly funded patient choice within substitution treatment. In Sweden, patients who would like to receive substitution treatment are normally referred to a specialist clinic based on their place of residence. Until recently, the queues were long, and the patients had to wait for months, sometimes even years.* (**Andersson and Johnson, 2020**, p. 105)

These authors interviewed more than 30 service users, and report that the possibility of choosing a clinic represents a decisive change which has shifted power in favour of patients,

leading to improved staff-patient relations, greater respect for patients and new opportunities for socialising. Clinic managers and stakeholders (interviewed as part of another project) confirmed that competition had pushed them to pay greater attention to the needs and requests of service users. For some service users, this also meant that they could access diazepine maintenance therapy, a controversial issue which raises complex questions:

> *This is an intriguing aspect of freedom of choice: should it be possible to choose something that may not be good for you? Many patients in substitution treatment are used to trying to solve their problems with medical or illicit drugs; they have what is known as 'the medical mind' ... Ultimately, it is the doctor's decision what medication to prescribe, but treatment measures should be taken in joint consultation with the patient, and patients in substitution treatment often show a great interest in their medication ... Should the patients' right to freedom of choice be valued more highly than how the treatment should be fashioned according to research and experience-based practice?* (**Andersson and Johnson, 2020**, p. 114)

Greenwood and Manning (2017) suggest that "[i]n the long run, it may be more beneficial to service users if service providers preserve choice and simultaneously ramp up engagement through motivational interviewing and other techniques that maximise clients' capabilities for developing an understanding of the natural consequences of their own actions" (p. 1058; see Mancini and Wyrick-Waugh, 2013). In relation to diazepine prescribing, methadone tapering and a range of other challenging issues, the user involvement paradigm offers no simple solutions, but may help service users and providers to work through the challenges on a case-by-case basis and to identify innovative solutions.

Laitila *et al.* (2011) interviewed 27 service users in Finland, who argued that user involvement in the planning and development of services is the best way to ensure that those services are effective. Only service users fully understand what it is like to engage with treatment services for problem drug use, and their experience is valuable. Unfortunately, their voices are not always heard, and one user suggested that these issues are linked:

> *It's easier to make decisions when you do not know the problem, or the heart or the core of the problem. Maybe it would be more difficult to make decisions if those concerned had their voice heard. You could see how difficult and complex the problems really are.* (Service user quoted in **Laitila *et al.*, 2011**, p. 4.)

Because of the obstacles to user involvement, it often requires a certain courage or initiative to participate, and this leads to variation over time and space (**Laitila *et al.*, 2011**). So, in order to encourage diverse service users to participate, flexible and innovative forms of involvement are needed, and the position and status of service users need to be improved and strengthened.

Larsen and Sagvaag's (2018) study, which was carried out in line with the principles of cooperative inquiry (with patient and staff co-researchers), identifies some of the most difficult operational issues raised by service user involvement. Staff were sometimes concerned that addiction could negatively influence service users' contributions, while patients feared being 'pathologised' by staff (i.e. their behaviour being attributed to drug addiction or its effects). Moreover, national legislation, guidelines and professional responsibility were seen as placing limits on the extent to which service users could be involved in making decisions about treatment – their own and that of other service users. For example, codes of conduct for staff and managers stipulate that care of patients is their first concern, in the form of 'satisfactory treatment' – a norm rooted in legal requirements, guidelines, organisational policy and patient expectations.

Power imbalances between service users and providers were accompanied by imbalances between different members of staff (specifically between 'milieu', 'treatment' and 'leader' staff members, which loosely coincide with non-clinical, clinical and managerial personnel). This leads the authors to ask rhetorically "[if] the staff lacked experience with acting as responsible subjects participating in changing their own disempowered situation, how could they empower patients to take action against oppressive practices?" (Larsen and Sagvaag, 2018, p. 8). They argue that in Norway patients have "begun to peel back the veil on some deeply-rooted dilemmas in substance abuse treatment" (p. 8), and this metaphor captures the challenges that user involvement poses within the area of drug treatment. The authors conclude by launching an appeal for reciprocal empowerment based on transforming services, overcoming barriers and reducing relations of dependence.

Frank and Bjerge (2011) draw attention to the everyday tensions that are generated by application of the principles of user empowerment in the context of opioid agonist treatment. A focus on control (to reduce the consumption of illegal drugs during treatment, to reduce the risk of overdose, and to avoid drug leakage onto the black market) can be seen as undermining the drive for greater equality in relationships between staff and users. As **Frank and Bjerge (2011)** observe, "Methadone prescription is the part of drug treatment where influence or self-management is hardest to encourage" (p. 205).

When policy is translated into everyday practice – which is the only way in which it can be implemented – how do practitioners negotiate these kinds of tensions? **Frank and Bjerge (2011)**, drawing on a number of studies of different institutions, observe that the outcome of this process is typically influenced by the local context and existing practices: "These practices are conditioned by historical, cultural, economic and political elements from the outside and also constituted by existing positions, norms and relations inside the institution" (**Frank and Bjerge, 2011**, p. 203). Because of the complex problems that service users in drug treatment often present with, there is a tendency to perceive them as "citizens in need of help" rather than "self-managing citizens who can make their own decisions". In a similar way, opioid agonist treatment is subject to conflicting policies: one which emphasises user involvement and self-management, and another which focuses on control and regulation.

Frank and Bjerge (2011) studied how these tensions played out in four clinics providing opiate agonist therapy which were provided with additional resources so that they could develop initiatives for empowering users. One way in which practitioners responded was through "client differentiation": concentrating limited resources on well-adjusted users who were more likely to benefit from involvement. This yielded greater personal satisfaction for professionals, as they could achieve visible results without having to invest in users with more complex problems. Another way they responded was by concentrating on the perspective of the service user and by using more varied strategies to control how medication is used, although there is ultimately no way of avoiding dilemmas:

> *Staff approaches supplementary consumption of illegal drugs by focusing on the users' own preferences and needs. If the user sees better quality of life and not abstinence as the treatment goal, staff will work in that direction. Although still recognizing that methadone and supplementary consumption of illegal drugs can be a lethal cocktail, staff manage it not by sanctions and control but by concentrating on the users' perspectives and how they can manage to gain at least some control over their lives, not only over their drug habits.* (**Frank and Bjerge, 2011,** p. 206)

Frank and Bjerge (2011), discussing the tension between individualised needs and standardised

services, argue that economic resources, staffing limits, time pressures and local rules and regulations typically lead to the adoption of standardised approaches to service provision. The resulting services are designed to fit users reasonably well in a cost-effective manner, but leave little room for individual problems or solutions. If an institution experiences constraints, and practitioners' contact hours with service users are reduced, this can have a negative effect on the therapeutic alliance (Reyre *et al.,* 2017).

Bjerge and Nielsen (2014) provide a useful overview of a study carried out in the early years of the new Millennium of a low-threshold methadone treatment project in Denmark that was organised in accordance with the principles of empowerment, user involvement being seen as fundamental to improving services. Between 2001 and 2004, four methadone pilot projects were established and provided with extra resources to enhance psychosocial support, to provide better resources (e.g., workshops, common rooms, kitchens) and to try out new forms of teamwork and service provision. For example, users could get help on an ad hoc basis when they needed it, rather than relying on planned weekly meetings or formal requests. The service aimed to adopt a holistic approach to treatment, involving users in all decisions concerning them (p. 77). The Ministry of Social Affairs also funded research on these projects, which was carried out by the Centre for Alcohol and Drug Research at Aarhus University. Over the course of 4 months of fieldwork, and following semi-structured interviews with all 6 staff members and with 10 (out of 17) users, the authors identified a number of key dilemmas, such as how to reconcile the intentions of policy-makers with the everyday realities of treatment centres:

> *Many users have been in treatment for many years and have been socialized according to what we characterize, in the words of Adams (1996), as ideas deriving from 'the treatment paradigm'. This paradigm dominated social policies until the late 1990s. Social workers, not the users, were seen as experts who defined problems in relation to the expertise of the helping profession and to the solutions offered. Roughly speaking, either drug addicts adjusted their behaviour (i.e., to receive methadone they had to stop their heroin consumption) so that they could be included in the treatment programme or they were excluded from help because they were 'not motivated to change' (i.e., under the spell of drugs) (Järvinen and Andersen, 2009).* (**Bjerge and Nielsen, 2014**, p. 76)

By contrast, the 'empowerment paradigm' emphasises the responsibilities of the user and is often presented as a panacea for all of the inherited ills of existing treatment systems. Research carried out in Scandinavia shows, however, that the past continues to weigh heavily on the present, with users who are accustomed to playing a passive role often expressing little interest in participation and empowerment.

Storbjörk *et al*. (2016) present the findings of another Scandinavian study of user involvement in a research report published by the Centre for Social Research on Alcohol and Drugs. A total of 36 service users and 23 service providers were interviewed at two points in time (for a total of 110 interviews involving 130 individuals) to track progress in relation to perceptions, substance use and life problems. Roughly half of the service users were satisfied with their level of involvement (based on a coding of the content of the qualitative interviews) and the same proportion were categorised by interviewers as having had a high level of involvement. The interviewers rated only one tenth (11%) as having low user involvement.

In this study, service users were more likely than service providers to argue that coercion in various forms just does not work and that lack of involvement inevitably tends to trigger resistance. Many of the interviewees viewed user involvement as a necessary characteristic of

a satisfactory treatment system and an essential prerequisite for successful outcomes. Only a small number of users and providers questioned the importance of user involvement, referring for example to cases where a lack of user involvement in forced treatment did not prevent a positive outcome.

Bjerge *et al*. (2014) point out that many service users shift responsibility for their well-being to staff, asking for practical help rather than autonomy, and social workers often delay the formalisation of action plans for individuals who are not able to make decisions about their treatment and options: "[t]heir task is no longer about enforcing the right kind of choices on users, but about improving their concrete life situations in the here-and-now, however slightly: getting them a proper meal, arranging for assistance from other public agencies, etc." (p. 72).

Summary

Encouraging participation and empowering service users appear to be two sides of the same coin, and both require a change in attitudes, relationships, rules and behaviour. Only service users fully understand what it is like to engage with treatment services for problem drug use, and their experience should be considered valuable. Because of the complex problems they often present with, there is a tendency to perceive them as "citizens in need of help" rather than "self-managing citizens who can make their own decisions". Many service users view user involvement as a necessary characteristic of a satisfactory treatment system and an essential prerequisite for successful outcomes. In Sweden, the possibility of choosing a clinic represented a decisive change which shifted power in favour of patients, leading to improved staff-patient relations, greater respect for patients.

Theme 3. Organisational practices

The third theme relates to the organisational context of drug treatment, recovery and harm reduction services, including the laws, rules, regulations, guidelines and frameworks that shape the encounter between service users and service providers. Under this broad heading it is possible to distinguish between: (3a) the organisation of drug treatment services; (3b) procedures for making decisions; (3c) the importance of (small) innovations; (3d) patient-centred care; (3e) outcomes. All of these sub-themes are of relevance to both the involvement of service users in their own treatment and their representation in relation to the redesign and reorganisation of services more generally.

Theme 3a. The organisation of drug treatment services

We suggested at the beginning of this report that user involvement is not a component that can be simply added to existing drug treatment services without changing them. Relationships, power and rules are closely interrelated and user involvement is the product of coordinated change across all three dimensions, giving rise to a virtuous cycle. Formalistic models of user involvement rarely achieve their goals and research designs that seek to isolate and test specific aspects of user involvement frequently fail to find significant effects (see, for example, **McKay et al., 2015**). Alongside these organisational forms, there must arguably be corresponding changes in the distribution of power and the development of more equal relationships.

When analysing the organisation of drug treatment services, it is important to bear in mind the different ways in which legislation and formal regulations can influence decision-making and relationships. **Laitila et al. (2011)** note that this can encourage organisations to become rigid, hierarchical and rule-bound bodies that force service users to 'follow the rules'. They point out that Finnish culture encourages people to be reserved and obedient, with collective participation and the public expression of opinions being rather uncommon (**Laitila et al.,** 2011, p. 5).

Another aspect of drug treatment that is of potential relevance relates to the substances that service users may be using. Surveys of people on opioid agonist therapy reveal high levels of ongoing, non-prescribed drug use, including widespread use of cannabis, benzodiazepines and alcohol (Apantaku-Olajide et al., 2012). One of the difficulties posed by high levels of benzodiazepine consumption among service users is that if clinicians do not prescribe this drug on a long-term basis (and in the absence of a formal protocol), patients are likely to buy them on the street. This is a considerable risk factor in any case, as diazepines are involved in most overdose deaths in Ireland, in conjunction with heroin or methadone (Health Research Board, 2017). This highlights the complexity of user involvement in relation to prescribing, responsibility for which rests with medical practitioners. Neale et al. (2013) describe how some service users seek to come off methadone without telling their doctor, perhaps because the latter is opposed to this course of action (cf. **Ayres et al., 2012**).

These issues are very challenging for treatment providers, but the first step in tackling them is to create the conditions for more effective communication between prescribing doctors and service users. As **Kavanagh (2012)** observes, where formal communication breaks down, dangerous 'street myths' and hidden practices can proliferate. The innovative solutions to

improving access to naloxone described by O'Carroll *et al.* (2020) represent a good example of how a commitment to harm reduction and user involvement can lead to improvements in services, even where this involves challenging existing assumptions and regulations regarding medical prescriptions.

The study by **Davis *et al.* (2020a)** on the experience of implementing patient-centred care at Kedesh Rehabilitation Services in Australia provides further insights into these issues. In this community-based non-profit organisation, four overarching themes emerged from interviews with staff: the importance of being flexible and adapting treatment to the needs of clients (as these evolve over time), the need to maintain a comprehensive focus on the holistic needs of service users, to be open-minded (with regard to new possibilities) and to be inclusive (e.g. by making room for mistakes and being compassionate). As they sought to encourage user involvement, staff described relationships as becoming more authentic, but they also had more difficulties defining boundaries and even justifying the resulting differences in how people were treated.

Brener *et al.* (2019) evaluate an intervention involving a training and relationship-building programme in five treatment services in Australia, including the development of user involvement initiatives that were tailored to each service. They found that people who actually engaged in these projects gained a much more detailed and practical understanding of what user involvement entails. They suggest that ongoing workshops geared towards the implementation of practical, task-driven activities could represent an effective way of promoting consumer participation within drug treatment services. This impression is reinforced by the finding that consumer participation tends to be greatest in services where staff believe that this is beneficial, and vice versa, although they also emphasise that attention must be given to resources:

> ...*specific care should also be taken when promoting and advocating for consumer engagement initiatives as it was found that at times it was difficult to balance the expectations of consumers with limited service resources. Beyond limited resources, such a project also relies on the capacity and overall service commitment to implement engagement practices. This can easily lead to disappointment and unwillingness to participate in the future engagement activities.* (**Brener et al., 2019**, p. 8)

The user involvement projects were supported at local level by the Network of Alcohol and other Drugs Agencies (NADA) and funded by the Australian Government Department of Health. A consumer and a staff representative from five treatment services attended training on consumer engagement, stigma and discrimination. The five services were asked to develop an action plan, to obtain the support of managers and recruit and train co-facilitators who would be responsible for implementing these plans at local level, working alongside staff and service users and the NADA project coordinator. Interviews were carried out before and after the implementation of the projects with 27 service users and 7 providers:

> *The model and its training activities seem to foster relational changes within the services, and trust and empathy seemed to increase. Our findings also suggest that relationships between fellow consumers improved, and that consumers used the training within an overarching agenda of self-improvement and skills acquisition.* (**Brener et al., 2019**, p. 32)

At the same time, professional participants felt that lack of guidance regarding their role, high existing workloads, the fixed-term nature of the project, lack of motivation by key staff, lack of

involvement by managers and high turnover among both staff and service users at the host sites weakened the initiative. Staff members who participated in the activities discovered that supporting and encouraging service users required a considerable amount of time. For example, the stigmatising ways that service users acted towards one another, around drug of choice or route of administration, could undermine their willingness to get involved.

Treloar *et al.* (2011) summarise the results of an evaluation of projects which provide opiate agonist therapy, detoxification and residential rehabilitation programmes to enhance user involvement in five drug treatment services, again in Australia. The aim of the projects was to involve service users in service planning and delivery, with 10 people being interviewed at each site and at two points in time, including staff and service users who were directly or indirectly involved in the initiatives. The projects involved training and employing service user representatives or consultants, establishing a 'consumer participation council' or 'consumer reference group'. One staff member observed that "it's quite intimidating to think that members of that client group are going to have access to us at a level where they're not on the other side of a counter" (p. 975).

At the beginning of the project, staff tended to talk about user 'stability' as a precondition for involvement (referring to reduced or no substance use or being on opiate agonist therapy). Ironically, the stability of the services themselves proved to be the main determinant of success or failure, primarily in terms of staff turnover and training. The authors reach the following conclusion:

> *In each case there were significant delays and disruptions to the project, explained by senior staff as the result of a lack of resources in an already overstretched, under-resourced service. Staff participants also acknowledged that they had consistently underestimated the amount of work involved in implementing the demonstration projects.* (**Treloar *et al.,* 2011**, p. 975)

The structural characteristics of drug treatment provision are also relevant to the question of user involvement. **King (2011)** mentions an important feature of the Irish drug treatment system, namely its division into two sub-systems: one for the provision of methadone and one concerned with psycho-social support. Although counselling is available within the treatment centres which are primarily concerned with prescribing and dispensing methadone, this service appears to be under-resourced and difficult to access. Because of the rules and organisational climate of these centres, service users tend to limit the amount of time they spend in the clinics. A parallel network of treatment providers has developed, with a focus on counselling, behavioural therapy, group activities, mutual support and training.

The differences between these forms and sources of treatment have not been explored sufficiently in the literature. As we show below, there is evidence that the user involvement paradigm faces fewer barriers to implementation in the community drug projects than in the medically-managed treatment centres. The highly critical accounts of drug treatment services in Ireland that have been published since the early 2000s relate mainly to the large drug treatment centres.

Moore *et al.* (2019) provide the following summary of the philosophy guiding one community-based treatment programme (STAR Project Ballymun):

> *The person-centred care approach facilitates the formation of a partnership between staff and service users in which they work together to achieve personalised recovery*

goals unique to each individual service user. The non-punitive approach stipulates that service users are not punished or judged for having a relapse, which results in the reduction of shame and the promotion of honesty. This non-punitive stance is experienced by service users as facilitative to their recovery, with some participants reporting that this approach was less evident in other models of addiction treatment. Trauma Informed Care allows service users to seek appropriate treatment for any possible underlying issues they may have, allowing them to fully engage in the service.
(**Moore *et al.*, 2019**, p. 5)

The service users interviewed by these authors described some of the punitive measures and sanctions they had experienced in other services where, if a service user had a relapse, they would be encouraged to feel ashamed and inadequate: "I have seen other places where if you have a relapse you are put on the naughty step, you are separated from the other clients" (p. 44). This meant that service users were more likely to be dishonest, particularly where punishment extended to the withdrawal or reduction of opioid agonist therapy. A service user interviewed by **Healy (2019)** recounted an episode of this nature at a large drug treatment clinic: "I sat in the wrong seat and she (doctor) clobbered me across the back of the head, her face was all red and she was irate. She treated us all like children, like seven-year-olds. I remember she called us all animals because we were talking in the waiting room" (p. 177).

By contrast, one of the service providers interviewed by **Healy (2019)** described a community drug project: "There's no prerequisite here for total abstinence. You don't have to, and there is no rule that total abstinence is the goal of the project. The goal of the project is to reduce the harm caused by using street or illicit drugs. So, if someone comes to us using or buying benzodiazapam, we will try and develop a programme where people can get on the right dose and stabilised via the relevant medical care" (**Healy, 2019,** p. 157). Healy provides the following overview of this issue:

Community Drug Projects are usually Community Employment Schemes for recovering drug users. The standard model operates from Monday to Friday and is a confluence of recovery, counselling employment skills and education. Although Community Drugs Projects do not prescribe methadone, many of their clientele are also MMT patients and therefore these Projects could be termed an adjunct service to MMT. Ancillary services, services in which the client can discuss issues and problems, for example, counselling and the use of care plans, can be integral to recovery for some clients. Many participants were critical of their MMT service while stating that the treatment they received from their Community Drugs Project promoted partnership, autonomy, dignity, respect and equality; the basic tenets of rights centred and holistic care.
(**Healy, 2019**, p. 159)

The sharp contrast between the two main contexts in which drug treatment services are provided in Ireland suggests that one way of encouraging service user involvement and to improve users' experience of treatment would be to integrate medical assistance into community drug projects, including doctors as members of the multidisciplinary care team. This would expose them to innovations and developments in the philosophy of drug treatment and encourage them to be accountable to users and other staff members. The focus of the service would then be to develop a strong therapeutic alliance between the service user and practitioners, regardless of whether the latter are counsellors, key workers, physicians, nurses, psychotherapists or psychologists.

Some of the submissions by stakeholders that Farrell and Barry (2010) summarise in their

evaluation study for the HSE (*The Introduction of the Opioid Treatment Protocol*) also argue that it would be preferable to have smaller and more geographically disseminated services rather than large clinics providing drug treatment services. They suggest that "[t]here is potentially considerable benefit from modifying services to have a range of key workers from multidisciplinary professional backgrounds including nursing and drug workers ... 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" (p. 24).

Within the medical wing of drug treatment provision, it is also important to recognise that there is a further distinction between the provision of opioid agonist therapy by specialist clinics run by the HSE, on the one hand, and by General Practitioners, on the other. As Moran *et al.* (2018) indicate, it was initially anticipated that service users would access services via specialist methadone centres before transferring to the care of a GP in the community. Data from the Central Treatment List indicate that most service users never make this transition.

Further information on the provision of drug treatment services in the context of primary care comes from **Latham's (2012)** study of nine urban general practices in Dublin City. She draws on interviews with 25 service users who were proposed by their GP. These patients said that they appreciated certain aspects of the primary care setting ("It's not a drug treatment centre, like it's a doctor's surgery but like nobody knows what you're here for" (p. 151), including the possibility of having an influence over their methadone dosage (although some of the GPs were described disparagingly as 'phy [methadone] doctors' who were always in a hurry to hand over a prescription and get rid of the patient). One of the issues that emerged from this study was that GPs can have difficulty meeting service users' needs in terms of counselling and ongoing support.

In a comparable UK study, **Alves *et al.* (2021)** interviewed 24 service users receiving opioid agonist therapy in a primary care setting. The interviewees once again highlighted the importance of 'being treated like a human being'. This entailed having the opportunity to discuss clinical decisions, feeling respected and receiving treatment that is tailored to individual needs. Study participants also valued the experience of 'feeling like family' at the primary care service and appreciated it when staff went above and beyond their duties to provide assistance (which was mentioned 177 times). This highlights some of the strengths of the primary care network, including continuity of care, access to general health services, receiving treatment near home and feeling like a patient at a GP clinic rather than a 'suspicious addict'.

In terms of overall service delivery, however, the fragmentation of service provision between a medical and a psycho-social component goes against the research evidence, which emphasises holism and a balance between psychosocial and medical interventions via personalised, small-scale services (NICE Clinical Guideline 51; cf. **Welch *et al.*, 2017**). The research literature is unequivocal on the need to tackle practical problems and to manage withdrawal and other symptoms while working on underlying social and psychological difficulties, all of which is impossible if the service user is sectioned into a physical body, a mind and a set of social ties (Marchand *et al.*, 2020). The service user should be treated as a whole person, where each sphere of life is connected to the others. If the different practitioners involved in providing treatment work in different organisational settings, maintaining an integrated approach and involving the service user in all aspects of their treatment become difficult or impossible.

Moran *et al.* (2018) interviewed 24 clients attending a methadone clinic in Limerick and found that most did not have a good relationship with their GP, often concealing their drug use

and opioid agonist treatment to avoid stigmatisation. Many failed to see drug dependence as a chronic relapsing disorder, often rooted in adverse childhood experiences and requiring "tailored interventions for the treatment of clients' stress from psychologists, counsellors, psychiatrists and General Practitioners (GPs), all working collaboratively" (Moran *et al.*, 2018, p. 13). GPs often do not have the specialist skills or experience to deal with the complex issues posed by adverse childhood experiences, trauma, opiate use disorder, mental health problems and severe deprivation. This is partly due to their high workloads, which mean that appointments must be of short duration, making it difficult to develop supportive relationships that can provide help when it is needed.

Further evidence in relation to this point comes from an undergraduate dissertation by **Kavanagh (2012)**, which is based on interviews with key workers: "[o]ne important aspect of provision which can determine the success or otherwise of MMT [methadone maintenance treatment] is how MMT operational systems work in conjunction with local community drug projects" (p. 31). Key workers at all three projects studied by Kavanagh were in agreement that engagement between agencies involved in providing drug treatment was basically determined by GPs or clinics, and that medical personnel were often unwilling to engage with other professionals and users (p. 34). One interviewee observed that "[t]heir attitude is 'it's a medical issue and as such a key worker has nothing to do with it'" (p. 35).

In Scandinavian countries, by contrast, opioid agonist therapy tends to be treated as one aspect of drug treatment, with psychiatrists, social workers, nurses and assistants playing a role in facilitating shared decision-making and user empowerment even in relation to medical treatment. In Denmark, for example, employees at treatment centres include physicians, nurses, counsellors, psychologists and psychiatrists (**Frank and Bjerge, 2011**). Physicians prescribe, nurses dispense methadone and counsellors, psychologists and psychiatrists help drug users by providing support and therapy. This kind of organisational environment appears to be more conducive to the development of collaborative and trusting relationships between service users and providers and appears to contribute to the higher levels of service user involvement observed in the Scandinavian countries.

Summary

When analysing the organisation of drug treatment services, it is important to bear in mind the different ways in which legislation and formal regulations can influence decision-making and relationships. Involving service users has ramifications in terms of resource requirements, more because staff members need more time to support service users and to respond to their requests and needs. In terms of overall service delivery, the fragmentation of service provision between a medical and a psycho-social component goes against the research evidence. If the different practitioners involved in providing treatment work in different organisational settings, maintaining an integrated approach and involving the service user in all aspects of their treatment become difficult or impossible. One way of encouraging service user involvement and to improve users' experience of treatment in Ireland is to integrate medical assistance into community drug projects, including doctors as members of the multidisciplinary care team.

Theme 3b.Procedures for making decisions

Manning and Greenwood (2019) argue that opportunities to make informed and effective choices regarding treatment and care can help to restore an individual's sense of control. Self-determination theory holds that people respond negatively to situations that undermine their sense of control (Deci and Cascio, 1972), whereas contexts that offer choice can foster engagement and closer relationships. Interestingly, this holds even for seemingly trivial aspects of life, as Manning and Greenwood (2019) point out. As we note elsewhere in this report, enabling service users to exercise control over the small as well as the larger aspects of their treatment is part of a progressive agenda of user involvement that promises to improve their treatment outcomes and well-being.

The role of patients in making choices about treatment is increasingly recognised as an important aspect of patient-centred care (**Joosten *et al.,* 2011a**). Policies have been introduced in many countries to promote the active involvement of patients in treatment-related decision-making, and this generally takes the form of shared decision-making. This is a process whereby treatment providers engage patients in evidence-based decisions that support the patient's preferences (**Guille *et al.,* 2019**, p. 27). Mutual understanding can be achieved via communicative action in a situation where participants are free to express their ideas, feelings or judgements without being coerced (Sundet *et al.,* 2020).

There is evidence that shared decision-making leads to better retention rates and measurable reductions in substance use and psychiatric severity during treatment (Friedrichs *et al.,* 2016; Joosten *et al.,* 2009). The service user and provider cooperate during the decision-making process by expressing their preferences, discussing options, and jointly agreeing a treatment plan. Shared decision-making is often based on a set of procedures known as patient decision aids, which provide information in a standardised way and capture patient characteristics and preferences that are relevant to treatment (**Mooney *et al.,* 2020**). Such decision aids supply information about options, provide outcome probabilities, allow for the expression of patient values, offer structured guidance for deliberation and provide evidence to support statements (**Guille *et al.,* 2019**). Decisions can be made about the setting for treatment (i.e. inpatient or outpatient, type and location of treatment centre), the type of treatment to be received (a specific medication, therapy or type of support) and treatment goals.

A good example of shared decision-making is described by **Guille *et al.* (2019)**, who gathered feedback from pregnant women with opiate use disorder who engaged in shared decision-making with their health care provider using a decision aid designed to help facilitate an informed decision to continue or taper opiate agonist therapy during pregnancy. A total of 22 women participated, and 14 decided to continue, while 8 decided to taper their buprenorphine or methadone. All but one of the participants agreed or strongly agreed that they were provided with sufficient medical information, and all but two agreed or strongly agreed that they were provided with evidence and risk probabilities associated with treatment options.

Treatment goals are problem areas related to addiction on which the patient wishes to work during treatment. **Joosten *et al.* (2011b)** developed a shared decision-making intervention to periodically discuss and evaluate a range of treatment goals during a three-month period of inpatient treatment in three addiction treatment centres in the Netherlands. Treatment goals were assessed using the Goals of Treatment Questionnaire, which was extended by applying a Q-sort methodology. Motivational interviewing techniques were used to reach final agreement on the goals of treatment and the authors describe this as an essential part of the intervention:

The greatest differences between the patients and clinicians were found for Physical health (patients > clinicians) and Psychological distress (clinicians > patients). However, a high degree of correspondence was generally found between patient and clinician with regard to the number of treatment goals identified and their relative importance. The results further showed that treatment goals of both patient and clinician become more closely aligned during treatment. (**Joosten et al.,** 2011b, p. 273)

Shared decision-making may be contrasted with the 'paternalistic' model, where the service user has no autonomy and no role, the practitioner being assumed to know what is best for him or her. Charles *et al*. (1997) describe shared decision-making as "a mechanism to decrease the informational and power asymmetry between doctors and patients by increasing patients' information, sense of autonomy and/or control over treatment decisions that affect their wellbeing" (quoted in **Joosten et al.,** 2011a, p. 1038). In another study, a greater number of individuals who received the decision-making aid were inducted on methadone, retained for longer (based on total days of methadone treatment), and were more likely to receive methadone and extended-release naltrexone than controls (**Mooney, 2020**).

McKay et al. (2015) use a sequential multiple assignment randomised trial to assess whether patients who enter drug treatment but drop out after a brief period have better retention and substance use outcomes if they are given a choice of treatment options. The participants were mainly African-American adults enrolled at one of two intensive outpatient programmes in Philadelphia for cocaine dependence. The authors found no evidence that choice influences engagement or substance use outcomes, although the study had low power due to the fact that very few participants who were given the opportunity to choose between different types of treatment actually opted for non-standard forms of assistance.

Joosten et al. (2011a) assess whether shared decision-making influences the relationship between service users and providers. A randomised controlled trial was conducted in three addiction treatment centres in the Netherlands which provide a three-month inpatient programme for people with problem use of psychoactive substances. In this study, involving 31 clinicians (with a background in nursing science or social work) and 212 service users, a shared decision-making tool was contrasted with treatment agreement as usual (the control condition). Shared decision-making was operationalised using a structured intervention whereby service users and providers systematically and frequently discussed and evaluated a wide range of problem areas and treatment goals in order to reach agreement.

Service users who received the shared decision-making intervention perceived a significant increase in autonomy, control and extravert interpersonal behaviour, compared with those in the control condition. The former group thus became more open and sociable, while those in the control condition were more likely to adopt a silent/reserved style of interaction. Where differences between clinician and patient were greater at baseline, in terms of interpersonal behaviour, more change was observed.

An interesting extension of shared decision-making involves personal health budgets. As a result of the introduction of personal budgets as part of a pilot study in the UK, service users were found to have higher well-being and a better quality of life, to take greater responsibility for their care (**Welch et al., 2017**). This type of intervention requires more time and organisational resources, as operators must spend more time with service users and more paperwork must be completed. One frontline staff member made the following observation about the benefits:

We were working with little bits of the client rather than the whole client. And I think

that what we're developing here is a much closer relationship with the core elements of the client. I'm actually liaising with the criminal justice system, the health system, this person's children's nursery, all on one client, who's got a PHB [personal health budget]. It didn't happen before because the role of the care manager would be to meet the person, to assess what treatment they needed in the community and more or less say to them, 'We think you should go to some counselling. So I'm going to send you there for 4 weeks'. There also wasn't a lot of client ownership in that. (**Welch *et al.,* 2017**, p. 1638)

During this pilot study, a number of dilemmas arose with regard to boundaries which are in a certain sense characteristic of the user involvement agenda. For example, staff had doubts about what kinds of services could be purchased – was it legitimate to fund leisure activities with a view to motivating the service user and developing a pathway to recovery? To what extent were financial responsibilities compatible with various stages of the treatment process? Interestingly, similar doubts were expressed in other areas of the health service where personal budgets were implemented, and the authors conclude by emphasising the importance of effective leadership from senior managers, who must support staff members who have direct responsibility for implementing these measures.

Summary

The role of patients in making choices about treatment is increasingly recognised as an important aspect of patient-centred care. Policies have been introduced in many countries to promote the active involvement of patients in treatment-related decision-making by means of shared decision-making. This is a process whereby treatment providers engage patients in evidence-based decisions that support the patient's preferences. The service user and provider cooperate during the decision-making process by expressing their preferences, discussing options, and jointly agreeing a treatment plan. Shared decision-making may be contrasted with the 'paternalistic' model where the service user has no autonomy and the practitioner is assumed to know what is best for him or her. An interesting extension of shared decision-making involves personal health budgets. As a result of the introduction of personal budgets as part of a pilot study in the UK, service users had higher well-being and accepted greater responsibility.

Theme 3c. The importance of (small) innovations

The MSIC action group studied by **Goodhew (2019)** adopted goals that were simple and achievable, such as nominating a police liaison officer, obtaining a computer and providing better bags for storing takeaway injecting equipment. The aim was to secure small improvements that could provide service users with the motivation to persevere, and an opportunity to develop better relationships with each other and with service providers. A frequent comment regarding user involvement is that this has the effect of changing the 'vibe', 'atmosphere' or 'feel' of a service in a positive way (see, for example, Crawford, 2013). This helps to explain why service users and staff members typically provide a positive assessment of the impact of user involvement initiatives. Their subjective experience is typically positive, because there are improvements in the organisational climate and in the relationship between service users and providers.

User involvement in the design of services has been promoted using co-production, an

approach in which researchers, practitioners and the public work together for the generation of knowledge, sharing power and responsibility from the start to the end of the project (**Hussey et al., 2019**). Co-production can be defined as "the voluntary or involuntary involvement of public service users in the design, management, delivery and/or evaluation of public services" (Osborne *et al.,* 2016, p. 639; cf. **Larsen *et al.,* 2020**). The concept of co-production can thus be applied to treatment services themselves. An example comes from the Royal Society for Arts, Manufactures and Commerce's (RSA's) Whole Person Recovery approach, which demonstrates commitment to user involvement, while noting the structural obstacles to this, as "[t]reatment and recovery services have targets and outcomes to meet, robust risk assessment, business management considerations and operational guidance to adhere to" (Pascoe and Robson, 2015, p. 48).

Hussey *et al.* (2019) use a co-production approach to develop harm reduction materials that focused on promoting low dead space syringes (which reduce the risk of passing on blood-borne viruses if syringes are shared after changing only the needle). This project shows that people who inject drugs can participate in this kind of initiative and bring a specific perspective to the table. The authors conclude that peer co-production enabled them to design harm reduction materials that resonated with their intended audience, while treating people with respect, thus increasing the likelihood of influencing behaviour.

Rance and Treloar (2015) study a user involvement initiative – the CHANGE Project – which was introduced in three Australian drug treatment services. In 2012, the NSW Users and AIDS Association (NUAA), a state-based drug user organisation, was contracted by the New South Wales (NSW) Ministry of Health to undertake this initiative in two publicly funded opiate agonist therapy services and one non-governmental residential rehabilitation service. The initiative led to the introduction of new activities or policies which were determined by service users in collaboration with the NUAA project worker. In addition, NUAA coordinated a three-day workshop at each service, with one day each for service users and staff, before both groups were brought together on the final day. Approximately 10 participants from each of the three services were recruited, and semi-structured interviews were conducted at baseline and again six months later.

The innovations included a 'welcome diary' for new residents, a service users' newsletter, a policy review committee and the establishment of tea and information stalls. Once the project began, the opportunity to speak out about relatively minor issues relating to the service assumed great relevance for service users, particularly where involvement took on a collective dimension. By introducing a more 'personalised' form of communication within otherwise predictable everyday interactions, the project enabled participants to change. This was experienced as empowering by staff as well as service users, as it helped them to overcome their fears and establish a bond: "you can talk to them on a personal level, not through the dosing window".

It became apparent, as these boundaries were gradually called into question, that staff and service users had not been interacting effectively. Staff rarely entered areas like the waiting room where consumers congregated and the spatial barriers within the treatment centre reinforced the social barriers between and within these groups. In one of the services, removing security guards from the clinic was a key change, and small changes like encouraging service users to stay after receiving their treatment were loaded with symbolic significance. Having a cup of tea in the treatment centre gave service users a way to interact with staff on a more equal footing, disrupting the formal and unequal relationships which had previously shaped their interactions. For service users, the opportunity to have a voice overcame the dehumanisation

that characterised the treatment experience, enabling them to feel like 'they are people too' (**Rance and Treloar, 2015**, p. 34). The authors point out that demoralised service users are unlikely to participate, just as suspicious and fearful staff members are unlikely to want them to become more involved.

In Denmark, service users are expected to take part in planning activities at their treatment centre: deciding the menu for the following week, organising excursions, inviting guest speakers, and so on. Joint meetings with staff are used to accustom users to discussing, deciding and engaging in self-management (**Bjerge *et al.*, 2014**, p. 74). In practice, however, low levels of participation, conflicts between users, individual difficulties in participating in discussions and lack of engagement in activities mean that this aspect of user involvement is difficult to implement. **Bjerge *et al.*** point out that you cannot compel people to act autonomously if they are unable to do so, and that achieving greater autonomy sometimes requires social workers to act on behalf of service users. The achievement of greater autonomy is a slow, uneven and sometimes unpredictable process in which user involvement plays a key role, against the backdrop of therapeutic assistance and support. Improving the life situation of service users is just as important as increasing their independence, and requires support and a combination of multi-sectoral services and interventions.

Summary

Initiatives to promote user involvement are often described as changing the 'vibe', 'atmosphere' or 'feel' of a service in a positive way. This helps to explain why service users and staff members typically provide positive assessments of these initiatives, pointing to improvements in the organisational climate and relationships. User involvement in the design of services can be promoted using co-production, an approach in which researchers, practitioners and the public work together for the generation of knowledge, sharing power and responsibility. In one service, removing security guards from the clinic represented a key change, and small things like encouraging service users to stay after receiving their treatment had symbolic significance. Having a cup of tea in the treatment centre gave service users a way to interact with staff on a more equal footing, disrupting formal and unequal relationships.

Theme 3d. Patient-centred care

A patient-centred approach to the provision of care is often viewed as a way of tackling the notable history of paternalism in the field of drug treatment, as well as the systemic stigma and disempowerment experienced by service users (**Davis *et al.*, 2020a**). Patient-centred care[20] seeks to be respectful of, and responsive to, the service user's preferences, values and needs (Dunlap *et al.*, 2018) by adopting a shared decision-making model. This has been shown to increase patient knowledge, understanding of risks, and sense of control over their treatment. However, it has proved challenging to demonstrate the positive effects of patient-centred care in empirical studies (see, for example, Dunlap *et al.*, 2018; Schwartz *et al.*, 2017).

Hawkins *et al.* (2017) piloted a care management model for a group of veterans in the US with

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20 As this approach originated in the general healthcare arena, the term 'patient' is used, rather than 'service user'.

severe substance use problems. This model sought explicitly to overcome the limitations of conventional treatment, such as time-limited episodes of care, requirements to abstain from using substances, standardised care, lack of coordination across different service providers, and minimal or no follow-up:

> *Historically, patients who utilize SUD [substance use disorder] treatment services have had limited involvement in the design, refinement, and implementation of those services. Patient involvement provides opportunities to identify facilitators and barriers to participation and to use this information to refine services to meet patients' needs and preferences. Further, services directly informed by patients are more likely to be appealing, relevant, and meaningful to the target population, which contributes to the overall successful implementation and sustainability of treatments.* (**Hawkins et al., 2017**, p. 194)

Patients appreciated a personalised approach to treatment that was responsive to their needs, allowed them to have input into treatment decisions, and was flexible even if substance use occurred. These characteristics of the care approach avoided the inflexible "pass or fail" approach to evaluating treatment progress that often characterises drug treatment services (cf. **Harris and McElrath, 2012**), and facilitated better relationships and improved communication between service providers and users:

> *A majority of patients also described CMM [care management model] providers as caring and interested in them as persons. This sub-theme recurred throughout interviews, but notably was observed when patients were asked about CMM services considered helpful to their recovery. Patients noted these attributes helped them feel listened to and understood and contributed to a belief that providers were concerned about their welfare and genuinely interested in them. ... Patients reported feeling a level of trust with providers, which they defined as being able to safely address their concerns or issues without fear of being judged.* (**Hawkins et al., 2017**, p. 200)

As mentioned earlier, trust is particularly important when providing services to marginalised and stigmatised social groups and is a fundamental condition for service user involvement. In this study, as in others, when asked about what worked in their treatment, users highlighted the importance of feeling listened to, understood and cared for (**Hawkins et al., 2017**, p. 201). Similar findings have been reported in the context of mental illness, chronic health conditions and psychotherapy, with meta-analyses consistently reporting larger effects for empathy and the strength of the therapeutic relationship than for specific types of therapy or particular characteristics of the therapist or service (Kuusisto, 2011; Miller and Moyers, 2015).

The fact that the care management model studied by these authors emphasised continuity of individual care (rather than group sessions) over the course of a year by a social worker and a psychiatrist, based on the principles of patient-centred care, led to the development of supportive relationships between the service user and the provider. In concrete terms, therefore, this and similar studies provide clear indications regarding how service providers can promote user involvement: the first step is flexible, non-judgemental, continuous and individualised support with a view to establishing trust and building up empathy. On this basis, it is possible to listen to the voices of service users and understand their needs. Service user involvement then develops as they address these needs in a holistic manner.

Wenaas et al. (2021) investigate service users' experiences with interdisciplinary team meetings (to which they are invited in Norway) and seek to identify barriers to successful user

involvement. Semi-structured interviews were carried out with five male service users, and team meetings involving these users were also observed. The first problem they identify is that individual service users can be faced with up to five different professionals, some of whom they may not know, and they can easily feel overwhelmed. Second, where service users express their views, professionals frequently do not have any appropriate answers and fall back on non-committal responses:

> *Responsibilisation has some inherent paradoxes. On the one hand, individuals are expected to take responsibility for their lives. On the other hand, they have to adapt to the demands that services impose upon them and to threats hanging over them, including the loss of social benefits. That dynamic does not confer total freedom of choice, especially not for individuals whose life situations may mean that they are marginalised and dependent upon the help that they receive.* (**Wenaas *et al.,* 2021**, p. 199)

This study suggests that for user involvement to be successful, both service users and staff need considerable support, as each group has to learn to communicate effectively with the other, to develop stronger relationships, assume greater responsibility, question their own assumptions, tackle social stigma as well as having the resources to actually resolve problems.

Summary

A patient-centred approach to the provision of care is often viewed as a way of tackling the notable history of paternalism in the field of drug treatment, as well as reducing the systemic stigma and disempowerment experienced by service users. Patients appreciate a personalised approach to treatment that is responsive to their needs and flexible even if substance occurs. In one study, use of a model that emphasised continuity of individual care (rather than group sessions) over the course of a year, by a social worker and a psychiatrist, led to the development of more supportive relationships between service users and providers. This and similar studies suggest that the first step towards service user involvement is the provision of flexible, non-judgemental, continuous and individualised support with a view to establishing trust and building up empathy. It is then possible to listen to the voices of service users and to achieve a better understanding of their needs. Service user involvement can develop as they address these needs together in a holistic manner, with appropriate organisational support.

Theme 3e. Outcomes

Andersson *et al.* (2017) seek to assess the impact of service user involvement by measuring treatment satisfaction among service users who completed an inpatient substance abuse treatment programme at two public clinics in Central Norway which offer inpatient treatment for patients with substance use disorders. A questionnaire was completed by 188 patients before discharge, and subsequent analyses demonstrated that patients who reported high satisfaction with staff competence and who had opportunities to affect their own treatment were more likely to report a positive outcome of treatment.

Like many other studies published after 2000, **Storbjörk *et al.* (2016)** found no clear and consistent relationship between user involvement and treatment outcomes (defined either in terms of substance use or overall life situation). Attempts to match service users to optimal

treatment methods are generally viewed to have failed, and studies based on randomised assignment of service users often yield inconclusive results. At the same time, service users and providers stress the importance of user involvement in terms of effective therapeutic alliance, retention within treatment, and life situation (**Storbjörk et al., 2016**, p. 12). Further evidence for the importance of user involvement comes from studies which show that factors such as therapeutic alliance and locus of control are predictive of positive outcomes. Nevertheless, it remains the case that empirically demonstrating the positive impact of user involvement remains a challenge across all sectors, including most types of health and social service. This challenge is not specific to drug treatment, recovery and harm reduction services.

In recent years, researchers have sought to integrate the perspectives of service users within the research process by developing "patient-generated outcome measures" which enable service users to build a personalised questionnaire, where the items to be measured are defined by the patient themselves (Alves *et al.*, 2013). Patient-reported experience measures are questionnaires that ask service users to reflect on what happened during their encounters with service providers, focusing on factual information rather than subjective assessments. By contrast with satisfaction measures, which tend to elicit high ratings and can overlook problems, the measurement of patient experiences can play a positive role in improving care (**Davis *et al.*, 2020a**).

Some of the people who responded to the consultation carried out by the UK Government in 2011 (over 280 written responses were received from individuals and organisations working in the drug and alcohol treatment field) stressed the importance of including measures of stress, anxiety, depression and physical health when assessing the outcomes of treatment, alongside measures of substance use and treatment adherence (National Treatment Agency, 2012). Participants in the consultation also argued that recovery planning at individual level should be collaborative, user-led and service-facilitated, covering all important areas of the service user's life.

This consultation reflects the shift that has taken place in the UK since the early 2000s towards user involvement and recovery as key elements of treatment. One participant suggested that "In a recovery-focused system, the culture must value the input of the service user, their family and carers and redefine service user involvement to create a more equal partnership in their own care, and in the planning of the services and research. Service users (and former service users) can be central to providing training for staff and helping professionals to understand the importance of creative risk taking in supporting people to grow" (quoted in National Treatment Agency, 2012, p. 6). Another submission referred to the "personalisation agenda", arguing that people should be allowed to choose an individually-tailored care package (p. 8) from a menu of options.

Neale *et al.* (2015) developed a scale to measure progress during treatment by asking service providers to select the items that they considered most appropriate. When service users were shown a range of possible measures, they pointed out that it was not realistic to expect people recovering from problem drug use to be free of anxiety, depression and loneliness, to have good physical health, to live independently, to have confidence in themselves and to find a job. They pointed out that being over-confident could lead a recovering drug addict to let their guard down, whereas feeling lonely could mean that they are keeping drug-using peers at a distance and are growing stronger and more independent. They also noted that "being able to trust other people" or "having a good relationship with family members" would not be appropriate measures for people who have overcome childhood abuse. Another difficulty when seeking to measure progress towards recovery is that everyone is different, and pathways to recovery

can diverge. As Neale *et al*. (2015) observe, people in recovery cannot simply cast off personal histories of difficult relationships, social problems, poor health, interrupted education and poverty (p. 32).

Harris and McElrath (2012) note that client retention in opiate agonist therapy has often been used to gauge the effectiveness of this treatment. Retention is deemed to be important because it reduces the likelihood of relapse into heroin use, and in turn, heroin overdose and injecting behaviours associated with blood-borne viruses. However, clients who have left treatment during the early stages of opiate agonist therapy are often excluded from retention studies (Fischer *et al.,* 2007). This omission can artificially boost the overall retention rate, making it appear higher than the true value. This form of selection bias is important, particularly because dropping out of opiate agonist therapy tends to occur more frequently within the first few months of treatment. In their review of the literature, Fischer *et al*. (2007) conclude that "patient retention . . . is the exception rather than the rule" (p. 3).

Summary

Demonstrating the impact of user involvement remains a challenge in the health and social services as well as in relation to drug treatment, recovery and harm reduction. In recent years, researchers have sought to integrate the perspectives of service users by developing "patient-generated outcome measures" which enable service users to build a personalised questionnaire, where the items are defined by the patient themselves. A similar tool, known as "patient-reported experience measures", ask service users to reflect on what happened during their encounters with service providers, focusing on factual information rather than subjective assessments. When discussing outcome measures, researchers have argued that it is not necessarily realistic to expect people recovering from problem drug use to be free of anxiety, depression and loneliness, although measures which capture improvements in well-being should be included when evaluating treatment outcomes.

6

Service providers' experiences of user involvement

In order to extend the range of this integrative evidence review, we also consulted 18 stakeholders from Ireland and other countries, including researchers, administrators, user representatives, and professionals. These consultations took the form of semi-structured online (Zoom) interviews lasting between 45 and 90 minutes each. During these encounters, we elicited the participants' opinions and experiences regarding various aspects of user involvement.

We adopted a 'snowball' sampling approach to identify participants: we began by asking contacts to provide the names of people with experience of service user involvement in the context of drug treatment services, both in Ireland and at European level. We then spoke to these individuals and progressively extended our list of contacts. Our aim was to include practitioners and administrators from the different types of drug treatment, recovery and harm reduction services described in Chapter 2, as well as representatives of advocacy groups that have contributed to debates about service user involvement in Ireland.

The following organisations and individuals participated, as well as three stakeholders who preferred to remain anonymous:

National Addiction Centre, King's College London (21/12/2020)

1. Professor Joanne Neale, Professor of Addictions Qualitative Research

Correlation – European Harm Reduction Network (22/12/2020)

2. Eberhard Schatz, Coordinator for Netherlands and Germany

Intervention on Addictive Behaviours and Dependencies (SICAD), Lisbon (7/01/2021)

3. Dr João Goulão, Director General

UISCE[21] (National Advocacy Service for People who use Drugs in Ireland) (18/01/2021)

4. María Otero Vázquez, Community Development Officer

5. Lynn Jefferys, Peer Support Worker

'Better Together' Online Community Recovery Service (19/01/2021 and 25/01/2021)

6. Jim O'Dwyer, Development Worker, South East Regional Drug and Alcohol Task Force

7. Gordon Kinsley, Development Worker, Southern Regional Drug and Alcohol Task Force

CityWide Drugs Crisis Campaign (26/01/2021)

8. Anna Quigley, Co-ordinator

9. Joan Byrne, Co-ordinator

Ana Liffey Drug Project (9/02/2021)

10. Tony Duffin, Chief Executive Officer

National Family Support Network (11/02/2021)

11. Aoife Frances, Policy Officer

Service User Rights in Action (SURIA[22]) (5/03/2021)

12. Dr Richard Healy, Researcher

School of Social Policy, Social Work and Social Justice, University College Dublin (24/03/2021)

13. Professor Sarah Morton, Director, Community Partnership Drugs Programme

HSE Community Healthcare Organisation, Dublin North City and County (30/04/2021)

14. Brian Kirwan, Social Inclusion Manager

Regional Drug Coordination Unit, HSE Mid-West Drug and Alcohol Service, Limerick (13/04/2021)

15. Rory Keane, Regional Drug Coordinator

16. Anonymous Dublin doctor (7/07/2021)

17. Anonymous general practitioner (15/03/2021)

18. Anonymous academic researcher (15/02/2021)

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21 Funded in the 1990s as a service user platform, UISCE currently uses a professional peer partnership approach to advocate for the rights of the community of people who use drugs in all decision-making spaces.

22 SURIA is a service user-led group that campaigns for the recognition of the rights of service users, for a more equal doctor–client interaction, for the abolition of supervised urinalysis, and for periodic and meaningful review of treatment, choice of treatment, and implementation of an independent complaints procedure.

We asked each participant how they had encountered and addressed issues relating to service user involvement and about the challenges they had faced in that context. We asked them to describe interesting or illuminating experiences regarding service user involvement in the context of drug treatment, rehabilitation and harm reduction services, and we invited them to identify enabling factors and obstacles to involvement and empowerment.

All interviews were recorded and transcribed in full and subjected to thematic analysis. During the latter stage of the analysis, we read repeatedly through the transcripts and extracted passages that were particularly useful or relevant. These extracts were assigned to the categories that had already emerged from our literature review (see Chapter 5) to facilitate the convergent analysis of these different sources of evidence.

In the following pages we present the results of this analysis. The sub-themes relating to the relationship between service users and practitioners and those relating to social power are directly relevant to the question of service user involvement within the treatment setting, although sub-theme 2c, "Shifting the balance of power" also touches on the representation of service users in a wider sense. The sub-themes relating to organisational practices are pertinent not only to the treatment setting, but also to the involvement of service users and people who use drugs in debates and decision-making regarding the development and redesign of services. The final sub-theme relating to organisational practices ("Representing service users") addresses this issue explicitly, and this sub-theme was added in order to accommodate extracts relating to this issue. This is one area where stakeholders are well-placed to go beyond the academic literature and provide insights into how service users can be involved in policy-related debates and decisions.

Theme 1a. Building and maintaining trust

All of the practitioners we interviewed emphasised the importance of building equal and honest relationships with service users. Speaking of the online group Better Together, which was established by the South East Regional Drug and Alcohol Task Force, Jim O'Dwyer described some of the challenges that user involvement poses for practitioners:

> Now, so we go around the room, and everyone... the questions themselves are based on a kind of reflective process. ... But when we come around, I answer that question for myself, so we don't ask people questions that we are not willing to answer for ourselves. Yeah, and what that does is it changes the dynamic. ... That's what co-production is. For some professionals, it goes against everything they've been trained to do. (Jim O'Dwyer, SERDATF)

Jim O'Dwyer believes that this process is beneficial to all participants, both service users and practitioners. Service users "found connection to be something that really helped them get over the trauma, so that they weren't reliving that traumatic experience all the time. And so this experience of connection is trauma healing in and of itself. And we've learned to adapt to that." He observes that "our professionals – HSE counsellors – what they have said is that they don't actually want to go back to working in any other way other than co-productively. It has been hugely enriching to them. They have learned so much through the lived experience."

In primary care, general practitioners (GPs) typically deal with service users individually, and need to be aware of the power differentials that characterise this situation. At the same time,

all of the doctors we talked with emphasised the importance of building close and supportive relationships:

> *So I think the benefit of knowing somebody [in the context of primary care] is that you know where they are at, at this particular time. It may not be the same position tomorrow, but at least you have some idea. The other thing is I have been there for 5 or 6 years, usually through ups and downs, I have been told to f*** off more times than whatever and usually the relationship is stronger for that over time.* (Anonymous GP)

These descriptions of supportive relationships stand in marked contrast to accounts of the large drug treatment clinics, which our stakeholders tended to describe in very similar terms:

> *The clinic system exists because those were set up originally to address addiction. Some of the clinics are high security, it's like, you know, that 'drug users are dangerous', so you need places that are safe. When you walk in those clinics you have your security guards and reverse mirrors, you're searched, the guard has the keys to open the doors. When you set up a place like a prison, people react as if they're prisoners.* (anonymous Dublin doctor)

> *In what would be seen as our central methadone clinic in Ireland – which is Trinity Court – to enter that clinic you have to go through – and this isn't an exaggeration – you have to go through almost airport security. It's "Take your belt off and empty your pockets" and you go through a metal detector, the whole lot, everything... So can you imagine how that would make you feel going in there? And you do this every day. So straightaway away it's 'us and them', as opposed to a relationship or a therapeutic relationship. It just never develops, you know, and it's never going to develop in that type of environment.* (Dr Richard Healy, SURIA)

More than one interviewee pointed out that, regardless of the context, doctors' responsibility for prescribing opiate agonist therapy can itself transform the nature of their relationship with service users:

> *It's difficult, because with methadone... If there is a consultation with me and somebody, and there is methadone in the middle, there is a power imbalance invoked by that relation. ... You need to think very carefully about the power imbalance, because of this constant tension, because of this prescribing relationship.* (Anonymous GP)

A number of other risks must be managed carefully when providers seek to build collaborative and trusting relationships with the people who use their services. A key issue in this context relates to fear, and the ways in which both service users and providers defend themselves against it:

> *The biggest constant that I have learned in all these years is – particularly with people with addictions – they are used to being let down, and they are waiting for you to let them down, too.* (Anonymous GP)

> *But I would say there is fear as well. People who use drugs, in the minds of GPs and otherwise, can be unpredictable, they can be violent – this is the perception. ... The conversation with the students that I bring here is "Actually, the person that has just left the room there has injected two bags of heroin this morning, probably. In fact, the only reason why they are here to talk about their health issues is because they have*

injected heroin – that is part of what they need to do to get up and running during the day." (Anonymous GP)

What I took out of that is the idea that very often our service users will build a relationship with us or have a very generative experience with us as practitioners if we can communicate that we understand their world. But the risk is that you, as a practitioner, you know, can get overtaken by that world. So, you know, how do you get alongside your service users' experience with it... because maybe on an unconscious level that's what we're defending against all the time, when we think about designing these structures and doing this work, because it's really hard, you know, to really genuinely and thoroughly get alongside the world of your service user. (Professor Sarah Morton, UCD)

These extracts reveal the difficulties involved in negotiating and maintaining trusting relationships in the presence of fears and risks on both sides of the service user–service provider bond. If collaborative relationships provide the foundations for a well-functioning system of user involvement, it is clear that establishing these foundations requires considerable effort and perseverance.

Summary

All of the practitioners we interviewed emphasised the importance of building equal and honest relationships with service users. A number of risks and challenges must be addressed in this context. These include fear, power differentials and legal responsibilities. The accounts we heard of supportive relationships stand in marked contrast to the situation at the large drug treatment clinics, which our stakeholders described as oppressive institutions that keep service users isolated and in a position of subordination. By contrast, stakeholders described positive examples of service redesign and user involvement that could potentially be extended and replicated. Collaborative and trusting relationships were frequently described as the foundations of user involvement.

Theme 1b. Showing empathy

Empathy – being aware of and sensitive to the feelings and experiences of another person – is closely related to building supportive relationships. We identified a number of passages in our interviews with stakeholders that relate to this issue, or that describe the difficulties that can arise when practitioners fail to empathise. One factor that helps service providers to show empathy is related to their own life experiences:

You'll find that a lot of people that work in these services have lived experience, there is a lot of people that are working in drug services that have experience. Which can be... it can be a benefit, and it can also be a hindrance at other times, in some cases. In other cases, it's an amazing thing, because they're really driven by what they have to do, and they're interested in what service users have to say. (Brian Kirwan, HSE Manager)

Nonetheless, criticism of GPs was relatively common, particularly in relation to their insensitivity to service users:

I'm not betraying confidentiality for the sake of this, because I'm using an example. One individual was diagnosed with borderline personality disorder plus addiction. They're having serious nightmares and anxiety tremors, and never had them before – they have only had them since they've engaged in medication [methadone]. There's no sleep – there's nightmares. And we know this is a side effect of the medication. ... They approach their doctor and the doctor turns around and says, "Look, we'll review that in a month's time." ... And this is the experience that people are having. And people don't seem to listen at all. (Jim O'Dwyer, SERDATF)

We've spoken to participants and our interviewees said, "I don't even think my doctor knows what I look like, because I go in there and they're just staring down at a computer screen and they're just looking up my urine samples, and writing the prescription and just handing it to me." (Dr Richard Healy, SURIA)

One GP described the methods he has adopted to teach medical students how to improve their capacity to empathise:

I would bring medical students... to my clinics before COVID. ... I would say: "You think you are here to learn from me, but you are not, you are here to learn from [name], who is an expert. I have learned more from [name] than I have from any textbook about drug use. And [name] is going to teach me and you about how this works and why does somebody start injecting heroin." Over time, the patients really, really, really like it. ... A lot of students never had a conversation with someone using drugs or someone under the influence of using drugs. (Anonymous GP)

The next extract provides an illuminating account of how power-holders can use their resources and influence in order to redress the power imbalance in their relationship with service users. As we indicated earlier in our literature review, it is often necessary for more powerful participants to take practical steps to equalise a relationship. One way of doing this, as we have seen, is to focus on the value of lived experience:

I work from the perspective that anyone that I'm working with – be they a service user on the group art programme or, you know, on the drugs programme, or on an educational course – their lived experience is infinitely superior to anything that I've read, known, or worked with, so finding a way to communicate that really early on – that their lived experience is not just of equal value but of superior value, and deserves to be privileged – I think is really important. (Professor Sarah Morton, UCD)

By building empathy into the relationship between service providers and service users it is possible to achieve more equal relationships. Another way of pursuing this goal is to emphasise the centrality of service users to the service itself:

We do try and promote the idea that it is their service. And that they have a sense of ownership as well. And it's not about them coming once a week or every 2 weeks, just about their treatment. In the sense – community is too strong of a word – this idea that they have a vested stake in the service. ... That idea of trying to promote that clients have confidence, that they have a voice and if there is something they need to say to the service – either around their own treatment or whatever broad perspective – we are very much there. (Rory Keane, Regional Drug Coordinator)

In the next section, 'Theme 1c. Creating a space for effective communication', we turn to the issue of communication, which is closely related to the nature of the relationship between

service users and service providers. As was the case in our literature review, this issue was often at the centre of our interviews with stakeholders, and once again emerged as a crucial dimension of drug treatment, harm reduction, and recovery services.

Summary

Empathising – being aware of and sensitive to the feelings and experiences of others – is an important aspect of building supportive relationships with service users. In our interviews with stakeholders we collected a considerable amount of information on this issue, including several accounts of the difficulties that arise when practitioners fail to empathise or erect defensive barriers to insulate them from service users. One way of building empathy and promoting service user involvement is to focus on the value of lived experience and to place service users at the very centre of the services they attend.

Theme 1c. Creating a space for effective communication

Several interviewees emphasised the importance of communication in relation to the different aspects of drug treatment services, from admission to recovery. Communication is important because patients have different needs and experiences, but also because feeling listened to and understood is often a precondition for effective treatment. Communication is a two-way process, although the stakeholders we interviewed underlined the need for service users to be heard and for service providers to listen more attentively:

> There is, of course, a need for a conversation around medication and therapy and to be able to do that. The problem we have at the moment is that we have people that have entered into services, that are in a really challenging position, and don't feel that they can have that say. (Jim O'Dwyer, SERDATF)

João Goulão, General Director of addiction services in Lisbon, Portugal, made the following observation about the importance of communication:

> The only key aspect that I can express is to create mechanisms where people can express clearly without fears, without any kind of restrictions, that we can discuss openly. So there are some proposals that are realistic and we can take on board and say, "Okay, we can move in that direction." (Dr João Goulão, SICAD)

Several other stakeholders made similar remarks:

> In a fairly recent study, we asked people about different ways of receiving opioid pharmacotherapy, you know – whether a tablet, a liquid, a depot injection, an implant, or even as a hypothetical nasal spray, and they had so many different views. ... there are as many different viewpoints as there are people. And that's why I think asking people, communicating with them, is key to the whole process. ... when I've been speaking to people about treatment options, they don't tend to mention policies, they tend to mention the way that the clinician treats them, the way the doctor treats them, the way they're treated by the pharmacy staff, and the way that people stigmatise them for their treatment. (Professor Joanne Neale, King's College London)

This simple concept – that you can only know what service users need if you listen to them – has a number of far-reaching consequences for user involvement, as María Otero Vázquez from the advocacy group UISCE points out:

> *So, for me, it will be, first of all, like, empowering people that people feel that what they're saying is valid, and they're being listened to. Actually, if you are implementing things that are responding to the needs of people, the chances are that they're going to work better. At the same time... our intentions can be the best, but because you're not the person that is living that situation at the moment, you may be forgetting to account for challenges that people may face. Or, you know, the stigma that people face, and how that will impact participation in a certain project that you want to implement.* (María Otero Vázquez, UISCE)

Of course, communication is likely to collapse if services do not actually respond to service users' requests:

> *So what we're very clear on is that in order for involvement to work in a service, there has to be buy-in from management that will say, "Whatever you discover, we would be willing to implement it, if it's within our remit." And that's why you can have procedures all day long for involvement, but if they actually don't have a focus on using the information that they get, and prioritising it, it is going to be tokenistic anyway.* (Jim O'Dwyer, SERDATF)

> *And so, you know, they felt that a service user forum would be the key way to advocate for reform and for change and for resources to be allocated to that side of the country and to help support people that had problems. But what became quickly apparent was that, whilst they were trying to feed into the Task Force what they needed, and to be part of the table of decision-making at the Task Force level, nothing happened. So it was a complete waste of time. And it was very demoralising for them, because they were in a stage of their lives where they were clean, they were abstinent, they wanted to give back, they wanted to support others.* (Anonymous academic researcher)

Professor Joanne Neale stresses the importance of telling service users why specific decisions are being made:

> *Communication is key: if you don't tell people what is happening and why, then you can't possibly expect them to understand. Again, it's like many other forms of health care. So much of user involvement is just remembering that alcohol and drug treatment services are often no different from other kinds of treatment. If you don't explain things to people, they can't make meaningful decisions.* (Professor Joanne Neale, King's College London)

An important issue that emerged in a number of interviews relates to the possibility of establishing meaningful communication with service users who are at specific stages of their treatment journey:

> *A treatment centre asked us: "How can I ask somebody how they're feeling when they're detoxing?"... To which we responded: "How did they sign the consent form to go into the service if they're so sick?" And this is... this is part of the difficulty that you will encounter when you go out, is that some people still think they're saving people. Some people still think that they have the right to talk for somebody when they're 'saving' them.* (Jim O'Dwyer, SERDATF)

Just because somebody is really marginalised and they struggle in terms of what's going to happen in the next half an hour, we shouldn't use that as an excuse: "Well there is no point in asking what they want." And in some respects that makes it even more important to have that conversation with them, outside their immediate treatment needs. It is trying to get the balance right so that it is effective and that it's meaningful. (Rory Keane, Regional Drug Coordinator)

The stakeholders we interviewed in the course of this research emphasised how difficult it can be to resolve this contradiction within the everyday context of drug treatment and harm reduction services. On the one hand, free communication is an essential condition for understanding needs and formulating care plans. On the other, communication often appears to be impossible due to power imbalances, addiction, stereotypes, and fear:

There is this real tension around the stages of people's recovery and journey. So their lived experience – we want to privilege that. But also, they may be in a trauma response, they may be in a detox situation, they may be affected by their medication or substance misuse at that particular time. So there's a whole range of things that compromise them potentially, you know, at that moment. ... So how do we actually enact this, because we have to acknowledge those kinds of vulnerabilities? (Professor Sarah Morton, UCD)

Faced with this tension, most of our stakeholders stressed that, although this issue cannot be resolved in abstract terms, service providers can and should seek to manage and overcome it through their practice: "Because how I cope with that bigger kind of question is to say: 'All I can do is work on what's in front of me, and then see what changes'" (Professor Sarah Morton, UCD). This resonates with the Scandinavian research we summarised earlier in this report, which emphasises how professionals must, through their practice, identify concrete, if partial, solutions to these tensions, while being aware that there are no easy solutions.

Several stakeholders argued that the medical profession must take steps to reflect critically on its practice within drug treatment and harm reduction services, and to embrace rather than resist change. Another valuable example of critical reflection on medical practice is found in the following extract from our interview with a Dublin doctor:

There's two problems. One is the clinics, because they're a power base and if you get rid of them you have a lot of people with no role so it's very hard to dismantle the system – you're left with a lot of people with no role. And so that is the difficulty. The second issue is that general practitioners, particularly down the country, are not particularly enthused about taking drug users on for treatment. ... We often have people who become homeless because they can't get treatment locally. ... So general practice has an issue. (Anonymous Dublin doctor)

Rory Keane links the challenges facing medical practice with the shortcomings of the training system for doctors, and the need to overcome stereotypes and stigma that are rooted in their limited experience and knowledge of the social dynamics of problem drug use:

As you move away outside the field of recovery, the staff hasn't really been trained in relation to understanding the dynamics of problematic drug use... Some of their responses are informed by suspicion or fear or stigma. But what is really key for me, they are not listening to the service user and they are not hearing what the service user is saying. (Rory Keane, Regional Drug Coordinator)

Rory Keane also provides a useful account of communication between service users and providers in Limerick. This extract also sheds light on the role of managers in creating the conditions for service user involvement:

> *If clients have a negative experience, if they are not happy, it is actually very easy for them to get to talk to me or one of the clinical leads. ... We would very much invite feedback – particularly negative feedback. ... My office would be in the same building as the methadone clinic, so a lot of clients would know me by name. When they go in and out into the clinic they could just grab me and say: "Look, I am not happy about this, we have a problem with this, can I talk to you about this?"* (Rory Keane, Regional Drug Coordinator)

Summary

All of the stakeholders we interviewed argued that communication is important within drug treatment, recovery and harm reduction services because patients have different needs and experiences, but also because feeling listened to and understood is an essential element of effective treatment. Our interviewees underlined the need to create mechanisms whereby people can express themselves freely and without fear, so that complex issues in relation to medication, substance use, trauma, family relationships, mental health and living conditions can be addressed in an open way. This simple concept – that you can only know what service users need if you listen to them – has far-reaching consequences for services and practitioners. Even when patients are experiencing adverse symptoms or struggling with the effects of detoxification, communication is an essential part of treatment. Stakeholders emphasised the need for training and support in order to prepare practitioners for the challenges involved in overcoming stereotypes and communicating effectively with service users.

Theme 2a. Stigmatisation

As we noted in our extensive review of the literature, researchers often refer to social stigma when seeking to explain the marginalisation of drug treatment service users and the challenge of promoting user involvement. The stakeholders we interviewed in the course of this project also emphasised this issue:

> *There is a massive stigma to being an injecting drug user. Heroin, of all drugs, has a massive stigma attached to it. And more of it has actually to do with the poverty than the heroin. A lot of the drug-related stigma is based on the people who are most visible, who are the people who are most disadvantaged, because they are more likely to be on the street, they are more likely to be homeless. They are looking for drugs – they are the visible people. There are lots of fairly wealthy people who sit in their own homes and use lots of drugs, but they don't bother you, because you don't see them. ... There is a stigma around using drugs and there was a class divide where the people coming into those clinics were seen as being far less educated than the staff, the doctor.* (Anna Quigley, CityWide Drugs Crisis Campaign)

> *I think it's stigma. I think, if you're dealing with someone who has cancer, you're not blaming their family for giving them cancer. But there's definitely an element of that*

if you're dealing with an 18–19-year-old who's addicted to heroin, and their mother is saying, "Tell me what's going on," you know, there's definitely an element of stigma around thinking, "What kind of mother were you?" ... So I think there has to be a model where people are considered in the support plan 100%. (Aoife Frances, National Family Support Network)

One of the GPs we interviewed linked stigma with professional practice, emphasising the need for practitioners to reflect critically on their assumptions and to be supported and encouraged to overcome the negative impact that societal stigmatisation has on the provision of drug treatment services:

Doctors don't get a whole lot of training in addiction. If you were to let someone know that the next person they're going to see in the waiting room has used heroin in the morning and has crack in their pocket, and they are going to go home and use after they talk to you, it's not something we are used to or prepared for. There are initiatives now, like North Dublin City GP Training and other things, slowly changing things. But it's not something that we are used to. (Anonymous GP)

Interestingly, João Goulão from Lisbon argues that Portugal developed progressive drug treatment policies and services in the 1990s due, at least in part, to the cross-class nature of the heroin epidemic in that country, which counteracted the stigmatisation of people who use drugs:

So in my view, it's important to understand in the spread of the problems is that it happened cross-cutting, not something that was only related to minorities – ethnic or others, but it happened in all social groups. Of course, it was particularly important in the ghetto and among poor people, but it spread also in the middle class, the upper class. ... So from the very beginning of it, I believe – this is the way I read the situation – there was a very humane approach. (João Goulão, SICAD)

Eberhard Schatz, from Correlation – the European Harm Reduction Network, links the social stigma surrounding drug treatment service users with the criminalisation of people who use drugs:

In countries where you really have a high level of criminalisation, it is almost impossible to develop [user involvement]. ... In many countries, possession and use of drugs are not criminalised so harshly anymore, so that's a good thing. ... Secondly, in terms of the general society, you need to provide an opportunity for people to make their voices heard, and support systems are definitely also needed. ... And then, of course, you have to adapt the services in line with the key principles: that you accept people and the choices they make in their lives, that you assess them on an equal level and recognise their self-determination. (Eberhard Schatz, Correlation Network)

This point was also made by Tony Duffin, Chief Executive Officer of the Ana Liffey Drug Project:

Service user participation is important – in terms of service provision, governance of an organisation, and national policy. With regard to national policy, how we decide to set our policies, our laws, ultimately decides how people are treated. For example, we support the implementation of the State's health-led approach to the possession of drugs for personal use. Which is a policy choice informed by civil society – which includes people who use drugs. When this policy is implemented, we won't notice much of a change immediately, but with time we will start to see the situation improve and drug-related harms decrease. (Tony Duffin, Ana Liffey)

Summary

Several stakeholders addressed the question of stigmatisation during our discussions. One GP emphasised the need for practitioners to reflect critically on their assumptions, suggesting that they may need support and encouragement to overcome the negative impact of societal stigmatisation. Practitioners need more training to prepare them for working in drug treatment, recovery and harm reduction services. An effective way of pursuing this goal is to provide opportunities for trainees to interact with people who use drugs and with service users so that they can learn from their lived experience.

Theme 2b. Policing moral and social boundaries

This theme explores the role of boundaries within the context of drug treatment and harm reduction services: social barriers that serve to limit contact with stigmatised groups. Service providers are often exposed to social pressures which lead them to distance themselves from people who use drugs. This can prevent them from expressing empathy and from developing a collaborative and equal relationship with service users. Anna Quigley, Coordinator of CityWide Drugs Crisis Campaign, points out the pertinence of these boundaries in relation to the development of treatment services, particularly as far as the normalisation of drug treatment within the network of primary health care providers is concerned:

And again, to be fair to the people in the health services who put a lot of work into trying to develop the GP services, a lot of the GPs didn't want to know. And we have to be honest, one of the reasons GPs didn't want to know was because some of their other patients didn't want people in their clinics who were drug users. (Anna Quigley, CityWide Drugs Crisis Campaign)

Multiple boundaries are maintained within the system of drug treatment services, where they tend to isolate and penalise service users:

There is one treatment centre on Pearse Street, Trinity Court, where people can go nationally if there isn't treatment available locally in their own area. So they can go to the national … But it's also been used – and again the health service has always disputed this, but some of them would admit this off record – but it has been used as a 'punishment' service when people misbehaved locally. You treat people's behaviour – and yes, sometimes people did behave badly under the influence of drugs – all of that was part of the way the services developed and part of the mindset, and it takes a long time to shift that. (Anna Quigley, CityWide)

Another disciplinary technique that has been documented in the literature – as we saw earlier in this report – relates to the reduction of medication as a way of punishing service users who have a` relapse:

I mean, they dock your medication if you're having problems. I mean, for me, that's the same as somebody who is a diabetic and maybe isn't abiding by their diet and therefore they take their insulin off them. That's what it is, almost, that's how ridiculous this is, you know. So if somebody is struggling with heroin use, they reduce their methadone. Why would you do that? … So that's the punishment that they will use,

and a lot of people will just end up leaving the clinic then. And this is leading to people dying, in reality. People have resorted to drug use and are dying, you know, over some urine samples. I mean, it's just, it's... it's criminal. (Dr Richard Healy, SURIA)

Summary

Service providers are often exposed to social pressures which lead them to distance themselves from people who use drugs. This can prevent them from expressing empathy and from developing collaborative relationships with service users. Boundaries are often erected within the system of drug treatment services, where they tend to isolate and penalise service users. One key challenge that practitioners and service providers face when seeking to promote service user involvement is identifying and dismantling these boundaries and building trusting relationships with the people who rely on their services.

Theme 2c. Shifting the balance of power

This theme explores the ways in which it is possible to shift the balance of power within drug treatment services in favour of service users. As we saw earlier, the research literature provides a detailed description of the different ways in which people who use drugs are marginalised, stigmatised, and disempowered in society and in their encounters with health care, drug treatment, and harm reduction services. In this section we will summarise the views and experiences of our stakeholders in relation to this issue.

Most stakeholders noted that while the principles of service user involvement have largely been accepted by policy-makers, administrators, and service providers, their practical implementation remains a challenge. By focusing on the issue of power, it is possible to shed light on this paradox and to identify areas where change is possible. Our stakeholders identified five key sources of power that need to be considered in relation to service user involvement in drug treatment and harm reduction services: access to material resources, collective participation, involvement in service provision, professional corporatism, and public policy.

Starting with the question of material resources, Aoife Frances of the National Family Support Network drew attention to the importance of providing public funding for advocacy organisations, in order to enable them to promote and support the involvement of service users:

Particularly in terms of funding, a lot of the time the Drugs Strategy – the Department of Health – they give funding out and they just think of the Strategy as the Task Forces. And the three of us [UISCE, the National Family Support Network, and Pavee Point Traveller & Roma Centre] have to be like: "What about us?" (Aoife Frances, National Family Support Network)

In general terms, promoting user involvement requires resources at all levels, from policy-making to service delivery:

What I see all over Europe is that it is still very difficult, even for organisations which are trying to do a good job. They encounter barriers and challenges that are difficult

to address and overcome. So if you have a really long-term perspective, and you approach that very carefully, then you may reach the point of having an honest form of peer involvement. Otherwise, many of those attempts fail because there is not enough support in place, including the necessary financial resources. (Eberhard Schatz, Correlation Network)

So whilst in principle user involvement is a good thing, there are reasons why people may not actually actively embrace it in the way that you think they will and, in the same way, there are very legitimate reasons why it's very difficult to implement it if you're a clinician and you don't have more than one medication to offer. It's very difficult to offer a patient meaningful choice without being just tokenistic if you don't have resources, if you don't have time. (Professor Joanne Neale, King's College London)

The second way that service users can shift the balance of power in their favour is by participating on a collective basis, by forming advocacy groups, and by formulating shared demands:

If you have participation from a service user group, I also think it gives you, like, an authoritative voice as an agency, you know, that you have to be taken seriously. Because that's one of the key things that's worked for us and UISCE and for Pavee Point – I mean, we're kind of a package deal – you need three organisations around the table of the Drugs Strategy that aren't just a Drug and Alcohol Taskforce. We're the only three representative bodies, if that makes sense – the rest are all chairs and coordinators from different Task Forces... So we kind of stick together. ... And the fact that the three of us have structures that enable service user participation means that we do have much more of an authoritative voice. (Aoife Frances, National Family Support Agency)

The third way in which people who use drugs can shift the balance of power is through direct involvement in service provision, as Eberhard Schatz of the Correlation Network observes, arguing that this can be seen as the ultimate aim of the 'cascade' of user involvement, from consultation to shared decision-making, peer co-production, and self-determination:

[By focusing only on service user involvement] you exclude what is for me an even more interesting development than user involvement: the self-organisation of users. Sometimes it's an informal group, sometimes it's a registered entity, sometimes they work with services giving advice or being a critical voice in case of complaints and things like that, or even developing their own services for the community. ... I mean, that for me is the highest form of involvement. And if groups (or however you want to call them) achieve that – if they run a needle exchange programme, I mean – that is perfect, because they know exactly where the people are, they know what they need and so on – and they are acknowledged as part of the services. So that is really the best way to do it. (Eberhard Schatz, Correlation Network)

However, these developments must be supported in an appropriate way, so that professional expertise is integrated with lived experience and the preferences and needs of service users are considered:

If people with personal experience of addiction are running treatment services, they'll certainly be very attuned to it [service user involvement]. But you could also argue that if somebody's been through treatment themselves, they might have strong views about what works, and that might be based on their experience. So the question is, can they

stand back from their own personal experience, and take a more objective approach to it? (Professor Joanne Neale, Kings College London)

The fourth form of social power at play within the context of drug treatment and harm reduction services derives from the corporatist mobilisation of professionals in defence of their own interests and occupational culture. This can lead to a defensive orientation towards organisational change within drug treatment services, which in turn can obstruct innovations in professional practice. Eberhard Schatz, whose organisation in Amsterdam runs drop-in centres, night shelters, consumption rooms, mental health programmes, and harm reduction services, provides the following example:

> *We had examples in our own organisation, with social workers, for example. If you open up to peers, they sometimes feel attacked… Maybe not attacked, but you can have a kind of competitive situation where a peer – who didn't study counselling or whatever – comes and says, "Hey, this is the way, I do it like that." That is sometimes difficult for professionals to accept, and to see that as providing a new way to communicate and to help and serve people. So that is also an internal issue which is sometimes difficult.* (Eberhard Schatz, Correlation Network)

One of our interviewees describes another professional culture which is linked with the traditional model of psychiatric care in mental health institutions:

> *The treatment of addiction has somehow ended up in the realm of the psychiatrists… And they still have this whole approach, that somehow, addiction is a problem, addiction is a psychopathology, addiction needs to be controlled. … I think that the idea of control becomes paramount, the addiction needs to be controlled… the patients need to be controlled.* (Anonymous Dublin doctor)

Professor Sarah Morton, Director of the Community Partnership Drugs Programme at the UCD School of Social Policy, Social Work and Social Justice, stresses the importance of developing professional practice in a coherent and uniform manner within each organisation, providing incentives for practitioners who are willing to engage with service users in an open and collaborative fashion:

> *I don't think you can compel them [practitioners], because straightaway, the first place they need to start is that their service users are equal, if not, you know, of greater value than them as experts – that's very challenging. So I think that you can make recommendations, you can set up structures. … But you can never enforce that. I think you can make it very attractive. … I think you make it attractive by funding. … So where there's prizes, awards, profile, money, and positive feedback, and people experience the benefits, then they'll change as organisations.* (Professor Sarah Morton, UCD)

Finally, several stakeholders emphasised that policies and guidelines can also help to shift the balance of power towards service users by encoding their rights and entitlements:

> *So a lot of them have told us: "I'd never make a complaint about my clinic, never. No matter what they're doing, I would never make one." Because you're basically complaining to the person who you're complaining about, you know. It's not independent, it's all in-house, so it's never going to work – it's not independent. … We've involved the Ombudsman… we have identified an avenue where you can make a complaint, and make a proper complaint, and we're trying to really educate service users to do this, to take that fear away.* (Dr Richard Healy, SURIA)

Summary

The stakeholders we interviewed identified five key sources of social power that need to be considered in relation to service user involvement in drug treatment and harm reduction services: (1) access to resources, (2) collective participation, (3) direct involvement in service provision, (4) professional corporatism, and (5) public policy. Starting with the first of these, our interviewees noted the importance of providing public funding for advocacy organisations as well as increasing staffing levels so that practitioners have the time to build better relationships with clients. Where service users formulate shared demands and organise autonomously to develop services, this can also shift the balance of power in their favour. It is easy to overlook the challenge that service user involvement poses to established occupational groups, whose prestige, influence and power are sometimes reflected in specific ways of organising service provision. There is thus a need to develop and unify professional practice in order to embrace this challenge by creating material and occupational incentives that reward innovation. Finally, stakeholders noted the need to strengthen the entitlements and rights of service users by means of policy, by creating effective and impartial procedures for registering complaints, requests and suggestions, for example.

Theme 3a. The organisation of drug treatment services

Another issue that can exert a considerable influence either on facilitating or obstructing service user involvement is the organisation of drug treatment services themselves. We touched on this earlier in this chapter, when we contrasted the large drug treatment clinics in Dublin with smaller clinics, perhaps based in the primary health system. One interviewee emphasises the role that medically managed clinics can potentially play within the system of drug treatment and recovery:

> *I know of other clinics where they don't have any security. ... And I think they may on occasion transfer a person from one clinic to another if there are behavioural issues – I think they do it rarely, maybe once every few years – but they don't exclude. If you are excluded from one of the main clinics... I have come across cases where they have nowhere to go and basically have to go back onto drugs as they cannot access methadone or other treatments.* (Anonymous Dublin doctor)

A similar approach is adopted by the Ana Liffey Drug Project: "We keep the barriers to availing of our services as low as possible, and we don't bar anybody from our services. We may have to tailor the service that we can provide them with. The challenge – to think of ways to remain engaged with people who need our support – is ours and not the other way around" (Tony Duffin, Ana Liffey)

Another example of how a different way of organising and delivering services can facilitate service user involvement is the Better Together project in the South East Regional Drug and Alcohol Task Force, which was established in the context of the COVID-19 pandemic and related restrictions on physical meetings. The use of online meetings facilitates a collaborative approach by allowing regular meetings where each participant – practitioner or service user – is treated as an equal:

> *It's people with lived experience and professionals working together to provide support for people with substance misuse and mental health challenges. So everything we offer*

is done from a co-production point of view. We start every morning with a spiritual group at eight o'clock. We have an 'Open the door to recovery' group for people who are coming in or being referred, or are coming in themselves, at a quarter past nine in the morning. At 10 o'clock in the morning we have a check-in, and that's where people just come in and say what's ahead of them for the day: maybe what are their challenges and what tools are they going to use in order to kind of embrace the day. We have a reflection at night, we have a women's group on a Tuesday and an anxiety group on a Wednesday, we have a family group on a Thursday and we do 'emotional hangovers' – a series that we're doing now at the moment, after Christmas. Every single thing we do is done through co-production. So we all work together. (Jim O'Dwyer, SERDATF)

These examples highlight an interesting challenge for all services that target vulnerable or marginalised populations, including migrants, homeless people, sex workers, people who use drugs, and those from the LGBT+ communities. This challenge is whether service providers and practitioners who are sensitive to the needs of these populations should seek to meet their needs directly by changing their own practice or whether they should focus on changing services more generally. This tension can give rise to acute personal and professional dilemmas, when practitioners are faced with the reality of discrimination and marginalisation across the system.

By welcoming people who use drugs into their services and practices, listening attentively to their needs, and working in an open and collaborative way in order to identify solutions, practitioners who have the human and professional qualities that are necessary in order to establish supportive therapeutic relationships with people who use drugs tend to attract other patients who are in a similar situation. At the same time, they may even repel 'mainstream' service users, giving rise to 'niche' services where members of marginalised groups feel more enfranchised. This leads to a polarisation in service provision, which lets the mainstream services off the hook. Arguably, what is needed is greater commitment across the system, and at all levels, to generalise the insights and experience of those exceptional practitioners who have built social inclusion into their services and found ways of encouraging marginalised service users to get involved in treatment decisions and service development. Rather than being ghettoised and abandoned to their 'vocation', these practitioners and services should be rewarded and used as a tool to improve other services:

You do see a bit of change, even a change in language, how they use language around user involvement. At the higher level – at managerial level, and policy level – I don't see a whole lot of change. ... Where we need to see the change in Irish policy is in that leadership at managerial level, to see that managerial buy-in. Because if you have managerial buy-in, you are in a great place to begin looking at service user participation embedded across the whole service. (Gordon Kinsley, SRDATF)

Rory Keane provides a useful framework for tackling this dual challenge of engaging service users and developing organisational capacities against the backdrop of community development. This formulation emphasises the potential benefits to the population as a whole, as inclusive services are not only better at supporting marginalised groups but are more effective at identifying and addressing the needs of service users in general:

There is a lot of evidence in relation to health care that shows really important things: there is staff engagement, in terms of really working with the staff to engage and be committed to their work and their mission. And also your engagement with service users and your patients. Two relatively simple concepts, but they are hard to do. They

pay real beneifts in terms of better outcomes. ... The second thing is, I suppose if you look from a public health perspective, a lot of public health is around bringing public health issues down to the local community. ... If you want to see changes around problematic drug use, you also need to look at it from a community dimension, and part of it is around people and communities who are marginalised and don't have a voice. (Rory Keane, Regional Drug Coordinator)

Summary

The organisation of drug treatment services is an important factor in relation to service user involvement. Some services have found that the use of online meetings facilitates a collaborative approach by allowing regular meetings where each participant – practitioner or service user – is treated as an equal. There is however a risk that more inclusive services can become niche services – islands in a sea of indifference – which lets other services off the hook. What is needed is greater commitment across the system to generalise the insights and experience of exceptional practitioners who have found ways of encouraging marginalised service users to get involved in treatment decisions and service development.

Theme 3b. Procedures for making decisions

This is a complex theme, and the stakeholders we consulted provided a rich range of perspectives on the role of procedures in relation to decision-making. It is perhaps appropriate to start with one of the problems that was most frequently mentioned during the interviews: the challenge of implementing shared decision-making within opioid agonist therapy:

It is really difficult. There is no other medication that I would ask the patient what dose he would like to take. I am just thinking this out and this isn't [necessarily] my opinion. Medically and indemnity-wise, me going to medical school for 12 years is to take prescribing decisions. And if we jointly take a decision and it causes the patient harm, I am really at fault. ... From methadone, patients want to come off really quickly. And I know from experience – beyond this patient, because of my training – that the risk of overdose is massive. And the patient may say: "I want to come down." And I say: "No, I think we need to hold." And they say: "Well, this isn't shared decision-making, I want to come down." What I am doing is I am not denying – okay, well I am, if I make that decision, I am denying... I suppose it's how you go about explaining. I have no skin in the game, I have nothing to gain by not reducing somebody, but I know from experience that if you come down very quickly, your risk of overdose is higher. And usually from experience where I have done this in the past, people come back and say: "You've let me come down too quickly, what were you doing?" ... Even with the absolute will to have this kind of shared approach, you are trying to keep somebody safe. (Anonymous GP)

But if I'm telling you that I've been on methadone for 10 years, and I would like to come down, or I want to get off methadone, even if you know that it's going to be challenging for me – because I'm sure it will be, and maybe you have experienced it with other patients – at least listen to me and validate that experience. And let's talk and let's kind of agree on how we can do it. (María Otero Vázquez, UISCE)

[In the Task Force] most of them were still on long-term methadone on the service user forum, and they didn't want to be on methadone anymore. And there was this power imbalance with the prescribing doctors. That's the other level, that's where, you know... The doctors felt that they should be on low-dose methadone... and many of them said, "I really don't... I'm being held back. I want to be completely clean. I want to get on with my life, and I have this, this, this shackle around my leg, held by the doctor." And these were people that were on methadone for over 20 years. (Anonymous academic researcher)

Tony Duffin of Ana Liffey links this issue with the broader question of the management of clinical risk within professional practice: "It has been said that the management of clinical risk has become a barrier to service provision." This highlights the way in which systemic factors such as legislation, liability, and professional self-governance can influence the way doctors manage the prescription of methadone, reducing their willingness to consider reducing methadone with patients who may be at risk of withdrawal, relapse, or overdose. It also suggests that concerted efforts will have to be made – involving not only service users, but also policy-makers and representatives of professional bodies – in order to create a space within which GPs and patients feel adequately supported to work collaboratively towards recovery.

The next issue that was raised by our stakeholders relates to obstacles to involvement by drug treatment service users. The following extract provides an overview:

I think somebody who is actively using drugs a lot of the time, they won't be interested, you know, in goaltending things unless there is something in it for them, more or less. If they're really, really, really annoyed, you will get them to engage. And as you said, you put it nicely there, they will 'have more pressing issues' if they're actively using substances. And those pressing issues are a thing called addiction, which will consume them and allow them and want them to be actively using drugs. So everything else goes out the window from that point, because it's this thing of "Oh, yeah, well, it would be nice to be able to sit here and talk to you about my problem, but I'm busy, I have to go and get drugs, I have to go and get the money for drugs, or I have to go and make it to the clinic, or I have to go and do what I have to do." And I find that when people are on opioid substitution treatment, they kind of mellow out a little bit, and that's when you can probably... It's easier to get them to engage with service user forums and stuff like that. (Brian Kirwan, HSE Manager)

All of the stakeholders we interviewed were in agreement that service users do not always want to get involved in deliberations about policy and service delivery, as Eberhard Schatz observes:

The idea that if you open the door, then everybody's happy and wants to take part and is active in preparing, delivering or even thinking about new policies – no, that's not the case. It's only a smaller group. But it's the same, I think, on the side of professionals: the majority of professionals working in services don't think too much about policies and things like that. They just work, and they have their 8-hour job and that's it. So that is maybe not even such a big difference – there are only a few who are really thinking more and trying to improve and to develop. (Eberhard Schatz, Correlation Network)

Rory Keane recounted his experience of trying to encourage service users to get involved in debates about service delivery: "We have been looking at this with the Drugs Task Force in the Midwest in the last 3 or 4 years: how do we do this in a way that is meaningful and kind of effective? Our conclusion at the minute is that it is difficult to do it properly and it's difficult to

do it right." This is due to the complexity of the challenges that many service users have to deal with in terms of day-to-day pressures around substance use, homelessness, and mental health problems, but also in terms of orientation, skills, motivation, and resources:

> *A lot of people are so marginalised that they are really living kind of moment-to-moment, because of these environmental stresses around them, and in terms of the trauma they might be carrying within them. Their focus has to become very, very short-term, in terms of: How do I get through the next couple of hours, the next day?' That kind of space to contemplate about 'what's going to be best for me' is very difficult to do, because they are thinking about what happens NOW. So certainly that lack of social support people are having, their lack of very, very basic needs being met, is an enormous obstacle in terms of people's own recovery and in terms of engaging them in that kind of service user involvement space.* (Rory Keane, Regional Drug Coordinator, capital letters show emphasis)

> *You can definitely see it [user involvement] should be a win-win situation, but there are... different intended and unintended consequences. For example, if you are consulted at every step of treatment decision-making, it can slow the whole treatment process down.* (Professor Joanne Neale, King's College London)

As a result of these pressures, some practitioners rely on relatively informal processes of involvement, which place less of a burden on service users and can take into account the 'ups and downs' of their journey towards recovery. The search for appropriate procedures should be taken seriously in the study of service user involvement, as it can lead to important innovations within professional and organisational practice. As Rory Keane observes, "One of the things we have looked at and haven't been able to do yet is: 'How do we capture and amplify the voice of the service users in terms of their experiences? Who can work with service users to support them?'"

As we saw earlier, advocacy groups such as UISCE, the National Family Support Network, SURIA and the CityWide Drugs Crisis Campaign have also tackled this issue, and have found that a relatively informal network of representatives, peers, volunteers, and service users can be mobilised quickly and effectively to consult people about key issues and to encourage them to get involved in research, debates, and consultations. Most stakeholders were in agreement that form should not prevail over function, and that structures such as service users' forums, for example, do not always represent an effective response to the challenge of user involvement.

Professor Sarah Morton has experience of establishing and developing structures to facilitate user involvement in the area of residential drug treatment services. Her views are worth quoting in full, as they deal directly with the crucial question of how one can actually build up practical structures that encourage service users to express their opinions:

> *You get this really odd mix of feedback and input from the clients – including the women. About 40% of it is about the washing machines, the plumbing, the showers, the furniture and the meal times, and access to Netflix. ... I think the other 60% is very real, it's very gritty, it's very, you know... If we're particularly talking about women in residential settings, you know, it's being really confident about saying, "We need more of this, we need less of this,?" you know... So from that I have surmised that if you put a lot of work into the structure of the feedback and participation, and if you work really hard to make that normalised, you get really rich information and feedback from service users. ... So I think there has to be a designated structure, and there has to be*

clarity on the purpose of those structures. … And of course, an ongoing structure needs to be constantly reinvigorated, because otherwise it becomes an empty shell. … And, of course, if you have an ongoing structure, what are you going to do? You're going to discuss the toilets and the showers and the door that doesn't lock properly before you're going to have, you know, some of those really difficult emotional conversations. … And these are really uncomfortable spaces, because… you're asking people to collaboratively work together, and for those who have less power to critique what you're doing. And if you're not able to even have a conversation about that as line management or practitioners, how are you going to design systems that are actually going to work? (Professor Sarah Morton, UCD)

The key point that emerges here is that even relatively simple and straightforward forms of consultation – such as introducing a comments box or using feedback forms – demand that service providers address their own issues in terms of hierarchies, organisational culture, professional practice, and managerial commitment:

If there are tensions between line managers and staff… and it doesn't matter what they're about, but if they're there, that's going to create a significant block. … I think it's because in order for your service user… for that to be a generative, positive experience, they need to see something modelled. So if the practitioners they're working with cannot model respect and collaboration and inquiring conversations, then you can't expect your service users to do that, because although they have greater expertise, they also have greater vulnerability. (Professor Sarah Morton, UCD)

Summary

Systemic factors such as legislation, liability, and professional responsibility can influence the way practitioners manage decision-making in the context of drug treatment, recovery and harm reduction services. Some stakeholders argued that concerted efforts at these different levels are needed in order to enable physicians and patients to work collaboratively towards recovery. Due to the complexity of the challenges that many service users face in their daily lives, it can be difficult for them to get involved in discussions about services. Informal processes of involvement have the potential to provide these service users with a voice, even where they are unable to participate in committees, fora or conferences. Advocacy groups also use informal interactions to consult people quickly about key issues. Their networks of peers, volunteers, and service users could play a supporting role during the transition towards more inclusive services. In this context, it is important for service providers to be aware that even relatively simple forms of consultation demand that service providers address issues such as organisational culture, professional practice, and managerial commitment in order to ensure that a coherent and effective approach to service user involvement is adopted at the organisational level.

Theme 3c. The importance of (small) innovations

As many of our stakeholders observed, service user involvement is motivated not only by the principle of inclusion but also by its potential to generate innovations in relation to policy and services. Shared decisions are often better decisions, it is suggested, as they draw on the experience and knowledge of those who actually use services. In this section, we explore how our stakeholders described this capacity for innovation, and how user involvement enabled service providers to identify better policies and procedures in specific contexts. Aoife Frances provided the following example:

> They wanted to basically develop a consistent framework across all their HSE rehabilitation and treatment centres... We managed to get a family support question in where they're doing the needs assessment with the person who uses drugs. There's now a question where they say, "Do you have a family member? Would you like them to be involved?" ... So the trigger is supposed to be that if they say yes, then they are referred directly to us, the family member is referred to us. (Aoife Frances, National Family Support Network)

Another example of innovation, inspired by the recovery movement, is described by Brian Kirwan:

> What's next is a recovery café, that will be able to be open for people to come and play music on a Friday night, to be able to serve a social enterprise where they sell coffee and cake and make the money that would pay for the staff, you know. It'd be a social enterprise and have AA [Alcoholics Anonymous] meetings and CA [Cocaine Anonymous] meetings and NA [Narcotics Anonymous] meetings and SMART Recovery meetings. And, you know, then to bring along other drug users because that drug user and client group – they might never become drug free, but if they get some bit of recovery into their life, they will then be able to maintain the methodology, or their life improves, or their health improves, and that's our job. (Brian Kirwan, HSE Manager)

Being at the centre of these debates and innovations, and seeing that they can influence services, even in small ways, can encourage service users to get involved, leading to further improvements in services and increased participation. This process must be supported by policy-makers, managers, and practitioners, and resources are required to sustain the enhanced drug treatment, harm reduction, and recovery services that are developed through involvement:

> What we've seen, I can tell from our own experience, is that when you do meaningful involvement, you'll see a really good environment, and they will want to be involved – service users will want to be involved more. So when it's done well, they want to be involved more. Meaningful engagement is actually about being willing to go on a journey with people, and it is literally about co-discovery, and that's what makes it meaningful. (Jim O'Dwyer, SERDATF)

> I've been at an awful lot of forums to do with drugs over the last 15–16 years, right? I have never heard much in relation to women in recovery. ... So what we're able to create is actually an opportunity for women where we address the issues of intimacy and recovering femininity. ... We're not talking about beating an addiction, we're talking about recovering a femininity and a dignity. We also know that eating disorders was a huge issue. So we had a 6-week group on eating disorders for women in recovery.

We had 17 women on it for the 6 weeks. And so there are things that people with lived experience want to talk about, but the services aren't hearing. ... So what we've discovered with women is that we can respond to that. We can't say, "Yes, I've heard you" and then do nothing. (Jim O'Dwyer, SERDATF)

Sometimes the innovations generated by user involvement go beyond the individual service, as Rory Keane illustrates in the following extract, where the whole agenda of intervention was altered by user involvement:

One of the things we do on the drugs side is we always talk about treatment, but treatment isn't always what people need. People often think in terms of a more general population view, that the answer to the drugs problem is treatment. Whilst treatment is obviously key, drug use is symptomatic of either historical problems or environmental stress. ... One example is... the seaside town of [name], which again would have quite serious problems with deprivation and marginalisation and quite severe drug use. We did provide treatment there... but it didn't make any difference. From discussions with them and that kind of engagement, what became apparent was for some of the more high-risk, vulnerable people there was nothing for them to do. What the Mid-West Regional Drugs & Alcohol Forum has done with the Clare Sports Partnership is to set up recreation offices where they work with these young people around occupation and recreation. It's a small thing and doesn't work for all, but what it's done is it's moved the discussion around the drugs problem away from the idea that 'It's about treatment.' (Rory Keane, Regional Drug Coordinator)

In a similar vein, innovations inspired by user involvement can originate outside the sphere of drug treatment while remaining relevant to people who use drugs. A good example is the Community Partnership Drugs Programme at University College Dublin, which makes educational opportunities accessible to people recovering from problem drug use. Once again, this extract suggests that user involvement can guide innovations in service development that overcome the boundaries between different areas of policy:

It's a really interesting programme, in that we take 20 to 25 students per year, they do a 1-year intensive programme which is also an undergraduate professional qualification. They come from a range of histories – the majority would have their own direct experience of substance use or be very involved in their family or community. ... So in its most extreme form, there are certainly some students on the programme who would have maybe left school at 13 or 14. ... So we're taking people that have that level of severe educational disadvantage, bringing them into essentially a first-year university programme and by the end of that year they're going on into mainstream second year if they so desire. It's quite challenging and quite an amazing programme. (Professor Sarah Morton, University College Dublin)

Summary

Service user involvement is motivated not only by the principle of inclusion but also by its potential to generate innovations in policy and services. Having an influence on innovations in service design and delivery – including small improvements – encourages service users to get more involved and is functional to their recovery. To be effective and sustainable, this process needs the support of policy-makers, managers, and practitioners and extra resources may

be needed to implement change. A creative approach is required, with an emphasis on inter-sectoral collaboration and identifying ways of satisfying emergent needs by accessing resources from other organisations and sectors.

Theme 3d. Patient-centred care

As we noted earlier in this chapter, we cannot assume that service users will always want to be involved in debates and decisions regarding the services they use. This is one reason why the concept of patient-centred care is so important in drug treatment, harm reduction, and recovery services, as it holds the promise of providing better care for all service users, not only those who have the motivation to participate in debates about policy:

> We often say it about community involvement. The vast majority of people in local communities don't really want to be involved at the level of deciding what the drug services are. They want them to be there. The vast majority of people, they just want to get on with their lives. So they have an interest in the specific things that impact on their lives, but generally they won't care that much and won't be engaged in other issues. And I think people who use drugs are similar: the key issue for them is that they would like to get the treatment that works for them. Some people will inform themselves hugely about it, some will link in with a group like UISCE, but a lot of people, they will just go to the service they are given. (Anna Quigley, CityWide)

The concept of patient-centred care thus resonates with informal procedures for consulting service users, such as those described earlier. Professor Joanne Neale suggests that services seeking to enhance participation should think carefully about this issue:

> I think being aware of the various things that you can do to increase service user involvement is a good starting point. So that you choose things that you're able to do most effectively and you avoid promising things you can't deliver on, and you avoid tokenism, you avoid asking people what they want and then basically going ahead and making the decision for them. (Professor Joanne Neale, King's College London)

This is not to say that formal representation is not an important aspect of user involvement, a point that stakeholders stressed, but it is worth bearing in mind that it is not the only way forward. Innovations are possible in relation to the key question that Brian Kirwan voiced: "How do we capture and amplify the voice of the service users in terms of their experiences? Who can work with service users to support them?" (Brian Kirwan, HSE Community Healthcare Organisation, Dublin North City and County). The procedures used to 'capture and amplify' the voice of service users are likely to vary depending on the type of service concerned and the local context, just as support structures vary:

> Obviously, the whole idea of having groups – you know, service user groups… I know some addiction treatment services did surveys of their own patients… just to get feedback on what they felt the service was… that they were providing for people. That helped inform them on how they provided the service. You know, I think also there is constant representation in terms of getting their voice heard. (Anonymous Dublin doctor)

> For me, as a practitioner, for me as a professional, right, one of the things – the

first things – that I had to let go of was my own fixed idea about what service user involvement was. So in the Southeast, we interviewed 80 people in recovery. … And we asked them a question: "What were the barriers to education and treatment?" And what they came back with was pretty astounding. What they told us was that none of it was working. … Well, they did say what they wanted was social connections. So what we did was we set up a recovery centre in Kilkenny, for people in recovery. … And we started to get involved in recovery colleges, and out of that… That's how we ended up with Better Together. (Jim O'Dwyer, SERDATF)

João Goulão emphasises the importance of working on these different levels, in order to empower service users within the context of treatment, with a view to enhancing their self-esteem, improving services, and achieving better outcomes:

You know, I think that there are two levels of participation. One with the organisations that lobby, that advocate for several movements. Another level is the very pragmatic and very, very basic response to effective needs. … I think there's a lot of movements of the two, to create more and more organised participation of civil society, including organisations of users. But I'm really interested in having a more close relation, with more pragmatic inputs coming from those users or organisations. (João Goulão, SICAD)

Another key issue that the concept of patient-centred care highlights is that treatment plans must be appropriate for service users, rather than being standardised:

There is a diversity of needs of people who use drugs… the diversity of that isn't really matched by what is out there in terms of treatment. Like with somebody recently, you know, they were saying, "Oh, I'm only using a little bit of heroin at the moment, like just smoking a little bit of heroin, but mostly I'm using tablets and smoking crack, you know." But someone was trying to advocate for them to get on methadone. … And I was like: "Well, if you don't want to go on methadone, you shouldn't have to, you know, you should… have some other option, you know what I mean, rather than going on opiate substitution treatment." (Lynn Jefferys, UISCE)

Around choice of treatment, I mean, there's Suboxone and other drugs out there, which are far more effective than methadone, and you don't get offered them in Ireland – it's methadone or nothing. And that's what we mean by choice of treatment. And if you want to take an abstinence approach… there's very little opportunity for that in Ireland. … So there's no choice, it's these long clinics and the clinics then become just life-consuming. (Dr Richard Healy, SURIA)

Summary

Patient-centred care seeks to make providers more sensitive to the needs and preferences of their clients. Practitioners talked about crucial moments in their professional development in which they learned out how to give service users a voice and how to actively listen to what they were saying. They described how this enabled them to match treatment and other support more closely to what service users actually needed, rather than making assumptions or adopting a standardised model of care.

Theme 3e. Outcomes

In our discussions with stakeholders, the issue of treatment outcomes was rarely addressed, for reasons that Professor Joanne Neale explains in the following extract:

I'd like to be able to say that user involvement improves treatment outcomes, but I don't think we've ever done an RCT [randomised controlled trial] to actually say that. So as a researcher, one has to be a little bit cautious about saying that. It's certainly the case that people who've been involved in treatment decisions are more satisfied with the treatment, and probably stay in treatment longer – we know that retention in treatment is associated with good outcomes. But I think it requires a more complex, sophisticated study design to actually draw the conclusion that there's strong evidence. I don't think we have that kind of evidence yet. (Professor Joanne Neale, King's College London)

Theme 3f. Representing service users

The stakeholders we interviewed as part of this project had much to say about the representation of service users at various levels. This is a complex issue, and it is important to understand the historical, cultural, and political context of drug treatment services, the differences between urban and rural areas and how these affect services:

There was not only a little bit of a pull factor from the policy-makers, but there was a bigger push factor in that service users were absolutely furious with the way they were being treated. There was a lot of anger. So in those initial meetings [in the 1990s], there was a lot of anger. Our job was to try and filter that anger a bit, try and make sense of it, try and get people a bit organised. ... To get them in to talk with people about what maybe was possible. So that was the birth of it. Out of that came a more structured UISCE, that was called the Service Users' Forum, SUF. (Joan Byrne, CityWide)

There was a huge amount of anger and that. ... It emanated mostly from one clinic, the largest clinic in the North Inner City – City Clinic – that's where a lot of the service users that we were working with went... They felt that they weren't being listened to, they felt they were being treated by some doctors very badly, a lot of people were angry, upset, tearful, frustrated, and a lot of people had died as well from overdoses. ... But certainly what we were able to do with those initial meetings – and they were very well attended – the room was packed – so what we were able to do as kind of facilitators or supporters of this process, we were able to gauge the level of anger. ... But we needed to be able to get people to sit down and think that it's possible to change things. That wasn't easy, because people didn't trust what was going on over there. (Joan Byrne, CityWide)

As services were developed through the Drug Task Forces in Ireland, there was an awareness that service user representatives could get involved:

There were discussions about who should be involved in these networks: "It should be only people who are no longer using or only people who are engaged in services, and not people who are using drugs and disengaged from services." Those issues are still

quite live there: which are the voices that you consult with? What are the people that you are bringing in as part of your participation strategy? Of course you need to link to people who are not engaged to services to ask why are you not engaged with services? A lot of these issues emerged very quickly and I think a lot of them are still there... So that was the 2000s. (Anna Quigley, CityWide)

This process was contradictory, because commitments to service user representation at a policy level were often not matched – according to most stakeholders – by an adequate commitment to implementing this principle. Failure to understand and to address this contradiction within the key organisations providing services may have contributed to the decline in service user involvement in recent years.

More recently, UISCE has been joined by SURIA, which focuses on achieving change in drug treatment services through dialogue with policy-makers and service providers, and through independent research and a focus on individual rights:

[Most] members would be either still using drug services, using methadone, or else formerly have used them. ... And so what we would do is we would go out – it's peer-led research – we would go out and actually collect the research ourselves. And I would usually write it up then, and then we would take that to key stakeholders. We've had dialogue events where we've had service users and service providers... where, you know, we'd have service users discussing their narrative of use and services, and service providers discussing... from their side. (Dr Richard Healy, SURIA)

In Ireland, this contradiction has assumed a particular form: on the one hand, representatives are increasingly represented on national committees and the National Drugs Strategy, due to lobbying by groups such as UISCE and SURIA, and due to the support of other organisations and actors. Alongside positive movements at the level of policy, legislation, and national structures, this creates the impression that service user involvement has made progress. On the other hand, those involved with service users on the ground have observed a decline in user involvement over the same period:

If you read our National Drugs Strategy, it very clearly states the importance, how crucial it is to have communities involved in key decision-making. It doesn't say consultation, it says decision-making. But there is a lot of frustration that it's not at the decision-making level. We are consulted when the agency, whoever... If they want to consult you, they will. If they don't want to, they won't. ... The decision about when and where the consultation would happen is not actually taken at the table where we all sit, it's taken back in the agencies, and that is one of the ways we have gone backwards. (Anna Quigley, CityWide)

As this process has continued, and Task Forces have experienced greater difficulties in including service user representatives, advocacy groups such as UISCE, the National Family Support Network, and Pavee Point Traveller & Roma Centre have been asked to fill this gap: "Our organisations are bringing our service user group together to get input, and then bringing it back to the Strategy – that's kind of the Strategy's way of ticking the box and saying, 'There is service user participation'" (Aoife Frances, National Family Support Network). Several stakeholders highlighted the importance of involving families whenever possible, but also emphasised the difficulties inherent in this process:

Often when family members call the service, I would talk to them and explain in very

broad terms that "unless your adult son or daughter gives us permission to talk about it, unfortunately because of their right to confidentiality we cannot share information, but that is not because we don't want to". So family relationships, often being very broken and fractured, makes it tricky. Sometimes family relations can be of enormous support. (Rory Keane, Regional Drug Coordinator)

Brian Kirwan observed that "The Dublin Task Forces are struggling to maintain service user representation, and most of them do not have a rep [representative] who feeds into a network of service users, or a functioning service user forum" (Brian Kirwan, HSE Community Healthcare Organisation, Dublin North City and County). The HSE aims to address this situation by working with advocacy groups to identify service user representatives in the Task Force areas and to strengthen their support base and networks. María Otero Vázquez described how her organisation seeks to facilitate the participation of people who might otherwise be excluded from public consultations:

The language that was being used for the questions [in the consultation about the National Drugs Strategy] was completely inaccessible, it was assuming loads of knowledge that people would have in terms of structures of services or treatment... So we had to do a lot of work when it came to... informing people about what the questions were... And we went out and asked people, and then we had our submission for the Department of Health, and I think back then we talked to around 90 people. (María Otero Vázquez, UISCE)

We referred earlier to the importance of informal methods of user consultation within the model of patient-centred care, noting that this can enrich and complement the formal representation of users on forums or committees. Jim O'Dwyer from the South East Regional Drug and Alcohol Task Force argues that involvement has to be part of everyday practice and must reach all service users, a point also made by other stakeholders:

I don't know an Irish general practice that has a patient involvement group, for any purpose, not to mind with this. It would depend why it's done and how it's done, that it's not tokenistic. ...I think it's a no-brainer once it's done at a disaggregate level, so it's not me having to have a group at my practice. Maybe in, for example, Community and Healthcare Organisation Area X – maybe to have a patient group at that level. And again, there is no point unless there are clear aims and there are things that they can actually change. (Anonymous GP)

Tony Duffin argues that any difficulties in setting up forums and representative structures for service users do not necessarily prevent service providers from taking their ideas on board:

Over the years, for our strategic planning processes, we have engaged with our service users about the activities of the organisation. We go to people and ask them their opinion on issues. People tell you 'This wouldn't do anything' or 'That is a good idea' and you move forward collectively with service users and funders, staff, and board members. (Tony Duffin, Ana Liffey)

At the same time, developing a well-functioning service users' forum, with representatives participating in decision-making, is a valid goal for Task Forces and service providers, as long as they are committed to supporting service users to get involved. The following extract helps to focus attention on how important it is to fully support representatives who agree to serve on decision-making bodies:

I remember, when I was facilitating a cross-Task Force group... we had a service users' rep – really good – and the service users' rep said at the time, and it was really huge for him to say it... people were kind of frowning at his participation – he wasn't turning up – then eventually, with a bit of support he said: "I live hand to mouth, I didn't have the bus fare." ... The coordinator didn't even realise. (Anna Quigley, CityWide)

We encountered a number of positive accounts of how formal representation can work effectively within drug treatment services. For example, an academic researcher described her experience carrying out research in a Task Force, where "they had their own service user and they were very vocal and very clued in. And they really wanted us to get the right information. And the approach there was different, the Task Force was much better at including them." Another positive experience was recounted by Rory Keane:

We are lucky in the Mid-West [Drugs Task Force], we have a very high functioning forum, so people work very well together there. ... We have done a lot of work with the reps coming from some of the affected communities ... It's quite an intimidating structure – the full Task Force when it meets could be up to 31 people, you've got people there from statuary agencies, from the guards – but we have done a lot of work in the Mid-West trying to – again addressing those power imbalances – make it a forum where... Our chair is very good at inviting in all different perspectives in terms of facilitating those consultations. (Rory Keane, Regional Drug Coordinator)

Summary

The stakeholders we interviewed described the complexities involved in ensuring the representation of service users. In the 1990s, public meetings in Dublin enabled service users to express their grievances for the first time: they weren't being listened to and felt angry and upset about how they were treated by practitioners in the clinic system. This process influenced the development of the Drug Task Forces, but formal commitment to service user representation was not matched by practical efforts to empower service users within treatment. Advocacy groups played an important role in making the voices of service users heard, but service providers have been slow to adopt new methods of service delivery that embrace informal as well as formal engagement and promote service user involvement. A key issue is that service users will not provide critical feedback on services – which is essential to service user involvement – unless they feel secure, safe and respected when attending services.

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Service users' experiences of user involvement and the factors that promote successful participation

The focus of this report is service user involvement, and it is important that the voices of service users themselves are included within it, not just those of practitioners, experts, researchers, and representatives. To this end, we developed an innovative research design based on multistage sampling and the use of digital technology in order to conduct online interviews with 24 service users from around Ireland. This aspect of the research was complex, and we carefully studied every aspect of the process of contacting service users, obtaining informed consent, speaking with them, safely archiving recordings and transcriptions, minimising risk, and ensuring that support was available to the participating service users after each interview. Ethical approval was provided by the Royal College of Physicians of Ireland in August 2021 (see Appendices 6 and 7).

This phase of the research was supported by UISCE, SURIA and CityWide, and we discussed the research design with representatives of these organisations in order to gather their observations and to learn from their experience. All three organisations have considerable experience of research involving people who use drugs and with the users of drug treatment, recovery and harm reduction services. Their advice was very valuable during this project as it enabled us to contact a wider range of service users than would otherwise have been possible and to increase our capacity to achieve acceptance and consent.

In the first stage of the sampling process, we contacted service providers, practitioners, and voluntary groups in different parts of the country in order to request their assistance in identifying service users who might be willing to participate. In some cases, this required a formal decision by a governing board or management committee. All organisations we contacted agreed to help us and contacted service users. After hearing about our project, any service users who were willing to participate were given the phone number and email address of the principal investigator and invited to make contact in their own time. In some cases, service

users asked to be contacted by phone, or a service provider or advocacy organisation set up the interview or provided technical assistance.

Once initial contact had been established, an appointment was made and the principal investigator sent the participant a Zoom link and password for the online interview, together with an information leaflet. At the agreed time, the participant used the link to open a videoconferencing session with the principal investigator. At the start of the interview the researcher summarised the information in the leaflet and obtained informed consent to record the conversation. One participant preferred not to talk over Zoom, due to lack of familiarity with this software, so the interview was carried over the phone. Any link between the interviews and identifying characteristics of participants (name, address, email, etc.) was avoided by using numerical codes.

The interviews were conducted between December 2021 and March 2022, in the form of semi-structured online (Zoom) interviews lasting about 45 minutes each (on average). During these encounters, we elicited service users' opinions and experiences of services, service providers, opportunities to receive information, and to participate in decision-making. The tone was informal and participants were encouraged to bring up any issues that came to their minds. Nearly all of the interviews were recorded and transcribed in full and a thematic narrative analysis was conducted. All interview volunteers were provided with a €25 voucher to thank them for the time they took to engage with the project.

Following the approach adopted during the analysis of interviews with stakeholders, we will use the categories identified earlier in order to describe the findings of our service user consultation. This facilitates the convergent analysis of these different sources of information, and covers the main themes that arose during the interviews:

Theme 1: The relationship between service users and practitioners

1a.   Building and maintaining trust
1b.   Showing empathy
1c.   Creating a space for effective communication.

Theme 2: Social power

2a.   Stigmatisation
2b.   Policing moral and social boundaries
2c.   Shifting the balance of power.

Theme 3: Organisational practices

3a.   The organisation of drug treatment services
3c.   The importance of (small) innovations
3d.   Patient-centred care
3e.   Outcomes
3f.   Representing service users.

The average age of participants was 43, with the youngest being in their late 20s and the oldest being in their late 50s. We interviewed a roughly equal share of men and women, with 14 participants living in Dublin and 10 in other parts of Ireland, mainly in large towns. When quoting extracts from the interviews, we indicate the gender and age group of the participant where this is feasible from the perspective of confidentiality. All interviewees had accessed drug treatment, harm reduction or recovery services over the course of the previous year and had first-hand experience of many different types of service, including statutory, private, and voluntary services.

We make sure that our interviewees are anonymous and that no individuals, services, or organisations can be identified by reading the extracts. This is why we do not identify the gender of any practitioners referred to in the interviews (we use he/she/they as appropriate). We have taken care to only present themes that emerged in several different interviews. Even where we cite a single extract, this was carefully chosen to represent a broader phenomenon rather than the idiosyncratic experience of a single individual. In fact, the similarities between the accounts of service users were striking, considering that they attended a range of different services in various parts of the country. This suggests that the obstacles to service user involvement discussed in this chapter have their roots in structural features of the drug treatment and recovery system in Ireland.

Our interviewees described their experiences with services, focusing on the relationships and structures that either facilitated or prevented them from influencing treatment. It was therefore necessary to identify passages directly relevant to the theme of service user involvement and to exclude those which discussed other aspects of services, which we hope to explore in subsequent publications. The material presented in this chapter is relevant to the involvement of service users within the treatment setting and the organisation of services more generally. However, only a small number of interviewees had experience of representing service users or participating in wider discussions about the design or organisation of services.

Summary

In order to ensure that the voices of service users were included in this integrative evidence review, we developed an innovative research design and interviewed 24 service users from around Ireland. This phase of the research was supported by UISCE, SURIA and CityWide and we discussed the research design with representatives of these organisations in order to make the process of participation as acceptable and safe as possible. In the first stage of the sampling process, we contacted service providers, practitioners, and voluntary groups in different parts of the country in order to identify service users who were willing to participate. The interviews were conducted between December 2021 and March 2022. Participants were encouraged to bring up any issues that came to their minds during semi-structured interviews. The average age of participants was 43, with the youngest being in their late 20s and the oldest being in their late 50s. We interviewed a roughly equal share of men and women, with 14 participants living in Dublin and 10 in other parts of Ireland.

Theme 1a. Building and maintaining trust

All of the people we interviewed believe that relationships between service users and practitioners should be based on trust. Their accounts are very similar to those of service users in other countries, as reported in the international literature. Trust is viewed as a constitutive element of therapeutic relationships and is described as a decisive factor in terms of the effectiveness of treatment:

> *If I was included into it from the start, I would have built up a better relationship with the doctor and I would have been easier able to go to him and say, "Look, these are my struggles" rather than: "There's the substance, put some of that in you and you'll be okay." You know, there was no relationship building there. And I think that's from the start, that I was desperate, and I was told "This is what you HAVE to do," and I felt I was trapped. Yeah. So how can I be open and honest with that person if I don't trust them?* (Interview 10, man aged 40–50 years, capital letters show any words that were heavily emphasised by the participant)

Being open and honest with practitioners about drug use, sharing thoughts, discussing traumatic experiences, tackling housing and legal problems, and seeking to understand the drivers of problem drug use in each individual case are key aspects of the treatment encounter that can only be addressed within the context of trust-based relationships. Our interviews with service users suggest that in the absence of these kinds of relationships, powerlessness, fatalism, and despair can take hold among clients:

> *Because if you fight it, you're just not going to win. It's not going to happen, and you're going to end up worse than you are.* (Interview 3, man aged 40–50 years)

A similarly resigned and despondent attitude towards drug treatment and recovery has been documented in qualitative studies carried out with service users in Ireland since the early 2000s, as we saw in the literature review. This arguably represents a rational adaptation to services that systematically fail to engage with the people who attend them and that discourage people from participating in decisions regarding their own treatment. It is easy to see how these depressed and resigned attitudes can quickly sap the motivation of people accessing services. Lack of alternatives and the impossibility of influencing treatment condemn service users to a life of silent desperation:

> *Another fellow said to me... he has to spend most of his dole on them crap tablets on the street... Because he can't get diazepam or any sort of sedative off his own doctor, so he has to go out and buy the crap on the street to feed his habit all week. And then he winds up... Like I said to him the other day when I was talking to him, I said, "You've got a lot of pizzas there!" And he says, "Yeah, they're only 69 cents in wherever." And I said, "You're not just living on them, are you?"* (Interview 5, man aged 40–50 years)

Service users generally find that there is greater openness to involvement and engagement among staff members who are at lower levels of the organisational hierarchy, and among non-medical staff:

> *Researcher:* How is the relationship with the attendants, the receptionists, and the pharmacist? Is that easier?
>
> *Participant:* The pharmacists are all great. The attendants that are there – I know

> *all of them by name – they're all great, and they'd do anything for you. But there's only so much they can do. They can't make the doctors do anything.*
>
> Researcher: *Would you say the problem is more to do with the medical staff, the doctors, rather than the others?*
>
> Participant: *I'd say it's down to the doctors.* (Interview 3, man aged 40–50 years)

One reason why more open and trusting relationships do not develop between service users and physicians is that the latter typically dictate the terms on which interactions take place, and often reduce – or are forced by time pressures to reduce – their direct contact with service users. It can be difficult, for example, to get an appointment with a doctor and service users note that doctors are only present in treatment centres for short periods of time each week or fortnight. This is not to suggest that physicians do not engage with their patients, or that they are incapable of building up trusting relationships with service users. We came across a number of examples of collaborative relationships relating to doctors in services which have invested time and effort in improving their relationship with service users:

> *I had a clinic yesterday, so I went in. "Give a sample." They trust me to go in and close the bathroom door and they trust me that I'm going to give them a sober sample, a clean sample. Do you know what I mean? And I went to the doctor then, and I'm trusted now – and this is a big thing for ANYONE to get, is a week's takeaway.* (Interview 1, woman aged 30–40 years, capital letters used for words which were strongly emphasised)

Summary

All of the people we interviewed believe that relationships between service users and practitioners should be based on trust. Being open and honest with practitioners about drug use, sharing thoughts, discussing traumatic experiences, tackling housing and legal problems, and seeking to understand the drivers of problem drug use in each individual case are key aspects of the treatment encounter that can only be addressed within the context of trusting relationships. in the absence of this, powerlessness, fatalism, and despair can take hold among clients. Service users generally find that there is greater openness to involvement and engagement among staff members who are at lower levels of the organisational hierarchy and among non-medical staff. One reason why more open and trusting relationships do not develop between service users and physicians is that the latter typically dictate the terms on which interactions take place, and often have little time for direct ontact and interaction with service users.

Theme 1b. Showing empathy

As we noted in a previous section, the demonstration of empathy is a key ingredient of trusting relationships, and service users appreciate practitioners who show that they care about them. The service users we spoke to provided numerous examples of key workers, counsellors, nurses, doctors, and managers who empathised with their plight and helped them to overcome their difficulties. Problems with housing are often a key testing ground for the development of

empathy and trust between service providers and service users in drug treatment and recovery. Even when it takes time and effort to find a solution to these problems, service users greatly appreciate the willingness of staff members to help them:

> *I showed them a picture of where I was living. Like I had a bed in my mam's, but it was, like, in a corner and there was mould everywhere. They said, "You're not living there, are you?" And I said, "Yeah, I've nowhere else to live." And they actually got me somewhere to live. It took a while, but if you keep at them...* (Interview 3, man aged 40–50 years)[23]

As we noted in our review of the scientific literature on service user involvement, expressing empathy can be challenging for practitioners, as it implies crossing boundaries, exposing oneself to the risk of failure, showing one's own vulnerabilities, and engaging emotionally with patients who may be experiencing difficulties or recovering from trauma. If you 'show you care', then, in a sense, you also 'have to care'. The resulting emotional labour has costs for practitioners – which should be recognised in training programmes, recruitment, and support structures for staff.

Our interviews confirm that the development of closer relationships can offer considerable rewards to both service users and practitioners, as it encourages engagement and retention, boosts self-esteem, and provides the foundations for more effective and satisfying professional practice. Service users often appreciate the small gestures that staff members make, based on an authentic connection:

> *And I looked down and I said, "That's [counsellor], what are they doing here?" [He/she] said, "Yeah, I just came in. I'm just checking up on you!" And they brought enough biscuits, and the teachers and all – they're all ex-addicts – and they were all saying, "Look at all the biscuits left! Let's have a cup of tea."* (Interview 3, man aged 40–50 years)

> *[He/she] goes to look for people who go missing [from the clinic]. They have found MANY people dead in their flats, you know what I mean? It's basically for that reason as well, for their safety and as well, because they went missing, they want to know where they are. Because they're not in prison – prison hasn't rang for their methadone, you know? So they know they're not in prison, so they must be at home. And that's why they go and check. And they make sure they get in the door.* (Interview 19, man aged 40–50 years, capital letters used to show emphasis)

It is also important to understand that the ability to empathise with service users is not confined to a small number of naturally altruistic or selfless individuals with a vocation for helping others. Our interviews reveal, by contrast, that most staff members can learn how to empathise with service users and build caring connections with them if they are provided with appropriate support and guidance. Influential practitioners – many of whom themselves learned this ability during the course of their professional experience – can contribute to the improvement of service delivery within their organisations. There is evidence that their mode of interacting with service users, and their caring attitude, is contagious. By providing others with an example of genuine and authentic interaction, where emotions are acknowledged rather than repressed, it is possible to gradually transform the ethos and practice of entire organisations:

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23 We avoid identifying the gender of staff members in order to ensure that they cannot be identified based on small details that may be present in the interview extracts.

And even, like, [name]'s staff, like, the nurse... She was unbelievable. She was so interactive. Like, we had a mobile number for her if we needed her, even on a Saturday or Sunday, she was there for us. She was, like a 24-hour-a-day nurse, you know what I mean? And she didn't have to be, but she wanted to be. She wanted to be able to help everyone. And that's what I mean by [name]'s team. [He/she] has people in there that I've never met... but they're now fighting... They were fighting for us to get housed. (Interview 1, woman aged 30–40 years)

I don't know what it is about [counsellor], it's totally different! What way would I put it? [pause] You feel that [counsellor] cares, that you're not just a number. [Yeah] That's exactly the way it feels. ... I'll tell you how I came to really trust [counsellor]... And I remember one night... and [counsellor] was really having a tough time and they actually spoke about it and they explained how they felt, and got upset. So to me, [counsellor] wasn't afraid or... Like, to me, that's a normal person. (Interview 6, woman aged 40–50 years)

In line with the international literature, service users point to the value of having people with lived experience of drug use working in services, and they suggested that they have the ability and willingness to trust and empathise with others:

I find that people who've been through it or come from that sort of background – you can always tell the ones in services, like workers who are from that sort of life or background or whatever, because they don't talk down to you and it's just a totally different experience talking to them. (Interview 18, person aged 20–30 years)

The greater involvement of service users within the treatment context has many important effects on the treatment process itself. For example, user involvement can help identify organisational practices that are harmful to the people who use their services. Without this feedback, practitioners may assume that they are acting appropriately and overlook these risks:

I think also, like addiction services could be more aware of certain things. Like, I had an assessment for [service] and it was REALLY traumatising both times. They were, like, 40 minutes late to see me and they don't realise that, like if you're hanging around those places, like dealers are circling like flies around a carcass. ... They ask you loads of questions that are really intense. ... I don't talk about that stuff a lot. And I got straight out of there and went to my dealer's place... (Interview 18, person aged 20–30 years[24])

All the services had so many positive things to say about "Our service is doing this and that." And then I came in and I said, "Well, actually, hold on a second. Here's an experience from a service user." And everyone was actually quite taken aback. And they said, "It's really surprising that we feel like we're doing such a good job, but then when the tables are turned, we're actually falling short in these areas." (Interview 9, man aged 30–40 years)

As we saw in Chapter 6, some service providers understand the importance of learning about service user involvement directly from people with lived experience of problem drug use and drug treatment. The benefits of doing so are potentially very great, as this is not only a cost-effective way of transforming services, it also opens up career pathways for service users who are in recovery. It is interesting to observe, in this respect, that many of the service users we interviewed said that they would like to help service users in the future, either as volunteers

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24 Capital letters show words that were heavily emphasised by the participant.

or as a career choice, following appropriate training. In recent years, a number of treatment programmes and projects have successfully promoted pathways to qualifications in social work and addiction studies for people in recovery. In this way, peer workers and advocacy organisations can contribute in several different ways to service development, by promoting service user involvement, by acting as role models for people in recovery, and by showing other staff members how to engage more effectively with clients:

> *And to be honest, I think the frontline services, which are, like, largely staffed by people who really know what it's like, or come from that sort of area or background or whatever, those are amazing. I've never felt intimidated to go down to a needle exchange or, like, talk to outreach workers and everything like that. It just honestly feels like person to person, and it doesn't feel like that with most of the system.* (Interview 18, person aged 20–30 years)

Summary

The people we interviewed provided examples of practitioners who empathised with them and helped them to overcome their difficulties. Problems with housing are often a key testing ground for the development of empathy and trust. Expressing empathy can be challenging for practitioners, as it implies crossing boundaries and exposing oneself to the risk of failure. At the same time, closer relationships can offer rewards to both service users and practitioners. Influential practitioners often influence their colleagues, and user involvement can help organisations to identify problems and risks. Involving peers within the process of service delivery is not only a cost-effective way of transforming services, it also opens up career pathways for service users who are in recovery. Peer workers and advocacy organisations can contribute in different ways to service development, by promoting service user involvement, by acting as role models for people in recovery, and by teaching practitioners how to engage more effectively with their clients.

Theme 1c. Creating a space for effective communication

Most of the service users who we talked to in the course of this project had very little contact with their doctors, and this limited their ability to communicate effectively with them. They described numerous difficulties in terms of making appointments, achieving continuity of care, and having the possibility of talking in private. The following extracts illustrate these weaknesses in communication between medical staff and patients:

> Researcher: *Did you have a longer conversation with the doctor about where you were going with the treatment and how to manage your existing use of opioids and so on? [pause] There was no conversation around how to manage that in the context of methadone?*
>
> Participant: *No, it was just "Okay, here's a piece of paper" that said start so-and-so on ten ml of methadone, "give it in to the pharmacy and come back tomorrow."* (Interview 9, man aged 30–40 years)

> Participant: What happens is in there… They don't give you the prescription. They tell the pharmacist up at the hatch and you go up there and they do all that.
>
> Researcher: You don't even meet the doctor when something like that happens?
>
> Participant: No. They pick up the phone, you barely talk to them. Even if you do see them, you're up at one end of the big office and you have to shout, and then the place is so small people can hear you, they can hear what is being said. (Interview 3, man aged 40–50 years)

> And they said, "I don't know when the doctor's going to be in, give your urine sample," which I did, and gave it back to the nurse. And the nurse then said, "I don't know when they are going to be in." And I said, "So when am I going to get me script?" And they said, "They will probably phone you later on in the day." And I said, "Well, that's not really good enough for me." (Interview 5, man aged 40–50 years)

A related issue is that many people feel that the risks and implications of their treatment were never adequately explained to them. Many stated that they had been pushed to take higher and higher doses of methadone without adequate plans being made for how they would detoxify from this, without receiving clear guidance, and without any opportunity to object or question decisions:

> A better doctor is a doctor that listens to you properly. My doctor – [name] – is only there [day] afternoon, but some [day] afternoons you'd go in and they wouldn't be there. So they leave a message when they want to see you. When you want to see them, you have to wait. It's madness! … Like, I've asked other doctors and they say, "We can't deal with you, we're not your doctor." "So what are you here for? What do you do here?" (Interview 3, man aged 40–50 years)

> And that service is just crap. It's, like, the worst service in the world. Do you know when you have to repeat yourself, like 150 times and you're like, "I'm just going to record myself and play it the next time for the next doctor, so I don't actually have to talk and waste my time!" They kept changing doctors. It was too often, like it was every couple of weeks, and the doctor was changing, do you know what I mean? (Interview 1, woman aged 30–40 years)

Summary

Most of the service users who we talked to in the course of this project had very little contact with their doctors, and this limited their ability to communicate effectively with them. Many feel that the risks and implications of their treatment were never adequately explained to them, describing how they had been pushed to take higher and higher doses of methadone without adequate plans being made for how they would manage this aspect of their treatment in the future.

Theme 2a. Stigmatisation

Perhaps unsurprisingly, the difficulties created by the stigmatisation of people who use drugs and those in drug treatment reverberate across all aspects of service users' experience. Our interviewees did not generally describe their experiences in these terms, however, as they were more likely to focus on specific episodes when they felt that they had been treated badly. This phenomenon has been observed in other studies of service access involving vulnerable social groups, where interviewees are reluctant to generalise beyond their own experience and may simply state that they were treated badly by a practitioner rather than referring to stigmatisation or discrimination.

In their interactions with drug treatment services, housing authorities, social services, and mainstream health care services, our interviewees had experienced many different forms of discrimination and disqualification. For example, when seeking medical assistance for health issues, many found that physicians defined them in an essentialist way based on their drug use – an example of the 'addict master identity' we discussed in Chapter 5:

> *Because a lot of the time I get told, "Oh well, they could be contributing – the opioids could be hiding things or this and that." And I'm like, "Okay, I'm not coming off them anytime soon. Don't even try it." You know? I also found a lot of the time consultants in the first appointment would try to blame the OST [opioid substitution therapy] for whatever problem.* (Interview 9, man aged 30–40 years)

> *Participant:*   *No doctor would take me on, it took me over 2 years to get a doctor. ["Wow"] Yeah, 2 years!*
>
> *Researcher:*   *What would they say? What would they say to you?*
>
> *Participant:*   *Full! That's what they told me, they were full [laughs bitterly]. So as soon as my name would come up, they'd say, "Like, no way, there's no way." (Interview 7, woman aged 40–50 years)*

In a similar vein, people in recovery often make comparisons between how they were treated by doctors in the period when they were in active use and after they became abstinent:

> *I hurt my back a long time ago, I had an injury and Jesus, I remember going into that doctor ages ago about that, when I was in addiction, and nothing was done about it. I was left, like, do you know what I mean? So now they're like, "Yeah all right, we're going to send you here, I'm going to write the letter for you, go down, leave it in and if they can't do anything for you, come back and we'll get you on the list, we'll get it sorted." And I was like, "Jesus, there's a change!"* (Interview 7, woman aged 40–50 years)

One service user described the plight of another person during the COVID-19 pandemic, and the difficulties they had with pain management:

> *They were after being involved in [an accident] and because they were on methadone, the doctors in the hospital had prescribed pain medication and they sent it over to the hotel via email or fax or whatever. And the hotel was dispensing their methadone – they took charge of that. But because they were on methadone, they wouldn't give them any sort of pain medication. … So they got another letter faxed over from their own PERSONAL GP, and they refused to get it for [him/her] again. So they left [him/ her] literally with no painkillers.* (Interview 14, person aged 50–60 years, capital letters are used to show emphasis)

One key area where the stigmatisation of people who use drugs has far-reaching consequences is in relation to housing, an issue that was emphasised by many service users. Although this may not be defined as a core concern of drug treatment services, resolving problems such as homelessness and poor living conditions is often a precondition for making progress in relation to substance use and mental health challenges. This is also a crucial testing ground where service users find out whether service providers care enough about them to help them improve a fundamental part of their lives:

> And even, like, the head of homeless services – they fought for us because we had no human rights, I mean, none! We were living with sewage inside the house and sewage outside. We had no working shower, no working cooker, no working washing machine, no oven. We had rats – I caught seven rats in one trap! And this [person] thought they could keep getting away with this because when they took over as landlord, we had just started back on the methadone programme. (Interview 1, woman aged 30–40 years)

Because they are likely to face stigmatisation in these other areas of their lives, it is crucial that drug treatment service users feel respected as people when attending clinics and programmes. Service users can feel stigmatised for a variety of reasons, including when they are unable to access services in their own area or when they are treated badly by staff:

> And one of the other guys was the exact same as myself, we have to get a train to [place] to get our methadone – we can't get it in town. It's like we're outcasts. (Interview 5, man aged 40–50 years)

> It was a different doctor that was there and they convinced me that within 3 months I'd be off all drugs. And I really believed that [person] [laughs bitterly] … and when I went back 2 years later I was told – and I still remember this – that I was a junkie and I am always going to be a junkie. And I was just resigned to that fact then, do you know what I mean? (Interview 10, man aged 40–50 years)

> I love it because there's no judgement. What way would I put it? When you go to a service, you're treated like an addict, but when you go to [service], you're treated like a human being. So, like, services… And I know it's not their fault, because it's what they were educated on. They were EDUCATED to look after and help the ADDICT, but they forget that we're also human, we're human beings. (Interview 6, person aged 50–60 years, capital letters are used to show emphasis)

Summary

In their interactions with drug treatment services, housing authorities, social services, and mainstream health care services, our interviewees had experienced many different forms of discrimination and disqualification. Indeed, managing health problems and tackling issues such as homelessness and poor living conditions is often a precondition for making progress in relation to substance use and mental health. This is also a crucial testing ground where service users find out whether service providers care enough about them to help them improve their lives. Because they are likely to face stigmatisation in these other areas, it is crucial that drug treatment service users feel respected as people when attending clinics and programmes.

Theme 2b. Policing moral and social boundaries

Service users are aware of the boundaries that separate them from service providers within the treatment setting but they often take these for granted. One way in which moral and social boundaries are maintained within the treatment setting is through urine testing associated with disciplinary measures such as exclusion from services, forced transfers, elimination of 'privileges', or reductions in medication. These practices often come to define the relationship between service users and practitioners, and are closely linked with wider processes such as the medicalisation of treatment, the stigmatisation of people who use drugs, and lack of trust between service users and providers.

Service users often feel that providers are seeking to manipulate their fear and uncertainty regarding access to opiate agonist therapy in order to avoid conflict and to ensure compliance with their rules. Their impressions regarding the arbitrary use of disciplinary measures are reflected in enormous differences in the way urine tests are used within different services; some services rely heavily on urine tests, while others do not even use them, as the following extracts show:

> *When I told them about my experience, they were like, "There is no evidence to back up urine testing, because we're prescribing you an opioid, so of course it's going to be positive for an opioid, you know?" And they said, "Just for formality, I will do one urine test before we begin treatment, and I will never do another one again." And that's exactly what happened. (Interview 9, man aged 30–40 years)*

> *Researcher:*   *And how often are you doing the compulsory urine tests?*
>
> *Participant:*   *Every 2 weeks. They ask for it every 2 weeks, or whatever. It could be spur of the moment, sometimes they'll say, "Here, give a urine" when you're not expecting it.*
>
> *Researcher:*   *They don't supervise it the way they used to, or do they?*
>
> *Participant:*   *No, which is ridiculous. There's no point taking them if they're not going to supervise them! [laughs] They're not going to even look at the temperature. There's no point in doing it. (Interview 3, man aged 40–50 years)*

Summary

One way in which moral and social boundaries are maintained within the treatment setting is through urine testing, associated with disciplinary measures such as exclusion from services, forced transfers, elimination of 'privileges', or reductions in medication. These practices often come to define the relationship between service users and practitioners, and are closely linked with wider processes such as the medicalisation of treatment, the stigmatisation of people who use drugs, and lack of trust between service users and providers.

Theme 2c. Shifting the balance of power

One of the ways that service users can shift the balance of power within drug treatment services is by changing treatment provider. A number of the service users we interviewed had been moved from one service to another at some point during their journey through the system, although it appears to be extremely difficult for service users to initiate this process. In most cases, once a service user has been assigned to a clinic, they have little chance of moving to another, which shifts the balance of power towards the service provider.

Service users often describe opiate agonist therapy in terms of control and coercion – 'liquid handcuffs' – echoing a prominent theme in the international literature. The implication, of course, is that the only way to shift the balance of power within treatment is to detoxify, which many service users hope to achieve:

> Participant: *I was desperate. I was desperate. I would have agreed to anything. So I think I was bent over a barrel.*
>
> Researcher: *And that gives the doctor an enormous power?*
>
> Participant: *Yeah, it gives the doctor an awful lot of power. So when I tried to improve me life – go out and get a job or stuff like that, when I was stable enough, they kept me on that clinic. … I had to get other HSE services to fight my corner, and other counsellors to fight my corner to get into treatment. … They threatened to send me into Pearse Street or to Ballymun, to a 'punishment clinic', if I went down and tried to force any of that stuff.* (Interview 10, man aged 40–50 years)

> *There's people that went on a methadone programme and I know a couple of my friends have died. They went on a methadone programme thinking they were going on to detox. And 10 and 20 years later, they're still on this clinic with no support.* (Interview 8, woman aged 40–50 years)

> *And a lot of times I wanted to detox and my doctor refused to detox. They had me on the assumption that I wasn't able to come off the methadone, and that that was going to be my life, that I was going to be on that for the rest of my life.* (Interview 7, woman aged 40–50 years)

While it is relatively straightforward to choose between different community drug projects or counsellors, it is much harder for service users to move from one doctor or treatment centre to another. In Chapter 2, we described the rules and regulations that limit freedom of choice in relation to drug treatment in Ireland, and in our literature review we described how the ability to change facilities led to immediate and significant improvements in the experiences of Swedish and English service users. At any rate, service users in Ireland often have little prospect of changing the way they receive medical assistance for problem drug use, whether they are getting treatment at a GP clinic or a specialised drug treatment centre:

> *I did have another doctor that I would have – a private doctor – that I would have went to, to collect my prescription, and they had always told me to go back to my doctor that prescribed me the methadone. It was them I needed to talk with, and they just refused to give me a detox.* (Interview 7, woman aged 40–50 years)

This lack of alternatives can lead service users to make extreme decisions, such as refusing to take prescribed medicines, deliberately getting arrested, or dropping out of treatment completely:

> Participant: *I was on my original dose, which is 85 ml. And I thought to myself, "The longer I stay on this, I'm not going to do it." So I refused to go up and give my urines. And they docked me each week. That's exactly what I did. It was very dangerous what I was doing.*
>
> Researcher: *So you used their disciplinary procedures to come down, basically?*
>
> Participant: *Yeah, that's exactly what I did, over a period of 3 months I have come down. Like it was 10 ml and then it was 7 ml and then it was 5 ml and it was down to 3 ml, two ml. And then when I got to the 2 ml, I decided not to go over and get it because I knew it was just going to prolong it.* (Interview 7, woman aged 40–50 years)

Another way of shifting the balance of power between practitioners and service users is via the complaints system. When managed correctly, this system can play a role in defusing conflict and 'repairing' trust-based relationships following misunderstandings, although this demands management skills and a strong commitment to service user involvement at the organisational level:

> *But me and a particular staff member, [he/she] was looking down on all of us a bit, and I was finding I was constantly having smart answers back off [him/her]. It was a constant thing… so I said, "I want to speak to a manager." So the following week, I went into the clinic, and [name] was there. So [he/she] called me aside and said, "You wanted to speak to the manager, so I came out to see you." … [He/she] brought me into the room, and [he/she] sat down, and I sat down and [he/she] said, "Tell me your side of it." And [he/she] listened so fairly to everything that I had to say, you know? And then [he/she] listened to the other side, and [he/she] resolved that conflict, believe it or not, which I thought would never be resolved.* (Interview 1, woman aged 30–40 years)

Summary

One of the ways that service users can shift the balance of power within drug treatment services is by changing treatment provider. In most cases, however, once a service user in Ireland has been assigned to a clinic, they have little chance of moving to another, which shifts the balance of power in favour of the service provider. While it is relatively straightforward to choose between different community drug projects or counsellors, it is much harder for service users to move from one doctor or treatment centre to another. This lack of alternatives can lead service users to make extreme decisions, such as refusing to take prescribed medicines, deliberately getting arrested, or dropping out of treatment completely. Another way of shifting the balance of power between practitioners and service users is via the complaints system. When managed correctly, this system can play a role in defusing conflict and 'repairing' trust-based relationships.

Theme 3a. The organisation of drug treatment services

One of the striking issues to emerge from our interviews with service users relates to the lack of integration between mental health care and drug treatment services. Given the close integration between drug treatment services and mental health services in many other countries, and the growing awareness of the importance of managing 'dual diagnosis' patients, this aspect of the Irish system is rather surprising. The following four extracts are representative of the different ways in which this issue impacts on treatment, harm reduction, and recovery:

I left the mental health clinic in [place] because they just did not want to treat me whatsoever. Initially, they were like, "No, you need to get on OST because that could be masking symptoms." And then as soon as I was on the OST, I was told "You need to get off it as soon as possible." And I had absolute battles with the doctors to try and get some sort of treatment. And they ended up prescribing me, like 12.5 mg of [substance] and 12.5 mg is, like, you cut the lowest dose cut in half and you take that three times a day. It did nothing, you know? (Interview 9, man aged 30–40 years)

Participant: My goal really is, because I'm stable now with my mental health, my goal really is to detox off the methadone.

Researcher: Did you talk to your psychiatrist about that, or would he or she have any experience?

Participant: What happens there is, if I mention the methadone, [he/she] will ask me where I am with the methadone and what have you, but as soon as it comes to it being prescribed, it's got nothing to do with [him/her]. ... Like, I think the dual diagnosis in this country, to be honest, to use a nice word, would be a disgrace. I really do. ... there's no communication between them. That's why we're all going around in circles. (Interview 5, man aged 40–50 years)

Obviously, the system is just like... Not even just drug users, but the system is ridiculously overwhelmed. And, like, I've had a referral to community mental health in the last 6 months, and nothing has come of that. I see the counsellor who is attached to my local methadone clinic. I see [him/her] every week before I collect my script and everything. I get antidepressants and antipsychotics prescribed by my methadone doctor based on what I told [him/her] I was on years ago – they are not qualified to do that! (Interview 18, person aged 20–30 years)

They don't understand the concepts. They don't understand the drugs, the doses, the interactions. It's like there's a wall there, and then it makes it very hard for the addiction clinics, because if you ARE prescribed psychiatric medications, you know, when you pick up the phone to discuss it: "Well, is this going to have an interaction with methadone or Suboxone?", they're like, "I don't know." (Interview 9, man aged 30–40 years, capital letters used to show emphasis)

This is a structural feature of drug treatment services in Ireland that may initially appear to be unrelated to service user involvement. Arguably, however, this kind of division makes it more difficult for service users to influence their treatment, as they cannot address the different facets of their treatment in an integrated way. If service users are to be empowered and given a voice, then services must listen to what they have to say, and this means that all services and all practitioners involved must listen and act in concert.

This is the only way to ensure that treatment decisions are informed by a full understanding of the patient's situation and how he or she is progressing. In mainstream health care, this kind of role is typically played by GPs, who have responsibility for evaluating test results, prescribing treatment, and assessing how different therapies might be integrated in order to achieve a desired outcome. Many of the people attending drug treatment clinics have nobody who can play this role, as their GP cannot make decisions in relation to the medications prescribed at their clinic, and the clinic doctors are not in a position to provide general medical care or to implement the recommendations of mental health specialists.

Another interesting theme that emerged during our interviews with service users relates to the role of managers in promoting engagement and shared decision-making. In services where managers are committed to this paradigm, all or most staff members are also found to be committed to service user involvement, and are able to express empathy, to build trusting relationships, to involve people in decisions, and to open up a space for effective communication at all levels of the organisation:

> Researcher: *Was that just because there was a different ethos in [service] or because there were different staff figures or people with different ideas, or what was it?*

> Participant: *People with a different understanding of addiction. Because the [person] in charge – [name] – is a big advocate for… giving people their own say in their own recovery. [He/she] set a good tone for how that programme should be run.* (Interview 10, man aged 40–50 years)

It is also evident that for many service users it is difficult to get information about drug treatment services, how they differ, and whether they could be useful in light of their specific needs:

> *I had always thought [name] was a garda, up to 6 months ago. [He/she] was never a garda, it was just when I heard "Task Force", that was the end of it! I didn't even know what [service] was actually there for and I didn't realise that I was the person, that I was the user that was being helped. I thought that I was not equal to them, kind of, but NOW I believe that a bit more.* (Interview 12, person aged 20–30 years, capital letters used to show emphasis)

The interviews we had with service users provided ample evidence of the difficulties involved in negotiating the jungle of services, and it is interesting that our research also showed that the same appears to be true of *staff members* at drug treatment services. There appears to be little contact between different services and little teamwork that stretches across organisational or sectoral boundaries. This is mainly due to the fragmentation of services and the divisions that exist between statutory services, private clinics, and voluntary bodies, which means that cooperation does not have a clear organisational justification. This is another structural feature of the Irish system that obstructs service user involvement. The barriers between mainstream health, mental health, social services, homelessness, and drug treatment services often make it difficult for service users to access these in the integrated ways that they need. In simple terms, if these services are not integrated, they risk becoming useless to people who are receiving treatment for problem drug use.

This is relevant to service user involvement because it has the effect of limiting service users' ability to make decisions. A good example of this is the way in which key workers are used

within drug treatment, harm reduction, and recovery services. Many services assign a key worker or case manager whose job it is to interact with clients and to support and guide them as they access services. Sometimes key workers are also counsellors. As a consequence, people attending a treatment centre for opiate agonist therapy, a community drug project, or a Community Employment Scheme, preparing for residential detoxification, and living in supported housing could have four or even five different key workers.

This paradoxical situation is the outcome of the organisational principles underlying drug treatment services in Ireland, and particularly the failure of the State to provide clear guidance regarding how the various pieces of the system can work together to provide service users with continuity, guidance, and a coherent treatment plan. What appears to happen is that service users are forced to become their own key workers, as they stumble through different parts of the treatment system and attempt to identify the services that they need:

> Participant: *I'm originally from [place] and the [name] hospital has a detox unit. In 10 minutes… Not even 10 minutes' drive away from my house and away from my clinic! And I was never encouraged to go over there and detox or stabilise. That was not something that was pushed to me. I had to go and find out from other people also at that clinic how I go about this.*
>
> Researcher: *Do you think if you had got the right information earlier on that you could have avoided those 19 years?*
>
> Participant: *An awful lot of hardships, yeah. And not only for me – for my family and for people around the community, because me using has a big ripple effect on my family, community, you know?* (Interview 10, man aged 40–50 years)

This organisational logic reduces the ability of key workers to perform an important role within the system: to act as a fulcrum for person-centred care and as a point of reference for multidisciplinary care teams that are based in different settings. The inability of these organisations to work together and to collaborate effectively at all levels places limitations on the scope for service user involvement within drug treatment services.

It is worth adding a final observation, which provides further justification for a stronger integration of services from the perspective of user involvement. Not all practitioners and services can be expected to develop close, empathic, and trusting relationships with service users. This is an uneven process, due to differences in approach, roles within treatment provision, and even in personality. The individual responsibilities assumed by physicians place them in a difficult role with great potential for conflict and misunderstanding. However, the lack of integration between services means that practitioners who struggle to maintain the trust of service users have no way of drawing on the support of colleagues who have already achieved their trust. The result is that a service user may have a great relationship with staff at a local drug project, for example, or with a counsellor, or with outreach staff, but still feel misunderstood and ignored when attending their clinic. In other words, service user involvement should be viewed as a collective aim and resource for the interdisciplinary, intersectoral, and interorganisational team that participates in providing treatment, harm reduction, and recovery services to people who need them.

Summary:

One of the striking issues to emerge from our interviews with service users relates to the lack of integration between services. If service users are to be empowered and given a voice, then providers must listen to what they have to say, and all practitioners involved must work together. Many of the people attending drug treatment clinics have no doctor who takes overall responsibility for coordinating their treatment. There is little contact between services and little teamwork across organisational and sectoral boundaries. The barriers between mainstream health, mental health, social services, homelessness, and drug treatment services make it difficult for service users to access these in the integrated ways that they need. Service user involvement should be viewed as a collective aim and resource for the interdisciplinary, intersectoral, and interorganisational team that participates in providing treatment.

Theme 3b. Procedures for making decisions

The service users we interviewed often described procedures for making decisions as 'opaque' and 'unclear', and had difficulty determining who had the authority to make certain decisions about treatment. This led to a paradoxical situation where practitioners who had never met the service user were making crucial decisions about their treatment. This leaves them with no possibility of participating in those decisions or even understanding their rationale:

> And [he/she] himself, every appointment would say, "You know, I really think you should be on Suboxone, not methadone, but that's not my decision. That's [name]'s [decision], and that's what [he/she] decided, you know." And it just felt like, "Okay, so there's a [person] sitting in an office, who has never met me, but is making all the decisions for me [pause], yet the doctor who I see every day, in front of me, disagrees!" It was so contradictory and so unprofessional. (Interview 9, man aged 30–40 years)

Another issue that was brought up during our interviews with service users relates to the heterogeneity of prescribing practices within addiction clinics. This problem is discussed in the Scandinavian literature on service user involvement and underlines the value of consulting service users directly. There appear to be few protocols in place to guide medical decision-making in this crucial area of treatment. Depending on the service, and on the individual practitioner who is making the decision, approaches to prescribing vary greatly. For example, one service user describes the rationale that was followed by his doctor:

> He was never judgemental and [he/she] was just like, "Well, that's why I'm here. I'm here so you don't have to do all of that." And I'm on, like, 5 mg, four times a day, of diazepam, which is quite a large dose. But he was like, "Look, it's better that even if you're taking a large dose, that it's under medical supervision rather than you just taking loads of tablets without anybody knowing anything about it." (Interview 9, man aged 30–40 years)

This experience stands in sharp contrast to that of another service user:

> Participant: What happened was they wanted me off the benzos [benzodiazepines]. So I went and said it to my psychiatrist. But I said I was struggling and they put me on Lyrica. ... And when I went back up to the hospital, Dr

> *[name] went crazy. [He/she] said [he/she] wanted the number of the psychiatrist, because Lyrica can alter the methadone, it can actually cause overdose. … [he/she] said, "You can go on diazepam, 2 mg, three times a day and we'll detox you from that." …*

Researcher: Was that enough to keep you going?

Participant: *No it wasn't. It was nowhere near enough.* (Interview 5, man aged 40–50 years)

> *This certain doctor, [he/she] is doing it with everyone, [he/she] is bringing them in every day because they're taking benzos, when I was coming here for 5 years and no one said a word to me about benzos… and, like, there's fellows going in, and I know for a fact they're taking cocaine and they're getting weekly takeaways. It's just crazy. But if you're honest and you're not giving dodgy urines or anything like that, you get treated worse, I think [laughs bitterly].* (Interview 3, man aged 40–50 years)

During our research, we were often struck by the amount of knowledge and the depth of understanding that service users have of the treatment process, in both its pharmacological and non-pharmacological dimensions. As a result of their knowledge – of themselves, of the nature of their dependency, of the effects of different drugs – they felt that they could contribute to the decision-making process in a valuable way, as the following two extracts illustrate:

> *When I left the hospital, they wrote me out a prescription for OxyContin. And I said, "I'm not taking that. I am NOT taking that, I just absolutely refuse to take it!" And I said, "You can write it in my notes, because I'm not taking it. I'm already on methadone, is that not a painkiller?" – because I'd looked it up. And [he/she] said, "Well, you're kind of right, and I wouldn't be going on that stuff either, to be honest with you."* (Interview 3, man aged 40–50 years, capital letters used to show emphasis)

> *So I started to take the [substance] again and I started to get relief in the [substance]. And no matter how much I said to the psychiatrist… They wouldn't prescribe me them. And then I said to them, "I've been taking some on the street, but they're from a doctor." They said, "Well, they're from the street." And I said, "No, I make sure when I take tablets that they come from a chemist, like, you know?" … When I got that bad with taking the [other substance] and that, I went to the doctor again… and I said to them, "Listen," I said, "I'm going to have to probably go on methadone or something." Suboxone – that's what I was aiming for, because I was aware that it was a better option.* (Interview 5, man aged 40–50 years)

Due to their empirical knowledge of different kinds of substances, service users are often able to provide information regarding what is likely to be effective for them in terms of pain relief, reducing symptoms, and avoiding withdrawal. This is particularly important when accessing mainstream health services, as the following extract illustrates:

> *My tolerance is so high, the sedation drugs don't work. And then they just say, "Well, we have to continue on anyway," and I have to go through pain or the discomfort, and I remember everything that happens. And even when I do general anaesthetic… The last time I woke up in, like, bawling crying, ten-out-of-ten pain. … But I find that the doctors in the hospitals – consultants all the way to interns – they just have no idea. They have no idea, no information, and they're not willing to learn either.* (Interview 9, man aged 30–40 years)

A related aspect of service user involvement has to do with the potential for people attending services to use their knowledge and experience to help other service users. The following example highlights how the lived experience of service users can give them a type of understanding that can complement and reinforce that of physicians and other practitioners:

> *It started with the medication meeting, because... I was able to help people an awful lot after that, because I know an awful lot about medication, especially because so many times I tried to come off it, and this time I'll just slowly do it, and I'm going to slowly come off. But, like, before I'd want to rush it, and you'd often hear people coming off, "I want to come off 5 ml this week." But if you do that, your body is getting a shock. Whereas I've been doing it PROPERLY the last year. (Interview 12, person aged 20–30 years, capital letters used to show emphasis)*

One of the most contentious aspects of shared decision-making in the context of drug treatment services – which has been widely discussed in the scientific literature, as we saw earlier – is the management of opiate agonist therapy. We saw in Chapter 6 how medical practitioners sometimes struggle to reconcile the principles of service user involvement with their own sense of individual responsibility for prescribing medication. Our interviews also show that many service users are frustrated with the reluctance of their doctors to support them through the process of detoxification, with the aim of reducing their dependency on methadone:

> *The only problem I have, as I was explaining to [name] here, was that I'm trying to get off the methadone altogether and I want to go back working and I'm having problems with [doctor]... I'm getting depression, [he/she] doesn't want me to come down off the methadone. ... I seem to be thinking I'm banging my head against the wall and I think that [he/she] just sees me or any other person on methadone as a cheque in the bank at the end of the month. ... I've ASKED [him/her] about it and [he/she] said that [he/she] wants to [pause] – I'm laughing as I say this – [he/she] wants to make sure that I'm stable. Now, I haven't touched anything else in a couple of years. Like how more stable can I get? ... Every time [he/she] hits me with this 'stable' thing, it just hits me with a brick wall. (Interview 14, person aged 50–60 years, capital letters used to show emphasis)*

Summary

The service users we interviewed often had difficulty determining who had the authority to make decisions about their treatment, as the doctors they met may simply implement decisions taken by other doctors higher up the hierarchy. Another issue that was brought up during our interviews relates to the heterogeneity of prescribing practices: there appear to be few protocols in place to guide medical decision-making in this crucial area of treatment. We were often struck by the knowledge and depth of understanding that service users have of the treatment process, in both its pharmacological and non-pharmacological dimensions. Due to their experential knowledge, service users are often able to provide information regarding what is likely to be effective for them in terms of pain relief, reducing symptoms, and avoiding withdrawal. However, many service users are frustrated with the reluctance of their doctors to support them through the process of detoxification, with the aim of reducing their dependency on methadone.

Theme 3c. The importance of (small) innovations

In the course of our interviews with service users, we encountered several examples that illustrate the importance of innovation within services and confirm that small steps towards user involvement can have a large impact on drug treatment, harm reduction, and recovery services:

> *And I'd often be out having a cigarette and, say, all the key workers and all that would come out. So I'd walk away because I'd feel that uncomfortable feeling of being in the presence of professional people. ... So they came out another day and I was walking away, so [name] said, "No," [he/she] said. ... "Sit and have a conversation." [He/she] said, "No one is any better than anyone. ... Just because I'm a key worker, it doesn't make me better than you." Like, I never walked away after that, I kind of just sat and had a chit-chat with them and then I'd go back. When I come outside of the treatment centre, I was well able to speak up for myself no matter what.* (Interview 6, person aged 50–60 years)

> *There's other staff members there that you can talk to. Like, I've had accommodation problems and they were able to help get me letters for the Council. They can offer food hampers to people. I mean, there's so many things like that that they do. You know, it really is... it's not just "Go in and get your prescription." It's a full service.* (Interview 9, man aged 30–40 years)

As we saw earlier, the academic literature on service user involvement in drug treatment services emphasises the importance of involving users in the development of individualised care plans, which is an important element of drug treatment services:

> *I didn't feel, in that clinic... Like I said, I didn't have a voice. Looking back on it, now – I never had these words back then – but I didn't feel like an individual. I didn't feel like I had any say. ... Yeah, so they didn't sit down and say, "Look, you're entitled to have some sort of input to your care plan, and to the strategy of getting drug free, if that's what you so choose."* (Interview 10, man aged 40–50 years)

One innovation that our interview volunteers often appreciated was the use of new technologies to provide support at more regular intervals and to reduce the social distance between practitioners and service users. Against the backdrop of the COVID-19 pandemic, some services used online platforms to link up with service users, identifying effective and innovative ways of using videoconferencing to provide them with support. In the following extract, the participant describes how service providers and other service users helped them to overcome a challenge in their life by using mobile videoconferencing software:

> *Like, I used to log on to the morning [session]. I had an awful problem, when I used to go and get my methadone, the fellow I used to buy tablets off of was right across the road from my chemist. Every f****** morning... It used to torment the heart and soul out of me. So I'd go onto the meeting, talk to the [other people], and only for them... They actually helped me. And even once or twice when he said, "Hello," I said: "I'm on a meeting, I can't stop and talk to you." Because I had the earphones in, obviously. ... Because they'd be talking to me and I'd have me video on and the whole lot. So [counsellor] would be telling me to stay calm, that there was no need to be worried.* (Interview 12, person aged 20–30 years)

In this kind of application, the platform itself contributes to service user involvement by allowing participants to feel at ease and by reducing the impact of social status and professional position on interactions. When people are able to meet in person once again, they often find that they can maintain the trusting and collaborative relationships that they developed through frequent online meetings. By simplifying the logistics of one-to-one and group meetings, practitioners also found that they could dedicate more time to service users and get to know them better. At the same time, it is important to ensure that online services do not exclude people who do not have the right kind of device or do not have access to internet.

Summary

One innovation that our interview volunteers often appreciated was the use of new technologies to provide support at more regular intervals and to reduce the social distance between practitioners and service users. Against the backdrop of the COVID-19 pandemic, some services used online platforms to link up with service users, identifying effective and innovative ways of using videoconferencing to provide them with support. It is important to ensure that online services do not exclude people who do not have access to digital devices or internet.

Theme 3d. Patient-centred care

As we have seen, service users have a unique perspective on treatment that cannot be substituted by practitioners or other stakeholders. For example, nearly all of the service users we spoke to emphasised the role of emotions within treatment and recovery services. The following two extracts illustrate the different ways in which service users approach this issue, and the importance of being able to bring emotions to the centre of the treatment process:

> I only knew a couple of emotions. The most powerful one was anger and frustration. I couldn't name that. I didn't know. ... Because that was just a natural state for me, it was just a natural state. ... Well, it took a long time for me to be able to voice it. I knew internally ... I knew it in here [pointing to his head], because, like I said, [he/she] has control over me and [he/she] is going to stop my methadone, and that means I'm going to have to go out and rob, and I might have to rob my family, and I don't want to be doing that. (Interview 10, man aged 40–50 years)

> It's like the floodgates in Ardnacrusha – I don't know if you know Ardnacrusha, but the floodgates there in Ardnacrusha, it's like they just open and all these emotions come back to you and all these memories – memories that you've been suppressing for years. So that's what you need the therapy for. If you don't have a support system lined up, there's no point in trying to get off the stuff, do you know what I mean? (Interview 1, woman aged 30–40 years)

It would also appear – based on the experiences of service users themselves – that their ability to choose counsellors contributes to the effectiveness of this service. This enables service users to try out different kinds of relationships until they find what works for them. The lack of coercion, or lower amount of coercion when attending counsellors – whether these are working at a treatment clinic, local drug project, residential treatment centre, private practice, mental health services, or a dedicated counselling service – means that the counsellor and the service

user can 'choose each other', which gives them an opportunity to demonstrate commitment and trust:

> Like, I seen one key worker, I felt that [he/she] just didn't care about me. [His/her] attitude stank. … So I didn't want to be rude, so I just texted [him/her] one day and I said, "Look," I said, "I don't want to be rude or I don't want to be smart, but I need somebody that cares about my well-being. And at the moment you don't." So I said I would prefer to see somebody else. And that was no problem. And I did see a key worker and I seen [him/her] for 5 years… [He/she] was ABSOLUTELY AMAZING. Amazing, [he/she] was. (Interview 6, person aged 50–60 years, capital letters used to show emphasis)

Summary

Nearly all of the service users we spoke to emphasised the role of emotions within treatment and recovery services. They emphasised the close link between their emotions and their substance use, and their need for emotional support during treatment. Their ability to choose counsellors was seen as contributing to the effectiveness of this service, as it enables service users to try out different kinds of relationships until they find what works for them.

3e. Outcomes

Our interviews with service users shed some light on the question of outcomes and how they are influenced by service user involvement. This is a complex issue with a number of different facets. One issue that emerged with force from our consultation was the way in which the rules and regulations regarding different forms of treatment can generate obstacles to accessing services. At the beginning, for example, service users may be left in the contradictory situation of having to continue using drugs in a harmful or illegal way for a prolonged period of time simply in order to be admitted to treatment:

> I was constantly on the phone to the nurse saying, "Like, come on, this is ridiculous – 4 weeks?" You know? And again, [he/she] just said, "It's just [name]. [He/she] just wants to make sure that we know what your kind of daily dose is, so we can give you the correct amount when we transition you onto another opioid." … And I almost felt like, "Oh God, now I need to put in extra effort to make sure that each test is positive, so I'll get the treatment." Which sounds, like, crazy. (Interview 9, man aged 30–40 years)

> But it was hard to stay going, because I had to stay using for the 3 months. … I had to stay using if I wanted to get on the methadone. … I just thought it was weird because I remember coming out of the clinic and me ma says to me, "So you have to stay using?" I know that sounds mad, but that's what they said. (Interview 12, person aged 20–30 years)

> The hardest part of seeing Dr [name] was that I had to go three times and give three dirty urines before I was put on the methadone. So that was a tough 3 weeks. Like, you're nearly there, but instead you were going out every morning and trying to get your fix, like, you know? And I wound up, like, basically what I was living on was… Say

I was on social welfare and I'd pay for my apartment and I'd probably buy a small amount of food, and the rest of it went on opiates, you know? (Interview 5, man aged 40–50 years)

These practices are due to the lack of willingness of physicists to involve users in making decisions about their own treatment, as these decisions are often based on the assumption that service users cannot be relied upon as a source of information. In the context of treatment services, this becomes a self-fulfilling prophecy, as service providers and service users get caught up in a game that excludes open and honest communication, where service users feel that if they tell the truth, they will be denied treatment:

Every time I went for, like, a detox clinic assessment, I had to do a piss test, like, EVERY time. And it's just like they're trying to catch you out. [pause] … or someone might talk down to you or whatever, because they're just, like, "What do you think will show up?" And I'm just, like, "Heroin, crack, benzos, hash." … I'm not stupid, like, I'm not going to try and lie to you and be like, "Oh, you know, nothing," and then when it comes back with all this I'm going to be like, "How the f*** did that happen?" I'm not an idiot, you know, so don't talk to me like an idiot. (Interview 18, person aged 20–30 years, capital letters used to show emphasis)

Similar observations can be made in relation to recovery, where service users are aiming to reduce or change their medication:

We're back on the roundabout now of another week's methadone and no contact with a doctor and no discussion about coming down… I think it was about 2 or 3 months ago we discussed coming down to 40 ml and going on Suboxone… That's gone out the window now, because I haven't seen [him/her]. … Well, [he/she] keeps saying to me, like sometimes I'll have a slip… and then [he/she] says to me, "This is the problem, this is why we can't move forward." But it's very easy to say that. But I could easily turn around and say, "You haven't seen me in 6 weeks." (Interview 5, man aged 40–50 years)

From the perspective of outcomes, it is important to recognise that people have different needs and different responses to treatment, and it is only possible to identify effective combinations of services through dialogue with service users. This is why the paradigm of service user involvement cannot be approached schematically, or defined in terms of institutional arrangements, organisational structures, or professional practices. Service user involvement can only be defined in relation to the services themselves, and the scope they provide for listening, providing information, and enabling people to make choices. This means that service user involvement inevitably takes different forms in different parts of the treatment system.

If treatment is, by contrast, approached in terms of finding ways to maintain control over service users or waiting for them to slip up, then it will not realise its full potential in terms of outcomes. The following extract shows how close interactions between practitioners and service users can make recovery more achievable:

Researcher: *So tell me, who was following you? Who were you attending? You said now that you're going to HSE addiction services in [place] and so on and the outreach workers. So you were dropping your methadone with them? ["Yeah."] And they were helping you and following the whole thing?*

Participant: *Yeah.*

> Researcher: They were in agreement, they thought it was a good idea?
>
> Participant: Yeah. They said to me that they thought, obviously, about treatment centres – they always tried to promote them as well. But if this was what I wanted to do, that they were going to support me, because they did obviously see that I was trying to make a change. (Interview 1, woman aged 30–40 years)

When thinking about outcomes, and ways of measuring and evaluating what drug treatment, harm reduction, and recovery services achieve, it is important to include personal growth, improved self-esteem, and better subjective well-being as measures. Our interviews provide considerable evidence that building more inclusive relationships with service users has a positive impact on these aspects of people's lives:

> Participant: I think I've gained so much knowledge and to be honest, being clean over the years and the way the staff have treated me in there, they've made me feel like "[Name], like you're actually worth something, what you're doing is valuable."
>
> Researcher: Because in the other places and particularly in [place], they didn't give you that hope, I guess?
>
> Participant: No, no, no, they didn't. Their incentive was that I built up my dole when I got out of there. And for me, like I said, money is not an incentive. (Interview 2, man aged 30–40 years)

> I think it's sort of an inside job – that's a medication and that did help me, it served its purpose at the time, there's no doubt about that – but to move on in my life I had to set myself goals and I had to experience change and growth in myself. (Interview 4, person aged 20–30 years)

Service user involvement is therefore likely to encourage a redefinition of the outcomes of drug treatment. When talking about their experiences, many service users describe how they have benefited from specific services and interactions in terms of personal skills. Relapsing after an episode of treatment was rarely seen as negating the value or importance of that experience, suggesting that the outcomes of treatment should not be measured in terms of short-term substance use, and that perhaps we should consider services in combination when seeking to determine their impact. Service users who are in recovery often talk about how specific aspects of several different services helped them to achieve a better life and to reduce their dependency on substances.

Summary

The rules and regulations regarding access to treatment can generate formidable obstacles. At the beginning, service users may be left in the contradictory situation of having to continue using illicit drugs in order to be admitted to treatment, a difficulty that could potentially be overcome through service user involvement. Service user involvement should be viewed in relation to services themselves, and the scope they provide for listening, providing information, and enabling people to make choices about their treatment. When thinking about outcomes, and ways of measuring and evaluating services, it is important to include personal growth, improved self-esteem, and better subjective well-being as potential outcome measures.

Theme 3f. Representing service users

The final theme we analysed using our interview transcripts relates to the representation of service users. In line with recent publications in Ireland, we found that service users had little direct contact with advocacy groups and little or no contact with user representatives. This was often a product of their feelings of powerlessness and exclusion:

> Researcher: *Have you ever come in contact, like, with a service users' forum or representatives? Is there anybody who could represent your perspective in there?*
>
> Participant: *No, I'm afraid to actually say anything about it, because it might backfire on me, they might say, "We'll take your Sunday takeaway off you!"* (Interview 3, man aged 40–50 years)

The only examples of formal consultation that we encountered involved initiatives within organisations that have invested in service user involvement in recent years:

> *But I remember in [service] there was, it was funded by [organisation], and they did come down once a month and ask all the service users about, "Is there any suggestions that they'd have?"... People would bring stuff up, like about the food and stuff like that, that looking back now, probably wasn't really that important, because the food there was absolutely lovely, I thought. ... At least for some people it can just be deflection and people are just... It's kind of... People might find it hard to be honest in a group full of people about suggestions they think, because they might be afraid that people criticise them. ... if they brought the people back when they were, like, 2 years drug free, I think the people would be able to reflect a lot more and have a lot more better suggestions than when they are in treatment.* (Interview 4, person aged 20–30 years)

The results of our interviews suggest that formal representation and complaint procedures are unlikely to take hold and to be attractive to service users until certain basic features of treatment services have been addressed:

> *When I did ask... it was someone called [name]; I was talking to [him/her] on the phone and [he/she] was just... [pause] I can't even tell you the way [he/she] spoke to me! It was like [he/she] was talking to a dog. ... [He/she] talked to me like I was just a piece of... I don't want to say the word... terrible! [pause]. Terrible. So I'm not even trying again, I'll just go with the flow.* (Interview 3, man aged 40–50 years)

In fact, the only examples we came across of more assertive service users, who were willing to put their name to complaints, to contact advocacy groups, and to get involved as service user representatives, were themselves attending services that promote service user involvement in treatment decisions. The reason is simple: these service users feel secure in their relationship with practitioners and have no fears about treatment being withheld or about being punished for what they say:

> *Now when I see consultants and people in the hospital, if I don't feel like I get a good experience or I feel like they are not being professional or they're using the OST or the benzos to kind of blame, I will absolutely be the first person onto patient advocacy in that hospital. And the amount of responses I've gotten which have actually been surprisingly... You know, it's been the clinician actually admitting, "I don't know a lot about that."* (Interview 9, man aged 30–40 years)

In the absence of these enabling conditions, the aspiration of being able to help other service users and to contribute to improving services is often projected into the future, to a time when service users are less dependent on the services and more qualified to speak about them:

> *I am hoping to go back to college in September when I come off the methadone and do the addiction studies course and hopefully work with either [organisations]. … Like, I want to be able to give people a voice who don't have a voice. Like, I didn't have a voice and I wasn't being listened to, and I had no human rights.* (Interview 1, woman aged 30–40 years)

The willingness of service users to participate in this consultation testifies to their ability to get involved and to participate in debates about drug treatment, harm reduction, and recovery services. Unfortunately, because of stigmatisation, fear, and other considerations, this was only possible because we could guarantee their anonymity.

Summary

The service users we interviewed had little contact with advocacy groups and little or no experience of user representatives or service user fora. Formal representation and complaint procedures are unlikely to be attractive to service users until certain basic features of treatment services have been addressed. The only examples we came across of assertive service users, who were willing to get involved as service user representatives, were attending services that promote service user involvement within the treatment setting.

8

Conclusions

The theme of service user involvement has attracted increasing attention since the 1990s, and has come to be seen as central to the development of more effective services in a range of different areas of provision. National strategies and policies have recognised the importance of listening to service users and incorporating their experiences, perspectives, and needs into the evidence base for policy development. This international trend has led to high-level policy statements in many countries – including Ireland – that emphasise the need for person-centred care, shared decision-making, the empowerment of service users, and more collaborative relationships between practitioners, service providers, and the people who access treatment.

It is therefore timely to carry out a wide-ranging integrative review of the evidence on service user involvement in the academic literature, in public debates, and involving service users and practitioners themselves. In the preceding chapters of this report, we synthesised academic research on service user involvement, provided an overview of the perspectives of stakeholders and experts, and explored the views and experiences of service users.

The most challenging part of this study was undoubtedly the user consultation, which was planned and carried out against the backdrop of public health measures to reduce the spread of COVID-19. This involved developing a research design that did not place service users at a greater risk of contracting the virus but ensured that they would receive support and help before, during, and after participating in the project. We were mindful that participating in interviews about their experiences could potentially involve reliving painful experiences. For this reason, we relied on service providers, practitioners, and advocacy groups to contact service users who they felt would be willing and able to participate in a short interview, and to provide them with support during this process.

A key characteristic of service user involvement is that it can assume radically different forms based on the context, with most observers agreeing that this is not just a component that can be bolted onto existing systems of treatment provision. As we noted earlier in this report, service user involvement must be analysed in relation to each service, and viewed as a dimension of the service itself. User involvement requires a context-sensitive, innovative, and relational approach that is likely to vary with the context, and relies crucially on the empowerment and valorisation of the operators who work in treatment services. Without the alignment and constant improvement of professional practice across services, and without effective coordination from above, services are unlikely to be 'fit for the purpose' of involving service users.

The practitioners and service users we interviewed provided detailed descriptions of a wide variety of services, including residential treatment centres, detoxification services, private hospitals and clinics, specialist clinics, GPs, community drug projects, self-help groups, counsellors, pharmacies, and low-threshold facilities. Individual pathways through this constellation of services are often complex and individual experiences vary greatly based on stage in recovery, patterns of substance use, personal goals, living conditions, family situation, early life experiences, underlying issues in relation to physical and mental health, and a range of other factors.

The interviews we carried out confirm that many service users seek treatment with the aim of improving their health or quality of life and ending their dependence on drugs. They often see treatment as a way of normalising and stabilising their lives and view recovery as a way to achieve a more meaningful life, to participate in social activities, to have hope for the future, and to improve their social relationships. Service users have goals that go beyond the reduction of drug-related harms and embrace issues such as housing, training, mental health, improvements in personal and family relationships, volunteering, and paid employment.

During our literature search, we identified seven systematic reviews relating to the theme of user involvement, which provide some insights into this issue. Davis *et al.* (2020b) review quantitative studies of patient-centred care and identify 25 publications, which suggest that patient-centred care can yield health benefits for patients. Fisher *et al.* (2021) summarise the evidence on shared decision-making in the context of dual diagnosis, concluding that this leads to greater patient involvement in decision-making, higher levels of agreement between clinicians and patients, a stronger therapeutic alliance and improved patient knowledge of treatment. Friedrichs *et al.* (2016) conclude that user involvement is likely to lead to better relationships, higher self-esteem, new skills and less stigmatisation of service users. Goodhew *et al.* (2019) document improvements in service quality following the inclusion of users in decision-making bodies. Marchand *et al.* (2019) reach the conclusion that certain enabling factors must be in place in order for patient-centred care to be effective. Marshall *et al.* (2015) identify different ways of involving peers in drug treatment and harm reduction services and note the importance of systemic factors like the stigmatisation of people who use drugs. Ti *et al.* (2012) also identify stigmatisation as a key barrier and emphasise the role of advocacy groups and peer support workers within drug treatment, recovery and harm reduction services.

The results of this integrative evidence review are in harmony with the findings of these existing review studies, but extend them in important ways, as we will show in this chapter. This is partly due to our superior coverage of the literature, including a larger number and a wider range of studies and a much better coverage of the Scandinavian literature. It is also evident that the academic literature does not cover all of the issues that stakeholders and service users in Ireland encounter in relation to user involvement, particularly in relation to the structure of service provision and the fragmentation of roles and responsibilities.

The research questions that guided this study relate to different forms of service user involvement, how they are understood by service users and practitioners, and how they influence the outcomes of treatment, recovery, and harm reduction services. In this chapter, our aim is to identify points of convergence and divergence between researchers, practitioners, stakeholders, and service users. Mirroring the structure of the previous chapters, we will organise this discussion thematically, focusing on the three key aspects of service user involvement: relationships, social power, and organisational arrangements.

Theme 1. The relationship between service users and practitioners

The issue that is most consistently emphasised in the academic literature on service user involvement is the need to establish collaborative relationships between staff and the people who use services. Researchers have presented strong evidence to support the view that being treated with respect, not being judged, and being valued as a person are fundamental characteristics of this two-way relationship. This facilitates the establishment of a bond that is based on trust, which in turn leads to more effective and open communication and a stronger focus on mobilising the resources and knowledge that the service user brings to the encounter. In the absence of trust, service users may avoid sharing sensitive information, resist or oppose the recommendations of staff, or drop out of treatment.

The academic literature reveals a paradox, as many practitioners who are aware of the benefits of collaborative relationships with service users nevertheless remain trapped within a logic of stigmatising, judgemental, oppressive relationships. Due to structural factors that are rooted in the organisational context, the professional culture, and the social norms of drug treatment, it can be difficult for service users and practitioners to collectively break out of this vicious cycle of mutual fear and suspicion.

It is essential, researchers advise, to understand that defensive routines and practices within drug treatment services are typically motivated by fear on the part of professionals and other staff members. Research suggests that cultivating empathy among practitioners through sustained engagement with service users during their training and careers can be an effective way of breaking down these barriers. Due to the effects of trauma, stigmatisation, disadvantage, and isolation, relationships between providers and service users are often fragile, which makes it more difficult to shift towards new forms of practice. The academic literature notes the value of using peer workers, mentors, and volunteers to reinforce relationships with service users and to facilitate reciprocal understanding. The incorporation of representatives and advocates at all levels of the system can ensure that service users' needs are heard, and the literature provides guidance on the kinds of supports that are required in order to go beyond tokenism and to incorporate user representatives with decision-making processes.

The service providers we interviewed were selected on the basis of their experience of facilitating user involvement. In harmony with the academic literature, they emphasised the need for practitioners to open up to service users, to be honest about their emotions and uncertainties, and to build close and supportive relationships. The resulting experience of trust and social connection is beneficial not only to service users, they observe, but also opens up new areas of professional practice that can be rewarding for staff. The domain of professional practice and development is thus a strategic one when planning interventions to promote service user involvement.

The capacity to empathise with service users, and thus to be sensitive to their feelings and needs, is a 'soft skill' that is often not part of the academic curriculum. Stakeholders point out that some practitioners spontaneously develop these skills as a result of their own life experiences, attributes, and professional development. Depending on their role, these practitioners can exert a positive influence on the people working beside them and, if they have managerial responsibilities, their influence can extend to an entire organisation. Recognising the value of the aforementioned skills during recruitment procedures is thus an important step towards promoting inclusive services.

Certain kinds of services appear to be more likely to develop close and supportive relationships with service users. This suggests that the skills involved in empathising with service users can be learned, and that all services have the capacity, in principle, to achieve this goal. The interviews we carried out with GPs who work closely with people who use drugs provide evidence that sustained engagement with service users, from medical school onwards, can equip students with the skills they need to develop supportive relationships with members of vulnerable groups.

The stakeholders we interviewed argue that a key step in the process of involving service users in their own treatment and in decisions about services is to recognise the value of their lived experience. By consciously drawing on this knowledge, professional practitioners can address the power imbalance that characterises relationships within the treatment setting. A second step is to encourage ownership of services and to show service users that they can have a voice and a stake in these services, that they are entitled to use them and to shape them to fit their needs. This shift further empowers service users by recognising the central position they occupy within treatment, recovery and harm reduction services.

Many of the practitioners and researchers we interviewed are of the opinion that these kinds of changes in the culture of service delivery can generate a virtuous cycle of involvement that becomes self-sustaining over time. When the relationships and organisational culture of service delivery become more supportive of clients, they argue, it is possible to manage tensions – including those around prescribing and pharmacotherapy – in a more effective way. All interviewees emphasised the importance of open and honest communication – actively listening to service users – as the key to developing more effective services. This is perhaps the central idea behind the paradigm of service user involvement: services are more effective when they address the needs of clients, and they can only find out what service users need by listening to them. Decision-making processes also tend to be more effective when they make optimal use of the available information and when they are shared rather than imposed.

The interviews we carried out with service users allow us to extend this analysis of the role of trust, empathy, and communication in drug treatment and recovery services. While our sample of stakeholders included people who are known for their commitment to service user involvement, our service users form a more heterogeneous group. Although we gathered many accounts of trusting and effective therapeutic relationships – particularly with counsellors, nurses, and key workers – there were also many detailed descriptions of dysfunctional relationships that were characterised by sharp asymmetries of power. In many cases, these involved physicians who did not develop a relationship with service users beyond fleeting encounters centred on the results of urine tests and one-sided decisions about medication, or physicians who appeared to be following rigid treatment plans that were never discussed with service users.

By combining these 'positive' and 'negative' images of relationships between service users and providers, it is possible to build up a picture of the main social dynamics that characterise the treatment setting. Service users generally aspire towards trusting, respectful relationships in which it is possible to discuss problems, explore solutions, and to reach decisions consensually. This aspiration is based on their commitment to achieving their own personal recovery goals, and their belief that practitioners are there to help them in this journey. When they do not feel respected and understood, and when they are unable to influence decisions or to obtain information, they may not have the self-confidence and skills to object, to make a complaint, or to ask for help. If they are not able to change services or to find a way forward, they are likely to adopt a passive role shaped by survival strategies, adaptation to lack of power, and self-medication.

The interviews also provide inspiring accounts of staff members who go 'above and beyond' their job description in order to help service users, and who develop new approaches to treatment and new ways of organising services that appear promising. In some cases, these individuals were influential enough to transform a whole service and to set in motion a virtuous cycle of involvement and innovation. But it is also clear from our interviews that collaborative relationships do not just emerge spontaneously. Distrust of service users can become a self-fulfilling prophecy. Building a different kind of relationship requires a sharp transition on the part of both service users and practitioners. There are risks involved in this process, but we have gained a better understanding of what these risks are, following more than two decades of research and pilot projects since the early 2000s in a range of different countries and contexts.

Theme 2. Social power

One of the most important structural features that inhibits the development of trusting, collaborative relationships within the treatment setting derives from asymmetries in power, status, resources and professional authority. Because of the inherited culture of drug treatment systems, service users are often stigmatised at the same time as they are provided with assistance. This places great pressure on treatment providers to distance themselves from service users.

Academic research has described the links between societal, institutional, and internalised forms of stigma, which impact on all aspects of the encounter between people who use drugs and treatment services. Stigma often imposes a penalising identity (the 'addict') on service users, which affects how they are treated by health services, pharmacies, social welfare services, housing organisations, and drug treatment services. Stigmatisation processes are also refracted by gender, ethnicity, social class, and other characteristics, creating specific difficulties for women with young children, immigrants, Travellers, and the residents of poor neighbourhoods as these forms of stigma interact and reinforce each other.

A key issue is whether it is possible for professional practice to overcome the debilitating effects of stigma, or whether it inevitably reflects and reinforces the inequalities and power disparities that exist in wider society. The academic literature from Scandinavia suggests that this is not inevitable, and the effects of progressive policies for service user empowerment, over the course of more than 20 years, are evident in the case studies and qualitative research carried out in Norway, Sweden, and Denmark. Policies include freedom of choice between doctors and drug treatment service providers in Sweden, the integration of services within a single structure, funding and support for user representatives and carefully specified legal rights and entitlements. At the same time, the Scandinavian research reveals the difficult dilemmas that are inherent in the process of user empowerment and involvement.

The picture painted by this impressive body of research contrasts sharply with research carried out in Ireland over the same period. The evidence from this country indicates that even practitioners and staff members are highly critical of their own services, describing them as 'punitive', 'dictatorial', and 'controlling'. Our stakeholder interviews confirm the crucial importance of power and stigmatisation within the context of drug treatment services and note the way in which stigma is rooted in wider policies and laws. They point out that service user involvement can be encouraged or discouraged by high-level policies and political discourses regarding problem drug use. They also highlight the importance of promoting self-reflection and training for professionals who work with deprived groups and victims of trauma.

The advocacy organisations and researchers we spoke with provided a clear description of the large drug treatment centres in Dublin, problematising the way in which they treat service users, the protocols they adopt in various situations, and their almost carceral approach to treatment provision. Their accounts are in line with published research on drug treatment services in Ireland. The provision of treatment at these clinics is, in a sense, the antithesis of service user involvement. The stakeholders we interviewed largely confirm that the principal forms of delivery of medical treatment for problem drug use – general practice and dedicated clinics – are both characterised by fundamental weaknesses. This does not mean that they do not fulfil an essential role, or that the practitioners who work in these organisations are not committed to their patients' well-being. However, it does suggest that they are not realising their full potential.

Because of their reliance on these two organisational forms, medical practitioners almost inevitably emerge from these interviews as the occupational group that has greatest difficulties with involving service users and establishing collaborative relationships. Stakeholders believe that this situation can only be remedied through a combination of organisational, cultural, and professional change which incentivates and rewards practitioners who engage with their clients in a more open, collaborative, and inclusive way.

Although our interviews with service users largely confirm this overall picture, they also provide a tantalising glimpse of how physicians, managers, and other practitioners can use their social power and skills to enable service users to have a greater say in their treatment. Although many service users never encounter this type of practitioner, those who do are influenced in a positive and lasting way. It is encouraging to recognise that shifting power to service users, and providing them with more choices and support, will benefit the services and practitioners who are most committed to their empowerment and recovery, and most sensitive to their needs.

It is interesting to note that service users themselves rarely talk about the physical barriers, demeaning practices, and rigid rules that stakeholders emphasise in their accounts of the obstacles to service user involvement within the drug treatment system. Instead, service users emphasise the social relationships that characterise those settings and the meanings that are jointly created within treatment centres and clinics. Where staff members reach out to them and demonstrate that they care about their welfare, service users are much more accepting of the delays, inconvenience, rules, and constant monitoring that may characterise addiction services. As well as focusing on these problematic procedures, it is thus essential to give priority to building collaborative relationships.

We have dedicated considerable attention in this report to issues such as prescribing, tapering medication, and criteria for accessing different kinds of services. Our interviews confirm that many users aim to achieve detoxification but, paradoxically, encounter resistance from treatment providers who feel that they are not ready, or that their probability of achieving these goals is too low for it to be worth trying. Whether they are right can only be ascertained when practitioners encourage service users to pursue their goals in a supportive and trusting environment. It is worth noting, in this context, that the HSE Clinical Guidelines for Opioid Substitution Treatment (2016) specify that dose reduction "should be based on client assessment and on client direction" (p. 36).

Theme 3. Organisational practices

The organisational context of drug treatment, recovery and harm reduction services generates a number of mechanisms that can either facilitate or impede service user involvement. A fundamental insight that is emphasised in the academic literature is that formalistic approaches to service user involvement which equate this with institutional innovations like service user forums, care plans, or charters, are unlikely to achieve their goals. This is because they ignore the fact that relationships, power, and rules are closely intertwined, and making progress towards user involvement requires coordinated movement along all three axes.

As we suggested earlier in this report, researchers often contrast shared decision-making with the paternalistic model of service provision, where practitioners are assumed to know what is best for their clients. Although the evidence is somewhat mixed, the concept of shared decision-making appears useful. For example, the evidence on choice of treatment provider and personal treatment budgets suggests that these can contribute to the empowerment of service users. We also summarised research showing that relatively small-scale innovations can facilitate new styles of interaction and pave the way for greater user involvement if staff are supported and ready to make this shift.

The literature on service user involvement also highlights the importance of person-centred care, which seeks to be respectful of the service user's preferences and needs. There is a close link between person-centred care and building trusting relationships: it is through providing person-centred care (and thus helping to resolve difficulties in other areas of the client's life) that service providers demonstrate that they care about them and can be trusted, and develop the skills and motivation that are needed in order to promote their autonomy.

It is in relation to organisational practices that the resource implications of supporting service user involvement are most evident. Being flexible, adapting treatment to the evolving needs of clients, maintaining a comprehensive focus on the client as a person, considering innovative solutions and possibilities, making room for mistakes, and building closer and more authentic relationships all require time and continuity in the relationship between service users and practitioners. Person-centred models of treatment typically place greater demands on practitioners in terms of time, uncertainty, advocacy, discussion, and reflexivity. Staff members who are inadequately trained, motivated, and supported may not commit their time and energy to uncertain programmes of organisational change.

At the same time, it is important to note that some practitioners and services are already moving in the direction of greater user involvement and instituting new programmes and models. This is also what service users are requesting, and an impressive body of evidence suggests that this paradigm is likely to become more and more influential in coming years. Identifying the key features of pioneering services is an important research goal that can help to develop more effective programmes for generating change within mainstream services. Research from a range of different countries suggests that the integration of medical treatment, mental health services, psycho-social support, and other forms of assistance (training, housing, employment, etc.) is conducive to service user involvement, perhaps because more challenging aspects of treatment can be tackled by 'leaning on' high-trust relationships.

In the course of this study, we interrogated the evidence in relation to the question of outcomes. A key question is whether it is possible to ascertain whether greater service user involvement leads to better rates of retention in treatment, lower rates of relapse, lower

levels of substance use, higher life satisfaction, or better health. This turns out to be a difficult question to answer. One reason for this is that the effectiveness of treatment models is typically measured using randomised controlled trials or by exploiting differences between services or regions in observational studies. The very nature of service user involvement makes it difficult o carry out this kind of assessment, so we must rely primarily on qualitative data that can provide insights into the ways in which user involvement affects treatment. This challenge applies to all areas of service provision – including health and social services more generally – and is not specific to drug treatment, recovery and harm reduction.

Our interviews with stakeholders yielded a number of interesting observations in relation to the organisational context of drug treatment services in Ireland. For example, many interviewees pointed out that service users find themselves trapped in large and impersonal clinics because they have few alternatives and little choice. It remains the case that many GPs are reluctant to accept people who use drugs or who are receiving treatment for problem drug use, and most medical doctors who are involved in providing these services do not appear to work as part of a multidisciplinary team. This situation could, perhaps, be ameliorated by appropriate policies and incentives, and our stakeholders provided examples of smaller, medically managed clinics that do not rely on security guards, rarely transfer patients, and are committed to developing collaborative and supportive relationships with service users.

The development of treatment services that are more welcoming and inclusive of service users can give rise to a dilemma for practitioners. These services are at risk of becoming 'niche' services in which drug treatment service users feel enfranchised, reducing the pressure on others to meet the needs of this group. This risk is particularly evident for GP-led clinics, and helps to explain why many GPs may feel reluctant to accept patients on opiate agonist therapy or other forms of treatment for problem drug use. At a systemic level, it is important to find ways to generalise from the positive experiences of the pioneers of service user involvement, without condemning them to remain islands in a sea of indifference.

It is interesting to consider how organisational structure and institutional features relate to service user involvement. Our interviews provide some insights into this issue, and highlight the need for innovation at local level. First, many stakeholders emphasise the need for managerial support and buy-in when extending and deepening the engagement of practitioners with service users. Where innovations and changes to organisational practices are identified by practitioners and service users in collaboration, it is important that managers are willing to implement the required changes. Second, organisations appear to be more inclusive when managers remain in close contact with service users and find opportunities to talk to them and encourage them to express their opinions. It is important for managers to manage conflicts and difficulties involving service users in an open manner, listening attentively and helping clients and staff members to empathise with each other.

The importance of organisational culture and mission is highlighted by the positive assessments our stakeholders provided of low-threshold services as far as service user involvement is concerned, both at national and international level. Due in part to their immersion in the philosophy and practice of harm reduction, and in part because of the ways in which staff are selected and self-select into these services, these frontline and outreach services appear to be particularly effective at involving service users. This is also encouraged by the widespread use of peer workers and volunteers with lived experience of problem drug use and by the lack of coercion that characterises low-threshold services. It is important to draw on these experiences and to use them in order to identify learning opportunities for practitioners across drug treatment, health, and recovery services.

Another issue that has become increasingly clear during the COVID-19 pandemic is that appropriate use of new information technologies holds potential for enhancing service user involvement in the context of drug treatment, recovery, and harm reduction services. This is because these technologies facilitate relaxed, informal, and frequent interactions between service users and practitioners on a level virtual playing field. As service users can access these services from their own home, they can be reconciled more easily with family responsibilities, bypassing physical and social barriers. This avoids the risk of exposing service users to potential triggers for substance use in and around treatment centres and can provide them with the possibility of establishing meaningful connections with services and other service users.

One ingredient that appears to improve the capacity of services to consult with and involve service users is the way in which they engage with their own staff members. Organisations that support and work with staff to develop and unify their practice appear to be more willing and able to involve service users. This suggests that the user involvement paradigm is as much about how organisations work with their own practitioners as it is about how they reach out to clients. The experts we interviewed pointed out that it requires training, supervision, and mentoring in order to bring a complex organisation to the point where it is capable of successfully involving service users.

Stakeholders provided several examples of how services were transformed as a result of becoming more open to service users' needs, preferences, and knowledge. Closer engagement with service users enabled them to go beyond just 'treating the symptoms' in order to identify and tackle at least some of the issues that were preventing service users from changing their patterns of drug use, including trauma, homelessness, powerlessness, lack of education, and mental health problems. When service users felt that they could trust practitioners, and services were actively listening, it was possible to expand the scope of drug treatment and to mobilise resources outside their perimeter more effectively.

Our interviews with stakeholders also highlighted the role of advocacy groups and organisations in capturing and amplifying the voices of service users and in providing them with support and information so that they are better equipped to engage with services, managers, and policy-makers. As long as there are treatment providers that do not listen to service users, advocacy groups will have an important role in helping service users to file complaints and to demand respect. However, our interviews suggest that advocacy groups also have an important role to play in the development of more inclusive services and that they are ready to engage with service providers at an organisational level in order to achieve this goal.

Another key feature of advocacy groups is that they provide a structure that enables service users to participate in debates and decisions at higher levels, beyond the immediate treatment setting. This has proved exceedingly difficult to achieve, as many stakeholders noted, partly because the very foundations of systematic service user involvement are still shaky or absent in many services.

Advocacy groups also enable service users to draw on their lived experience and to provide feedback to services following their own recovery. This is a powerful mechanism that services have yet to harness. It is clear from our interviews that people who are in recovery, and who have successfully navigated treatment services, have considerable insights into the nature of the interface between services and service users, high credibility with the latter, and often strong motivation to participate in debates and research on how to improve treatment.

Turning now to the interviews we conducted with service users, a number of important issues

emerged, some of which have not received sufficient attention in the academic literature. First, it is clear that the lack of integration between mental health care and drug treatment services creates difficulties for service users and makes it difficult for them to participate in decisions about treatment. This is because service users with a dual diagnosis typically require coordinated support and advice from mental health services as well as specialists in the treatment of addiction. The impressive integration of drug treatment services in Scandinavian countries – bringing together physicians, psychiatrists, psychologists, counsellors, social workers, and nurses within a single organisational setting, with strong links to statutory services providing housing, education, and income support – may be a key enabling factor in relation to service user involvement. The 2020 Mental Health Policy document Sharing the Vision emphasises the need for integrated services across primary care and specialist mental health services in the context of drug treatment, and the evidence we collected in the course of this project provides strong support for this aspect of the Dual Diagnosis Improvement Programme.

Second, the service user interviews highlighted the difficulties involved in determining appropriate individual pathways through a rather fragmented universe of services. Staff at all of these services – including key workers – face difficulties when seeking to adopt a system-wide approach. The proliferation of services following different logics, based on the context and the underlying philosophy of service delivery, may be a source of flexibility and innovation, but it would appear that the fragmented nature of the Irish system poses challenges in terms of service user involvement.

Third, service users identified a number of paradoxes and 'traps' that are built into drug treatment services, which leave them in a state of ambiguity and uncertainty about how they should behave and what they should expect from services. For example, when they initially request treatment for problem drug use, service users are often expected to continue using illegal drugs for a 'trial period', so that practitioners can monitor their drug use with urine tests. Conversely, when they decide to reduce their dependence on methadone or other opiate agonists, they may find that treatment providers are opposed to this objective or do not believe that it is achievable.

The reliance of many medically managed clinics on urine testing also creates a paradoxical situation in which decisions are based on the results of tests, rather than on honest discussion with service users. This pushes service users to look for ways of avoiding, manipulating, or exploiting this process. The heterogeneity of prescribing practices leaves many service users with the impression that medical decision-making is essentially arbitrary and their requests for explanations do not always receive a satisfactory response.

Fourth, an important finding of this research project is that the institution of service user representatives is unlikely to be effective if service users do not feel secure and respected in the treatment settings that they continue to rely upon. This is one reason why it is misleading to think about service user involvement in hierarchical terms, with involvement in policy discussions representing the highest form and being consulted about treatment options the lowest. The evidence from this review suggests that these different modes of participation are internally related and that service user should be defined in more unitary and less schematic terms.

Finally, the results of our service user consultation suggest that services can draw on a number of resources in order to become better at engaging with their clients. These resources include people who have experienced problem drug use and who are often motivated to engage with services. Our interviewees identified volunteers and peer workers as a crucial component of

effective services, and spoke of their determination to contribute to making services more effective in the future. Another resource is the existence within the drug treatment system of innovative practitioners and services that have already found ways of engaging with service users.

There are many key workers operating in different parts of the system who have extensive experience of encouraging service users to express themselves and to identify goals. With additional support, these key workers could bridge the gaps between services and help to unify practices in relation to user involvement across the system as a whole, following the Scandinavian model.

Service users have a unique perspective on drug use and drug treatment. In order to effectively meet their needs, service providers must listen to what service users have to say and respond appropriately. Implementing this principle is a complex challenge, as it brings to light the different ways in which structural factors and features such as fear, stigmatisation, unequal power, lack of resources, and the management of services have shaped interactions between service users and providers over many years. The people who attend drug treatment services often have complex needs, implying that treatment providers must be able to provide a solid multidisciplinary and interorganisational response. Service users greatly appreciate all genuine attempts to help them, but they would be even more appreciative if these responses were not simply left to the goodwill and individual initiative of staff members.

The narrative summaries and evidence presented in this report show that researchers, policy-makers, managers, and practitioners in Ireland and other countries sometimes struggle to understand the role of service user involvement in relation to drug treatment services. However, there is enough evidence to state with confidence that considerable benefits can be gained from pursuing this new paradigm, although this process poses challenges. Meaningful forms of service user involvement – including collaborative relationships between practitioners and service users and ways of representing the latter in decisions about services – are not going to emerge spontaneously without targeted interventions. Policy statements are not sufficient on their own, and must be transformed into a programme of change that can win the support of the actors most centrally involved in drug treatment, harm reduction, and recovery services.

Appendix 1
Studies included in the literature review

Qualitative

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Appendix 2 Search procedures used – databases and websites

1. Embase research database (Embase.com)

Searched 11/09/2020

Set number	Search query	Records identified
#46	#44 AND [abstracts]/lim	6,514
#45	#44 AND #43	6,647
#44	2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py OR 2018:py OR 2019:py OR 2020:py OR 2021:py	14,930,441
#43	#33 AND #42	10,724
#42	#34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41	544,092
#41	((participation OR participating OR participants OR participate) NEAR/4 (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR 'non professional' OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	64,151
#40	(('involvement' OR involving OR involved) NEAR/4 (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR 'non professional' OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	59,330
#39	((contribution* OR contributing OR contributed) NEAR/4 (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR 'non professional' OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	13,370
#38	((engagement OR engaged OR engaging) NEAR/4 (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR 'non professional' OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	22,646
#37	((consult OR consultation OR consulting) NEAR/4 (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR 'non professional' OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	10,183

Set number	Search query	Records identified
#36	((influenc* OR recruit* OR collaborat* OR say OR role OR preference* OR partnership OR partnering OR empower) NEAR/4 (consumer OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR 'non professional' OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	160,660
#35	'joint decision making':ti,ab,kw OR 'shared decision making':ti,ab,kw	12,945
#34	'decision making'de OR 'family decision making'de OR 'patient decision making'de OR 'shared decision making'de	253,411
#33	#10 AND #32	**210,264**
#32	#18 OR #31	**2,255,302**
#31	#19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30	**629,782**
#30	'low threshold service':ti,ab,kw OR *'low threshold agency':ti,ab,kw	72
#29	((opiate* OR opioid* OR morphine OR heroin OR methadone) NEAR/5 (treatment* OR service* OR unit OR units OR center OR centers OR centre OR centres OR facilit* OR recovery OR 'social integration' OR reintegration OR 'social inclusion')):ti,ab,kw	29,197
#28	((needle* OR syringe* OR inject) NEAR/5 (exchange* OR suppl* OR access* OR provision OR provid* OR distribut* OR dispens* OR pack* OR program* OR service* OR center* OR centre* OR scheme* OR facility OR facilities OR area* OR pharmacy OR pharmacies OR unit OR units OR room*)):ti,ab,kw	39,635
#27	((opioid OR opiate OR morphine OR heroin) NEAR/3 (substitut* OR replace* OR maintenance)):ti,ab,kw	4,820
#26	((substitut* OR maintenance OR therapy OR treatment) NEAR/4 (methadone OR buprenorphine OR subutex OR suboxone)):ti,ab,kw	10,925
#25	OST:ti,ab,kw OR 'oral substitution treatment':ti,ab,kw OR *'oral substitution therap'*:ti,ab,kw	2,614
#24	Naloxone:ti,ab,kw	28,674
#23	(consumption NEAR/5 (room OR rooms OR facilit*)):ti,ab,kw	959
#22	Detox*:ti,ab,kw	55,498
#21	((drug OR drugs OR substance* OR narcotic) NEAR/5 (treatment OR service* OR unit OR units OR center OR centers OR centre OR centres OR facilit* OR recovery OR reintegration OR 'social inclusion' OR 'social capital')):ti,ab,kw	247,838
#20	'12 step':ti,ab,kw OR '12 steps':ti,ab,kw OR 'twelve step':ti,ab,kw OR 'twelve steps':ti,ab,kw OR 'narcotics anonymous':ti,ab,kw	2,268
#19	'drug dependence treatment'/exp OR 'narcotics anonymous'de OR 'detoxification'/de OR 'drug detoxification'/de OR 'drug withdrawal'/de OR 'naloxone'/de OR 'buprenorphine'/de OR 'buprenorphine plus naloxone'/de	306,503
#18	#11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17	**1,685,234**
#17	(behavio* NEAR/2 therap*):ti,ab,kw	39,321
#16	(cognitive NEAR/2 therap*):ti,ab,kw	33,087

Set number	Search query	Records identified
#15	(therapeutic NEAR/2 communit*):ti,ab,kw	2,655
#14	(residential NEAR/2 (communit* OR care OR program*)):ti,ab,kw	8,442
#13	(pharmacological NEAR/2 (therapy OR therapies OR treatment* OR program*)):ti,ab,kw	46,717
#12	Counseling:ti,ab,kw OR counselling:ti,ab,kw OR psychotherap:ti,ab,kw OR *psychosocial:ti,ab,kw OR *reinforcement:ti,ab,kw OR motivation:ti,ab,kw OR *contingent:ti,ab,kw OR *recovery:ti,ab,kw OR 'social reintegration':ti,ab,kw OR 'social inclusion':ti,ab,kw OR 'social capital':ti,ab,de	1,099,426
#11	'counseling'de OR 'patient counseling'de OR 'social support'de OR 'mental health care'/exp OR 'community care'/de OR 'community mental health service'exp OR 'case management'/ de OR 'health care'/de OR 'rehabilitation'/de OR 'community based rehabilitation'/de OR 'residential care'/de OR 'therapeutic community'/de OR 'cognitive therapy'/exp OR 'behavior therapy'/ de OR 'social capital'/de OR 'reintegration'/de	678,632
#10	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9	**848,789**
#9	(('para methoxymethamfetamine' OR phencyclidine OR piperazine* OR psychoactive OR solvent* OR subutex) NEAR/5 (problem OR use OR uses OR users OR using OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse*)):ti,ab,kw	34,337
#8	((methoxetamine OR methylamphetamine OR methylamfetamine OR methylone OR mushroom OR mushrooms OR naphyrone OR opiate OR opiates OR opioid OR opioids OR opium OR 'para methoxyamphetamine' OR 'para methoxymethamphetamine' OR 'para methoxyamfetamine') NEAR/5 (problem OR use OR uses OR users OR using OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse*)):ti,ab,kw	52,920
#7	(('amyl nitrate' OR amphetamine* OR amfetamine* OR 'anabolic steroid'* OR 'benzodiazepine'* OR 'butyl nitrate' OR codeine OR ecstasy OR ecstacy OR cannabis OR cocaine OR crack OR diamorphine OR hallucinagen OR hallucinogen OR heroin OR ketamine OR khat OR 'lysergic acid diethylamide' OR lsd OR mephedrone OR marijuana OR mdma OR methadone OR methamphetamine* OR methamphetamine) NEAR/5 (problem OR use OR uses OR users OR using OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse*)):ti,ab,kw	85,693
#6	((drug OR drugs OR substance* OR narcotic* OR polydrug) NEAR/5 (problem OR use OR uses OR using OR users OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse)):ti,ab,kw	413,228
#5	(('prescription drug' OR 'prescription drugs') NEAR/5 diver*):ti,ab,kw	191
#4	(('illicit drug' OR 'illicit drugs') NEAR/5 inhal*):ti,ab,kw	73

Set number	Search query	Records identified
#3	('analgesic agent'* NEAR/5 (misuse* OR misusing OR abuse* OR abusing OR dependen* OR addict* OR polyabuse)):ti,ab,kw	28
#2	((narcotic* OR polydrug OR drug OR substance) NEAR/5 (intox* OR consumption)):ti,ab,kw	10,363
#1	'substance abuse'/exp OR 'substance abuse' OR 'narcotic dependence'/exp OR 'narcotic dependence' OR 'drug abuse'/exp OR 'drug abuse' OR 'amphetamine abuse'/exp OR 'amphetamine abuse' OR 'analgesic agent abuse'/exp OR 'analgesic agent abuse' OR 'illicit drug inhalation'/exp OR 'illicit drug inhalation' OR 'inhalant abuse'/exp OR 'inhalant abuse' OR 'drug misuse'/exp OR 'drug misuse' OR 'drug intoxication'/exp OR 'drug intoxication' OR 'addiction'/exp OR 'addiction' OR 'cannabis addiction'/exp OR 'cannabis addiction' OR 'drug dependence'/exp OR 'drug dependence' OR 'intravenous drug abuse'/exp OR 'intravenous drug abuse' OR 'cocaine dependence'/exp OR 'cocaine dependence' OR 'amphetamine dependence'/exp OR 'amphetamine dependence' OR 'benzodiazepine dependence'/exp OR 'benzodiazepine dependence' OR 'methamphetamine dependence'/exp OR 'methamphetamine dependence' OR 'multiple drug abuse'/exp OR 'multiple drug abuse' OR 'phenyclidine dependence' OR 'phenyclidine abuse' OR 'prescription drug diversion'/exp OR 'prescription drug diversion'	531,068

2. The HRB National Drugs Library (https://www.drugsandalcohol.ie/)

Searched 27/11/2020

Search	Number of records retrieved
Title matches any of "consultation consult consulting engage engagement engaging involve involvement involving influence influencing collaboration collaborate collaborating participate participation participating partnership partnering centered centred focused advocacy" AND Year/Date Range is 2011 or more	249
Title matches any of "shared" AND Year/Date Range is 2011 or more	8
Subject matches any of "inclusion and exclusion" (Ignoring: "and") AND Year/Date Range is 2011 or more	105
Subject matches "community involvement" AND Year/Date Range is 2011 or more	274
Subject matches "programme planning (strategy)" AND Year/Date Range is 2011 or more	250
Subject matches "outreach" AND Year/Date Range is 2011 or more	5
Subject matches "advocacy" AND Year/Date Range is 2011 or more	70
Total number of records retrieved	0

3. The CENTRAL Register of Controlled Trials (Cochrane Library)

Searched 1/12/2020

Set number	Search	Number of records
#1	(((participation OR participating OR participants OR participate) NEAR (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers))):ti,ab,kw	17,650
#2	(("involvement" OR involving OR involved) NEAR (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	3,808
#3	((contribution* OR contributing OR contributed) NEAR (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	588
#4	((engagement OR engaged OR engaging) NEAR (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	2,330
#5	((consult OR consultation OR consulting) NEAR (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	1,588
#6	((influenc* OR recruit* OR collaborat* OR say OR role OR preference* OR partnership OR partnering OR empower) NEAR (consumer OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	18,340
#7	("joint decision making" OR "shared decision making"):ti,ab,kw	1,316
#8	MeSH descriptor: [Decision Making] explode all trees	3,921
#9	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8	42,806
#10	MeSH descriptor: [Substance-Related Disorders] this term only	3,853
#11	MeSH descriptor: [Amphetamine-Related Disorders] this term only	279
#12	MeSH descriptor: [Cocaine-Related Disorders] this term only	1,037
#13	MeSH descriptor: [Inhalant Abuse] this term only	5
#14	MeSH descriptor: [Marijuana Abuse] this term only	595
#15	[mh "Narcotic-related disorders"] OR [mh ^"Phenycyclidine abuse"] OR [mh ^"Psycoses, substance-induced"] OR [mh ^"Substance abuse, intravenous"] OR [mh ^"Substance abuse, oral"] OR [mh ^"Substance withdrawal syndrome"]	3,671

Set number	Search	Number of records
#16	[mh ^"Marijuana use"] OR [mh ^"Opiate substitution treatment"] OR [mh ^"Substance abuse treatment centers"] OR [mh "Illicit drugs"] OR [mh ^"Prescription drug diversion"]	931
#17	((narcotic* OR polydrug OR drug OR substance) NEAR (intox* OR consumption)):ti,ab,kw	4,247
#18	("analgesic agent*" NEAR (misuse* OR misusing OR abuse* OR abusing OR dependen* OR addict* OR polyabuse)):ti,ab,kw	14
#19	("illicit drug*"):ti,ab,kw	624
#20	((drug OR drugs) NEAR diver*):ti,ab,kw	376
#21	((drug OR drugs OR substance* OR narcotic* OR polydrug) NEAR (problem OR use OR uses OR using OR users OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse)):ti,ab,kw	54,517
#22	(("amyl nitrate" OR amphetamine* OR amfetamine* OR "anabolic steroid*" OR benzodiazepine' OR "butyl nitrat" OR codeine OR ecstasy OR ecstacy OR cannabis OR cocaine OR crack OR diamorphine OR hallucinagen OR hallucinogen OR heroin OR ketamine OR khat OR "lysergic acid diethylamide" OR lsd OR mephedrone OR marijuana OR mdma OR methadone OR methamphetamine* OR methamphetamine) NEAR (problem OR use OR uses OR users OR using OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse*)):ti,ab,kw	10,043
#23	((methoxetamine OR methylamphetamine OR methylamfetamine OR methylone OR mushroom OR mushrooms OR naphyrone OR opiate OR opiates OR opioid OR opioids OR opium OR "para methoxyamphetamine" OR "para methoxymethamphetamine" OR "para methoxyamfetamine") NEAR (problem OR use OR uses OR users OR using OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse*)):ti,ab,kw	12,138
#24	(("para methoxymethamfetamine" OR phencyclidine OR piperazine* OR psychoactive OR solvent* OR subutex) NEAR (problem OR use OR uses OR users OR using OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse*)):ti,ab,kw	2,223
#25	#10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24	72,368
#26	#9 AND #25 with Publication Year from 2011 to 2020, in Trials	2,134

4. Cochrane Database of Systematic Reviews (Cochrane Library)

Searched 1/12/2020

Set number	Search	Number of records
#1	(((participation OR participating OR participants OR participate) NEAR (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers))):ti,ab,kw	17,650
#2	(("involvement" OR involving OR involved) NEAR (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	3,808
#3	((contribution* OR contributing OR contributed) NEAR (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	588
#4	((engagement OR engaged OR engaging) NEAR (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	2,330
#5	((consult OR consultation OR consulting) NEAR (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	1,588
#6	((influenc* OR recruit* OR collaborat* OR say OR role OR preference* OR partnership OR partnering OR empower) NEAR (consumer OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers)):ti,ab,kw	18,340
#7	("joint decision making" OR "shared decision making"):ti,ab,kw	1,316
#8	MeSH descriptor: [Decision Making] explode all trees	3,921
#9	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8	42,806
#10	MeSH descriptor: [Substance-Related Disorders] this term only	3,853
#11	MeSH descriptor: [Amphetamine-Related Disorders] this term only	279
#12	MeSH descriptor: [Cocaine-Related Disorders] this term only	1,037
#13	MeSH descriptor: [Inhalant Abuse] this term only	5
#14	MeSH descriptor: [Marijuana Abuse] this term only	595
#15	[mh "Narcotic-related disorders"] OR [mh ^"Phenycyclidine abuse"] OR [mh ^"Psycoses, substance-induced"] OR [mh ^"Substance abuse, intravenous"] OR [mh ^"Substance abuse, oral"] OR [mh ^"Substance withdrawal syndrome"]	3,671

Set number	Search	Number of records
#16	[mh ^"Marijuana use"] OR [mh ^"Opiate substitution treatment"] OR [mh ^"Substance abuse treatment centers"] OR [mh "Illicit drugs"] OR [mh ^"Prescription drug diversion"]	931
#17	((narcotic* OR polydrug OR drug OR substance) NEAR (intox* OR consumption)):ti,ab,kw	4,247
#18	("analgesic agent*" NEAR (misuse* OR misusing OR abuse* OR abusing OR dependen* OR addict* OR polyabuse)):ti,ab,kw	14
#19	("illicit drug*"):ti,ab,kw	624
#20	((drug OR drugs) NEAR diver*):ti,ab,kw	376
#21	((drug OR drugs OR substance* OR narcotic* OR polydrug) NEAR (problem OR use OR uses OR using OR users OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse)):ti,ab,kw	54,517
#22	(("amyl nitrate" OR amphetamine* OR amfetamine* OR "anabolic steroid*" OR benzodiazepine' OR "butyl nitrat" OR codeine OR ecstasy OR ecstacy OR cannabis OR cocaine OR crack OR diamorphine OR hallucinagen OR hallucinogen OR heroin OR ketamine OR khat OR "lysergic acid diethylamide" OR lsd OR mephedrone OR marijuana OR mdma OR methadone OR methamphetamine* OR methamphetamine) NEAR (problem OR use OR uses OR users OR using OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse*)):ti,ab,kw	10,043
#23	((methoxetamine OR methylamphetamine OR methylamfetamine OR methylone OR mushroom OR mushrooms OR naphyrone OR opiate OR opiates OR opioid OR opioids OR opium OR "para methoxyamphetamine" OR "para methoxymethamphetamine" OR "para methoxyamfetamine") NEAR (problem OR use OR uses OR users OR using OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse*)):ti,ab,kw	12,138
#24	(("para methoxymethamfetamine" OR phencyclidine OR piperazine* OR psychoactive OR solvent* OR subutex) NEAR (problem OR use OR uses OR users OR using OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse*)):ti,ab,kw	2,223
#25	#10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24	72,368
#26	#9 AND #25 in Cochrane Reviews	51

5. Epistemonikos (https://www.epistemonikos.org/)

Searched 1/12/2020

Search	Number of records
(title:(((participation OR participating OR participants OR participate OR "involvement" OR involving OR involved OR contribution* OR contributing OR contributed OR engagement OR engaged OR engaging OR consult OR consultation OR consulting OR influenc* OR recruit* OR collaborat* OR say OR role OR preference* OR partnership OR partnering OR empower*) AND (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers)) OR "joint decision making" OR "shared decision making") OR abstract:(((participation OR participating OR participants OR participate OR "involvement" OR involving OR involved OR contribution* OR contributing OR contributed OR engagement OR engaged OR engaging OR consult OR consultation OR consulting OR influenc* OR recruit* OR collaborat* OR say OR role OR preference* OR partnership OR partnering OR empower*) AND (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers)) OR "joint decision making" OR "shared decision making")) AND (title:(((narcotic* OR polydrug OR drug OR substance) AND (intox* OR consumption)) OR ("analgesic agent*" AND (misuse* OR misusing OR abuse* OR abusing OR dependen* OR addict* OR polyabuse))) OR abstract:(((narcotic* OR polydrug OR drug OR substance) AND (intox* OR consumption)) OR ("analgesic agent*" AND (misuse* OR misusing OR abuse* OR abusing OR dependen* OR addict* OR polyabuse))))	117
(title:(((participation OR participating OR participants OR participate OR "involvement" OR involving OR involved OR contribution* OR contributing OR contributed OR engagement OR engaged OR engaging OR consult OR consultation OR consulting OR influenc* OR recruit* OR collaborat* OR say OR role OR preference* OR partnership OR partnering OR empower*) AND (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers)) OR "joint decision making" OR "shared decision making") OR abstract:(((participation OR participating OR participants OR participate OR "involvement" OR involving OR involved OR contribution* OR contributing OR contributed OR engagement OR engaged OR engaging OR consult OR consultation OR consulting OR influenc* OR recruit* OR collaborat* OR say OR role OR preference* OR partnership OR partnering OR empower*) AND (consumer* OR client* OR user OR users OR lay OR community OR communities OR collective OR family OR families OR "non professional" OR representative OR representatives OR public OR patient OR peer OR carer OR carers)) OR "joint decision making" OR "shared decision making")) AND (title:("illicit drug*" OR ((drug OR drugs) AND diver*) OR ((drug OR drugs OR substance* OR narcotic* OR polydrug) AND (problem OR use OR uses OR using OR users OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse))) OR abstract:("illicit drug*" OR ((drug OR drugs) AND diver*) OR ((drug OR drugs OR substance* OR narcotic* OR polydrug) AND (problem OR use OR uses OR using OR users OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse))))	283

Search	Number of records
(("amyl nitrate" OR amphetamine* OR amfetamine* OR "anabolic steroid*" OR benzodiazepine' OR "butyl nitrat" OR codeine OR ecstasy OR ecstacy OR cannabis OR cocaine OR crack OR diamorphine OR hallucinagen OR hallucinogen OR heroin OR ketamine OR khat OR "lysergic acid diethylamide" OR lsd OR mephedrone OR marijuana OR mdma OR methadone OR methamphetamine* OR methamphetamine) AND (problem OR use OR uses OR users OR using OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse*)) OR ((methoxetamine OR methylamphetamine OR methylamfetamine OR methylone OR mushroom OR mushrooms OR naphyrone OR opiate OR opiates OR opioid OR opioids OR opium OR "para methoxyamphetamine" OR "para methoxymethamphetamine" OR "para methoxyamfetamine") AND (problem OR use OR uses OR users OR using OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse*)) OR (("para methoxymethamfetamine" OR phencyclidine OR piperazine* OR psychoactive OR solvent* OR subutex) AND (problem OR use OR uses OR users OR using OR misuse* OR misusing OR abuse* OR abusing OR consum* OR dependen* OR addict* OR polyabuse*))	79
Total number of records	0

6. Google Scholar

Searched 28/11/2020; the top 50 results were screened

Search	Number of records retrieved
Search phrases: involving users in planning substance abuse treatment services	10
Search phrase: shared service planning substance abuse	0
Search phrase: user participation in service planning "substance misuse"	10
Total records downloaded	20

7. The US National Institute of Drug Abuse (NIDA)

Searched 30/11/2020:

Search	Number of records identified	Number of records downloaded
user involvement	14	1
Koustova (key named person)	18	0
OTIPI (key named department)	0	0
NIH HEAL	0	0
Centricity	1	0
centric	1	0
patient-centred	0	0
advocacy	0	1
patient-focused	0	0
empower	0	0
stakeholder	0	0
Total records downloaded	34	2

8. The online resources of the US Substance Abuse and Mental Health Services Administration (SAMHSA) (https://www.samhsa.gov/)

Searched 2/12/2020

Search	Number of records identified	Number of records downloaded
centricity	1	1
centred	2	0
shared	4	4
engagement	0	0
consultation with users	0	0
user involvement	1	1
stakeholder	2	2
user influence	0	0
collaboration	0	0
partner	0	0
Total records downloaded	10	8

9. European Monitoring Centre for Drugs and Drug Addiction (www.emcdda.europa.eu)

Searched 2/12/2020

Search	Number of records
centric	0
centricity	1
centred	0
user	0
shared	0
engagement	0
consult	1
user involvement	3
stakeholder	1
user influence	0
collaboration	0
partner	0
Total number of records	6

We also conducted a Google search as follows, but no relevant records were identified:

*user planning drug treatment services site:*emcdda.europa.eu

From the EMCDDA site we also followed links to obtain:

Service User Involvement Treatment Framework in Wales (1 report)
Northern Ireland government documents (2 reports)

10. British Library catalogue (http://explore.bl.uk/primo_library/libweb/action/search.do?vid=BLVU1)

Searched 9/12/2020

Search	Number of records identified	Number of records downloaded
Anywhere: user involvement AND anywhere: substance abuse AND 2011–2020	4	2
Anywhere: user + involvement AND anywhere: substance use NOT anywhere: substance+abuse AND 2011–2020	1	1
Anywhere: user + participation AND anywhere: substance+use AND 2011–2020	3	0

Search	Number of records identified	Number of records downloaded
Anywhere: User + participation AND anywhere: substance+abuse AND 2011–2020	1	1
Anywhere: user +i nvolvement AND anywhere: service+planning AND anywhere: substance AND 2011–2020	0	0
Anywhere: user + participation AND anywhere: service+planning AND anywhere: substance AND 2011–2020	0	0
Anywhere: service + planning AND anywhere: substance AND 2011–2020	29	0
Subject: substance abuse AND anywhere: consultation AND 2011–2020	2	0
Subject: substance abuse AND anywhere: consulting AND 2011–2020	8	0
Subject: substance abuse AND anywhere: engaging AND 2011–2020	5	0
Subject: substance abuse AND anywhere: engagement AND 2011–2020	3	0
Subject: substance abuse AND anywhere: involving AND 2011–2020	4	0
Subject: substance abuse AND anywhere: influencing AND 2011–2020	8	0
Subject: substance abuse AND anywhere: collaboration AND 2011–2020	2	0
Subject: substance abuse AND anywhere: participation AND 2011–2020	4	0
Subject: substance abuse AND anywhere: partnership AND 2011–2020	4	2
Subject: substance abuse AND anywhere: partnering AND 2011–2020	3	0
Subject: substance abuse AND anywhere: advocacy AND 2011–2020	5	2
Subject: substance abuse AND anywhere: patient–centric AND 2011–2020	0	0
Subject: substance abuse AND anywhere: shared AND 2011–2020	1	0
Subject: substance abuse AND anywhere: community AND 2011–2020	32	1
Total number of records downloaded	0	0

11. gov.wales website

Searched on 10/12/2020 using the following Google commands:

Search	Number of records retrieved
user + participation site:gov.wales	5
substance + abuse site:gov.wales	3
user + involvement + substance site:gov.wales	3
citizen involvement + evaluation site gov wales	1
substance misuse abuse + evaluation site gov wales	0
Total number of records retrieved	12

12. International Drug Policy Consortium (IDPC) (www.idpc.net)

Searched 10/12/2020

Search	Number of records retrieved
user + participation site:idpc.net	1
user + involvement site:idpc.net	2
citizen involvement + evaluation site:idpc.net	0
Total number of records retrieved	3

13. Scottish Drugs Forum (IDPC) (http://www.sdf.org.uk/)

Searched 10/12/2020

Search	Number of records retrieved
user + participation site:sdf.org.uk	1
user + involvement site:sdf.org.uk	1
citizen involvement + evaluation site:sdf.org.uk	1
Total number of records retrieved	3

14. DrugWise (https://www.drugwise.org.uk/)

Searched 10/12/2020

Search	Number of records retrieved
user + participation site:www.drugwise.org.uk	0
substance + abuse site:www.drugwise.org.uk	0
user + involvement + substance site:www.drugwise.org.uk	0
citizen involvement + evaluation site:www.drugwise.org.uk	0
substance misuse abuse + evaluation site:www.drugwise.org.uk	0
Total number of records retrieved	0

15. Drugs.ie (https://www.drugs.ie)

Searched 9/12/2020

We screened the 'features' pages and identified 2 reports. We also screened the web page: National strategy documents and reports and the page on 'Global reports', but did not identify any further reports.

16. Participation Cymru (www.participationcymru.org.uk/)

Searched 10/12/2020

We worked through the website and found reports on the following pages:
case studies web page (1 report)
models of engagement web page (1 report)
participation policy web page (1 report)
other publications page (0 reports)

17. Pompidou Group (https://www.coe.int/en/web/pompidou)

Searched 7/12/2020

We checked the home page and identified 1 report and the Publications list which yielded 4 reports.

18. Addiction Policy Forum (https://www.addictionpolicy.org/)

Searched 30/11/2020

The 'projects' page, the 'research' page and the 'publications' page were checked. One report was identified.

19. Patient-Focused Drug Development (PFDD) Initiative of the FDA (https://www.addictionpolicy.org/)

Searched 30/11/2020

https://www.fda.gov/industry/prescription-drug-user-fee-amendments/fda-led-patient-focused-drug-development-pfdd-public-meetings
Session on 'opioid use disorder' was downloaded
Session on stimulant use disorder was downloaded

We reviewed documents on
https://www.fda.gov/patients/learn-about-fda-patient-engagement
3 guidance documents downloaded

20. The Addictions Centre at King's College London (https://www.kcl.ac.uk/ioppn/depts/addictions/index)

Searched 30/11/2020

We looked at all of the pages under the 'research' heading and looked through all their listed publications. 9 records were identified.

21. Action on Addiction in the UK (https://www.actiononaddiction.org.uk/)

Searched 3/12/2020

We scanned the whole website and identified 1 report.

22. Civil Society Involvement in Drug Policy (https://csidp.eu/)

Searched 7/12/2020

Identified 2018 conference papers.

23. International Network of People who Use Drugs (https://www.inpud.net/)

Searched 7/12/2020

The following web pages were checked:
key publications page – 8 reports
position papers page – nothing additional
responses and letters page – nothing additional
statements, announcements and presentations – nothing additional
harm reduction alerts – nothing additional

Appendix 3 Publications excluded based on full-text screening

Agrawal, S., Capponi, P., López, J., Kidd, S., Ringsted, C., Wiljer, D. and Soklaridis, S. (2016) From Surviving to Advising: A Novel Course Pairing Mental Health and Addictions Service Users as Advisors to Senior Psychiatry Residents. *Academic Psychiatry*, **40**(3), pp. 475-480. Exclusion reason: No empirical evidence on involvement.

All-Party Parliamentary Group for Prescribed Drug Dependence (2018). *The Patient Voice: an analysis of personal accounts of prescribed drug dependence and withdrawal submitted to persons in Scotland and Wales*. Exclusion reason: No empirical evidence on involvement.

Alves, P., Sales, C. and Ashworth, M. (2013). Enhancing the patient involvement in outcomes: A study protocol of personalised outcome measurement in the treatment of substance misuse. *BMC Psychiatry*, 13, article 337. Exclusion reason: No empirical evidence on involvement.

Australian Injecting and Illicit Drug Users League (2011). *Treatment Service Users Project Phase Two Final Report*. Canberra: AIVL. Exclusion reason: duplicates the material presented in Treloar *et al.*, 2011.

Ayres, R. M., Eveson, L., Ingram, J. and Telfer, M. (2012). Treatment experience and needs of older drug users in Bristol, UK. *Journal of Substance Use,* **17**(1), pp. 19-31. Exclusion reason: No empirical evidence on involvement.

Barello, S., Graffigna, G. and Vegni, E. (2012). Patient engagement as an emerging challenge for healthcare services: mapping the literature. *Nursing Research and Practice*, pp. 905–934. Exclusion reason: No empirical evidence on involvement.

Benyamina, A. and Stöver, H. (2012) Barriers to treatment access and informed patient choice in the treatment of opioid dependence in Europe. *Heroin Addiction and Related Clinical Problems*, 14(4), pp. 65-80. Exclusion reason: No empirical evidence on involvement.

Brown, V. B., Harris, M. and Fallot, R. (2013). Moving toward Trauma-Informed Practice in Addiction Treatment: A Collaborative Model of Agency Assessment. *Journal of Psychoactive Drugs,* **45**(5), pp. 386-393. Exclusion reason: No empirical evidence on involvement.

Chatwin, C. (2010). User Involvement in the illegal drugs field: what can Britain learn from European experiences? *Safer Communities*, **9**(4), pp. 51-60. Exclusion reason: Published before 2011.

Collins, D., Alla, J., Nicolaidis, C., Gregg, J., Gullickson, D. J., Patten, A. and Englander, H. (2019). "If it wasn't for him, I wouldn't have talked to them". Qualitative study of addiction peer mentorship in the hospital. *Journal of General Internal Medicine*. Exclusion reason: No empirical evidence on involvement.

Crawford, S. and Bath, N. (2013). Peer support models for people with a history of injecting drug use undertaking assessment and treatment for Hepatitis C virus infection. *Clinical Infectious Diseases*, 57(2), pp. S75-S79. Exclusion reason: No empirical evidence on involvement.

Daddow, R. and Broome, S. (2010). *Whole person recovery: A user-centred systems approach to problem drug use*. London: RSA. Exclusion reason: Published before 2011.

Dale-Perera, A., Goulão, J. and Stöver, H. (2012). Quality of care provided to patients receiving opioid maintenance treatment in Europe: Results from the EQUATOR analysis. *Heroin Addiction and Related Clinical Problems*, **14**(4), pp. 23-38. Exclusion reason: No empirical evidence on involvement.

Dunlap, L. J., Zarkin, G. A., Orme, S., Meinhofer, A., Kelly, S. M., O'Grady, K. E., Gryczinsky, J., Mitchell and S. G., Schwartz, R. P. (2018). Re-engineering methadone. Cost-effectiveness analysis of a patient-centered approach to methadone treatment. *Journal of Substance Abuse Treatment*, **94**, pp. 81-90. Exclusion reason: No empirical evidence on involvement.

Englander, H. (2016). Understanding needs and engaging community partners to develop a hospital-based improving addiction care team (IMPACT). *Journal of General Internal Medicine*, **31**(2), pp. S446-S447. Exclusion reason: Invalid publication type.

Finnell, D. S. and Lee, J. (2011). Psychometric properties of the decisional balance for patient choice in substance abuse treatment. *Issues in Mental Health Nursing*, **32**(4), pp. 243-249. Exclusion reason: No empirical evidence on involvement.

Forward Trust (2019) *Involving service users and stakeholders as equal partners in the Forward East Kent Substance Misuse Service*. Exclusion reason: No empirical evidence on involvement.

Gartner, K., Elliott, K., Smith, M., Pearson, H., Hunt, G. and Martin, R. E. (2018). "People in regular society don't think you can be a good mother and have a substance use problem." Participatory action research with women with substance use in pregnancy. *Canadian Family Physician*, **64**(7), pp. e309-e316. Exclusion reason: No empirical evidence on involvement.

Geaney, C. (2016). *Supporting women to access treatment*. Ballyfermot LDATF. Exclusion reason: No empirical evidence on involvement.

Greenwood, R. M. and Manning, R. M. (2017). Mastery matters: consumer choice, psychiatric symptoms and problematic substance use among adults with histories of homelessness. *Health & Social Care in the Community*, **25**(3), pp. 1050-1060. Exclusion reason: Does not refer to drug treatment services.

Greer, A. M., Luchenski, S. A., Amlani, A. A., Lacroix, K., Burmeister, C. and Buxton, J. A. (2016). Peer engagement in harm reduction strategies and services: a critical case study and evaluation framework from British Columbia, Canada. *BMC Public Health*, **16**, 452. Exclusion reason: No empirical evidence on involvement.

Department of Health [N. Ireland] (2020). Making Life Better – *Preventing Harm & Empowering Recovery: A Strategic Framework to Tackle the Harm from Substance Use*. Belfast: Department of Health. Exclusion reason: No empirical evidence on involvement.

Hell, M. E. and Nielsen, A. S. (2020) Does patient involvement in treatment planning improve adherence, enrollment and other treatment outcome in alcohol addiction treatment? A systematic review. *Addiction Research & Theory*, **28**(6), pp. 537-545. Exclusion reason: Does not relate to problem drug use.

Hoffman, K. A., Green, C. A., Ford II, J. H., Wisdom, J. P., Gustafson, D. H. and McCarty, D. (2012). Improving quality of care in substance abuse treatment using five key process improvement principles. *Journal of Behavioural Health Service Research*, **39**(3), pp. 234-244. Exclusion reason: No empirical evidence on involvement.

HSE Mental Health Division (2016). *Partnership for change. Report of the Mental Health Reference Group*. Naas: Health Service Executive. Exclusion reason: No empirical evidence on involvement.

Hunt, N., Albers, E. R. and Sánchez, V. M. (2010). 'User involvement and user organising in harm reduction'. In: *Harm Reduction: Evidence, Impacts and Challenges*, pp. 333–354, edited by Tim Rhodes and Dagmar Hedrich. Lisbon: EMCDDA. Exclusion reason: Published before 2011.

Inchicore Bluebell Community Addiction Team (2013) *Inchicore Bluebell Community Addiction Team Strategic Planning Document 2014-2017*. Dublin. Exclusion reason: No empirical evidence on involvement.

Jones, A., Jess, K. and Schön, U. (2021) How do users with comorbidity perceive participation in social services? A qualitative interview study. *International Journal of Qualitative Studies on Health and Well-being*, **16**(1). Exclusion reason: No empirical evidence on involvement.

Joosten, E. A. G., de Jong, C. A. J., de Weert-van Oene, G. H., Sensky, T. and van der Staak, C. P. F. (2011a). Shared decision-making: increases autonomy in substance-dependent patients. *Substance Use & Misuse*, **46**(8), pp. 1037-1038. Exclusion reason: duplicate.

Joosten, E. A. G., de Weert-van Oene, G. H., Sensky, T., van der Staak, C. P. F. and de Jong, C. A. J. (2011b) Treatment goals in addiction healthcare: the perspectives of patients and clinicians. *The International Journal of Social Psychiatry*, **57**(3), pp. 263-276. Exclusion reason: duplicate.

Kennedy, M. C., Boyd, J., Mayer, S., Collins, A., Kerr, T. and McNeil, R. (2019). Peer worker involvement in low-threshold supervised consumption facilities in the context of an overdose epidemic in Vancouver, Canada. *Social Science and Medicine*, **225**, pp. 60-68. Exclusion reason: No empirical evidence on involvement.

Kuusisto, K., Knuuttila, V. and Saarnio, P. (2011). Pre-treatment expectations in clients: impact on retention and effectiveness in outpatient substance abuse treatment. *Behavioural and Cognitive Psychotherapy*, **39**(3), pp. 257-271. Exclusion reason: No empirical evidence on involvement.

Laitila, M., Nummelin, J., Kortteisto, T. and Pitkänen, A. (2018). Service users' views regarding user involvement in mental health services: A qualitative study. *Archives of Psychiatric Nursing*, **32**(5), pp. 695-701. Exclusion reason: Does not relate to drug treatment services.

Landrum, B., Knight, D. K. and Flynn, P. M. (2012). The impact of organizational stress and burnout on client engagement. *Journal of Substance Abuse Treatment*, **42**(2), pp. 222-230. Exclusion reason: No empirical evidence on involvement.

Manning, R. M. and Greenwood, R. M. (2019). Recovery in homelessness: The influence of choice and mastery on physical health, psychiatric symptoms, alcohol and drug use, and community integration. *Psychiatric Rehabilitation Journal*, **42**(2), pp. 147-157. Exclusion reason: Does not refer to drug treatment services.

Martin, P. and Tannenbaum, C. (2017) A realist evaluation of patients' decisions to deprescribe in the EMPOWER trial. *BMJ Open*, **7**, article e015959. https://doi.org/10.1136/bmjopen-2017-015959. Exclusion reason: Does not relate to problem drug use.

Millar, S. (2018). Public consultation for a new safe injecting facility in Dublin. *Drugnet Ireland*, **65**, pp. 9-10. Exclusion reason: No empirical evidence on involvement.

Mockford, C., Staniszewska, S., Griffiths, F. and Herron-Marx, S. (2012). The impact of patient and public involvement on UK NHS health care: a systematic review. *International Journal for Quality in Health Care*, **24**(1), pp. 28-38. Exclusion reason: Does not relate to drug treatment services.

Moran, L., Keenan, E. and Elmusharaf, K. (2018) Barriers to progressing through a methadone maintenance treatment programme: perspectives of the clients in the Mid-West of Ireland's drug and alcohol services. *BMC Health Services Research*, **18**(1), article 911. Exclusion reason: No empirical evidence on involvement.

National Treatment Agency for Substance Misuse (2012). *Building recovery in communities: A summary of the responses to the consultation*. London: NTA. Exclusion reason: No empirical evidence on involvement.

Neale, J., Nettleton, S. and Pickering, L. (2013). Does recovery-oriented treatment prompt heroin users prematurely into detoxification and abstinence programmes? *Qualitative study. Drug and Alcohol Dependence*, **127**(1-3), pp. 163-169. Exclusion reason: No empirical evidence on involvement.

Neale, J., Tompkins, C., Wheeler, C., Finch, E., Marsden, J., Mitcheson, L., Rose, D., Wykes, T. and Strang, J. (2015). "Your're all going to hate the word 'recovery' by the end of this": Service users' views of measuring addiction recovery. *Drugs: Education, Prevention and Policy*, **22**(1), pp. 26-34. Exclusion reason: No empirical evidence on involvement.

Neale, J., Panebianco, D., Finch, E., Marsen, J., Mitcheson, L., Rose, D., Strang, J. and Wykes, T. (2016). Emerging consensus on measuring addiction recovery: Findings from a multi-stakeholder consultation exercise. *Drugs: Education, Prevention and Policy*, **23**(1), pp. 31-40. Exclusion reason: No empirical evidence on involvement.

Nelson, G., Macnaughton, E., Eckerle Curwood, S., Egalité, N., Voronka, J., Fleury, M., Kirst, M., Flowers, L., Patterson, M., Dudley, M., Piat, M. J. and Goering, P. (2016). Collaboration and involvement of persons with lived experience in planning Canada's At Home/Chez Soi project. *Health and Social Care in the Community*, **24**(2), pp. 184-193. Exclusion reason: Does not refer to drug treatment services.

Ness, O., Kvello, Ø., Borg, M., Semb, R. and Davidson, L. (2017). "Sorting things out together": Young adults' experiences of collaborative practices in mental health and substance use

care. *American Journal of Psychiatric Rehabilitation*, **20**(2), pp. 126-142. Exclusion reason: No empirical evidence on involvement.

O'Carroll, A., Duffin, T. and Collins, J. (2020). Harm reduction in the time of COVID-19: Case study of homelessness and drug use in Dublin, Ireland. *International Journal of Drug Policy*, **87**, article 102966. Exclusion reason: No empirical evidence on involvement.

Orr, L. C., Barbour, R. S. and Elliott, L. (2013). Carer involvement with drug services: a qualitative study. *Health Expectations*, **16**(3), pp. e60-e72. Exclusion reason: No empirical evidence on involvement.

Palombi, L., Olivarez, M., Bennett, L. and Hawthorne, A. N. (2019). Community Forums to Address the Opioid Crisis: An Effective Grassroots Approach to Rural Community Engagement. Substance Abuse: Research and Treatment, **13**, pp. 1-7. Exclusion reason: No empirical evidence on involvement.

Parker, S., Dark, F., Newman, E., Korman, N., Meurk, C., Siskind, D. and Harris, M. (2016). Longitudinal comparative evaluation of the equivalence of an integrated peer-support and clinical staffing model for residential mental health rehabilitation: A mixed methods protocol incorporating multiple stakeholder perspectives. *BMC Psychiatry*, 16, article 179. Exclusion reason: No empirical evidence on involvement.

Patterson, S., Weaver, T. and Crawford, M. (2010). Drug service user groups: Only a partial solution to the problem of developing user involvement. *Drugs: Education, Prevention and Policy*, **17**(1), pp. 84-97. Exclusion reason: Published before 2011.

Penzenstadler, L., Soares, C., Machado, A., Rothen, S., Picchi, A., Ferrari, P., Zullino, D., Khazaal, Y. (2019). Advance Statements to Prevent Treatment Disengagement in Substance Use Disorders. *Canadian Journal of Addiction*, **10**(4), pp. 10-18. Exclusion reason: No empirical evidence on involvement.

Pettersen, H., Landheim, A., Skeie, I., Biong, S., Brodahl, M., Benson, V. and Davidson, L. (2019). Helpful Ingredients in the Treatment of Long-Term Substance Use Disorders: A Collaborative Narrative Study. *Substance Abuse: Research and Treatment*, **13**, pp. 1-9. Exclusion reason: No empirical evidence on involvement.

Pike, B. (2011). Involving service users: the Irish experience. *Drugnet Ireland*, **37**, pp. 5-6. Exclusion reason: No empirical evidence on involvement.

Polcin, D., Mericle, A., Howell, J., Sheridan, D. and Christensen, J. (2014). Maximizing social model principles in residential recovery settings. *Journal of Psychoactive Drugs*, **46**(5), pp. 436-443. Exclusion reason: No empirical evidence on involvement.

Rance, J. and Treloar, C. (2014). 'Not just methadone Tracy': transformations in service-user identity following the introduction of hepatitis C treatment into Australian opiate substitution settings. *Addiction*, **109**(3), pp. 452-459. Exclusion reason: No empirical evidence on involvement.

Ronconi, S., Casmaro, L., Keane, M., Castro, D., Košir, M., Lyubenova, A. and Gayo, R. P. (2018). *Civil Society Involvement in Drug Policy: Good Practice Collection*. Amsterdam: Correlation Network. Exclusion reason: No empirical evidence on involvement.

Schwartz, R. P., Kelly, S. M., Mitchell, S. G., Gryczinski, J., O'Grady, K. E., Gandhi, D., Olsen, Y. and Jaffe, J. H. (2017). Patient-centered methadone treatment: a randomized clinical trial. *Addiction*, **112**(3), pp. 454–464. Exclusion reason: No empirical evidence on involvement.

Snyder, M. (2013). Substance use and brain reward mechanisms in older adults. *Journal of Psychosocial Nursing*, **51**(7), pp. 15–20. Exclusion reason: No empirical evidence on involvement.

South East Regional Drug and Alcohol Task Force (2020). *Challenge and Change: Tackling Substance misuse in the South East Region. Reducing Substance Misuse Strategy 2020–2023*. Exclusion reason: No empirical evidence on involvement.

South East Regional Family Support Network (2013). *Involving family members and carers in treatment services*. Exclusion reason: No empirical evidence on involvement.

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Appendix 4
Interview schedule
for stakeholders

Presentation:

We have been engaged by the Health Research Board (in Ireland) to review the literature on user involvement in drug treatment and recovery services and to describe the current situation in Europe in relation to the implementation of policies to promote involvement and participation by service users and their families.

We have invited you to participate in a short discussion of this issue with a view to summarising the opinions and experiences of key stakeholders and experts. We would like to record the discussion, with your approval, is that OK? Before we use any direct references or quotations, we can provide you with a transcript for approval, but we would like to be able to cite you directly in the final report.

1. To provide us with some context, could you briefly describe your current role/position?
2. And in overall terms, how does service user involvement relate to your work?
3. Are you involved directly in the development or implementation of policies to promote service user involvement?
4. What are the main benefits associated with service user involvement, in your view?
5. Is it possible to measure and monitor these positive outcomes, in your opinion?
6. Do you see any significant disadvantages or drawbacks?
7. What about opponents of user involvement – who is most likely to be against this?
8. What kinds of challenges does service user involvement pose for policy makers/administrators/practitioners/advocacy groups? What would you say is the greatest problem that needs to be overcome?
9. Should service providers be compelled to incorporate user involvement into their practices?
10. Are you aware of any interesting examples of policies or practices for user involvement in relation to treatment or recovery? Are there any areas of treatment, any types of service or any countries or regions which are more likely to pursue this?
11. What forms of participation are the most interesting or promising, from your perspective?
12. Are there precedents in health care or public services more generally where service users are provided with a significant voice and a role in decision-making?
13. Does participation have the potential to change the nature of treatment and recovery services? In what kind of ways?
14. Are there any other developments in treatment and recovery services that are or could be linked with user involvement?

Appendix 6
Ethical approval for service user consultation

ROYAL
COLLEGE OF
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OF IRELAND

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19th August 2021

Frederick House
19 South Frederick Street
Dublin 2

RCPI RECSAF 149v2: Service user involvement in drug treatment services in Ireland

Dear Dr Pratschke,

Thank you for resubmitting your research proposal to the Research Ethics Committee at the Royal College of Physicians of Ireland for review.

The Research Ethics Committee's opinion is **FAVOURABLE.**

Please note that the committee requires the following to be submitted.

- A yearly update report.
- A premature termination report (if the research is stopped early).
- A completion report.

In the event of any adverse event occurring in the course of this research (e.g. breach of confidentiality), the committee should be informed as soon as practicable via the chair of the committee.

The committee would like to wish you every success with this project.

Yours Sincerely,

_____

Dr. Una B Fallon MB MA MSc. MICGP MRCGP FFPH FFPHMI

Chair RCPI Research Ethics Committee

MCRN 014313

Appendix 7 Information provided to participants in service user consultation

You are being invited to take part in a research study to be carried out online by Dr. Jonathan Pratschke, Social & Economic Research Consultant. Please read the information provided below and ask any questions you may have. You can change your mind about taking part in the study any time you like, without have to give a reason.

Why is this study being done?

This study aims to explore the current situation in relation to user involvement within drug treatment, recovery and harm reduction services in Ireland.

Who is organising and funding this study?

The study is funded by the Health Research Board and coordinated by Dr. Jonathan Pratschke, Social & Economic Research Consultant.

Why are you being asked to take part?

You are being asked to take part in this study because you have used a drug treatment service in Ireland in the past year.

How will the study be carried out?

This study is based on interviews, carried out online using the web. These interviews will take roughly 30 minutes and the sound will be recorded so that we can study the information you provide.

Your role

If you agree to participate, we will make an appointment for a single, short interview which will be like a conversation in which we ask you to talk about your experiences during treatment for problem drug use, particularly in relation to having your voice heard and participating in making decisions. During the interview we will be able to see each other using the video conferencing app but we will only record the audio of our voices. If you do not have access to the internet, we will arrange to do the interview over the phone.

Audio recording

You have the right to review and edit the transcript of your interview, if you so wish.

What are the benefits of this study?

This study will help to inform the Government, administrators, service providers and stakeholders regarding the current situation and key issues in relation to user involvement in drug treatment, recovery and harm reduction services. In this way, we hope that it will contribute to the provision of more effective, accessible and inclusive services which respect all service users and their individual preferences.

Recognition of participation

We will provide you with €25 voucher as a token of appreciation for your time and for sharing your experiences. We can also provide mobile phone credit to facilitate the interview.

Is the study confidential?

The contents of your interview will be treated as confidential and will never be shared with other individuals or organisations. The researchers will ensure that no information that could be used to identify you is ever disclosed or published. The results of the study will be presented in aggregate form, and all participants will remain anonymous at all times. Data will be stored anonymously to protect the confidentiality of all participants. Only the researchers directly involved in this project will have access to this interview in audio form or transcription, and the audio recording will be deleted after 3 years. We will, if you wish, inform you of research products that are based on these data.

Data Protection

We will use the information you provide during the interview in our scientific research on service user involvement in drug treatment, recovery and harm reduction services, in line with the General Data Protection Regulation 2016. The Principal Investigator will have overall responsibility for the security of all data, which will be stored securely. The interview transcripts will be stored so that they can be used to write reports, briefing documents and scientific articles. If you would like to withdraw from the study you can do so at any stage by contacting

the Principal Investigator, who will consequently delete any information collected from you. You have the right to access and correct your data, receive a copy of it, request it to be deleted at any point in time and to lodge a complaint with the Data Protection Commissioner if you feel that your rights and entitlements have not been respected in any way.

Consent to Future Use

We will use the information you provide during the interview for the present study and any future publications and research reports by the same researchers where it is considered relevant.

Further information

If you have any further questions about this study or if you want to opt out, please contact...

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