Nothing about us without us The Current Voices of the Irish Methadone Service Users Suria 2020

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Richard Healy Phd
National University of Ireland, Maynooth
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Suria 2020

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Preface

The *Service Users Rights in Action* (CAN and SURIA) is an independent group consisting of service users, former service users, medical professionals, service providers and community activists. We have been continuously carrying out research that highlights the many difficulties encountered by the Irish drug service user for almost a decade, since 2012. This Report, entitled *"Nothing About Us Without Us",* is informed by 121 surveys that demonstrate the current service user voice regarding their experiences and treatment as they use modern day methadone services.

It is both a stand-alone piece of research of current methadone maintenance treatment (MMT) (Foucault 2008) practice and also part of the longer-term monitoring by SURIA of the progressive realisation of the right to adequate health for those who avail of MMT. As a stand-alone piece, this research explores the current life narrative of the MMT client, however as a broader part of the long-term monitoring of the realisation of rights-based treatment for MMT clients that SURIA has undertaken, this report is the latest of four sets of data that SURIA have collected since 2012. The advantage of drawing from multiple sets of data is that it highlights the progression or regression of rights-based treatment, demonstrates trends and patterns in treatment and enables SURIA to seek accountability from services and key stakeholders. It informs our monitoring of MMT from the platform of human rights. The use of Participatory Action Research, which will be discussed, allows us to frame practices in a way that this can be achieved.

The report is presented in two parts.

Part One: This presents the data from the fourth round of peer led research conducted by SURIA in late 2019/early 2020. This research sought to represent the lived experience of the MMT client through the surveying of 121 MMT clients. The analysis of this data through the lens of human rights, evidence-based practice and the international evidence base presents the Irish system as one in need of serious reform. Clients, many desensitised or unaware of the ethos and objectives of holistic methadone care are staying on methadone longer, providing more urine samples, have a low quality of life and are rarely enjoying a life where their rights are being realised and a meaningful form of recovery is an attainable goal. Also, many feel controlled, surveyed and stated that their lives and choices were severely limited by the duties and obligations which their clinic required.

Part Two: This section locates this standalone piece of research into the longer-term monitoring and campaigning work of SURIA. We describe how PAR is ideally suited to the objectives of this Report, given that it is a cyclic research methodology that excels in emancipatory, monitoring research practice. We also compare and contrast the evidence emerging from this round of research with baseline data gathered in 2012, 2017 and revisited in 2017/18 as part of a Public Sector Duty Pilot Project under the auspices of The Irish Human Rights and Equality Commission (IHREC).

1. Introduction

MMT is currently the most widely used mode of treatment for Irish opiate users, with *The European Monitoring Centre of Drugs and Drug Addiction* (EMCDDA) stating that as per 2019, over 10,000 clients were actively availing of this mode of treatment in the State, (EMCDDA 2019). Almost from the inception of the Methadone Protocol (1998), as early as 2003 allegations of poor treatment (Lawless & Cox 2003, UISCE 2003) and human rights violations (ICCL 2015) began to emerge, from service users in the former and key rights monitoring stakeholders in the latter. In 2010, the HSE funded an evaluation of MMT and the practices it employed, (Farrell & Barry 2010). This Report, colloquially known as *The Farrell Report* was a damning indictment of Irish MMT practices and in particular, its continued overuse of urinalysis. In short, the Report maintained that Irish MMT had commenced in accordance with the international evidence base in 1998, however it had since failed to evolve as per best practice.

It was the relative failure of the HSE to change any of the practices that their own Report had been so critical of which led to the formation of SURIA and our first round of research, in 2012. Our second round of research commenced in 2017. Both sets of earlier research, alongside *Our Lives, Our Voice, Our Say* (SURIA 2018, a report published at the end of the pilot Public Sector Duty Project with the Irish Human Rights and Equality Commission (IHREC) presented a picture, which was also discussed in academic literature (Moran et al. 2018) that Irish MMT was failing many clients, was not consistent with the International evidence and was also in violation of a number of human rights instruments, primarily The Public Sector Duty, The Right to Health and The Right to Participate.

The publication of *Our Lives, Our Voice, Our Say*, which was again informed by peer-led research by SURIA, stated that “serious human rights and equality concerns based on the lived experience of service users have been expressed”, (SURIA 2018:5). For SURIA, as a group that monitors the human rights of drug service users, this was confirmation that rights were not in the process of progressive realisation, as per UN International Convention of Economic, Social and Cultural Rights, which was ratified by the State in 1976. Article 2 allowed for States to provide rights in accordance with their abilities, both economically and politically. As part of monitoring the service user journey of MMT clients, SURIA also held two dialogue events in 2015 and 2016. Dialogue seeks the co-creation of knowledge through the sharing of perspectives from within the service user/service provider relationship, (Bohm 2004). These highly successful events provided an opportunity for change and were attended by many key stakeholders, including Minister Catherine Byrne, who at the time was Minister of State overseeing the *National Drug Strategy*. It was the early rounds of research and these dialogue events that helped SURIA frame our campaign around four distinct shortcomings that were a constant finding in all our research. These were:

1. over reliance on testing (and in particular supervised urinalysis),
2. lack of choice regarding treatment,
3. lack of meaningful review and
4. absence of an independent and robust avenue for complaints within clinics

These four tenets or shortcomings, which emerged from multiple rounds of research became the core priorities of our research strategies.

Our third round of research resulted in the 2018 publication of *Our Lives, Our Voice, Our Say* in conjunction with the Irish Human Rights and Equality Commission. SURIA put forward twenty-eight recommendations that we believed would improve the outcomes and efficacy of MMT and also the human rights and lived experience of the MMT client. As such, we have remained steadfast in our objective to improve the lived experience of the contemporary MMT client in Ireland through the continued monitoring of the efficacy of the publication's recommendations and continued research. Through prolonged engagement with those who use a form of Public Health which rarely leads to real improvement in the quality of life of clients (Moran et al. 2018), we have continuously attempted to illustrate the lived experience of the MMT client as an individual whose life is often constrained by drug services in the guise of sanction and control. Our four rounds of research have each described a life of little choice, a failure to improve quality of life and highlighted human rights concerns and a range of invasive procedures that combine to advance the harsh realities experienced by some MMT clients.

2. Nothing About Us Without Us – 2019/2020

This Report now takes as its point of departure our latest research informed by data collected by our members in 2019/2020. The Report highlights the lives of the many clients who speak of being controlled by their service and the many rules and regulations which they must abide by if they are to continue to be treated. MMT has been described as a mode of social control that the client must adhere to, if one is avoid being sanctioned or punished (Harris & McElrath 2012). While we do not under-estimate the difficulties that professionals encounter in what can often be a challenging setting for health professionals, SURIA advocate for dignity and respect in all service user engagements, the implementation of evidence-based practice in these engagements and for quality of life to be the principal indicator of efficacious MMT.

This Report is informed by data collected from 121 participants using surveys which consisted of fifty-three questions including open ended question, Likert Scale (eg on a scale of 1 to 5….) and closed questions. We employed purposive sampling, drawing from our relationships with several key actors in a number of Irish harm reduction services in order to establish our research population. The surveys produced sufficient quantitative and qualitative data to continue with our agenda and aim of monitoring Irish MMT through a human rights lens towards the progressive realisation of Service User human rights to dignity, health and participation in their own health care planning.

2.1 The Service User Profile: The Ageing Irish MMT Client

As per standard practice the opening questions were based upon demographics, including age, gender, location, length of time in treatment, etc. Our research found that this information suggests the typical Irish MMT client is now older and in treatment longer, which arguably demonstrates that service users are now being prevented from re-integrating into society post treatment. As such MMT becomes a mode of treatment from which few emerge.

Figure 1: Cohort /Participants by Age

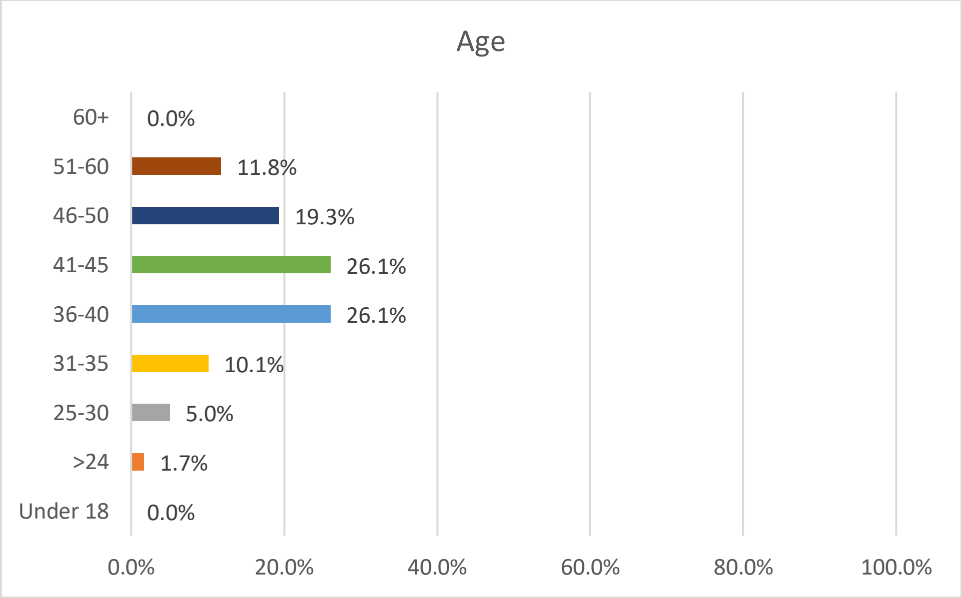
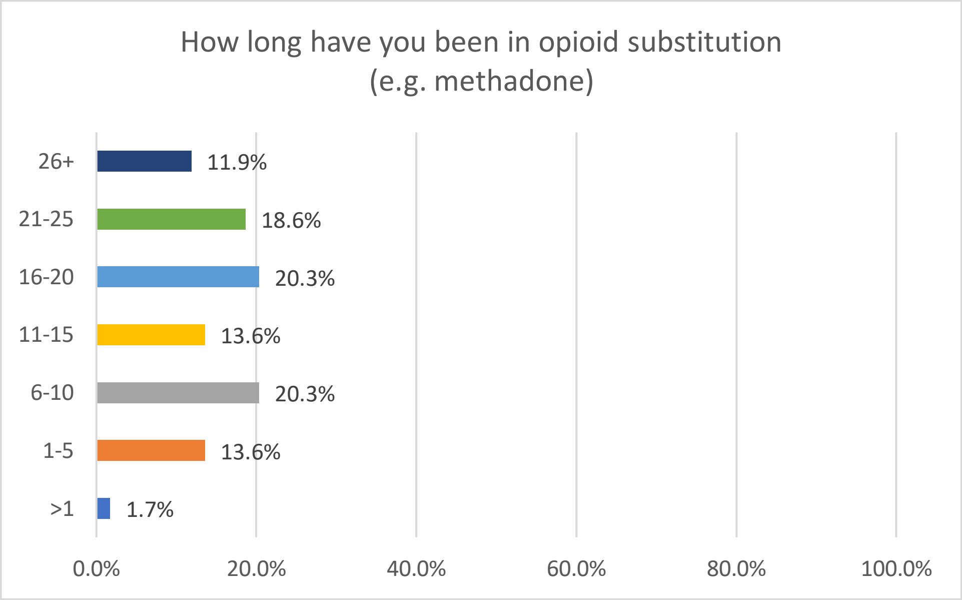
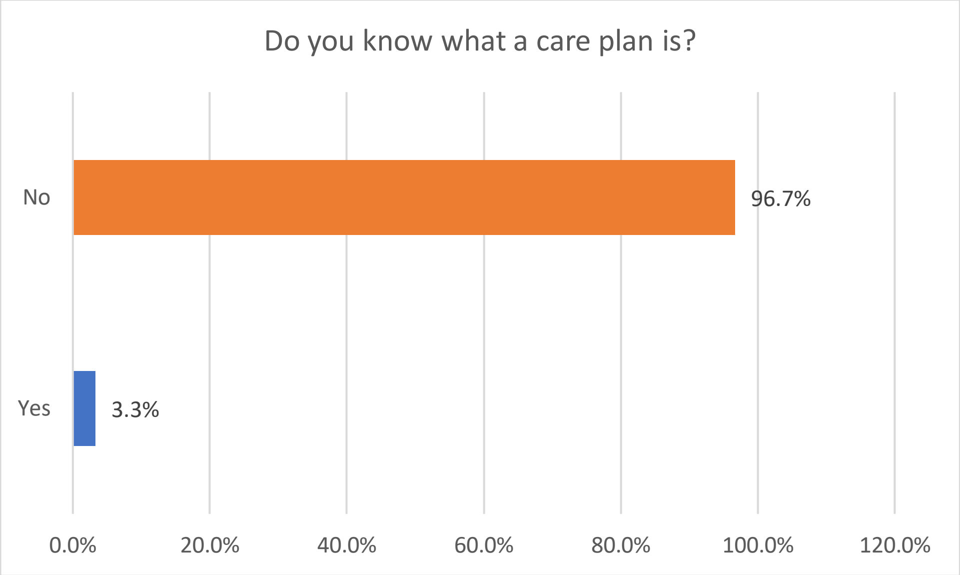


FIGURE 2: AMOUNT OF TIME ENGAGING WITH MMT (YEARS)



The ageing Irish MMT patient base has been explored in Irish academia (Carew & Comiskey 2018) and is arguably a consequence of the shortcomings regarding reintegration and quality of life. Our research found that 83% of the participants were aged between 36 and 60, while half (51%) had been engaging with their services for 16 years or more. From these figures, the evidence states that a large majority of our research participants had spent over half their life on methadone. This becomes problematic when the evaluation of services is examined. If clients maintain that their services are producing a higher standard of living and stimulating re-integration, the length of time on methadone could be argued to be unproblematic. It could be argued that denying treatment or reducing the length of treatment could have led to more harm and an early death. However, the overall evaluation of the service user life experience was routinely described as harmful, life inhibiting and undignified. Therefore, prolonged engagement with such a service is argued to do little to advance better outcomes in the lives of clients. 61% of our cohort reported that they were unhappy with their treatment provision, and this is more alarming when one considers that 97% of participants specified that they had never been offered an alternative to MMT.

FIGURE 3: THE LACK OF TREATMENT CHOICE



SURIA MAINTAIN THAT CLIENTS SHOULD RETAIN THE RIGHT TO ENGAGE WITH MMT FOR AS LONG AS THEY SEE FIT. HOWEVER, WHEN THESE SHORTCOMINGS ARE HIGHLIGHTED, COMBINED WITH THE LOW NUMBER OF CLIENTS WHO COMPLETE MMT, THE OUTCOME IS A LARGE CLIENT BASE IN LONG TERM TREATMENT IN WHICH THEY ARE BEING MISTREATED, FAILING TO BE REHABILITATED OR RE-INTEGRATED AND BEING DENIED THE ADVANTAGES OF EVIDENCE-BASED HARM REDUCTION. HARM REDUCTION THAT IS INFORMED BY EVIDENCE OFTEN REDUCES THE USE OF ILLICIT DRUGS, BLOOD BORNE DISEASE, MORTALITY RATES AND CRIME, (WARD, MATTICK & HALL 1998, KLEBER 1998, KEANE 2003). THE MODEL ITSELF EMANATES FROM THEN PIONEERING WORK, IN 1980'S LIVERPOOL THAT CONCENTRATED ON REDUCING THE HARM OF DRUG USE AS OPPOSED TO DRUG USE PER SE, (NEWCOMBE 1992 SINGLE 1995), PROMOTING AN AMORAL, NON-JUDGEMENTAL RECOVERY MODEL THAT INVOLVED MMT, VEIN CARE, NEEDLE EXCHANGE AND OUTREACH. THIS IS FURTHER MAGNIFIED WHEN WE DISCUSS URINALYSIS AND THE OVER RELIANCE OF SAMPLING.

2.2 Urinalysis – The Evidence Base, Cost and Monitoring of Supervised Sampling

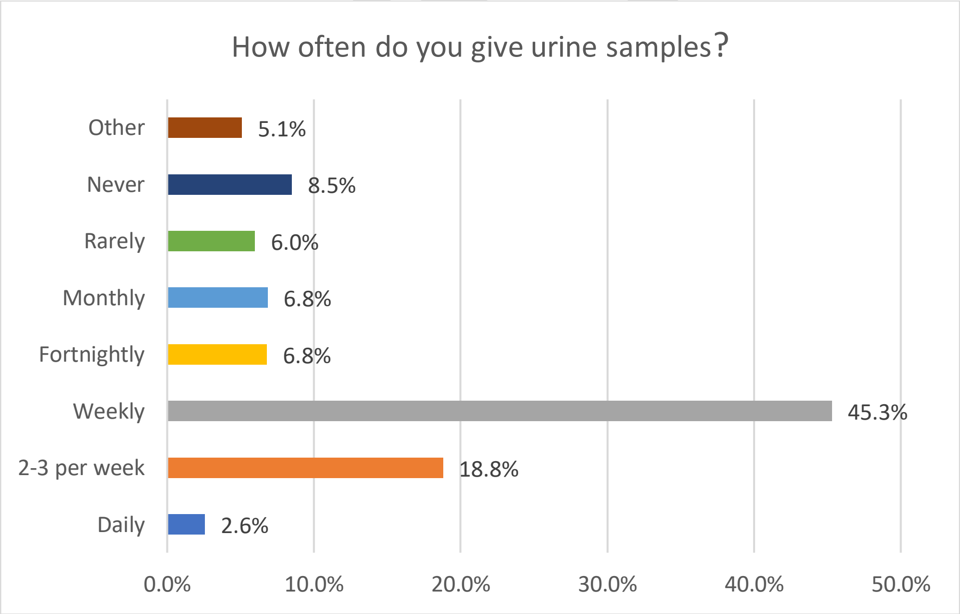
SURIA consider supervised urinalysis to be a minor, first victory of our campaign against the many invasive procedures that are part of Irish MMT. Our 2018 work with IHREC was closely followed by a change in policy, as the HSE directed that supervised sampling was “not required in routine clinical practice” in MMT. Despite this change, our research demonstrates that supervised urinalysis is still mandatory in some clinics (5%). Also, although the vast majority of clinics are working in accordance with this directed change, urinalysis is still being practiced as a mandatory obligation in a large number of clinics. A closer analysis shows that 67% are providing a sample at least once a week and within this population, one in five are providing two to three a week. This has been consistent in all of our research, with the exception of a sharp increase in those submitting 2/3 samples per week between 2012 and 2017. Evidence suggests that supervised urinalysis was costing Irish MMT services 5.5 million Euro per annum in 2009, (O'Súilleabháin 2009). It is reasonable to assume that a decade's inflation, and this increase, has further added to this cost.

In an emergent pandemic worldview, SURIA maintain that this practice must be re-assessed, with the limited resources that finance MMT being better employed increasing the efficacy of treatment, through training and the provision of a greater number of ancillary services to promote re-integration.

The centrality of sampling, which in the case of Irish MMT is almost always urinalysis, is argued to still be a key factor in what we maintain to be the various shortcomings of the human experience of methadone treatment. SURIA argue, as per Farrell and Barry (2010) that Irish MMT has become too entrenched in urinalysis and therefore abstinence has become a key indicator of successful treatment. Our point here is that reintegration, quality of life and choice appear not to be important outcomes in the lives of clients. As opposed to meaningful review, progressive therapeutic alliances and treatment based on dignity, respect and equality; testing, sanction and discipline routinely dominate the lives of methadone patients. This is an example of the propensity of Irish MMT service provision to again work at odds to the international evidence base. Ward, Mattick & Hall (1997, 1998) are regarded as key advocates of evidence informed methadone treatment and their work has long espoused that urinalysis does not reduce drug use.

SURIA ARGUE THAT ABSTINENCE AND PROHIBITION ARE STILL THE PERVADING GOALS OF IRISH HARM REDUCTION. THIS VIOLATION OF THE KEY AIM OF HARM REDUCTION IS A POSSIBLE FACTOR IN THE POOR OUTCOMES THAT ARE ROUTINELY PRODUCED BY OUR METHADONE SERVICES.

FIGURE 4: FREQUENCY OF URINALYSIS 2019 /2020



2.3 The Poor Quality of Life for the Irish MMT Client:

From its inception in 1960's New York, MMT was always intended, like all public health services, to improve the quality or standard of life of those who engaged with services, (Dole & Nyswander 1965, 1980). However, MMT is now often seen as a method of treatment that disrupts the lives of clients and creates a lifestyle that includes visits to doctors, clinics, pharmacies and the various other stakeholders who make up the service, (Newman 1976, Miller 2001, McElrath & Harris 2012, Finn & Healy forthcoming).

When evaluating their experiences of MMT, a large number of participants responded by stating that they felt “controlled”, “chained” or “trapped” by their clinic. As an advocacy group, we argue that there is a general feeling of constant observation and inhibition among clients, due to the multiple and repetitive duties and obligations that many services demand. Others claimed their “lives had been wasted”, with almost half of the participants stating that they did not envision themselves being “on it (MMT) this long” when they commenced methadone treatment.

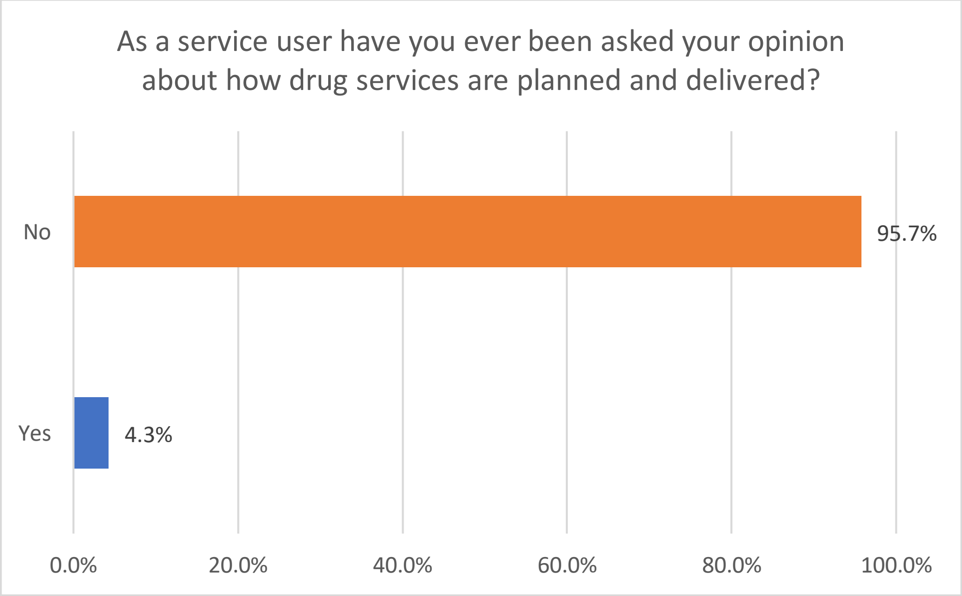
4% of participants stated that they were either in education, had employment or were engaging with some form of training. The majority of participants stated, in open ended questions that MMT had routinely restricted any opportunity to engage with any of these important avenues to meaningful rehabilitation and a higher standard of living.

SURIA will always attempt to seek the individual from the statistics and personify our participants. As a representative, advocacy group, we see this as vital, thus our primary aims and campaigns seek to improve the lived experience of MMT through the promotion of holistic treatment and the monitoring of the human rights of the person, in this case the drug service user. Following our prolonged engagement with service users,

SURIA CONTINUE TO MAINTAIN THAT THE QUALITY OF LIFE OF CLIENTS CAN BE IMPROVED THROUGH CHOICE REGARDING TREATMENT, DIGNIFIED TESTING, MEANINGFUL REVIEW AND RESPECTFUL TREATMENT PRACTICES THAT INCLUDE AN EFFECTIVE AVENUE FOR COMPLAINT. THE PERCEIVED IMPORTANCE OF TESTING AND ABSTINENCE IS ARGUED TO BE OVER-STATED, FREQUENTLY REPLACING COMMUNICATION BETWEEN SERVICE PROVIDER AND USER AND SOCIAL REINTEGRATION. OUR RESEARCH PUTS FORWARD A CLAIM THAT IT IS THE TEST AS OPPOSED TO THE PATIENT THAT IS IMPORTANT IN IRISH MMT, RESULTING IN TREATMENT THAT BECOMES DESENSITISED AND INSTRUMENTAL, WITH INDIVIDUAL WELL-BEING RARELY ADDRESSED.

2.4 De-personalising the MMT Client – The Lack of Treatment Choice and Meaningful Review:

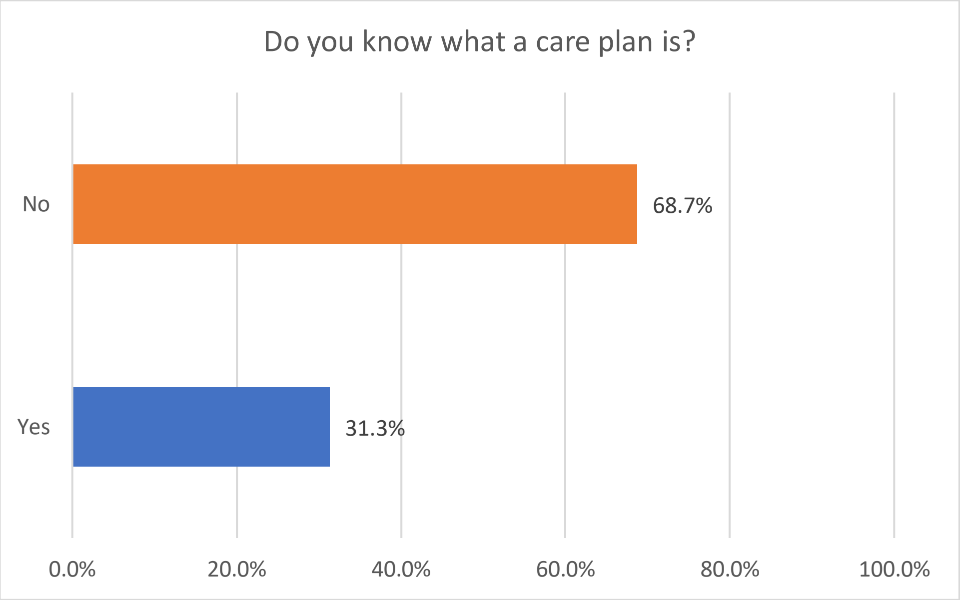
FIGURE 5: THE LACK OF SERVICE USER INTERACTION /VOICE



When this research explored choice of treatment and care plans, the results continued to suggest that the human rights of drug service users in Ireland were not in the process of progressive realisation. In fact, the statistics magnified the regression of rights-based treatment. The lack of treatment choice in the sense of alternative medications has been discussed, however our research supports the claim that there are also restrictions of choice within MMT that act as barriers to progressive change and meaningful treatment. Choice within the MMT system is here seen to include detoxification and more indirectly, some of the obligations that preclude the autonomy of the client—continual urinalysis, visits to clinics and/or pharmacies due to the refusal to permit takeaway dosages.

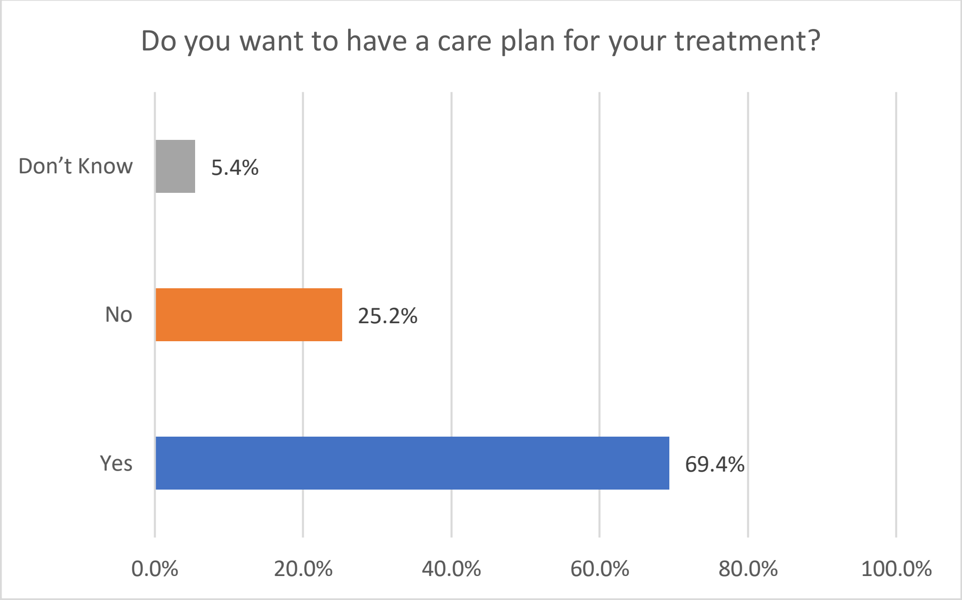
SURIA ARGUES THAT ABSENCE OF MEANINGFUL, CLIENT CENTRED CARE PLANS IN MANY SERVICES ALSO HAS THE EFFECT OF REDUCING CHOICE, WITH THE SERVICE USER BEING CONSTRAINED BY THE DECISIONS OF DOCTORS AND OTHER KEY ACTORS WHO OPERATE IN THE PROVISION OF METHADONE AT SERVICE LEVEL. A SUFFICIENT CARE PLAN WOULD ENHANCE THE DYNAMIC BETWEEN SERVICE PROVIDER AND USER AND ALLOW FOR THE PRACTICES OF MMT TO BE FRAMED AROUND THE LIVES OF CLIENTS.

FIGURE 6: CARE PLANS



However, the vast majority of our participants that were unaware of what a care plan is indicative of a public health population that is rapidly becoming desensitised to the shortcomings of contemporary MMT. It is unlikely that any other public health patient base are denied meaningful discussion with caregivers regarding their aims, objectives, plans and general dispositions regarding the progression of their treatment.

FIGURE 7: PARTICIPANTS WHO WANT CARE PLANS TO INFORM THEIR TREATMENT



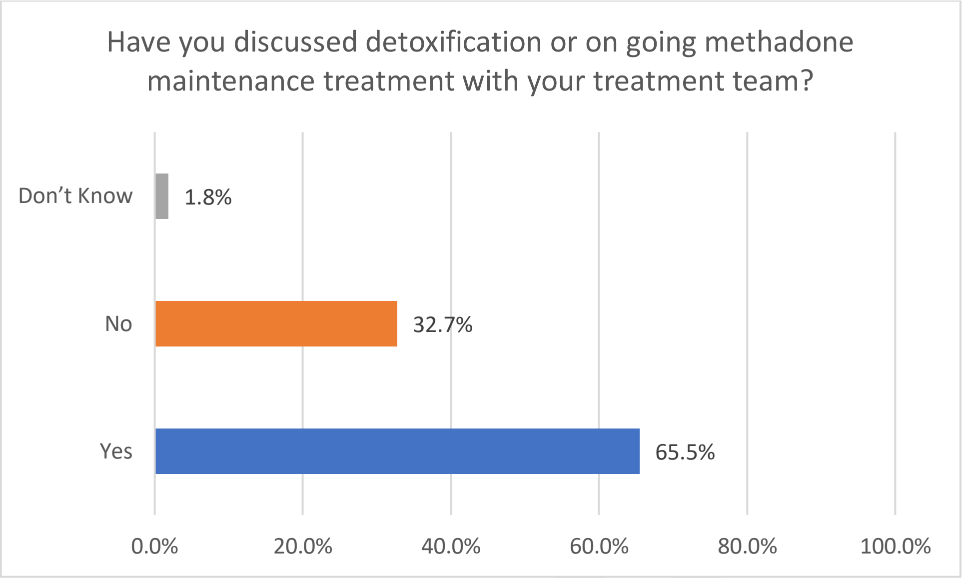
For those who did understand the dynamics and make-up of a care plan, 70% demonstrated that they recognised the advantages this could bring to their treatment, yet they were not available to them through their service provider. As such, Irish MMT is argued to constitute medication and little else in the form of ancillary care.

Detoxification is arguably a part of MMT that can be situated as treatment choice and part of a care plan. Regarding this, the research demonstrated that 30% of participants were never offered detoxification. While within the 70% that had discussed this with their care provider, we find many differing responses in relation to who brought up the subject and when was it discussed;

> *"I initiated it 6 months ago. I have to bring it up as it is never raised. I feel they do not listen to me."*
>
> *"Me, I asked about it. Quickly disappeared. Very ashamed for asking. Did not want to ask again."*
>
> *"Me. The first time. It is going well. Slow and managed well*

15% were not considered for detox due to "not being ready" with no discussion as to why. A number had only discussed this as they commenced their treatment and the subject was not re-visited. This evidence suggests that autonomy and choice appears poorly available from Irish MMT and this is magnified by the lack of meaningful review and care-plans.

FIGURE 8: DETOXIFICATION AS TREATMENT CHOICE



Again, we wish to highlight that we do not advocate for clients to be rapidly detoxed without careful and informed planning between service user and their doctor. As such, it should be an informed decision between services and clients, underpinned by treatment history, well-being and most importantly the choice of the patient.

When examining meaningful review, only one in five participants have regular discussion with their service provider which offers the opportunity to have a discussion regarding the accumulation of recovery capital[1] in their lives.

SURIA ARGUE THAT WITHOUT MEANINGFUL DISCUSSION AND THE POSSIBILITY OF ATTRACTIVE ALTERNATIVES TO DRUG USE, MMT CAN OFTEN BECOME A BLUNT INSTRUMENT IN THE ACQUISITION OF AN IMPROVED QUALITY OF LIFE. FURTHERMORE, MEANINGFUL REVIEW PROMOTES THE RECOVERY CAPITAL THAT IS THE PRECURSOR TO MEANINGFUL CHANGE AND SOCIAL REINTEGRATION. WE AT SURIA CAMPAIGN FOR INTERNATIONAL EVIDENCE TO BE THE PRIMARY INFORMANT OF PROGRESSIVE MMT. DOLE & NYSWANDER (1967), THE PIONEERS OF THE MODEL DID NOT ADVOCATE FOR TOTAL ABSTINENCE. AS SUCH, REINTEGRATION WAS SEEN TO BE THE BACKDROP OF A SERVICE USER EXPERIENCE THAT EXHIBITED CHANGE IN THE LIFE OF THE CLIENT.

FIGURE 9: MEANINGFUL REVIEW

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[1] Recovery Capital is a widely used phrase used to describe the skills, competencies or abilities that are intended to be beneficial in the client’s rehabilitation. These can include coping strategies, housing and the skills needed to live a drug free life.

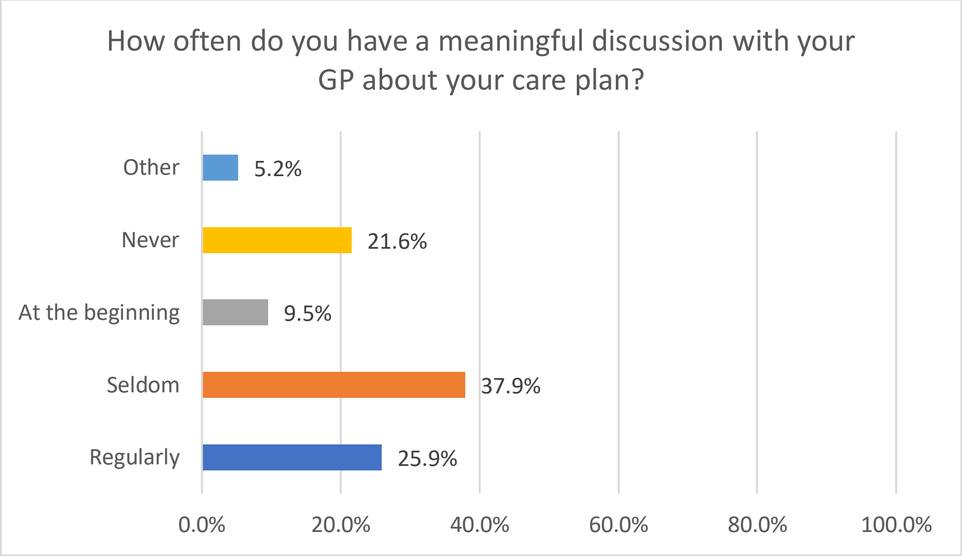
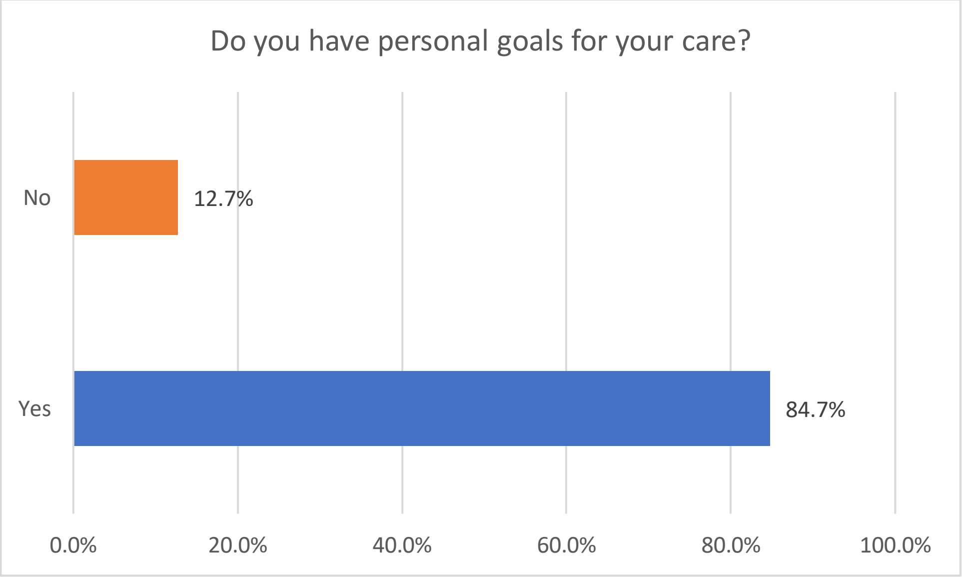


Fig 9 demonstrates a distinct lack of a meaningful and effective discussion between service provider and user, yet Fig 10 clearly suggests that an overwhelming majority of MMT clients have personal goals regarding their treatment. But statistics demonstrate a clear shortcoming in what SURIA maintain is a major shortcoming of contemporary Irish MMT, the lack of communication, and equal treatment to that of other public health services.

FIGURE 10: PERSONAL GOALS



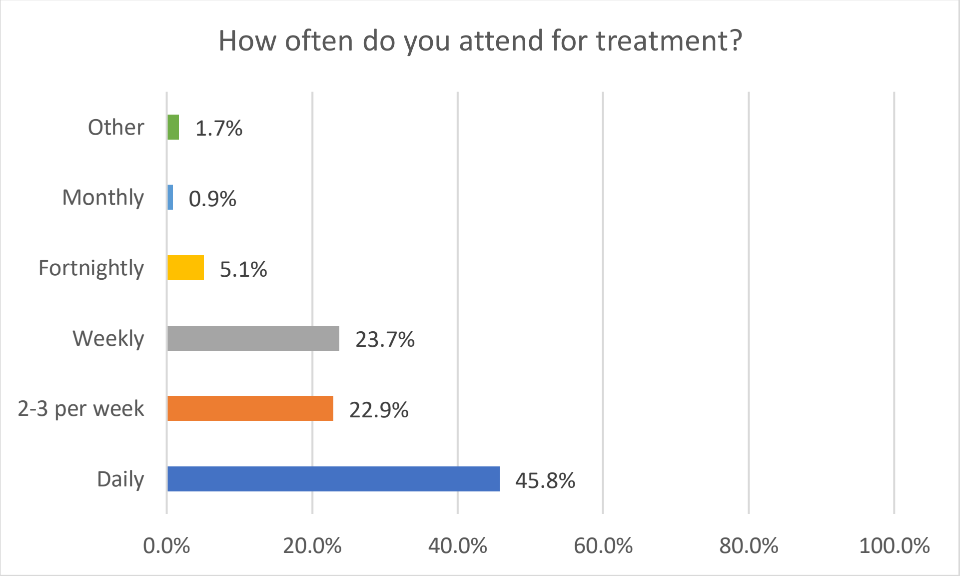
This data situates MMT as a mode of drug treatment that does not place the needs and life difficulties of the client as central to treatment. There is little communication and there appears to be a power imbalance within the service provider and user dynamic. With little communication, demonstrated by the lack of review and care plans, MMT cannot be considered client centred and holistic, nor does it offer the individualistic care that is required of drug treatment, (Miller 2001).

2.5 Centrality of Abstinence – MMT as Control

Personal goals and meaningful discussion are usually replaced with the heightened importance of abstinence. With this comes the afore-mentioned allegations from participants of a thinly veiled programme of control. As a rights-based peer group, our work is a continuous assessment of the merits of MMT as rights-based treatment, as opposed to a form of managing what is often considered a difficult to govern population. Our past and current research supports a claim that MMT is and was being used as "moral medicine", with sanctions and outcomes that extend far beyond the sphere of drug use. Many of these are a corollary of having to move clinics, having takeaways reduced and/or increased visits to any of the stakeholders who make up the methadone service. These sanctions often place severe restrictions on the lives of clients, some which include childcare, the expense of travel and the loss of the ability to work. As such, these measures of control are often not obvious, however the inhibitions they place on the lives of clients inform the control that has been cited by participants. Social control, according to Cohen is a set of organised practices in response to deviance that attempts to morally constrain a population, (1984).

We would argue that our research suggests that MMT is often employed in this way. Although this is a provocative claim and the intent of services is debatable, the evidence we have collected strongly sustains an argument that clients feel controlled and inhibited from living a normal life of the highest attainable quality. We have also discussed that MMT has a propensity to "govern too much", (Foucault 2008, Read 2009). This over-extension of power can often become oppression, suppressing the life of the client. This is further sustained when we examine the data in Figure 11 regarding the client's presentation at their place of care. 92% MUST VISIT THE CLINIC WEEKLY, 46% DAILY AND 23% 2-3 TIMES A WEEK. THIS IS AN EXAMPLE OF HOW SERVICES ARE POLICING THE CONDUCT AND DICTATING THE LIVES OF CLIENTS.

Figure 11: Frequency at which participants must engage in person with their services



We argue that no client should have to visit services daily, and even those who visit services 2-3 times a week have little chance of sustaining a normal life. To risk the overuse of the work of Mayock et al (2018) regarding social re-integration, we further argue that housing, work or education and the reconstruction of damaged relationships, the cornerstones or re-integration, are not possible within this environment. Also, with clinics being alluded to as “places of nuisance” and with the majority of participants stating in open ending survey questions that their primary objective was to “get off” methadone, we would argue that the over use of clinics for urinalysis and the dispensing of medication, is harmful to the well-being of clients. Many claimed that the everyday choice to go visit family or take a few days holidays was rarely, if ever possible. As such, it creates a life of repeated visits to doctors, pharmacies and area where the dealing of drugs is an obvious by-product of circumstance.

It is these many hidden obligations which combine to restrict the life of Irish MMT clients which is magnified by data that describes MMT as a life that is characterised by threats of sanction, invasive procedures, rights violations and a distinct absence of an avenue for a meaningful and attractive recovery or life.

2.6 Acceptance or Mistreatment – Collective Trauma:

Our research has demonstrated that the current Irish methadone system is in need of assessment, reform and continuous monitoring from key actors and human rights duty bearers. The provision of methadone requires a robust framework which is formed around the needs and lives of service users. That is, service users require more autonomy to make key decisions in their own lives regarding to rehabilitation and re-integration. We at SURIA again draw from the recent work of Paula Mayock et al (2018), who defines reintegration as a route to housing, education or employment and the reconstruction of the family unit. With a minority of 39% stating that their experience of MMT had been positive having a positive outlook of their MMT experience and outcomes, their reasoning was seldom underpinned by life progress and dignified, respectful treatment as per Public Sector Duty. These participants framed the apparent benefits of MMT as helping reduce crime, not experiencing withdrawal and having “a small bit of normality” in their lives.

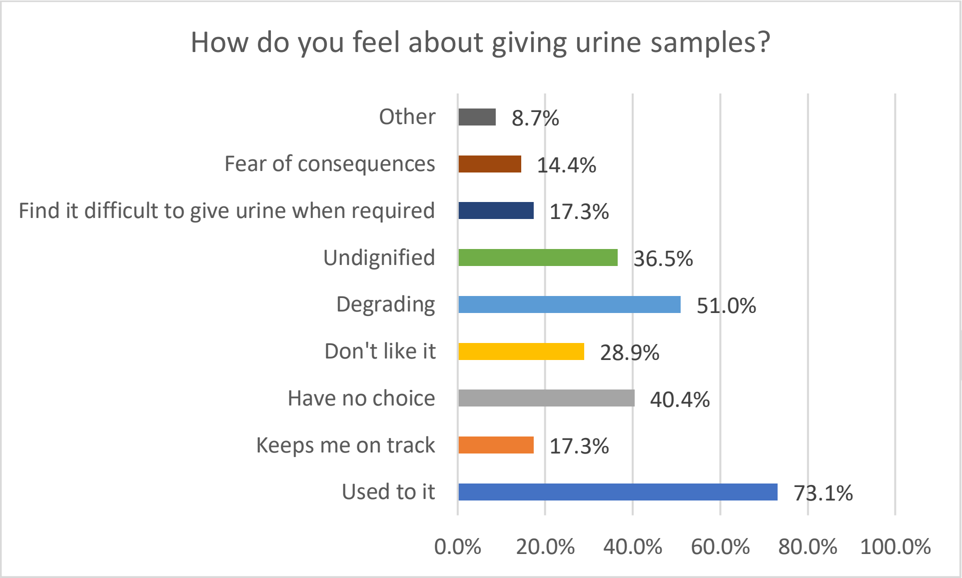
With expectation being so low, the lack of rights often becomes the norm, with stigma, shame and guilt being regularly discussed in many of the open-ended questions. A novel finding of this research magnified the lack of compassion or recourse for those who have developed problems with the use of benzodiazepines (including z-based) and other tablets purchased from the streets. As opposed to compassion and assistance, a large number of clients reported that this activity was treated with severe sanctions by clinics, with the responses including dose reduction, the removal of take-away doses and the refusal of any assistance. SURIA argue that this is a worrying development that must be immediately discussed with key stakeholders in the MMT system.

The normalisation of mistreatment, poor treatment and non-evidence-based treatment is again linked to the power of sanction, control and constraint. Some of the outcomes which are mentioned in the research are arguably the result of services penetrating too deeply into the lives of clients (Snoek 2015). These include health problems (dental problems and “the sweats” being the most common), stigma, shame, the inability to work or return to education and the financial cost of engaging with their MMT service. It is these outcomes which prevent social re-integration, reduce quality of life and inhibit person centred treatment. It is these research outcomes which underpin our argument that MMT services are restricting the recovery it is ostensibly attempting to promote. In the process, participants are experiencing what could be termed collective trauma with punishment and threats of sanction becoming everyday norms and occurrences.

Urinalysis is an invasive, aggressive procedure that has been central to our campaigns since our inaugural research. What is striking in Figure 12 below, a question that allowed multiple choice answers, is the large number of clients who have become “used to it” or feel they “have no choice”. In spite of the practice been defined as “degrading”, “undignified” or an obligation in which they “have no choice”, the fact that so many participants state they are “used to it” is indicative of the normalisation of mistreatment, the normalisation of being treated with little respect or dignity if one is to continue to be treated for their addiction. It is also argued that the large number of clients who claim that urinalysis “keeps them on track” reflects the shortcoming of Irish MMT, as it reinforces our claim that it is threat and sanction which are the primary instruments of care, as opposed to compassion, respect and rehabilitation, that is discussing and facing the cause of addiction.

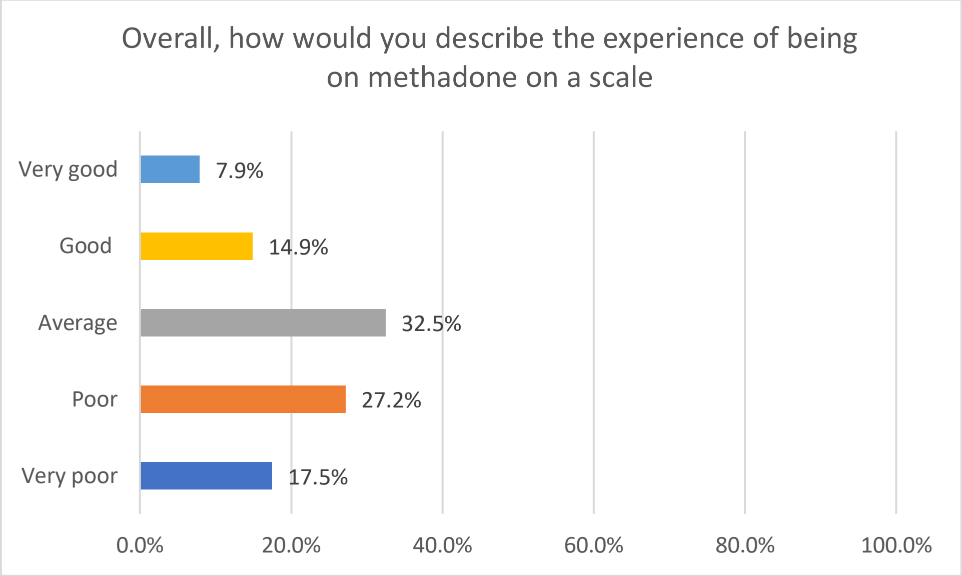
SURIA ARGUE THAT FEAR HAS NO PLACE IN RIGHTS-BASED CARE AND WHILE WE ACKNOWLEDGE THE LIMITED ADVANTAGES OF TESTING, WE BELIEVE IT SHOULD NOT BE THE MAIN FORM OF ASSESSING OUTCOME, TREATMENT, REHABILITATION OR HARM REDUCTION.

FIGURE 12: PARTICIPANTS’ OPINIONS OF URINALYSIS



The modes of control and discipline that we argue to be central to sample centred treatment are magnified by the lack of an independent and robust complaints mechanism. It is not beyond reason to state the research magnified the relatively negative perception the majority of participants hold pertaining to their treatment. The ramifications of urinalysis have been discussed, as have the general negative suppositions regarding both the lack of choice in treatment and use of care plans in treatment. These are arguably all intertwined in the general evaluation and rating of MMT that informed a distinct question in the survey.

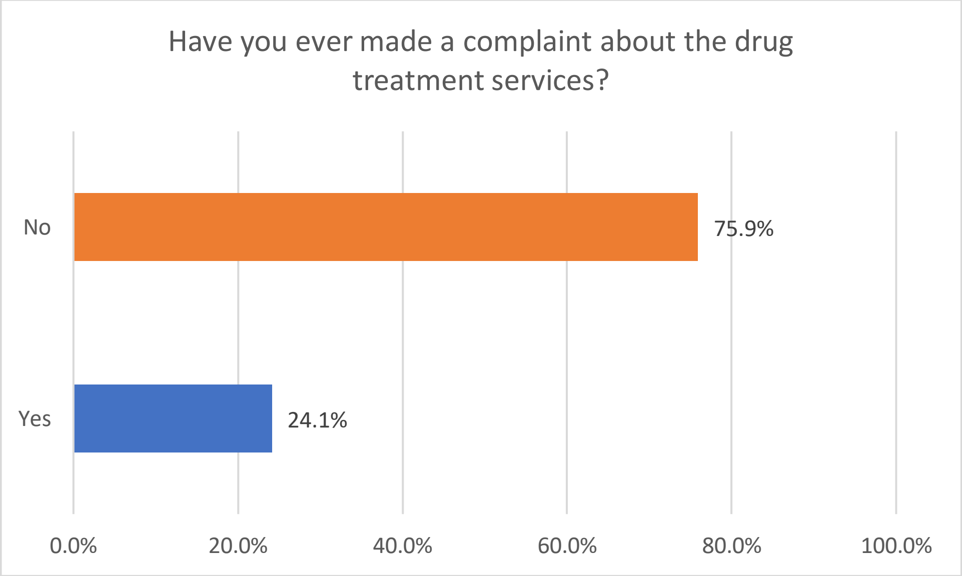
FIGURE 13: EVALUATIONS OF MMT



Participants were asked to rate the process as a sum of its parts in a scale ranging from 1 to 5, (Lickert Scale). As illustrated in Figure 13, just 23% of our research population rated their experience as being very good to good. Moreover, the remaining 77% rated their experience of MMT, that is as a form of health care with all the discussed variables considered, as average (32%) , poor (27%) or very poor (17%). As such, 45% of participants were of the opinion that their experience on MMT was below average. One could argue that these statistics advance a disillusioned, alienated and unhappy patient base and moreover, it would be expected to inform a high number of complaints that are reflective of this data. However, when our research discussed the opportunity for patients to engage with a complaint's procedure, it was shown that very few had, nor were they willing to.

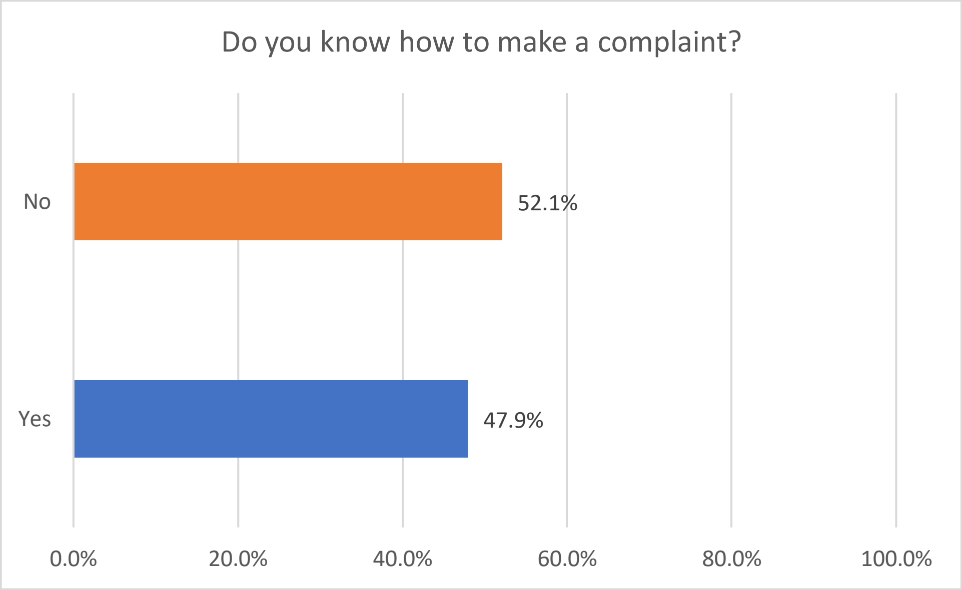
For SURIA, we find this indicative of a number of key issues. Firstly, it demonstrates that the independent avenue for complaint, part of our core principal set, is both poorly understood by clients, nor does it inspire the necessary confidence of clients.

Figure 14: Complaints made by clients



It must also be stated that among the 24% who claimed they had made complaints, there was a large number who considered these complaints to be casual comments to doctors and service providers as opposed to official complaints through the recommended complaints procedure and channels. This was amplified by the large number of clients who stated they were unaware of procedural obligations of making a complaint.

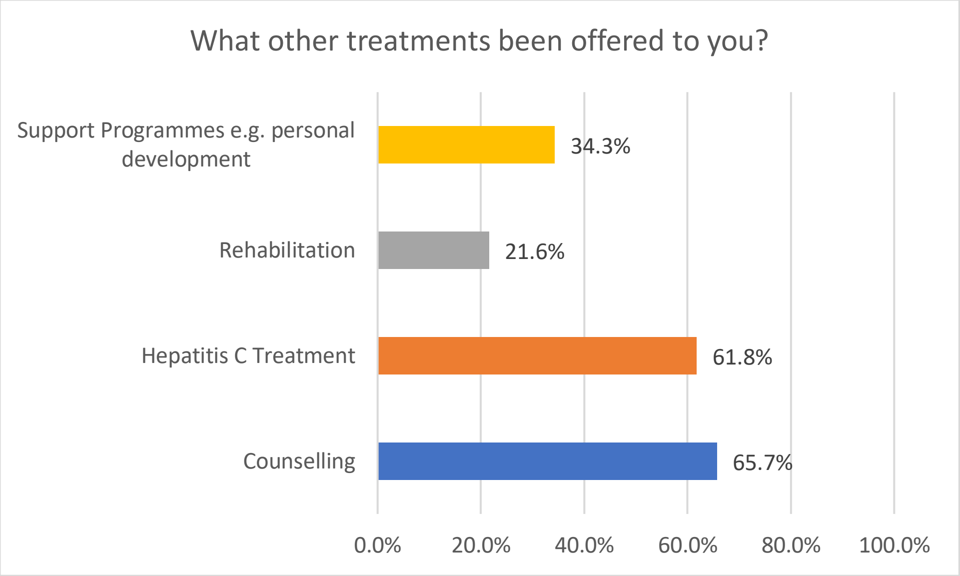
FIGURE 15: OVER HALF OF PARTICIPANTS ARE UNAWARE OF OFFICIAL COMPLAINT PROCEDURE



The lack of complaints, and the many participants who stated to have little or no knowledge of the complaint's procedure adds further validity and credibility to our thesis of the desensitising of MMT patients to poor treatment provision.

The further normalisation of the clinic as public health services that seeks to place morality above health and behaviour over the client's life choices further identifies how MMT can and does dehumanise the client, creating a particular form of health care with a focus on long term treatment, little progression and no attractive alternative to continuous drug use. Our evidence suggests that many clients have internalised and are expectant of this form of low-quality care and the life it informs, a form of care that would be unacceptable to any other public health population.

FIGURE 16: ANCILLARY SERVICES AND MMT: - WHERE AND BY WHOM ARE THEY OFFERED?



Furthermore, our data highlights the different services that participants engage with as they negotiate the complex methadone system. Throughout the interviews, the open ended questions made manifest that for the vast majority of clients, counselling, residential rehabilitation opportunities and Hepatitis C treatment, etc. were offered by needle exchanges, homeless services and community drug projects. Thus, their treatment was further complicated with little integration or communication. It is this poor form of treatment where dignity, respect and meaningful exchange or discussion have been replaced by long term obligations, duties, sampling and discipline.

Part Two

3.1 Introduction

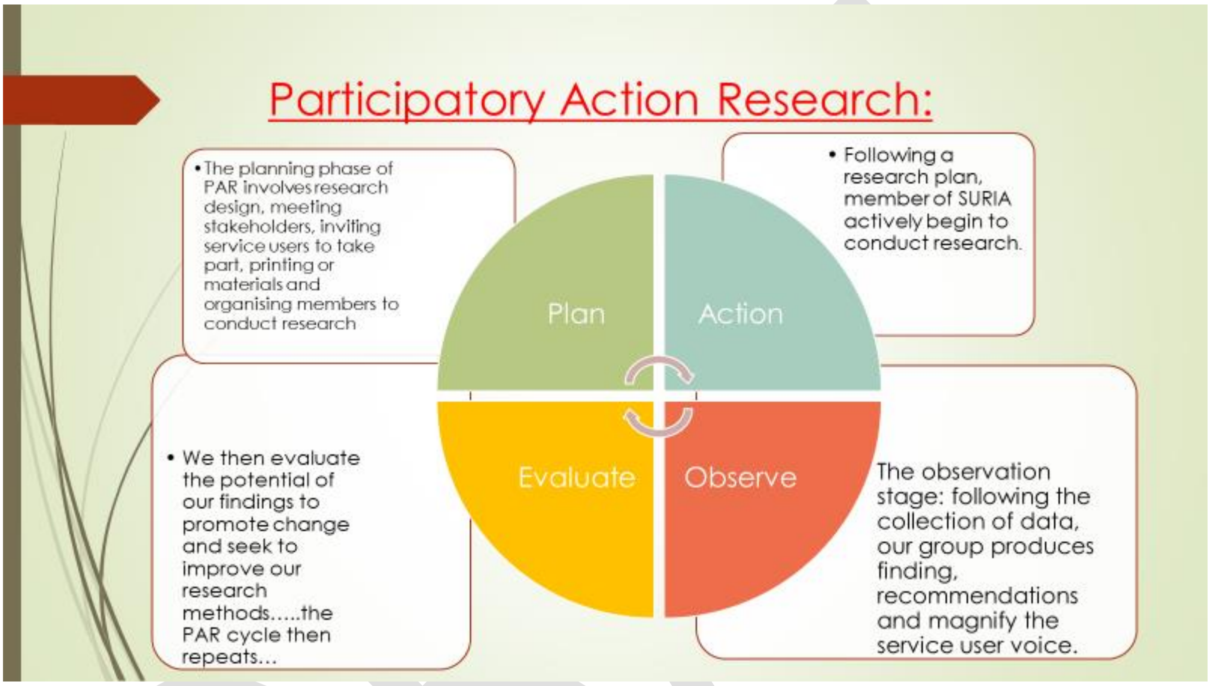
Part Two of the Report is a brief synopsis of our earlier rounds of research and an introduction to Participatory Action Research (PAR). As a research method that repeats, we will also discuss why we believe it has the key attributes required for the continual monitoring of human rights-based treatment. In order to monitor the progressive realisation of rights, one must explore past research results and seek trends and patterns from the platform and perspective of Human Rights and Equality Legislation. As previously discussed, the International Covenant for Economic, Social and Cultural Rights permits for the progressive realisation of rights, as such States are expected to operate within their means to protect vulnerable populations. SURIA's inaugural data was accumulated almost a decade ago, thus creating a backdrop against which we can make justified inferences regarding the conduct of key actors and stakeholders within this discursive space, regarding the realisation of human rights in the lives of those who use MMT services. Despite minor "victories" in our attempts to engender a more humane, holistic mode of care (primarily the cessation of supervised urinalysis), we now take as a point of departure, the addition of the quantitative data gathered by our team in 2012 and 2017, from which we seek these trends, patterns and changes or lack thereof. Prior to doing so however, it is perhaps beneficial to provide a concise definition of PAR.

3.2 The SURIA Methodology – Participatory Action Research:

Prior to our evidence informed inquiry into the patterns, trends and possible improvements in the lives of MMT clients, we outline the methodological approach which underpins our work. SURIA is an independent group consisting of service users, former service users, medical professionals, service providers and community activists, thus our research is informed by peer-led inquiry and research. Participatory Action Research (PAR), a cyclic research methodology that is beneficial in research with marginalised and disempowered populations is ideally suited to the objectives of this Report and the monitoring objectives of SURIA. PAR is both collaborative and empowering for vulnerable, marginalised populations, (McTaggart & Kemmis 2014). In this context, it allows for the voice of the service user to be at the forefront of activism, thus reinforcing the mantra of the International service user community; "Nothing about us, without us". As such, PAR enables and allows the service user to magnify and highlight their own perspectives of their treatment, granting them a rare chance to have a voice in their treatment narrative and providing the platform for that voice to be heard, (McTaggart & Kemmis 2014). In short, PAR is rooted in dialogue and pays specific attention to the right to participate, informing an avenue for the voice of those who use services to be heard, despite the frequent propensity for this voice to be ignored, (King 2011). Fundamentally, PAR consists of a repeating cycle of plan, action, observe and evaluate, (Khandou & Peter 2005). As a monitoring methodology which can be informed by both qualitative and quantitative data, PAR allows SURIA to use multiple data sets, chronologically arranged, to demonstrate change, examine trends and seek patterns in the data our team has collected from service users. We can then make evidence informed claims regarding the realisation of rights, the regression of rights and in general, monitor our recommendations and the dignity and respect afforded to MMT clients. Through research, SURIA have now collected an array of datasets that tell the story of the evolution or changes in MMT over the course of a decade. Most importantly, this is *according* to those that use MMT, as opposed to the normative model of individuals writing *about* the service user.

Following this decade of planning, action, observation and evaluation, our data now inhabits the space that is located between service use and provision, enabling us to discuss the methadone client narrative and the many nuances and contradictions it often involves. Our inaugural research was conducted in the year of the group's inception, 2012. This was followed by research in 2017, our work with IHREC and finally the work upon which this Report is primarily predicated. However, in order to carry out a convincing analysis, it is good practice to include the early research, as it is this which informs our monitoring of the service user experience and the often-changing life it creates for clients. Only then can one get a full perspective and overview of the progression, regression or efficacy of MMT practices in the past and present. Moreover, PAR enables the researcher(s) to continually improve our methodology and the research questions to be better aligned with our goals and objectives; rights-based treatment and better monitoring and analysis of the life experiences of clients.

FIGURE 17: PARTICIPATORY ACTION RESEARCH (PAR)



Participatory Action Research:

- The planning phase of PAR involves research design, meeting stakeholders, inviting service users to take part, printing or materials and organising members to conduct research

- Following a research plan, member of SURIA actively begin to conduct research.

- We then evaluate the potential of our findings to promote change and seek to improve our research methods…..the PAR cycle then repeats…

The observation stage: following the collection of data, our group produces finding, recommendations and magnify the service user voice.

3.3 Monitoring Progression and The Emergence of “Our Core Principles – 2012 & 2017:

Prior to SURIA’s work with IHREC, we conducted two research inquiries in 2012 and 2017, both of which were informed by quantitative surveys. Surveys are useful as they elicit large volumes of data, however their weakness often lies in the absence of rich, in-depth data. However, the advantage of our peer-led research by service users and former service users is that our data can be engaged with by researchers who have experience of Irish MMT. Both of these early projects produced the primary findings which have come to embody our campaign, aims and objectives, and our four “Core Priorities”. Furthermore, these findings have consistently re-appeared in all additional research carried out by SURIA. From our inception, supervised urinalysis and the lack of meaningful discussion with the service provider, choice of treatment and an independent, robust avenue for complaint have been found to be embedded in the service user narrative. The fact that the four core priorities were central to all research projects, all being repeatedly discussed by research participants, confirmed our strategy to underpin our work and campaign by these issues. We now return to these priorities, employing them as a lens from which we unpack the progression or regression of rights-based treatment. As such, Part Two employs this chronological data across these constants to examine and monitor the trajectory of rights-based treatment informed by an evidence base of service user narratives, experiences and evaluations.

3.3.1 Is the Profile of the Service User Changing?

Our early research suggested that the majority of clients were male, had been in treatment for between 10 and 20 years, with 66% of participants "hating" being on methadone in 2012 and 83% of clients evaluating their experience of methadone treatment as less than 5/10 on a Likert Scale of 1 to 10.

This is seen to have changed very little across all data sets, thus we argue that our most recent research is an outcome of a continual failure of MMT to re-integrate service users. The result is an alarming 64 of service users engaging with MMT for over 10 years and 30% for 20 years or more with the vast majority of these service users being unhappy with their treatment. Drawing again from the latest EMCDDA statistics, this corresponds to a populace of almost 10,000 public health patients who have engaged with MMT and are disillusioned by a lifestyle that has now dominated the majority of their lives.

FIGURE 18: TRACKING THE SERVICE USER PROFILE

Profile

2012	2017	2020
107 Service Users 55% male 45% female	132 Service Users 60% male 40% female	121 Service Users 57% male 43% female
50% aged between 30- 40 years	53% aged between 30 -40 years	36% aged 30-40 57% aged 40-60 93% over 30 years
66% hate being on methadone	83% rate it less than 5 on scale of 0 -10	77% rate it 3 or less on scale of 0-5

3.3.2 "Too Entrenched "in Urinalysis?

All statistical accounts demonstrate similar findings regarding urinalysis, with the 2017 data demonstrating a substantial increase in the frequency of the practice from one in twenty to one in four being required to provide samples 2-3 times a week. This increase is carried into the latest research.

FIGURE 19: UNPACKING THE FREQUENCY OF URINALYSIS

Urine sampling and Frequency

2012	2017	2019/2020
51% give samples weekly	56% give samples weekly	45% give weekly samples
6% give samples 2 -3 times per week	22.7% give samples 2-3 times per week	19% give samples 2 -3 times per week

How urinalysis is experienced

2012	2017	2019/2020
Detail given: 66% Do not like it	More detail given: 40% do not like it 50% find it degrading 27% find it undignified 23% say it is difficult to do 44% feel they have no choice	More detail given: 29% do not like it 51% find it degrading 37% find it undignified 17% say it is difficult to do 40% feel they have no choice 94% have experienced negative consequences in the past

FIGURE 21: SUPERVISED SAMPLING - 2012-2020

Supervised urines

2012	2017	2019/20
20% supervised	16% supervised	6% supervised
54% supervised with mirrors	65% supervised with mirrors	7% supervised with mirrors
		65% heat bottles

The more detailed surveys advanced by PAR have the obvious result of producing a more nuanced inquiry. We argue that urinalysis informs many of the problematic issues experienced by Service Users in the MMT system and that despite the international evidence (Ward, Mattick & Hall 1998) and the feelings of dis-respect, the lack of dignity and the negative connotations that are related to the practice, it is still central to the system. From the perspective of monitoring the realisation of rights-based, meaningful treatment, unpacking these statistics demonstrates that there has been little tangible change in how the service user is treated by service providers. As an independent monitoring group SURIA applaud the reduction of supervised urinalysis across the vast majority of services, yet we seek complete cessation of the practice.

3.3.3 Meaningful, Choice Driven MMT: An Overview

Meaningful discussion and the promotion and development of a positive therapeutic alliance between client and service provider is indicative of evidence-based care, where quality of life becomes the main aim of effective MMT, (Ward, Mattick & Hall 1998, Dole & Nyswander 1980). Unfortunately, the contemporary Irish MMT apparatus has seemingly replaced these with urinalysis, little meaningful review of treatment (30% of participants claimed to have had little treatment review with their service providers in 2017, down from 57% in 2012) and therefore poor communication and choice. An examination of care plans and meaningful discussion conveys a consist low level of goal-driven treatment since our inaugural research, while also demonstrating a tangible regression of meaningful recovery.

FIGURE 22: CARE PLANS AND CHOICE

Care Plans

2012	2017	2019/20
62% were never offered care plan	76% never offered care plan	65% never discussed a care plan with anyone
	75% would like one	69% do not know what a care plan is
	81% have personal goals relating to treatment, home family life, work, return to education	85% have personal goals relating to treatment, home family life, work, return to education

The vast majority of participants reported that MMT had become a barrier to progression in life (94%), while 95% of clients who took part were unemployed. The evidence suggested that MMT was now becoming a mode of care that was suppressing clients, with many feeling they were being treated as criminals with automatic aspersions being cast upon their character.

FIGURE 23: CLIENTS IN EMPLOYMENT /TRAINING /EDUCATION

Employment /training /education

2012	2017	2019/20
Question not asked	81% unemployed	96% not education, employment, or training
	70% see conditions of treatment a barrier	

Our research has always been consistent with that of Dole and Nyswander (1980:260), who stated that when methadone patients are mistreated, adversary relationships will develop as clinics rapidly become the “places of nuisance” which we have discussed. The client often lives a life of constant sampling, reward and sanction. As such, our research suggests that many live a life of restricted choice, little dignity, stigma and oppression. Furthermore, the fundamentals of the normative standards of public health care are rarely afforded to them. Figure 24 demonstrates how clients felt as participants in their own care. The lack of service user input is indicative of a mode of Public Care that considers clients as passive recipients of care as opposed to the consumers of a health service which should underpin client-centred recovery.

The steady increase to almost the entire research population maintaining that they have little input or participate is noted by SURIA. We regard this trend as being synonymous with the emergence of a more invasive and stringent form of MMT. This is again echoed as clients discuss their relationship with their service provider.

FIGURE 24: MEANINGFUL PARTICIPATION

Meaningful participation in treatment

2012	2017	2019/20
83% never asked opinion	84% never asked opinion	96% never asked opinion

FIGURE 25: LACK OF ALLIANCE AND RELATIONSHIP

Relationship with doctor

2012	2017	2019/20
43% say they do not have a meaningful relationship with their doctor	70% say they do not have a meaningful relationship with their doctor	45% rate their relationship with their doctor as between average and very poor

As discussed, it was from data elicited from these early rounds of research that would form the fundamental underpinnings of what would become the basis of SURIA's work and campaigns, which included radio coverage and taking part in an Oireachtas briefing, as we continued with our objective of framing Irish MMT within human rights, incorporating dignity, respect, participation and choice. The evidence highlighted the many difficulties and frequently harmful and risky outcomes of being a methadone client. Therefore, our continued point of departure encompassed the delivery of services, the lack of evidence-based practice and the reluctance of the Health Sector to employ the recommendations of The Farrell Report, a 2010 HSE funded evaluation of the Irish MMT regime.

3.4 The Public Sector Duty and MMT – Our Lives, Our Voice, Our Say (2018):

Our 2012 and 2017 research allowed SURIA to frame the Irish service user narrative within human rights. As such, both informed a platform from which Irish MMT could be explored under The Right to Health and The Right to Participate. Both are enshrined and ratified by a number of human right instruments. However, as this campaign was part of a pilot study of The Public Sector Duty, Article 42 of The Irish Human Rights and Equality Act within drug services, this was the principal focus of this peer-led, mixed methods informed research. As methadone services are Public Services or Bodies, the Duty was considered to be a human rights tool which was ideally suited with the aims, objectives and envisioned values of SURIA. The Public Sector Duty maintains that Public Bodies provide services where the service user is treated with respect and non-discrimination, while simultaneously they are expected to frame their services within the parameters of human rights. As duty bearers, services must standardise their practices, thus sustaining a therapeutic environment that enables the client to both realise and enjoy rights, as rights holders.

In general, the 2018 study further confirmed that the practices of some MMT services, as Public Bodies with a duty of equality and accountability, were continuing with modes of service provision that were precluding rights, with the Report further reinforcing our four basic tenets once more. Drawing from the viewpoint of progressive realisation, SURIA consider the Public Sector Duty to be a potential key instrument in the development of more client orientated service provision. The Report concluded with twenty-eight recommendations which we maintain are precursory to rights-based treatment. Recommendations are advantageous in monitoring both our work and the trajectory of rights-based care. We argue that the 2020 research suggests that services, "as highlighted in the" Farrell Report and other external evaluations (eg Priyadarshi 2012), routinely fail to follow international evidence and best practice and that this reflected in the general lack of progression in all facets of what SURIA consider to be rights-based MMT.

SURIA propose that participation, accountability, non-discrimination, equality and legality should be tangible entitlements of those who engage with the methadone system. We advocate for the methadone client to be a Public Health consumer who enjoys equal treatment and entitlements to those who engage with other modes of Public Health and Public Services. As such, The Public Sector Duty is pertinent and vital to our work. We argue that this Article is ineffective lest Duty Bearers are monitored and held accountable by the relevant stakeholders. As such, Public Bodies must have their service provision cogently policed. As an advocacy group, who regularly engage with service users, informing them of their entitlements and rights we will continue to conduct research and disseminate our results, seeking change, transition and service provision which is conducive with 28 key recommendations around which we could pivot our monitoring of MMT services. The fourth priority, the implementation of an effective complaint's procedure, is vital to the service user journey that we are trying to highlight. Not having the knowledge or ability to complain reinforces a level of docility in the service user voice. We argue it prevents this voice from being heard and enables non-accountability. Again, unpacking this over a decade reinforces our general consensus and key thesis that progressive realisation is not part of the policy development, implementation or service provision. Our hope is that this Report will continue to magnify and amplify the voice of the service user. We seek a public health service that aligns with others, treats MMT clients as other patients of public health, with respect, dignity and choice paramount.

4. Conclusion

In conclusion, this research, as both a stand-alone piece, and part of a longer-term monitoring of the progression of human rights in the lives of Irish methadone clients presents the Irish system as one in need of serious reform.

Clients, many desensitised or unaware of the ethos and objectives of holistic methadone care are staying on methadone for long periods, providing an unacceptable amount of samples, have a low quality of life and are rarely enjoying a life where their rights are being realised and a meaningful form of recovery is an attainable goal. Instead, our research concludes that Irish MMT has become consistent with the traditional analogy of "liquid handcuffs". Many participants used this metaphorical symbol to describe their life on methadone.

The spectre of abstinence, and the prohibitive mind-set appears to still dominate, and while SURIA's earlier work around supervised urinalysis seems to have engendered some progressive change, choice of treatment, meaningful review and an independent, robust complaint's procedure are still not being enjoyed by many service users.

The life narrative and experience of our participants is rarely seen as an attractive alternative to illicit drug use and outcomes appear poor. Participants allude to being controlled and disallowed from re-integrating with the labour market due to the obligations and demands that many services place upon them. As such, long term treatment with no tangible improvement in their lives was the frequent postulation. The accumulation of recovery capital and any level of social re-integration should be expected to be the minimum expectancy of services. Both would promote methadone as an attractive alternative to drug use. The contemporary Irish drug clinic fails to promote this mindset, the effect being long term MMT with little progression or change, a low standard of life, the non-realisation of basic human rights and a lifestyle that consists of repeated visits to doctors, pharmacies, clinics etc.

While SURIA, as a service user advocacy group, with an strong conceptual framework of rights-based treatment are highly critical of Irish methadone services, we do feel it is important to note that we recognise the potential for substitution therapy and distance ourselves from the stigmatising anti-methadone stance that dominates our country, (Carlin 2005, Bryan et al. 2000). We are critical of key actors, stakeholders, policy implementation and development and the inept service provision that permeates Irish MMT. As such, we recognise the benefits and respect the choice of the individual to avail of the form of care they wish, if that is their decision. Methadone, employed properly, informed by evidence and practiced by well-trained practitioners will or should, increase the standard of living of the client at a very minimum. If one chooses to remain using methadone, we strongly advocate for this right also. However, this Report, and the preceding three, illustrate convincingly the many shortcomings and rights violations that are all too common in contemporary MMT, while also highlighting that the methadone system, as a collection of obligation, duties and practices is not in the process of progressive realisation.

Furthermore, our research alludes to a slight regression in almost all areas of treatment. we again call for key actors to be held accountable, we again echo the 28 Recommendations of *Our Life, Our Voice, Our Say* and we re-iterate our primary objective of providing an outlet for those whom rarely enjoy treatment informed by dignity, respect and participation.

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Appendix

The 28 Recommendations of Our Lives, Our Voice, Our Say

Supervised and frequent urine sampling (Chapter 5)

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

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

The project steering committee:

1. Calls for an immediate cessation to the practice of supervised urine sampling by all drug treatment service providers
2. Calls for a cessation to the use of urine sampling as an evidence based approach for clinical decisions in relation to the service users, including as the basis for accessing treatment, withdrawing methadone or allocating "takeaway" doses to service users and contingency management
3. Recommends that the HSE provides training and awareness for medical and administrative staff on more evidence-based approaches to providing adequate levels of treatment and care to service users, including the limitations of urine sampling as a condition for service users accessing treatment
4. Recommends that the HSE provides training and awareness for medical and administrative staff on the diverse experience of people accessing drug services, including specific issues arising from urine sampling for particular groups - for example, women, transgender people, people with disabilities or people who may have suffered abuse
5. Recommends that the HSE provides training and awareness for service providers on the limitations of urine sampling and resulting barriers to accessing important supports when urine sampling is used as a criteria to determine access to services such as, for example, women's refuges
6. Recommends that the HSE actively promote a culture of dignity, respect and equality of participation for service users in the development and delivery of care plans and treatment to service users

Meaningful engagement and participation for service users (Chapter 6)

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

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

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

The project steering committee:

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

8. Calls for the HSE to put a greater emphasis on building a positive relationship and open dialogue between service users and service providers and for deeper and more meaningful service user engagement.
9. Calls for an immediate cessation to the partial or full suspension of medical treatment by service providers or by pharmacies as a reaction to anti-social behaviour. This includes restricting methadone takeaways as a form of punitive action.
10. Recommends the HSE uses the evidence contained in this report as the basis for assessing how current treatment structures impact negatively on the lives of service users, or potential service users.
11. Recommends, based on an assessment as outlined above, a redesign of current treatment and dispensing structures that better facilitate the participation of service users in living a more dignified and fulfilled life.
12. Recommends that that HSE design and promote dispensing and treatment structures that are person-centred and flexible, recognise the diversity of service users and aim to facilitate service users to engage in employment, training, education and carrying out family and caring duties.
13. Recommends that the HSE ensure greater flexibility in how services are delivered and a choice of services to accommodate the diversity of peoples' health needs and circumstances. This includes, for example, meeting gender specific needs; meeting the needs of people with disabilities; taking into account family or work commitments; and taking into account issues arising from the geographical distance between treatment services and where service users are living.
14. Recommends the provision of financial assistance for service users who have to travel to treatment clinics or dispensing pharmacies to avail of services that are not locally available.
15. Calls for the findings of this report to be widely disseminated to both medical and administrative staff in all drug treatment services in Ireland with a view to encouraging a service wide shift to a more client-centred service delivery model.
16. Calls for the HSE to actively support and resource the empowerment of service users with a view to building and developing the leadership of service users to self-advocate and support other service users to do the same.
17. Calls for the HSE to recognise the value of consultation and that service users are diverse and are not represented by one umbrella organisation.
18. Recommends that the HSE put in place a multi-pronged approach to facilitate the participation of service users that draws on a range of engagement approaches. For example, consultation should include a number of opportunities for participation such as engagement with individual services users across different services and geographical locations, focus groups with service users accessing different services and focus groups with a range of organisations representing or providing supports to service users.

Treatment choice and treatment plans (Chapter 7)

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

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

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

The project steering committee:

19. Recommends the HSE engage with service users to review the provision of information on treatment choice - including suboxone, subutex, methadone maintenance, methadone detox, methadone tablets,

residential and community detox - and ensure it is accessible and usable for all service users in all drug treatment services.

20. Recommends that the HSE ensure that when people start drug treatment, and at regular intervals thereafter, the implications for the different treatment choices available are more thoroughly discussed with them and reviewed regularly as their individual needs and circumstances change, ending the uniform approach to treatment.
21. Calls for the HSE to offer more flexible treatment options at more regular intervals taking into account the changing life circumstances, opportunities and challenges that are present at different stages in a person's life, particularly given the length of time that a person can be in opiate treatment.
22. Recommends that the HSE conduct a review of methadone dispensing practices, taking into account that supervised daily doses runs entirely counter to a holistic approach to treatment with a significant impact on the overall wellbeing of people using drug services and are a barrier to effective participation in employment, education, society, and family life. This review should take into account that most people availing of methadone treatment are stable and should not be required to attend every day for their daily doses. It should also consider, in particular, if consultation rooms could be used when dispensing methadone or if this could be more easily managed if the tablet form of methadone was available, as is the case with many other European countries.
23. Recommends that the HSE ensures that all drug treatment services provide meaningful holistic care plans that are informed by service users' personal goals and are clearly documented in an accessible manner and are subject to regular review and update.
24. Recommends that physical copies of care plans are made available to services users, and not just available on computers.

An effective complaints mechanism (Chapter 8)

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

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

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

The project steering committee:

25. Recommends that the HSE engage with service users to develop and implement a positive action plan to ensure that information on a complaints system is available in an accessible manner.
26. Recommends that the HSE ensure that all drug services create a supportive, open and transparent environment and culture to lessen fear and perceptions that there will be negative consequences / reprisals for making a complaint.
27. Recommends that the HSE ensure that all service users are informed of their right to make a complaint. This may include holding meetings to ensure that service users know how to make a complaint and are introduced to their complaints officer. Care should be taken to avoid conflicts of interest between complaints officers and patient advocates (and review officers) so that there is an independent system of complaints.
28. Recommends that the HSE ensure that service providers publish statistics, case studies and audits of complaints made by service users and use this information to inform their assessment of equality and human rights issues as part of their Public Sector Equality and Human Rights Duty under Section 42 of the *Irish Human Rights and Equality Commission Act 2014*.