

A scoping review for evaluation of drug rehabilitation outcomes and impacts in Ireland

An evidence brief



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List of abbreviations and acronyms

ALIVE	AIDS Linked to the IntraVenous Experience
AOT	Abstinence-oriented Therapy
ASI	Addiction severity Index
ATOS	Australian Treatment Outcome Study
CBT	cognitive behavioural therapy
CJS	criminal justice system
CTC	Coolmine Therapeutic Community
CTL	Central Treatment List
DAIS	Drugs and AIDS Information System
DATOS	Drug Abuse Treatment Outcome Study
Ddf	discharged drug free
DFDP	drug-free day programme
DORIS	Drug Outcomes Research in Scotland
DTORS	Drug Treatment Outcomes Research Study
eCass	electronic Comprehensive Addiction Services Solution
FAVOR	Faces and Voices of Recovery
GP	General Practitioner
HAART	Highly active antiretroviral therapy
HCV	Hepatitis C virus
HIPE	Hospital In-Patient Enquiry
HIV	Human Immunodeficiency Virus
HRB	Health Research Board
HSE	Health Service Executive

HTLV	Human T-lymphotropic virus
LIR	Life in Recovery
MMT	Methadone maintenance therapy
NDRDI	National Drug-Related Deaths Index
NDRIC	National Drugs Rehabilitation Implementation Committee
NDTMS	National Drug Treatment Monitoring System
NDTRS	National Drug Treatment Reporting System
NGO	Non-Government Organisation
NTA	National Treatment Agency
NTORS	National Treatment Outcome Research Study
OAT	Opioid agonist treatment
OST	Opioid substitution treatment
PPI	Public Patient Involvement
PROMs	Patient-reported outcome measures
PUP	Parenting Under Pressure
PWLE	People With Lived Experience
RCT	Randomised Control Trial
ROM	routine outcomes monitoring
Rosie	Research Outcome Study in Ireland Evaluating Drug Treatment Effectiveness
SABRS	Strengths and Barriers Recovery Scale
SDS	Severity of Dependence Scores
SMART	Self-Management and Recovery Training
SROI	Social Return on Investment
SURE	Substance Use Recovery Evaluator
TOP	Treatment Outcomes Profile
TTT	Tuairisciú ar Thorthaí Téarnaimh

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1 Introduction

This report presents the results from a scoping review for evaluation of drug rehabilitation outcomes and impacts in Ireland. The national drugs strategy includes a need to develop knowledge on rehabilitation outcomes, taking into account the experience of service users and families and examining outcomes across multiple domains. The outputs from this study include a recommendation of an evaluation methodology. The key objectives of this review are to:

Recommend appropriate research design options for measuring the impact and outcomes of the interventions provided in Irish drug treatment and rehabilitation services

Identify the rehabilitation impacts and outcomes for the users of these services

Identify the minimum sample or population size, duration of follow-up, and number of data collection time points for quantitative analysis.

Identify approaches to minimising loss to follow-up and their effectiveness

Identify the role routine information systems could play in impact and outcome evaluations

Identify the role of qualitative research in recording participants and their families' experience of drug treatment and rehabilitation services

Calculate the cost of impact and outcome research for each option considered

Detail the practical implications of commissioning an evaluation study based on the recommended research design, participation, consent, loss to follow-up, number of data collection time points, duration of such as study, cost, use of routine information systems, communications, and future measurement of outcomes and impact.

The review was carried out from late 2020 and involved a review of the literature on drug treatment and rehabilitation, particularly examining the outcomes measured within studies and how such outcome measurements were obtained, e.g. follow-up interviews or routine data collection. This took the form of a mapping of the international evidence on rehabilitation outcomes and also included an assessment of the routine information resources currently available in the Irish health system.

As outlined in the *National Drugs Rehabilitation Framework Document* (Keane, 2011), the National Drugs Rehabilitation Implementation Committee (NDRIC) has a role in overseeing and monitoring the implementation of the recommendations set out in the *Report of the Working Group on Drugs Rehabilitation* (Department of Community, Rural and Gaeltacht Affairs, 2007). The rehabilitation pathway proposed by the NDRIC positions rehabilitation within the Four Tier Model of Service Delivery (with residential rehabilitation being part of the highest tier), noting that the provision of the pathway is a shared responsibility across several sectors, including health. It recognises that rehabilitation is part of a journey that also includes treatment, but this journey is multifaceted and needs multi-sector involvement, reflecting that those who use drugs, particularly service users, have diverse and often multiple needs. While the Health Service Executive (HSE) is the lead organisation in terms of case management (e.g. ensuring that the individual's various needs are met, with input from a range of relevant organisations), the Case Manager overseeing this process for an individual may be a member of a different organisation, and may not necessarily be the individual's Key Worker. The roles of the Case Manager and Key Worker may differ, with the Key Worker being tasked with engaging with the service user, completing assessments, developing a care plan, and keeping relevant case/notes records. Neither the Case Manager nor the Key Worker is described within the *National Drugs Rehabilitation Framework Document* (Keane, 2011), as having a role in monitoring outcomes, particularly outcomes following rehabilitation.

The *National Drugs Rehabilitation Framework Document* does include reference to assessment and screening; however, both of these are seen as applicable at the start of a pathway or the individual's journey, or when transitioning up to or being referred on to a difference service. There does not appear to be a corresponding need to collect information at the end points of the journey or at regular intervals along the journey, although suggested outcomes are proposed as useful in care planning, with the proviso that the care plan should be based on SMART (specific, measurable, attainable, realistic and time-bound) objectives. As noted later in Section 2.2.1, monitoring systems such as the National Drug Treatment Reporting System (NDTRS) were established to collate assessments done primarily at the start of treatment/rehabilitation journeys and, currently, there is no comprehensive monitoring of the end point or outcome data.

The national drugs strategy, *Reducing Harm, Supporting Recovery: A health-led response to drug and alcohol use in Ireland 2017-2025* (Department of Health, 2021), includes the goal of promoting rehabilitation and recovery, thus building on the work of the National Drugs Rehabilitation Framework and the NDRIC. A separate goal, which is to develop sound and comprehensive evidence-informed policies and actions, is included in the national drugs strategy. Other goals include developing a suitably integrated information technology (IT) system that allows for the effective sharing and collection of appropriate outcome data and undertaking a study on rehabilitation outcomes, which takes into account the experience of service users and their families, and examines their outcomes across multiple domains, thus building on work already undertaken.

This is an important shift in the prioritisation of outcomes, as previous national drugs strategies have focused on more traditional outcome measures, such as service-defined success of treatment, and not focused on the experiences and perspectives of the people using these services. This shift is evidenced in wider literature around drug treatment outcomes and assessments, and will be discussed in more detail later in this report, for example in Sections 4.6 and 4.9. In summary, it is becoming increasingly acknowledged that the outcomes of treatment should reflect not only reduced drug use, mortality, and criminal justice measures but also quality of life improvements and other perceived benefits to the people receiving treatment and their families, as well as benefits to society as a whole.

This report first sets out the available information on rehabilitation services in Ireland, before introducing an evidence map of the literature on Irish and international studies on rehabilitation outcomes. The methodology used for this evidence map is described in Chapter 3, with descriptions of key studies in Chapters 4 and 5, beginning with international studies and then proceeding to consider previous Irish studies. In Chapter 6, we present a recommended approach to studying rehabilitation in the future, drawing on more recent work which combines patient-reported outcome measures (PROMS) with the growing recognition of recovery as an integral part of any treatment or rehabilitation outcomes. We also discuss the importance of involving people with lived experience of rehabilitation in the development of any outcomes monitoring in Ireland.

2 Available information on rehabilitation services in Ireland

In this chapter, we consider the available information on rehabilitation services in Ireland. We begin with a brief description of how rehabilitation was brought into the national drugs strategy, and then go on to highlight some of examples of recovery-focused services. All services contribute to the National Drug Treatment Reporting System which currently collects and collates information on drug use, treatment and rehabilitation in Ireland. We also briefly describe other sources of data, particularly where there may be potential to use some or all of these sources (as currently established) to examine outcomes or make enhancements or other developments to allow outcomes to be monitored.

2.1 Rehabilitation in Ireland

The National Protocols and Common Assessment Guidelines which accompany the National Drugs Rehabilitation Framework Document describe how residential rehabilitation services are placed within the wider Tier 4 services. Residential rehabilitation units are described as providing specialised addiction counselling which addresses the person's psychological, emotional, behavioural and personal/family issues. It also notes that there is 'step-down' or halfway house provision which may be required as a follow-on from this. These facilities address the ongoing rehabilitation needs of the clients and address ongoing training, education, accommodation and welfare needs. This differs from the more 'acute' inpatient provision which concentrates on medical stabilisation and detoxification.

Rehabilitation is not restricted to a residential setting, with daytime drug rehabilitation services provided by the Health Service Executive (HSE) such as Soilse which operates two facilities in Dublin or the Tabor Group providing a community-based programme in Cork. Just as those who present with drug-related problems are a diverse group, the range of services and organisations, and the specific work they do with patients or clients varies across locations and the needs of the populations served. The SAOL integrated programme of education, rehabilitation, advocacy and childcare is a good example of this, specifically working with women, children and community members in the North Inner City of Dublin.

More generally, the debate about the place that recovery has within the provision of drug treatment and rehabilitation services is ongoing, reflecting developments elsewhere in Europe and in the USA, with the need for people to be able to build 'recovery capital' articulated in the latest Government strategy and the launch of the Recovery Academy.

2.2 Information systems

There are two main information systems that collate information on drug use in Ireland and a third, restricted so far to North Dublin, which may have potential to be used if expanded. These are the National Drug Treatment Report System (NDTRS), the Central Treatment List (CTL) and the Drug and AIDS Information System (DAIS). These are each discussed in further detail in the following sections.

2.2.1 National Drug Treatment Reporting System (NDTRS)

The National Drug Treatment Reporting System (NDTRS) is a database that contains anonymous information, including treatment outcomes, about people in drug and alcohol treatment [and rehabilitation] in Ireland since 1995 and treatment outcome data since 2008. It is collated and maintained by the Health Research Board (HRB). Information is collected from general practitioners, low-threshold services (that provide low-dose methadone or drop-in facilities only), prisons, outpatient and inpatient centres. Data collection for the NDTRS is carried out via an online web-based system.

It is an epidemiological database that collects data such as basic demographics, the reason(s) for treatment and source of referral. Up to five problem drugs can be recorded (including alcohol) as well as

drug use history, risk behaviour in relation to injecting, type of treatment received and treatment outcomes.

2.2.2 The Central Treatment List (CTL)

The Central Treatment List (CTL) provides administrative data on those who are receiving methadone treatment in Ireland. In 2019, there were 10,318 individual patients on this list with 53% receiving treatment from clinics, 41% from their GP and 6% in prison. Trends from the period of 2006 – 2016 show that the number of patients on the CTL is steadily increasing each year.

Each patient is allocated a unique number and a treatment card is issued for patients when dispensed in community pharmacies. The list collects data, including the patient's name, address, date of birth, gender, date commenced on methadone, type of methadone treatment, prescribing doctor and dispensing pharmacist. Practitioners have a statutory obligation to report the initiation of treatment, and are paid per client in treatment. Patients on the List can be tracked via transfer and exit records.

2.2.3 The Drugs and AIDS Information System (DAIS)

The Drugs and AIDS Information System (DAIS) is a HSE system that records data about people seeking treatment in the North Dublin Area (the area covered by CHO 9, consisting of Dublin North, Dublin North Central and Dublin North West). It collates information on demographic characteristics, assessment prior to treatment, prescriptions, hepatitis C status, treatment programmes and rehabilitation integration services.

Comiskey and Snel (2016) tested the feasibility of linking data from laboratories providing screening tests (urine samples) with client intake data to model five-year drug treatment outcomes. That study demonstrated that data could be linked, matched and modelled retrospectively to develop outcome results that may be useful for policy-makers, service providers and service users.

2.2.4 NGO (non-governmental organisation) bespoke treatment reporting systems

A number of residential and outpatient services use their own bespoke client management systems. Some of these services have used their own systems to evaluate their interventions, in combination with client and family surveys and interviews.

Cuan Mhuire is Ireland's largest voluntary provider of addiction treatment services and residential rehabilitation. Its services are based on the philosophy of total abstinence. Client's progress through a systematic 12 week or 20-week residential programme. The organisation provides after treatment and family support services for up to two years. Cuan Mhuire has over 570 people in its centres nationwide and annually admits 2,500 clients to its centres.

The Tabor Group provides residential and community-based addiction treatments using the Minnesota Model. The group is comprised of Tabor Lodge (Primary Treatment Centre), Fellowship House (Secondary Treatment Centre for males), Renewal (Secondary Treatment Centre for females) and extended supported accommodation in the community for both males and females. In 2018 it published an evaluation of its services based on client data and on qualitative research (Ivers and Barry 2018).

Coolmine Therapeutic Community (CTC) was Ireland's first voluntary drug treatment service and began providing services in Dublin forty years ago. CTC supports 1,350 individual clients annually providing online psychiatry services, OST for pregnant women, Travellers and a New Communities Assertive Outreach service and a treatment pathways service for homeless clients.

2.2.5 eCASS (electronic Comprehensive Addiction Services Solution)

eCass is an information management system which, from the developer's website, says it is used by 85 addiction services across Ireland working at all levels of the National Drugs Rehabilitation Framework (include the Coolmine Therapeutic Community described above and others such as Merchant's Quay). It provides support for drop-in services, outreach, brief assessments, key working, care planning and case management, including the completion of NDTRS forms and the reporting to the Health Research Board.

2.2.6 Source of information on drug-related morbidity and mortality

There are two main sources of information on drug-related morbidity and mortality in Ireland. The Hospital In-Patient Enquiry (HIPE) system and the National Drug-Related Deaths Index (NDRDI).

HIPE collects data on patients discharged from hospitals across Ireland. It codes each diagnosis and procedure with internationally recognised codes and as such, can be used to identify people who use drugs (such as opiates) who have been in hospital. Nationally, these data are only collated at an aggregated level so cannot be used to explore individual outcomes. It has been used as a resource in previous epidemiological studies, such as a study that estimated the prevalence of opiate use in Ireland in 2014 (Hay et al., 2017). However, that study needed to seek approval from each relevant hospital and gain access to anonymised data at the local level; a process that was time-consuming and not entirely successful. It is unlikely that the HIPE system would be useful in monitoring drug treatment or rehabilitation outcomes unless there were substantial changes to the processes used to access the data or established routes to be able to link the data with other data **sources (such as those initiating treatment within the NDTRS)**.

The NDRDI reports on poisoning deaths (also known as overdose), which are deaths in the general population due to the toxic effect of a drug or combination of drugs, and on non-poisonings, which are deaths as a result of trauma, such as hanging, or medical reasons, such as cardiac events, among people who use drugs.

3 Evidence map of literature on evaluation studies on rehabilitation

The available literature on evaluation studies on rehabilitation was reviewed, including primary papers and systematic reviews based on longitudinal studies of drug treatment and rehabilitation. The approach was initially based on Arksey and O'Malley (2005) and their approach to scoping studies, however the specific information that was mapped (specific outcomes from treatment/rehabilitation and how they measured) resulted in a more ad-hoc approach to mapping available studies. The mapping exercise did, however, attempt to identify the nature and extent of the literature around drug rehabilitation outcome studies. This part of the review started off in a similar manner to a typical systematic review or scoping study (agreed search strategy, inclusion/exclusion criteria, review by at least two experienced researchers) but, for various reasons, gave mixed results which ended up with a small number of 'studies' which were identified from within the scientific review to a greater or lesser extent. It should be noted that the review of the literature identified scientific papers rather than specific studies, therefore there may be more than one paper arising from an individual study,

3.1 Methodology

In this section, we detail the methodological approach taken when carrying out the review of the literature, including the databases used in the search, the inclusion criteria, the process of reviewing published studies and the extraction of data. The main objective of the review was to identify studies that either evaluate or examine the effectiveness of drug or alcohol treatment or rehabilitation services, and to examine what data are collected on outcomes. This primarily focused on cohort or longitudinal surveys which follow up clients after leaving the service; it also focused on exploring what outcomes/approaches to measuring outcomes are used within these surveys.

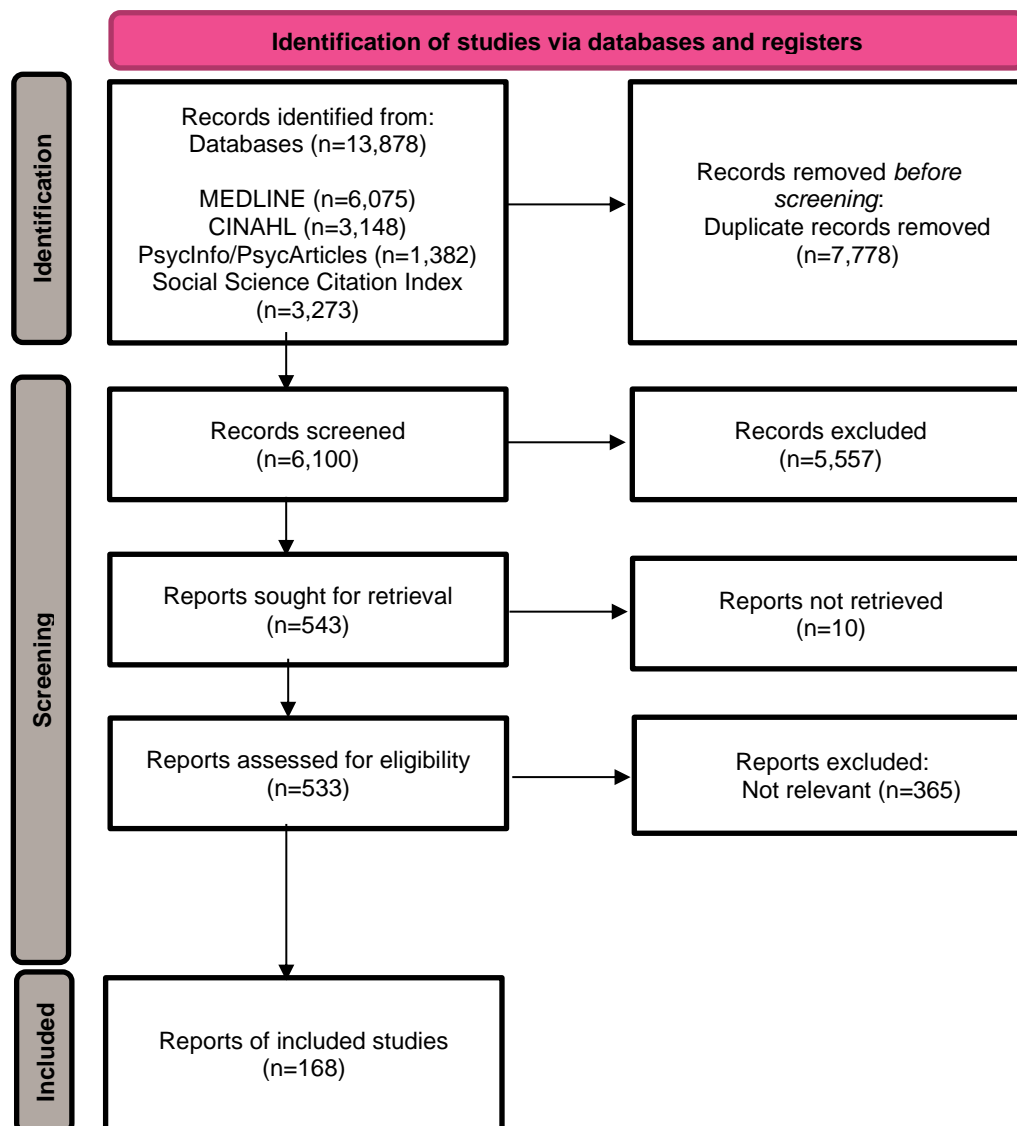
3.1.1 Literature search

Searches have been carried out on the following databases:

- MEDLINE
- CINAHL
- PsycInfo
- PsycArticles
- Social Sciences Citation Index via Web of Science

Full details of the search strategy used to search each database are included and the PRISMA flow diagram is given in Figure 1.

Figure 1: PRISMA diagram for the review of literature



3.1.2 Inclusion criteria

The main inclusion criteria were:

- Papers must have been published in peer-reviewed journals.
- Papers must have been published since 2000.
- Studies should relate to people who have engaged in treatment or support for drugs or alcohol (including Narcotics Anonymous or Alcoholics Anonymous).
- Studies that relate to smoking cessation should only be included if they discuss novel approaches to follow-up, e.g., smoking cessation projects that include routine follow-up by phone. To be clear, it would be the smoking cessation project that has follow-up built into the programme, not the research study 'evaluating' the project.

- Studies need to be a cohort study or a randomised control trial (where the study lists the outcomes various and tracks people over time). Either study design should follow up on clients after leaving treatment/rehabilitation.
- Studies that examine outcomes following other ‘interventions’ should be included if there is sufficient similarity to traditional drug treatment, for example, people who use drugs or alcohol leaving prison where they are contacted as follow-ups, or targeted support in other settings such as through GPs.
- Papers that refer to important treatment outcomes studies should always be included, even if they do not give detailed information about outcomes. The initial list of major studies were: ROSIE (Ireland), DORIS (Scotland), NTORS or DTORS (England), ATOS (Australia), VEDETTE (Italy) or named US studies, and additional studies were included when identified.
- Cohort studies that are based on samples of the general population (e.g. to examine factors that predict drug or alcohol use or entering into treatment) should be excluded.
- Studies that are small scale, addressing specific research questions should be excluded even if they recruit participants from treatment/rehabilitation, e.g. a study that followed 125 ‘substance abusers’ looking at antisocial personality disorder.

A pragmatic approach was taken to reviewing the literature, in that approaches that appeared to be new or innovative, or those which may not have previously been used in examining treatment outcomes for substance use were considered.

3.1.3 Data extraction

A formal critical appraisal method was not used; however, the following were listed as headings for the data extraction of the eleven studies identified for inclusion, with their associated journal articles. These headings and the wider data extraction process were agreed between the study team and those reviewing the literature.

Table 1: Main data extraction fields

Field	Notes
Study name	
Study design	
Authors	
Paper year	
Paper title	
Total study time period	Sometimes studies reported after different follow-up periods
Study population (descriptor) (including age group, sex, other demographics)	People who are engaged in treatment and/or rehabilitation for problematic drug use, including alcohol use. People who have existed formal treatment but are still engaged in a drug rehabilitation programme. People who are engaged in a named recovery programme or in peer support groups such as AA or NA.
Sample size	Some studies would report on subsets of their total sample size
Sample size justification	

Field	Notes
Loss to follow-up at data collection each time point	
Geographical coverage of the study, where applicable	
Intervention categories	Rehabilitation interventions that aim to ameliorate the psychological, medical or social state of individuals who seek help for their problematic drug or alcohol use. These will include drug-based interventions, such as opiate substitution treatments, detoxification treatments and a range of psychosocial interventions. In addition, family therapy, life skill programmes, access to education and employment, and housing first programmes should be included.
Outcome categories measured and means of measurement	The treatment, rehabilitation or social functioning outcome measure included in a standard classification of outcome measures, such as that compiled by the International Consortium for Health Outcomes Measurement (ICHOM).
Status of the study: completed or ongoing	The vast majority of studies were completed and most key studies were completed (with some described as approaches on-going)
Findings about intervention impact and outcomes	
Method used for follow-up	
Substances (drugs/alcohol/both)	

3.2 Results

3.2.1 Introduction

This section describes the results from the review of the available literature. A formal review of the literature was undertaken and the results are discussed in Section 3.2.2, however, for reasons outlined in Section 3.2.4, 17 'key' studies (seven carried out in Ireland and ten in other countries) were analysed in greater detail to inform recommendations on future outcomes research involving residential rehabilitation in Ireland. It should be noted that a main shortcoming of the search strategy was that it would identify papers rather than studies and often did not identify studies already known to the research team. This resulted in the team following up on grey literature and the literature included in previous systematic or scoping reviews such as de Andrade *et al.* (2019).

3.2.2 Systematic mapping of research literature

In this section, we describe the results of the scoping review. In total, the search criteria used across different data sources generated 13,878 records as noted previously in Figure 1. After duplicate records were removed, the titles and abstracts of 6,100 papers were screened to identify those where full text should be retrieved for a more detailed review. This initial screening was carried out by five trained reviewers (working independently with a lead reviewer available to advise on whether full text should be retrieved) which took the number down to 543. It was not possible to retrieve full text for 10 papers,

although a review of the titles, abstract and other available information suggests it is unlikely that the inclusion of these papers would have changed the analyses and thus the recommendations of this report. A team of three reviewers then reviewed the full text of 533 papers and either noted that, after this full review, the papers were not relevant according to the inclusion/exclusion criteria or went on to extract relevant data. It should be noted that more than one of the 533 papers and the 168 included papers may refer to an individual study (e.g. there were 33 papers identified from the search strategy that reported results from an individual study).

The papers reported on studies that were given different descriptions. Thirty-one were described as having some element of randomisation, although not all of these could be described as formal randomised controlled trials, which is perhaps expected due to the nature of the 'intervention' and difficulties in creating a placebo. There were 69 papers reporting on studies described as cohort studies (either prospective or retrospective) and 16 described as cross-sectional studies. Other papers used a wide range of descriptions therefore it was not possible to definitively classify into formal study designs for every paper. The countries the papers relate to are as follows: Australia (8), Brazil (2), Canada (13), China (3), Denmark (1), Finland (4), France (2), Germany (6), India (4), Iran (2), Ireland (7), Italy (1), Malaysia (3), Netherlands (2), New Zealand (2), Norway (2), Peru (1), Portugal (1), South Africa (1), Spain (3), Sweden (4), Switzerland (4), Taiwan (1), Tanzania (1), Thailand (2), Ukraine (1) United Kingdom (22), USA (60) and Vietnam (2). There were two papers that reported a comparison between the USA and Switzerland. A range of outcome measures were collected, primarily levels of alcohol or drug use and abstinence, with various tools employed.

3.2.3 Critique of approach to reviewing the literature

Having carried out a formal search of the literature using specific search terms and inclusion/exclusion criteria, it was noted that this approach generated a lot of information about a range of papers that were not particularly useful for formulating recommendations for future research, and also sometimes failed to identify relevant studies (or approaches) that could be useful to consider. The reasons for this include:

- We are interested in studies, not specific papers therefore our 'unit of analysis' was different to most systematic reviews
- Conflicting / competing information on different studies
- Publications are primarily focused on 'results', not methods
- The main search strategy did not identify studies identified from the search strategy used in a recent systematic review
- The main search strategy did not always identify some studies or approaches either known to the researcher or found in the grey literature.
- Some of the more interesting 'approaches' that may be of interest for those developing a rehabilitation outcomes study in Ireland would not necessarily be classed as a 'research study' so not always picked up in the search strategy.

The main results and recommendations of this report are based on ten international studies and seven studies previously carried out in Ireland. Two of the studies are perhaps better described as approaches rather than traditional research studies and following the detailed review of the literature, there were four additional papers reviewed that considered SMART recovery and patient-reported outcome measures (PROMs) (Beck et al, 2021; Gray et al. 2020, Kelly et al, 2020, Kelly et al, 2021).

3.2.4 Key studies

Table 2: List of included studies

	STUDY	MAIN AUTHORS	Location	Time Period
International				
1	ALIVE	Galai, Vlahov	US	1998-9
2	ATOS	Darke, Ross	Australia	2001/4; 2011
3	DATOS	Flynn	US	1995-2001
4	DORIS	Neale, McKeganey, Bloor	Scotland	2001-2003
5	DTORS	Jones, Donmall	England	1995-2000
6	LiR	Best, Laudet	Scotland/England/ Netherlands/Belgium	1997 -2004/5
7	NDTMS	Marsden, Eastwood, Strang	England	1995 - 2000
8	NTORS	Gossop, Marsden, Stewart	England	1995 - 2000
9	SURE	Neale	England	2016
10	VEDETTE	Salamina, Davoli	Italy	1998 - 2005
Ireland				
1	ROSIE	Comiskey	IRELAND	2003 - 2006
2	Coolmine	Babineau, Harris	IRELAND	2011 – 2013
3	Keltoi	White	IRELAND	2002 - 2006
4	Pathways to recovery	Mayock, Butler	IRELAND	2017 - 2018
5	Retention in methadone	Mullen	IRELAND	1999 – 2003
6	PUP	Ivers, Barry	IRELAND	2017 - 2018
7	SWAAT	Ivers	IRELAND	2020 - 2021

4 Key international studies

In this section we describe each of the studies identified as useful in information recommendation of futures studies in Ireland. This section has studies that have been carried out internationally and the next section describes studies that have previously been carried out in Ireland.

4.1 ALIVE (AIDS Linked to the IntraVenous Experience)

4.1.1 Study description

The ALIVE STUDY (AIDS Linked to the IntraVenous Experience)¹ originated in 1988 in Baltimore, USA in Johns Hopkins, Bloomberg School of Public Health, with its findings and participants playing a significant role in further studies, numerous publications, and changes in legislation (Johns Hopkins Bloomberg School of Public Health, 2021, Vlahov et al 1991, Wang, 2004, Galai et al 2003).

4.1.2 Study details

¹ <https://www.jhsph.edu/research/affiliated-programs/aids-linked-to-the-intravenous-experience/research/major-contributions/>

The ALIVE clinic opened in 1988 and recruited 2,960 injection drug users (IDUs) over a 13-month period with 24% participants HIV positive. The ALIVE study is community-based research, deemed one of the longest-running studies of IDUs with its original primary objectives being the assessment of the incidence and progression of HIV in IDUs. Over time, objectives changed to include access to and impact of treatment for HIV; evaluation of non-AIDS outcomes for the ageing cohort of participants; and ascertaining the incidence, progression, and treatment of co-infections such as hepatitis C. Several other studies, focusing on IDUs, were prompted by the ALIVE study (Johns Hopkins Bloomberg School of Public Health, 2021).

Between 1990 and 1992, studies were published on issues such as needle sharing and infection risks. In 1994, data from the ALIVE study enabled legislation to be passed in Baltimore to permit needle exchange services and formed the basis for the HERS study, an eight-year study of HIV in women and two nine-year studies REACH and DUIT of new-onset injection drug users. The ALIVE study made significant findings specifically in relation to estimates of Hepatitis E virus prevalence in drug users; the role of genetic markers (CCR5) on HIV infection and progression of disease; and development of an audio computer-assisted self-interview (ACASI) tool to capture self-reported risk behaviours (Johns Hopkins Bloomberg School of Public Health, 2021).

4.1.3 Methods

Two cohorts are followed and compared: ALIVE 1 consists of those with HIV seropositive IDUs compared to a sample of HIV seronegative IDUs. ALIVE II cohort consists of remaining HIV seronegative IDUs referred to Alive 1 HIV seroconverters.

4.1.4 Findings

The main findings and associated impacts since 1998 have been in the area of needle sharing, needle exchange programmes, risk factors for hepatitis B and C, HTLV, HIV viral load, HAART, HCV and HIV. IDUs are as aware, if not more so, about HIV as the population generally with increased awareness of safe use of injections reducing negative physical outcomes. Findings have also resulted in legislation permitting the development of needle exchange programmes and programmes subsequently evaluated.

4.1.5 Conclusion

- The ALIVE study is the largest ongoing study of its kind.
- ALIVE has made major contributions to the study of HIV/AIDS.
- ALIVE has formed the basis for introductions of needle exchange programmes and legislation.

4.2 ATOS (Australian Treatment Outcome Study)

4.2.1 Study description

The original Australian Treatment Outcome Study (ATOS) commenced in 2001 and sought to examine outcomes from heroin dependence during that time with over 40 research publications emanating from that research. This ongoing research commenced in October 2011 and was funded by the National Health and Medical Research Council, Australia. It sought to re-engage and re-interview the participants (N=615) in the initial 3-year ATOS study in intervals over 20 years (Darke, Williamson, Ross, & Teesson, 2006; Marel et al., 2020; Ross, 2006; M. Teesson et al., 2006; M. H. Teesson, Alys: Ross, Joanne: Darke, Shane, 2006).

This prospective cohort study is deemed to be a landmark study, conducting the longest and most comprehensive prospective follow-up of heroin users in Australia capturing patterns of use, remission and health service use (general and psychiatric) along with associated risk factors. The authors claim that this is the first time the physical health consequences associated with long-term heroin dependence will be researched over time.

The main research authors are Professor Shane Darke, Professor Maree Teesson, Associate Professor Lucinda Burns, Dr Joanne Ross, and Dr Sonja Memedovic (NDARC, 2021).

4.2.2 Study details

This ongoing research is a follow-up of the original cohort with five waves of follow-up interviews completed at 3 months; 1-, 2-, 3-, and 10/11-year post baseline. The 11-year follow-up rate was 70% (NDARC, 2021). The 18–20-year follow-up is ongoing with 96% of the original cohort (N=615) having completed at least one interview (Marel et al., 2020).

4.2.3 Methods

The 18–20-year follow-up commenced in 2019 and consists of 1) a structured interview; 2) physical health assessment; and 3) data linkage.

The follow-up interviews cover: mortality, abstinence, crime, psychopathology and suicidal behaviour in the 615 participants.

4.2.4 Findings

One-year outcomes show substantial reductions found in heroin and other drug use across three treatment modalities, with the majority who had entered treatment heroin abstinent. Substantial reductions also in criminality, psychopathology and injection-related health problems following treatment exposure at the 1-year follow-up. A dose response was noted with a greater 'dose' of treatment associated with more treatment stability.

4.2.5 Conclusion

- The current follow-up will provide data on the long-term effects of heroin use
- Annual mortality rate of Australians with heroin dependence (<1%) less than Asia (3%), Europe (2-3%) and North America (1–2%)
- High rates of retention at 12 months
- Substantial reductions in drug use, risk-taking, crime and injection-related health problems across all treatment groups
- Psychopathology was also dramatically reduced among the treatment modalities

4.3 DATOS (Drug Abuse Treatment Outcome Study)

4.3.1 Study description

The Drug Abuse Treatment Outcome Study (DATOS) was a prospective epidemiological study conducted in the USA between September 1995 to August 2001 that provided the opportunity to track the trajectories of a large sample of adults (N=10,010) who were admitted to treatment (DATOS, 2008; Hubbard, Craddock, & Anderson, 2003). The goal of DATOS was to examine complex associations of

patient characteristics along with the treatment process, environment, and outcome (Hubbard et al., 2003)

There were four types of programmes: 1) long-term rehabilitation; 2) short-term inpatient; 3) non-residential drug-free units; and 4) outpatient methadone maintenance (Frane & Ashton, 2002) studied over 5 years in the USA to assess the effectiveness of community-based drug treatment (DATOS, 2008).

Several other studies were carried out using this dataset (Flynn, Joe, Broome, Simpson, & Brown, 2003; Flynn, Porto, Rounds-Bryant, & Kristiansen, 2002a, 2002b; Hubbard et al., 2003; Murphy, 2008).

As in other studies such as NTORS, clients were assessed as they entered treatment programmes and followed them through, but while NTORS and other studies such as DARP and TOPS had opiate use as the dominant drug, DATOS included cocaine and particularly crack cocaine, with the majority of DATOS individuals using cocaine weekly, while one-third were using heroin (Frane & Ashton, 2002).

Two papers were published on the costs and benefits of methadone treatment in DATOS, with part 1 focusing on crime cost savings for discharged patients (left DATOS before 1 year of completed treatment) and continuing patients (Flynn et al., 2002a).

4.3.2 Study details

The intake sample (N=10,010) consisted of those who entered the 96 treatment programmes participating in DATOS during 1991-93. While 4,229 of eligible clients were selected for follow-up using a stratified random design, 70% of these were successfully interviewed at 5 years follow-up (n=2,966) (DATOS, 2008; Hubbard et al., 2003; Murphy, 2008).

Flynn et al. (2003) was a longitudinal study carried out in 2003, 5 years after intake on the DATOS, with a sub-group of opiate and cocaine users (n=432).

4.3.3 Methods

DATOS investigators looked at treatment processes, retentions, and outcomes in four domains significant for drug abuse treatment: 1) HIV risk behaviour; 2) Cocaine use; 3) Psychiatric comorbidity; and 4) Criminal justice status/activity. Four modalities were studied: outpatient methadone maintenance (OMM); long-term residential (LTR); outpatient drug free (ODF); and short-term inpatient (STI) (Hubbard et al., 2003).

There were two study intervention categories in this study: 1) Recovery, and 2) Non-recovery. In addition, there were two main outcome categories: 1) Recovered and 2) Non-recovered (Flynn et al., 2003).

4.3.4 Findings

The main outcome impact of DATOS is that cocaine and crack addiction is treatable, retention is closely related to outcomes, and support after treatment sustains recovery (Frane & Ashton, 2002).

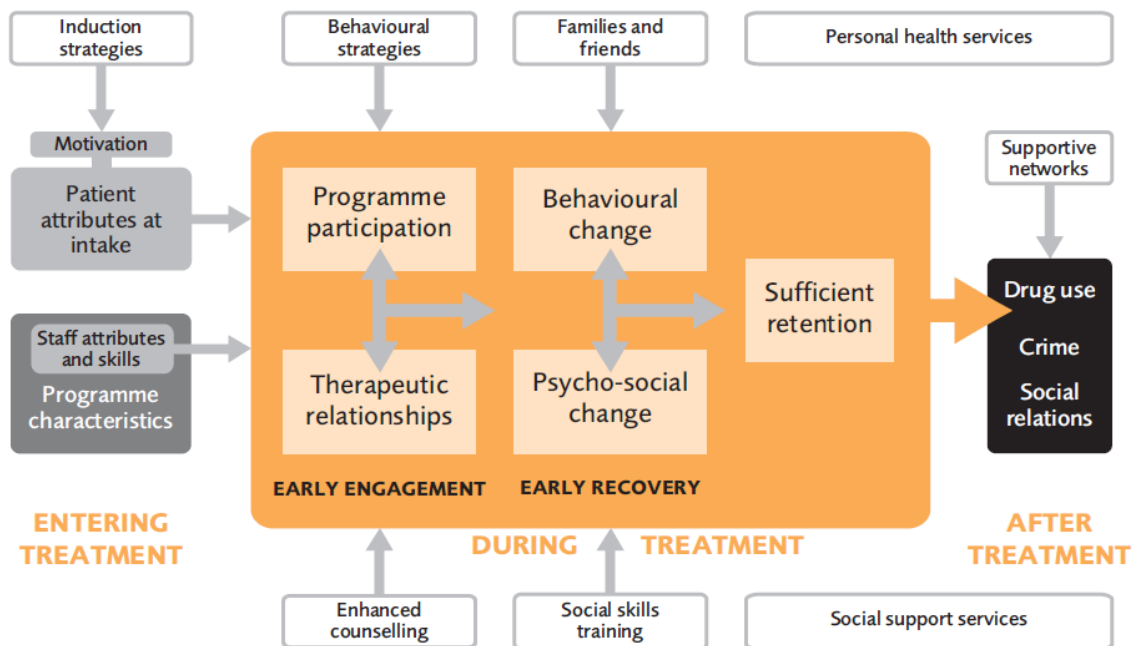
Findings were that a higher proportion of patients in the 'non-recovered group' had alcohol addiction and criminal behaviours prior to treatment but there were no other significant differences between groups. The 'recovery group' spent a longer time in treatment and this was considered important. Over one-quarter of those in recovery attributed personal motivation, a treatment programme, religion/spirituality, social networks, and their job/career as significant factors in their recovery process (Flynn et al., 2003).

4.3.5 Conclusion

- All treatments delivered with reasonable standard of quality are effective.
- The longer time spent in a treatment programme, the longer time in recovery.

- Social networks that support drug-free functioning are important for recovery.
- Crack addiction is treatable and saves money.
- Measures of engagement and progress provide early warning of potential drop out and promote intervention.
- Treatment quality is particularly important for clients with previous history of treatment.
- Client motivation heightens retention and improves outcomes.
- Lack of client motivation can be ameliorated with improved communication to recognise and reward engagement.
- Self-help strategies started in treatment and encouraged post-treatment prevent relapse.
- Counselling did not improve outcomes in residential settings.
- Increasing injection and sexual risk behaviours groups are of the highest public health concern with different treatment approach needed
- HIV prevention interventions should be developed and incorporated into drug treatment programmes.

Figure 2: Texas Christian University model for treatment process and outcomes: (Simpson, 2001)



4.4 DORIS (Drug Outcomes Research in Scotland)

4.4.1 Study description

The Drug Outcomes Research in Scotland (DORIS) study is an ongoing, longitudinal interview study considered the largest ever cohort study of drug users in Scotland (Bloor et al., 2008). Over 80 publications have resulted from the study.

4.4.2 Study details

DORIS has an ongoing cohort of illicit drug users (heroin, cocaine, amphetamine, methadone maintenance) (N=1,033) recruited at commencement of a new treatment episode across 33 drug treatment agencies, including community and prison-based centres, in 2001 to 2002 (Bloor et al., 2008). At 16 months, there was 78.6% retention of participants (Bloor et al., 2008) and 70% at 33 months (McKeganey et al., 2008), indicating little loss to follow-up.

4.4.3 Methods

Clients were followed up using an interview at 8 months and 16 months post intake with questions on drug use, treatment experience, along with health, relationship, and criminality outcomes (Bloor et al., 2008).

Dependence was measured at baseline and in subsequent interviews using the Severity of Dependence Scale with a score of seven or above and The Treatment Perception Questionnaire was used to measure satisfaction with treatment with a score of twenty or above (Bloor et al., 2008).

McKeganey et al. (2008) studied two categories of treatment services 1. Community based and 2. Prison based treatment at intake, 8 months, 16 months, and 33 months.

4.4.4 Findings

Findings were that Severity of Dependence Scores (SDS) fell significantly over time but the SDS score at baseline was found not to be predictive of drug or non-drug outcomes at 16 months (Bloor et al., 2008). The authors note that dependence is used as a core issue in treatment services but as severity of dependence does not predict future drug use, this needs to be reconsidered for future services planning and delivery (Bloor et al., 2008).

McKeganey et al. (2008) found that most positive changes occur 8 months after treatment with residential rehabilitation most effective for abstinence outcomes with good mental health scores at baseline associated with later abstinence. Methadone maintenance clients are not more likely to be abstinent at 33 months than other groups, except for cannabis use, but are less likely to use heroin than other groups (McKeganey et al., 2008).

According to McKeganey et al. (2008), the DORIS findings have made an impact in four main areas:

1. Contributed to drug policy development and discussion
2. Within prison service treatment has since expanded and more integrated with community services.
3. Findings enabled estimate of children with drug addicted parents to inform policy.
4. Increased understanding of drug-related deaths.

Other significant findings were in relation to assault committed by female drug users. Only one-fifth of individuals who had recently driven while under the influence of drugs were caught. In addition, they were only caught an average of once, although they frequently drove while taking drugs (McKeganey et al., 2008).

Participants who had experienced treatment prior to DORIS and those who had previously used self-help groups or been in contact with social services or a GP within 6 months prior to intake interview were significantly more likely to participate in an aftercare service (Vanderplasschen, 2010). The type of treatment modality was also a factor with those in residential rehabilitation far more likely to access aftercare than those who had received prison-based treatment, methadone maintenance or other

community-based treatment. Individuals who had a personal treatment goal of abstinence rather than harm-reduction were also much more likely to participate in aftercare after baseline treatment (Vanderplasschen, 2010).

Conclusion

- Severity of dependence does not predict future drug use.
- Methadone maintenance is the most effective treatment for reducing the frequency of heroin use.
- Methadone maintenance not effective in promoting abstinence.
- Residential rehabilitation appears to be the most effective in promoting abstinence.
- Marked differences in outcomes between community-based and prison-based drug treatment
- Negative staff attitudes in the prison services hampering treatment outcomes; staff training needed
- Policy should not concentrate solely on assault perpetrated by male drug users as female drug users also commit assault.
- Drug driving detection needs to be improved.

4.5 DTORS (Drug Treatment Outcomes Research Study)

4.5.1 Study description

The Drug Treatment Outcomes Research Study (DTORS) was a national multi-site, longitudinal study conducted between 2006 to 2007. DTORS was a major national evaluation of the effectiveness of drug treatment in England following up on the NTORS study which focused on the effectiveness of treating problem drug users between 1995 and 2000 (Barnard, Webster, O'Connor, Jones, & Donmall, 2009; Davies, Jones, Vamvakas, Dubourg, & Donmall, 2009; Donmall, Jones, Davies, & Barnard, 2009; Donmall et al., 2012; Jones et al., 2009; Jones et al., 2007). In the decade since NTORS, there were two major changes: a significant policy shift towards diverting offenders who were misusing drugs from prison and increasing levels of crack cocaine use which have implications for drug treatment.

The DTORS study focuses on Tier 3* and Tier 4* of the four-tier drug treatment and rehabilitation services in England: Tier 1 and Tier 2 provide advice, information, drug screening, and referral services. Tier 3 provides structured community-based services*. Tier 4 provides residential services*.

4.5.2 Study details

DTORS was conducted between February 2006 to March 2007 and followed the treatment progress of drug treatment seekers (N=1,796) over a 12-month period. Participants were predominantly male (73%), aged 25/34 years (47%), had committed offences in previous 12 months (72%), with the two main problem drugs being heroin (57%) and crack cocaine (12%) compared to NTORS where the most common problem drug misuse was heroin (Gossop 2015).

The study sample was originally calculated at N=2,600 with a 30% loss to 12-month follow-up estimated. However, the power of the sample was revised due to actual baseline sample of N=1,796 with a 40% loss to first follow-up assumed. Ninety-four out of 100 eligible DATS participated with all agencies providing community-based or residential treatment represented (N=342). There was a 3-stage sampling strategy aimed to provide nationally representative sample of clients, agencies and DATs which was supported by data from the NDTMS (National Drug Treatment Monitoring System).

The baseline sample included all those over 18 years who requested treatment for drug use problems during a nine-week sampling period, whether they received it or not. This contrasted with NTORS, which used stability of location as the main source of evidence and contact.

The study authors point out that relatively few clients present to drug treatment centres with stimulants as the main problem (Gossop, Marsden, & Stewart, 2000).

The DTORS clients reporting a stimulant (amphetamines, powder cocaine, and crack cocaine) represented one small subsample within the DTORS study (n=80; 13%).

4.5.3 Methods

The DTORS study was designed with three aspects to it:

- Longitudinal survey of outcomes for individual treatment seekers (N=1,796)
- Qualitative assessment of factors impacting on effective treatment (treatment seekers/service providers)
- An economic analysis

The impact of drug treatment on the following factors were assessed by DTORS:

- a) Drug and alcohol use levels
- b) Offending/criminal behaviour
- c) physical and mental health, using a 12-question health-outcomes tool designed to summarise self-report mental and physical well-being, and
- d) social outcomes, including employment, accommodation and parenting.

A number of circumstances in the treatment seekers' environment were noted as having the potential to act as a 'trigger' to relapse. Improvements in social functioning, therefore, are not only successful treatment outcomes in themselves, but they are considered to aid overall treatment outcomes. A number of improvements to treatment seekers' social context were observed at the survey's first and second follow-ups.

4.5.4 Findings

The DTORS study, which followed up on the changes in treatment and patient cohorts since implementation of the NTORS findings, acknowledged improvements in the effectiveness of treatment services in England.

The cost-benefit analysis concluded that treatments were effective in improving health outcomes and reducing costs of additional health and social care services. The net benefits of structured drug treatments were estimated to be positive overall and for around 80% in individual cases with a benefit-cost ratio of 2.5:1.

Some limitations were the loss to follow-up and the absence of a control group plus the cost of ancillary services prior to treatment and costs of referral were not included (Davies et al., 2009).

4.5.5 Conclusion

- Drug treatment is effective in reducing the harmful behaviours associated with problem drug use.
- Regardless of treatment provision and delivery, personal motivation is crucial to successful treatment.

- Treatment must be sufficiently flexible to meet the differing needs of treatment seekers.
- The criminal justice system (CJS) is an equally valid route into drug treatment.
- Drug treatment is cost-beneficial.

4.6 Life In Recovery (LiR)

4.6.1 Study description

The international Life In Recovery (LiR) study (Best et al., 2015; Best et al., 2014; Best & Savic, 2015; Best, Vanderplasschen, & Nisic, 2020; Best et al., 2018; Graham, Irving, Cano, & Edwards, 2018; McQuaid et al., 2017) began after the publication of findings from an online survey of people in recovery run by a US advocacy organisation Faces and Voices of Recovery (FAVOR). The survey was developed first as the Australian Life In Recovery (ALIR) survey (Best & Savic, 2015). With some minor amendments to the questionnaire format and method, the UK Life in Recovery (LiR) survey which facilitated comparisons across three European countries – UK, Netherlands, and Belgium (Best et al., 2015).

The study authors have sought to provide data on recovery from a European perspective as most recovery research has been carried out in the USA and Australia to date (Best et al., 2018). LiR has also been used in other countries such as South Africa and Canada (McQuaid et al., 2017).

Building on the LiR study and the SONAR study in Australia, the Recovery Pathways (REC-PATH) study uses a prospective design to map the different approaches to supporting recovery in four countries (Scotland, England, The Netherlands, and Belgium) that includes five means of behaviour change (Best et al., 2018):

1. 12-step programmes (AA, NA, CA, GA)
2. Peer-based recovery support (SMART)
3. Residential and community treatment
4. Outpatient treatment (maintenance/abstinence oriented)
5. “Natural recovery”

In the LiR study, recovery is viewed as temporal, with three stages: 1) Early recovery (year 1); 2) Sustained recovery (1–5 years); 3) Stable recovery (5 years+) (Betty Ford Institute Consensus Panel, cited in McLennan *et al.* 2009) with risk of relapse after 5 years continuous abstinence considerably reduced (Graham et al., 2018).

4.6.2 Study details

The UK survey, which retained much of the previous US and Australian questions, was conducted between March and June 2015 with 802 surveys completed. The online survey was distributed to a wide range of groups and communities across the UK and also used social media sites. The survey was in English, with the majority of respondents born in the UK (94.1%) and predominantly white.

4.6.3 Methods

The LiR survey addresses four key life domains that may be significantly impacted through active addiction:

1. Family and relationships
2. Finances
3. Psychological and physical health

4. Employment, education, and training

There were four categories of recovery compared:

1. In recovery (n=510)
2. Used to have a problem but not anymore (n=69)
3. Recovered (n=56)
4. Medication-assisted recovery (n=24)

The original US LiR measure had 44 items, with two removed for the Australian and UK versions as they were not relevant. The LiR has subsequently been adapted for use in several European countries and languages with just minor amendments (Best et al., 2020) and is available on the REC-PATH project platform: <https://www.rec-path.co.uk/>.

One study converted the LiR measure into a new scale called the Strengths and Barriers Recovery Scale (SABRS), thus reducing the number of items to 32 (Best et al., 2020) using a sample of participants from a European study (n=480) (Best et al., 2020).

The REC-PATH study (n=250) used a prospective cohort design employing both quantitative and qualitative methods (Best et al., 2018).

Another study in Canada in 2016 also adapted the LiR survey to reflect Canadian society, with further questions added which the authors claim was the first-time barriers to both initiating and sustaining recovery was examined (McQuaid et al., 2017). The survey was conducted using both English and French.

Alcohol was the most common substance used (93.3%) when actively in addiction with alcohol also the drug of choice by 50.5% of participants. Respondents also defined 'recovery' as including abstinence, health improvements, social connections, functioning and enhanced life quality (McQuaid et al., 2017). A key finding in this study is that participants used about six out of 17 available recovery programmes in addition to informal supports during their recovery period as well as online support websites and apps (McQuaid et al., 2017).

The Strengths and Barriers Recovery Scale (SABRS), based on LiR, found the following (Best et al., 2020): 1) Stepwise incremental changes in recovery strengths at different recovery stages; 2) Limited reductions in barriers to recovery, and 3) Association between greater strength in active addiction and greater recovery.

Participants in medication-assisted recovery groups reported significantly higher levels of unemployment, victimisation, and domestic violence commission along with poor quality of life and psychological health compared to other groups.

Again, there were gender differences with men reporting significantly more strengths in recovery during active addiction with women reporting significantly more strengths in recovery later. There were little differences relating to barriers in addiction and recovery between genders. Female participants scored lower on psychological health measures than males with females significantly more likely to be accessing support for mental health issues (46.5% females, 29.8% males).

4.6.4 Findings

Positive impacts from recovery, and sustained recovery, were found in the following areas:

1. Family life became more stable with reductions in children taken into care and domestic violence rates reducing from 39% for those in active addiction to less than 7% for those in recovery.
2. Health and well-being of individuals increased, with less engagement with chronic or acute healthcare services.
3. Employment and finances for individuals improved sharply, with three-quarters in regular employment.
4. Criminal engagement was considerably reduced.
5. Societal engagement was improved, with almost three-quarters engaged in volunteering activities.
6. Gender differences are clear, with women more reluctant to seek treatment but once committed to recovery, women report more strength.

4.6.5 Conclusion

- Recovery is both achievable and sustainable.
 - Recovery benefits individuals, families, communities and society.
 - Dissemination/advancement of knowledge of recovery will lessen stigma and discrimination.
 - Positive outcomes of recovery and continuance in the UK LiR mirrored the USA and Australia.
 - The SABRS survey (an iteration of LiR) increases power and ability to examine cultural variations in pathways to recovery.
 - More in-depth analyses of country variations needed
 - Exploration and testing of gender differences/patterns in recovery and addiction required
 - Women have a shorter but more intense period of difficulties with addiction.
 - Women have higher rates of recovery and retention – not necessarily treatment related.
 - Women are reluctant to seek treatment initially, for fear of losing their children.
- Sources: (Best et al., 2015; Best et al., 2014; Best & Savic, 2015; Best et al., 2020; Best et al., 2018; Graham et al., 2018; McQuaid et al., 2017)

The main limitations of these series of surveys relate to them being a self-selected sample which is often not reflective of the wider population exiting treatment or rehabilitation. The outcomes are self-reported, with recovery defined as what the respondent chooses it to mean, including 'used to have a problem but no longer do'. The impact of some of the more innovative approaches used in these series of surveys is unclear, such as moving to web-based questionnaires.

4.7 NDTMS (National Drug Treatment Monitoring System) data

4.7.1 Study description

The National Drug Treatment Monitoring System (NDTMS) is an established monitoring system which has been in operation since the 1980s and has been the information standard in the UK since 2007. Public Health England (PHE) are providers of drug and alcohol treatments and submits data monthly to the NDTMS at an individual level that is patient identifiable in order to monitor effectiveness of services; help improve outcomes for service users; plan and develop services to best meet local needs (NDTMS, 2019).

The NDTMS is ongoing and regularly amended and updated, for example, to improve data collection on specific target groups such as young people (NDTMS, 2020). Originally, the NDTMS used treatment waiting times, numbers of clients receiving structured interventions, and retention rates as indicators of effectiveness, however, in 2007 the Treatment Outcomes Profile (TOP) was used to assess effectiveness review clients' progress towards attaining personal treatment goals directly. Data for the past 28 days is recorded at the start of treatment, at subsequent reviews during treatment, and at discharge on the following: number of days of use of opioids, cocaine, amphetamines, cannabis, and alcohol; injection-related health-risk behaviour; client's subjective ratings of physical health, psychological health, and quality of life; client's reports of criminal behaviours.

Researchers have used the database to study specific areas such as dropout rates, discharged drug free (DDF) rates, re-presentation rates and retention (Beynon, Bellis, & McVeigh, 2006; Beynon, McMinn, & Marr, 2008); impact of pharmacological and psychosocial treatments on retention (Marsden et al., 2009); effectiveness of treatment for opioid use disorder (OUD) (Eastwood, Strang, & Marsden, 2017); effectiveness of treatment for opioid use disorder (OUD) (Eastwood et al., 2017).

4.7.2 Study details

Dropout and DDF rates were identified between the years 1998 to 2001/02 and re-presentations of drug users in the years 2005/5 (N=26, 415) (Beynon et al., 2006).

The NDTMS was used to identify duration of treatment for those commencing treatment between April 2005 and March 2006 (N=16,626) (Beynon et al., 2008).

The study by Marsden et al. (2009) claims to be the first to assess effectiveness of pharmacological and psychosocial treatments with heroin and crack cocaine users in the UK and was conducted over an 11-month period in 2008 (N=26415).

This study sought to assess the successful completion and non-re-presentation within 6 months post-discharge (SCNR) in the period 2008/09 (N=54,347) (Eastwood et al., 2017).

4.7.3 Methods

Study outcome measure standard when using the NMDTS is defined as the proportion of the cohort that successfully completed treatment within 12 months of commencement with no re-presentation within 6 months (SCNR) (Eastwood et al., 2018; Eastwood et al., 2017).

The National Treatment Agency for Substance Misuse (NTA) considers retention to be the best available measure of drug treatment effectiveness and set an annual target of retaining 75% of clients for 12 weeks or more (Beynon et al., 2008).

The NDTMS dataset was used to identify drug users who had 1. Dropped out, discharged drug free (DDF), and those who had re-presented. Those who were referred from the Criminal Justice system (CJ) were compared to those referred from other sources (Beynon et al., 2006).

Eligible participants (N=26,415) included users receiving pharmacological treatment (n=18,428) and psychosocial treatment (n=2,647) and were using heroin alone, crack cocaine alone, or both (Marsden et al., 2009).

All adults (54,347) who had initiated treatment and were identified by drug use and poly drug use (heroin; heroin/crack/alcohol; heroin/crack; heroin, crack, cannabis) along with age, employment status, and length of treatment as comparators (Eastwood et al., 2017).

4.7.4 Findings

Dropout rates are significantly higher for those coerced into treatment through the CJ system; increasing numbers in treatment were associated with greater dropout rate and reduced rate of those in DDF although those who dropped out but re-presented and re-engaged were doing so more quickly (Beynon et al., 2006).

The dropout rate was higher among Asian drug users, drug users from lower socio-economic areas, and younger clients from aged 18 to 34 in affluent areas. Dropout was less likely for alcohol use and older clients (Beynon et al., 2008).

The first 6 months after treatment are associated with reduced use of both heroin and crack cocaine; pharmacological treatment reduced use of both heroin and crack cocaine; and 3. Reduction for heroin users smaller than for users of both heroin and crack (Marsden et al., 2009).

Twenty-five per cent of participants successfully completed OUD treatment and did not re-present for treatment within 6 months, with the more time spent in treatment increasing the likelihood of successful outcomes, whereas OUD treatment should not be time limited (Eastwood et al., 2017). Black and minority ethnicities (BME) were more likely to recover in unadjusted models, however, when controlling for employment and stable housing, this difference was not evident (Eastwood et al., 2017). 59% of patients with alcohol use disorder successfully completed treatment within 12 months and did not re-present within 6 months.

4.7.5 Conclusion

- Coercion into treatment programmes by the Criminal Justice System does not work (Beynon et al., 2006).
- NDTMS needs to be constructed similarly to ATOS to facilitate a comparison/control group and make cross-country comparisons ((Marsden et al., 2009).
- As relapse is common in the 6 months post-treatment completion, 're-presentation' needs to be assessed in any measure of effectiveness (Eastwood et al., 2017).
- Further studies required on inter-relationship between substance use, employment, and housing (Eastwood et al., 2017).
- Alcohol Use Disorder is a chronic condition requiring continued support over time to delay relapse
- Duration of treatment may be critical for positive outcomes – in line with other literature (Eastwood et al., 2018).

4.8 NTORS (National Treatment Outcome Research Study)

4.8.1 Study description

The National Treatment Outcome Research Study (NTORS): the first large-scale, multi-site, prospective follow-up cohort study of drug misusers in the UK from 1995 to 2000 across 54 agencies (Gossop, 2015; Gossop, Browne, Stewart, & Marsden, 2003; Gossop, Marsden, & Stewart, 2000; Gossop, Marsden, Stewart, & Kidd, 2002, 2003; Gossop, Marsden, Stewart, & Rolfe, 2000).

4.8.2 Study details

NTORS was conducted between 1995 and 2000 (N=1,075), observing patient behaviour and substance misuse patterns with follow-ups at the 1 year, 2 years, and the 4–5-year stages.

Study participants were drug users admitted to four main treatment modalities:

- Methadone maintenance programmes
- Methadone reduction programmes
- Inpatient rehabilitation services
- Residential rehabilitation services

The study focused on regular treatment and conditions under which they operated (Gossop, 2015; Gossop, Browne, et al., 2003; Gossop, Marsden, & Stewart, 2000; Gossop et al., 2002; Gossop, Marsden, et al., 2003; Gossop, Marsden, Stewart, et al., 2000).

The main problem drug use in NTORS was heroin dependence compared to heroin and crack cocaine in a follow-on DTORS study a decade later.

4.8.3 Methods

The main methodology and procedures for NTORS is described in Gossop, Marsden and Stewart (1998). Data were collected using a structured interview, the Maudsley Addiction Profile (MAP) which was a set of structured research questions that focused on:

1. Substance drug use outcomes
2. Health risk behaviours
3. Treatment motivation
4. Physical and psychological health problems
5. Criminal behaviour
6. Treatment history

Almost all clients presenting with problematic use of multiple drugs, with opiate dependence being the most frequent.

There were four intervention categories used in relation to drug use:

1. Sharing
2. Injecting/not sharing
3. Using/not injecting
4. Abstinent

In relation to stimulant use specifically, three groups were assessed

1. Main problem drug
2. High frequency use
3. Low frequency use

These structured interviews were used to assess the above, including the self-reported use of drugs, alcohol, and were backed up with urine screening.

4.8.4 Findings

Findings provided data on the impact of the UK national treatment response to drug abuse issues which resulted in strengthening of drug treatments services and improving intervention results. The NTORS study was commissioned by a Department of Health UK Task Force.

One significant finding was that while one-third used crack at intake and at 4–5 years, the user profiles for both groups had changed. For those using crack at intake, use had more than halved. However, one-quarter of the non-crack users at intake were using by 4–5 years, with two-thirds being new to the drug (Gossop et al., 2002).

Injecting and sharing of equipment were substantially reduced among 732 drug misusers in both residential and community programmes at 1-year follow-up. Residential programmes clients were more likely to be abstinent at follow-up with users who were injecting at intake, but stopped at 1 year, achieving consistently good outcomes across a range of behaviours.

A very significant finding was that drug misusers with stimulant problems do approach existing treatment services in the UK and benefit from them without specialist treatment programmes in contrast to previous assertions in the literature. This study found that substantial improvements in substance use problems, injecting and sharing behaviours, psychological and physical health, and criminal behaviour were comparable with similar findings from another large study in the USA (Simpson, Joe, Fletcher, Hubbard, & Anglin, 1999) (Gossop, Marsden, & Stewart, 2000).

A significant finding in relation to alcohol is that while some improvements were found among a sample of drug-misusing clients (n=753), the majority of clients made little change to pre-treatment behaviours with heaving drinkers continuing to do so (Gossop, Marsden, Stewart, et al., 2000). In a sample of participants (n=418) who completed follow-up interviews at 1, 2, and 4–5 years, one-quarter of this sample were identified as heavy drinkers at intake with this cohort maintaining their drinking levels and more likely to be using non-opioid drugs at follow-up when compared with other groups (Gossop, Browne, et al., 2003).

The authors suggest that existing treatment services primarily geared towards opiate dependence and specialist drug treatment agencies need to offer treatment to drug misusers with stimulants. The point is made that nearly all drug users are ‘multiple’ drug users and cannot be easily identified as either heroin users or stimulant users (Gossop, Marsden, & Stewart, 2000).

The development and strengthening of assessment and treatment of drinking problems needs to be addressed by drug treatment services (Gossop, Marsden, Stewart, et al., 2000) while the commencement of crack cocaine use among non-users at intake suggests that improved treatment interventions need be developed (Gossop et al., 2002). The results show that there were very positive changes in injecting behaviour after treatment with authors suggesting that dependent drug users can achieve abstinence during treatment while changes in injecting behaviour can help clients who are resistant to abstinence to achieve this goal in the longer term (Gossop, Marsden, et al., 2003).

4.8.5 Conclusion

Existing treatment services (primarily geared towards opiate dependence) and specialist drug treatment agencies need to offer treatment to drug misusers with stimulants (Gossop, Marsden, & Stewart, 2000).

Nearly all drug users are ‘multiple’ drug users and cannot be easily identified as either heroin users or stimulant users.

Development and strengthening of assessment and treatment of drinking problems needs to be addressed by drug treatment services.

Commencement of crack cocaine use among non-users at intake suggests that improved treatment interventions need be developed.

There were very positive changes in injecting behaviour after treatment

Dependent drug users can achieve abstinence during treatment.

Changes in injecting behaviour can help clients who are resistant to abstinence to achieve this goal in the longer term.

4.9 SURE (Substance Use Recovery Evaluator)

4.9.1 Study description

Patient-reported outcome measures (PROMs) assess health status and related quality of life from the service user perspective (Neale et al., 2015, Neale et al 2016). The SURE (Substance Use Recovery Evaluator) study aimed to develop a PROM that could be validated, had good face/content validity, acceptability, and usability for people in recovery (Neale et al., 2016).

4.9.2 Study details

Patients/service users in recovery from drug and alcohol dependence (N=575) participated: 461 in person and 114 online.

4.9.3 Methods

A 30-item beta version was completed by 574 service users. Analyses included rating scale evaluation, psychometric properties assessment, factor analysis, and differential item functioning.

4.9.4 Findings

The beta measure had good face and content validity. The final measure was reduced from 30 items to 21, with factor analyses finding 5 factors:

1. Substance use
2. Material resources
3. Outlook on life
4. Self-care
5. Relationships

The tool can be used in private or in a therapeutic setting. SURE is completed by the service user and not by the clinician or other service provider staff.

The authors claim that a) it is the first tool that was developed with significant input from service users and b) that it specifically focuses on 'recovery'.

4.9.5 Conclusion

- The Substance Use Recovery Evaluator (SURE) is a psychometrically valid, validated, quick, and simple outcome measure developed with input from people in recovery
- SURE can be used along with existing outcome tools or on its own
- SURE measures recovery from drugs and alcohol and completed by the person in recovery in a private or therapeutic context
- Source: (King's College London, 2016; Neale et al., 2016).

4.10 VEDETTE

4.10.1 Study description

VEdeTTE1 was a national, longitudinal study conducted from 1998 to 2001 to evaluate the effectiveness of drug treatment services provided by the National Health Services in Italy (Bargagli et al., 2006; Davoli et al., 2007; Faggiano et al., 2021; Salamina et al., 2010).

4.10.2 Study details

A convenience sample of 115 treatment centres across 13 regional health offices were selected as representative of the service. There were 10,454 heroin users with about one-half of these who started a treatment during the study included in analysis (N=5,457).² Patients who had ongoing therapies at the beginning of the study were excluded (N=4,816). Fourteen per cent of participants were female. The study period lasted 18 months from September, 1998 to March, 2001 (Salamina et al., 2010). This was followed up by VEdeTTE2 in 2001, using a sample (N=2,200) of the same cohort contacted 2 years after enrolment, to evaluate effectiveness of treatments relating to long-term outcomes: rehabilitation and social integration.

4.10.3 Methods

There were three categories of patients:

1. Methadone maintenance therapy (MMT) 43.2%
2. Abstinence-oriented therapy (AOT) 46.3%
3. Community therapy 10.5%

Structured interviews were held with each participant on enrolment which included recording of clinical history and demographic information. At each presentation for treatment, a standard form was completed by staff, listing type of treatment, mean dose (methadone treatment), start date and finishing date of treatment. The following treatments were included: methadone maintenance; detoxification with tapering doses of methadone; detoxification with non-opiate drugs (in- and outpatient based); maintenance with naltrexone; therapy with psychotropic drugs; psychotherapy; counselling; job guidance; social advice; and residential and semi residential treatment (Bargagli et al., 2006; Salamina et al., 2010).

4.10.4 Findings

Type of therapy was a strong predictor of retention with AOT having lowest retention rates with psychotherapy halving the risk of dropping out.

OAT had a strong, protective effective on overdose mortality with drug treatment overall reducing overdose mortality risk by 80%. Substantially elevated risk of overdose in the first month of leaving treatment (Faggiano et al., 2021).

The use of heroin decreased according to the length of treatment, with the authors drawing direct comparison with NTORS cohort at 6-month follow-up (Bargagli et al., 2006).

While the number of females in this study were much lower at 14% than males, their drug use was considered to have a more severe impact on their daily lives with higher frequency of risk behaviours; psychiatric problems; higher mortality and prevalence of HIV and hepatitis. Additionally, women with

² Note: analysis was limited to the first therapy the participant started during the 18 months period

heroin addiction are more likely to live on their own or with a partner who is also uses heroin; and take care of children with or without a partner.

4.10.5 Conclusion

- Opioid agonist treatment (OAT) has stronger protective effects on overdose mortality risk than previous studies in Western Europe have found.

4.11 SMART Recovery: A Systematic Review

4.11.1 Study description

In contrast to the studies listed above, this section describes a systematic review of SMART (Self-Management and Recovery Training), which is a mutual aid programme that provides training and tools for people who want to change their problematic behaviour, including addiction to drugs, alcohol, cigarettes, gambling, food, shopping, Internet and others (<https://smartrecovery.org.uk/smart-recovery-programme/>). The review explored outcomes, process variables and feasibility.

4.11.2 Study details

This study was a systematic review of published and grey literature, with searches run in 2015 and 2016. 989 publications were initially identified, resulting in 12 included studies, Beck et al, 2021; Gray et al. 2020, Kelly et al, 2020, Kelly et al, 2021.

4.11.3 Methods

This review searched six electronic, peer-reviewed databases and four grey literature databases for English language SMART Recovery literature. Searches were performed in May-June 2015 and again in April 2016. Articles were identified and classified following three steps: identification and screening (989 studies identified); eligibility and classification (118 full-text publications manually reviewed); cross-checking (118 cross-checked, 12 agreed for inclusion). Twelve studies were identified for inclusion in the review, eight published in peer-reviewed journals and four unpublished dissertations.

Outcomes assessed included: addiction severity and consequences; process variables; feasibility. Effects of interventions were also assessed, although measures varied. Measures used included: mental health symptoms, percentage of days abstinent, standard drinks per drinking day, alcohol related problems, ASI (Addiction Severity Index), financial well-being and life satisfaction.

4.11.4 Findings about intervention impact and outcomes

SMART Recovery outcomes primarily focused on alcohol, and standardised assessment of other substance use was infrequent. Functional outcomes were rarely reported, and reporting of mental health status was poor. Treatment outcomes, such as they are reported, appear positive, but little is understood about the variables which may influence outcomes. Qualitative studies identified the mutual support aspect and lack of spirituality as important factors in favourable experiences of SMART Recovery.

4.11.5 Conclusion

More research on this area is needed, especially that which utilises standardised assessment tools and measures. Key areas for this are: mental health status; concurrent treatment and / or pharmacotherapy; quality of life; behavioural addictions; economic outcomes. More exploration of the active content of SMART Recovery and comparisons between other forms of mutual aid would also be beneficial.

4.12 SMART Track App

4.12.1 Study description

This study explored the feasibility, acceptability and preliminary outcomes of an mHealth ROM and feedback app (SMART Track) in SMART Recovery mutual aid groups. It was delivered in Australia.

4.12.2 Study details

The SMART Track app was developed in phase one of this study, and in phase two, 72 participants of SMART Recovery Australia were recruited to a nonrandomised, prospective, single arm trial of the app, Beck et al, 2021; Gray et al. 2020, Kelly et al, 2020, Kelly et al, 2021.

4.12.3 Methods

Four modes of data collection were used: ROM (routine outcomes monitoring) data directly entered by participants into the app; app data analytics (including number of visits, number of unique user visits, visit duration, time of visit, user retention); baseline, 2- and 8-week follow-up assessments (via telephone); and qualitative telephone interviews.

Tools used to measure outcomes included the Severity of Dependence Scale, Kessler Distress Scale and the Substance Use Recovery Evaluator (SURE).

4.12.4 Findings about intervention impact and outcomes

Significant reductions were reported over the duration of the study on the Severity of Dependence Scale and the Kessler Distress Scale, but no change was reported in the SURE. Qualitative data supported the acceptability of the app and the need for improved integration into the SMART Recovery groups.

4.12.5 Conclusion

The findings from this study support the feasibility, acceptability and utility of the SMART Track app for ROM and feedback, and also provide insight into ways to improve engagement. High attrition and low engagement rates are known challenges for working with this population, and sustained engagement with health apps is difficult to achieve, so this work is promising, suggesting that apps may offer a practical solution to outcome monitoring in people attending mutual aid groups.

4.13 Summary

In this section we summarise the findings from the international research examining drug treatment and/or rehabilitation. Many of the studies listed are traditional research studies, typically a university-based research team using interviews or questionnaires to track individual patients/clients through treatment and beyond examining and reporting on different treatment outcomes. One of the 'studies' used existing monitoring data to examine outcomes, indeed there have been other initiatives that linked different datasets on drug treatment and criminal justice contacts to examine particular outcomes (including mortality) that did not get identified by the literature screening (Pierce et al, 2015). The study, described as LiR, is more of a wider initiative developing quantitative methods for describing, monitoring and/or evaluating recovery. One study (SURE), and two others identified separately, were also more generically monitoring recovery particularly using PROMs, something which has the scope to either replace or enhance previous approaches as considering outcomes monitoring as a research process. Indeed, there does seem to be a move away from the large-scale research studies of the past and that could perhaps be considered as a move away from answering the question 'does treatment or rehabilitation work' on to questions about specific aspects of recovery or other treatment outcomes.

5 Key Irish studies

5.1 Introduction

In this section, we describe the key Irish studies that have been carried out. It should be noted that these were often identified from the grey literature rather than appearing in the results of the scoping review.

5.2 ROSIE (Research Outcome Study in Ireland Evaluating Drug Treatment Effectiveness)

5.2.1 Study description

The Rosie study (Research Outcome Study in Ireland Evaluating Drug Treatment Effectiveness) was the first, national, longitudinal treatment outcome study in Ireland for opiate use (Comiskey & Stapleton, 2010a; Comiskey & Cox, 2010; Comiskey & Stapleton, 2010b; Comiskey, Stapleton, & Kelly, 2012): a prospective cohort study comparing the effectiveness of different treatment modalities across a range of treatment settings. This observational study commenced in 2003 and followed participants at three timepoints:

1. Commencement of a new treatment episode (treatment intake)
2. Progress at Year 1
3. Post-treatment at Year 3 – to assess implications for future treatment policy

For ethical reasons, a randomised control trial (RCT) was not considered acceptable for this cohort, therefore, the study was designed to reflect treatment service provision, availability, and distribution nationally at the time of recruitment in 2003 with study completion in 2006 (Comiskey & Stapleton, 2010a). As all treatment modalities are not universally available across all health regions, those regions with opiate services were included to accurately reflect the service provision in Ireland (Comiskey & Stapleton, 2010b).

5.2.2 Study details

The study commenced in 2003 and was completed in 2006. Opiate users were recruited at intake (N=404) through three routes:

1. Methadone programmes
2. Abstinence-based treatments
3. Needle exchanges

While there was loss to follow-up at Year 1 (n=305), the follow-up interview rates are considered extremely high by international standards at 75%. Additionally, there was an increase in follow-up interviews at year 3 (n=357), representing a rate of 88.4% (C. Comiskey & Stapleton, 2010a).

5.2.3 Methods

There were three study outcome categories measured:

1. Abstinence
2. Treatment
3. Relapse

Further analysis was also carried out on a) treatment pathways; b) treatment setting impact; c) use of ancillary medical and social services; and d) effects of acquisitive crime committal rates in treatment.

5.2.4 Findings

Treatment pathway analysis identified three outcome groups at three years point: 1) not in treatment/not using illegal drugs; 2) in treatment/majority within methadone treatment; 3) not in treatment/using illegal drugs.

The ROSIE study concluded that treatment modality is not appropriate for longitudinal treatment outcome studies and long-term outcomes improved when clients returned to treatment regardless of treatment modality at intake and treatment relapse. Findings were that three years after intake 15% were drug free, 70% were in treatment, and 15% were not receiving treatment and using illegal drugs (Comiskey & Stapleton, 2010).

Analysis showed no statistical differences between these three outcome groups at intake. Those who were not in treatment and using illegal drugs at 3 years had also displayed little improvement at the 1-year time point while those who were drug free, not in treatment, and not using illegal drugs had shown improved physical and mental outcomes at the 1-year time point (Comiskey & Stapleton, 2010).

Methadone treatment, regardless of treatment setting, is effective in reducing a range of the drugs used. However, while drug outcomes for methadone treatment improved across all treatment settings, there was no improvement in health outcomes in any setting (Comiskey & Cox, 2010).

For those who had not committed an acquisitive crime at 1 year, those who used cocaine and benzodiazepines regularly were 6.5 times and 8 times, respectively, more likely to commit an acquisitive crime. For those who had committed an acquisitive crime at intake, heroin users at 1-year follow-up were nine times more like to have committed an acquisitive crime (Comiskey et al., 2012).

Access to ancillary services such as counselling, residential treatment, group work, or treatment episodes (prior to recruitment) during opiate drug user treatment were associated with improved outcomes in terms of abstinence, treatment, relapse, and using additional services (Comiskey & Stapleton, 2010).

5.2.5 Conclusion

- Treatment policy needs to focus on providing support and encouragement to individuals during the treatment relapse cycle.
- To achieve optimum health outcomes, opiate users need to be directed to treatment settings that best meet their needs.
- Service providers need to provide additional counselling and group work during all treatment modalities, particularly for those who lapse and relapse

5.3 Pathways through treatment: a mixed-methods longitudinal outcomes study of Coolmine Therapeutic Community

5.3.1 Study description

The Coolmine study used a longitudinal, mixed methods design, collecting both qualitative and quantitative data from the Coolmine Therapeutic Community (CTC) over a 24-month period (2011 to 2013) in order to evaluate drug treatment outcomes (Babineau and Harris, 2015)

5.3.2 Study details

Quantitative data were collected using the TOP (Treatment Outcome Profile) between February 2011 and February 2012, starting at intake to a primary treatment service and aiming for follow-up at 6-month intervals. A total of 144 clients took part in the baseline survey.

Qualitative data consisted of semi-structured interviews and was collected between March 2011 and June 2013. Interviews were carried out at four time points: treatment intake, 6 months, 12 months and 18 months, with 86 interviews completed with 28 clients.

5.3.3 Methods

The study aimed to gather baseline data on drug use, health and behavioural status of clients at point of entry to three CTC services (male residential (the Lodge), female residential (Ashleigh House) and the mixed-gender drug-free day programme (DFDP); to track their involvement with CTC and in the 18 months following; and to compare outcomes for clients of the different CTCs, as well as with outcomes from the ROSIE study.

Quantitative data collected used the TOP, which measures change and progress, focusing on substance use, injecting risk behaviour, crime, health and quality of life. The outcomes measured were physical and psychological health, quality of life, housing, education and employment, and criminal activity.

5.3.4 Findings

Programme retention rates for this study were high, with the majority of those who completed the final survey reporting no illicit drug use (72%). This was true for those who completed treatment (85%) but also those who discharged early (62%). Self-reported mental and physical health scores increased over the course of the study, peaking at the 6-month follow-up, but remaining higher on final evaluation than at baseline. This information was corroborated by findings from the qualitative interviews, although there were marked differences between men and women. Quality of life scores followed a similar trend, with women's scores being notably lower overall. Again, scores peaked at the 6-month follow-up, but remained higher at final evaluation than at baseline. Post-treatment improvements were reported by all participants, with qualitative data capturing the importance of hope and optimism, as well as the impacts of re-establishing relationships, establishing a routine and recovery-focused activity on improved fulfilment, joy and self-esteem.

Increases in employment and education were also found over the course of the study, with 5% of participants in paid work or education at baseline, increasing to 42% at final follow-up. Criminal activity reduced significantly by the end of the study, from 8.6% who had been involved in crime within the last 30 days at baseline, to 1.8% at the 24-month follow-up. Housing remained a challenge, with a small increase (21.7 to 22.8%) in those facing acute housing problems over the period of the study.

5.3.5 Conclusions

- Nearly all measured outcomes saw improvement over the two years that the study ran for
- Establishing a routine, relationship (re)building, employment and education were important
- Gender differences were noted in treatment pathways, experiences and outcomes

5.4 Keltoi residential rehabilitation programme: outcome study

The Keltoi programme focuses on a drug-free lifestyle and was set up using a model based on the assumption that rehabilitation focused on living skills and relapse prevention, instead of insight, results in more favourable outcomes (White, 2011). The Keltoi programme promotes brief interventions as outlined by Miller & Wilbourne 2002, using empathic listening, a person-centred approach, and a motivational component. The emphasis is on relapse prevention adopting a cognitive behavioural therapy (CBT) approach that focuses on substance misuse and training in coping skills (White, 2011).

5.4.1 Study description

The Keltoi study was an evaluation of a residential rehabilitation facility in Ireland for former opiate-dependent individuals using an uncontrolled cohort study from 2002 to 2004. Each client on admission was asked to complete an interview and again one year after completion of the residential component of the Keltoi programme and all clients that were asked (N=94) agreed.

5.4.2 Study details

Forty-nine individuals had previously enrolled on Keltoi programmes, bringing the total of all former Keltoi clients to 149. Fifty-three per cent (n=80) of all former Keltoi clients (n=149) were interviewed between 1- and 3-years post-discharge.

5.4.3 Methods

Outcome categories measured: abstinence from drugs (including alcohol, tobacco), health, injecting risk behaviours, sexual risk behaviours, suicidal tendency, mortality, crime and employment status.

5.4.4 Findings

Findings were that a high number (60%) were abstinent at follow-up, with minimal criminal activity recorded. However, several deaths occurred during the 4-year period of the study with detailed data on cause of death unavailable to assess whether it was directly drug related (White, 2011).

The authors make some comparisons with the ROSIE study and to the Smyth et al. (2005) study, which was deemed to be the closest comparative study to Keltoi (White, 2011).

Table 3: Comparison of ROSIE, Keltoi, Smyth et al studies

	ROSIE	KELTOI	SMYTH ET AL 2005
Treatment completion rate	66% (n=82)	77% (n=77)	
1 year follow-up rate	68% (n=54)	85.1% (n=80)	76% (n=113)
Abstinence	41% (n=34) at 1 year	60% (n=48) 1-3 years	23% (n=25)
Pre-interview days	90	30	30

The authors caution against direct comparison of the Keltoi study with international literature, particularly studies such as NTORS, DTORS, DORIS, DATOS, and ATOS as they were national studies with different pre-interview measures with abstinence defined differently, for example, DORIS and NTORS permitted alcohol use (White, 2011).

5.4.5 Conclusion

- Abstinence is attainable.
- Lack of outcomes-based evaluation in Ireland hinders development of strategic health policy
- Opportunity to maximise efficiency and effectiveness of DTS, especially rehabilitation, are limited
- Need for health-outcomes-focused monitoring system
- Need to increased awareness of abstinence-focused services
- Rehabilitation focused on living skills and relapse prevention instead of insight results in more favourable outcomes

5.5 Pathways to ‘recovery’ and social reintegration: The experiences of long-term clients of methadone maintenance treatment in an Irish drug treatment setting

5.5.1 Study description

This qualitative study examined the experiences of long-term individuals in MMT in an area of Dublin, Mayock and Butler, 2021.

5.5.2 Study details

All participants (N=25) had enrolled in MMT for the first time at least 10 years previously, with the majority (n=16) having accessed MMT more than 20 years prior to the study.

5.5.3 Methods

In-depth qualitative interviews using an introductory open-ended question “Can you tell me a bit about your life at the moment?” followed by a brief questionnaire to enable compilation of a sample profile: demographics, housing, education, employment/sources of income, family (number, age, residence of children resided) and physical and mental health.

Topics explored during the interview were: current living situation and housing; education, employment, drug use, and drug treatment history; experiences of drug treatment; challenges experienced; everyday life (daily routines, family and social relationships); physical and mental health; perceived social and health care needs and perspectives on the future.

5.5.4 Findings

Findings were that while there were many beneficial aspects to MMT, participants viewed treatment as a clinical regime in which they played a passive role, not viewing themselves as having agency or active in their treatment, with their own recovery path viewed as static and confined.

Participants did not report any progress in achieving social reintegration that the authors observe is viewed as a key aspect of addiction recovery and central to drug policy discussions in Ireland (Mayock & Butler, 2021).

The findings highlight a disconnection between drug policy and individual experiences that needs to be addressed.

5.5.5 Conclusion

- Clients of MMT are not achieving their own personal recovery goals
- Clients view their recovery path as static, being passive participants in a clinical regime
- Social reintegration has not been experienced by long-term clients of MMT
- Irish versions of ‘recovery’ concept have not delivered improved outcomes for MMT clients
- The current recovery/rehabilitation service is disconnected and needs to be replaced

5.6 A National Study of the Retention of Irish Opiate Users in Methadone Substitution Treatment

5.6.1 Study description

A national cohort study of opiate users (randomly selected) commencing methadone treatment was carried out between 1999 and 2003 in Ireland (N=1,269) (Mullen, 2012).

5.6.2 Study details

Opiate users in methadone substitution treatment who registered with the central methadone treatment list (CTL) in 1999, 2001 and 2003 were randomly selected retrospectively. The CTL is a real-time register of all patients prescribed methadone for opiate dependence in Ireland. Patients who leave treatment are ceased on the list and re-entered at each new treatment episode if the treatment gap is more than 1 month.

5.6.3 Methods

A data collection instrument was used to collate two sources of data: 1) The CTL data for each person (name, address, date of birth, gender, date methadone started, type of methadone treatment, prescribing doctor, date and reason for last exit); 2) Additional data on main problem drug, polydrug use (alcohol, benzodiazepines, or cocaine prior to this treatment), injecting, sharing and methadone treatment status, frequency of MM, dosage at 3 months and 1 month prior to exit or completion of 12 months treatment. An average methadone dose was created and used in further analysis.

5.6.4 Findings

The majority of participants were male (68.6%), and the mean age was 26 years. Ninety-five per cent were receiving methadone, with an average dose of 58mg; 75% were injecting, and 72% were using more than one additional drug such as benzodiazepines, cocaine, and alcohol.

Sixty-one per cent of those in methadone maintenance treatment remained in continuous treatment for more than 1 year. Retention was initially associated with age, gender, facility type, and methadone dose, however, age and gender were not found to be predictors of retention when figures were adjusted. Those who attended specialist treatment centres were twice as likely to drop out of treatment than those attending their primary care doctor while those who were receiving less than 60 g of methadone were also significantly more likely to leave (Mullen, 2012).

The main impact of findings relates to the dose of methadone being adequate (>60 mg) and opiate users' attendance at their primary care GP increasing the likelihood of treatment retention.

5.6.5 Conclusion

- Adequate dose of methadone increases treatment retention
- Primary care GP treatment was a successful method of retaining opioid users in treatment

5.7 Mother's experiences of the Parenting Under Pressure Program (PuP) in a Residential Therapeutic Community: A qualitative study

The PuP programme aims to support parents who are or have been either drug or alcohol dependent in order to improve child outcomes and functioning of the family with the programme delivered in a group format. The programme applies psychological principles relating to parenting, child behaviour, and regulation of parental emotion using a case-management model (J.-H. Ivers, Harris, McKeown, & Barry, 2021).

5.7.1 Study description

This study is an evaluation of the PuP programme, described by the authors as being the first study of its kind globally (J.-H. Ivers et al., 2020). The study took place in Ashleigh House at the Coolmine Therapeutic

Community, Dublin, Ireland, the only mother and child residential rehabilitation centre in Ireland and which caters for children under the age of 5 years (J.-H. Ivers et al., 2020)

5.7.2 Study details

The study took place in three waves between September 2017 and June 2018, with the focus on capturing women's experiences of the Pup programme while in residential treatment for addiction. While twenty-five women were enrolled on the PuP programme, two were discharged during the study. Participants were all mothers (N=23), and two interviews were conducted with each.

5.7.3 Methods

Interviews were conducted and content thematic analysis was used to identify and categorise themes. The first wave was used as the pilot, with the protocol for waves 2 and 3 refined based on the pilot feedback which suggested a pre- and post-programme interview.

5.7.4 Findings

Major themes were parental views of self-guilt, shared experiences with peers, importance of children and co-residing; building belief; expectations, challenge to change; challenges and benefits of the PuP programme; expectations and learning by affirmation from peers (J.-H. Ivers et al., 2021)

5.7.5 Conclusion

- Need to develop an integrated treatment response to address the harms associated with substance misuse
- There were clear benefits to the PuP programme which were consistent

5.8 Supporting Women to Access Appropriate Treatment (SWAAT) Study

5.8.1 Study description

The study combined a range of qualitative methods, including in-depth qualitative interviews; online community consultation; and an online forum in two areas of greater Dublin, Ballyfermot and Tallaght (J. Ivers, Giuliani, & Paul, 2021).

5.8.2 Study details

The study was conducted over 5 months between November 2020 and March 2021 using a purposive sample of women in treatment programmes. Key stakeholders were also included. Participants were as follows:

- In-depth qualitative interviews: women (n=22), stakeholders (n=22)
- Online community consultation (n=28)
- Online forum (n=25)

5.8.3 Methods

A range of qualitative methods were used to collect data from 1) Women who use drugs; 2) Key stakeholders directly involved in delivery of services to women using drugs; and 3) Key stakeholders indirectly involved in delivery of services to women using drugs.

Methods included in-depth qualitative interviews with women attending drug treatment services and key stakeholders, a live online community consultation and an online submission forum. The study evaluated the experience of women with drug and alcohol treatment needs in the Ballyfermot and Tallaght Local

Drug and Alcohol Task Force areas. National and international evidence on women attending drug and alcohol services were comprehensively reviewed. Interviews were coded and then analysed using thematic analysis.

Findings

1. All women participants used drugs first as children. More than one-half were in treatment less than 2 years with over one-quarter more than 3 years.
2. All women had experienced significant trauma with most having multiple traumatic events that included abuse, parental drug use, domestic violence, bereavement of partners and close family members through drugs misuse.
3. Women felt a sense of hopelessness and feared disclosure of their addiction would lead to loss of their children – a major barrier to treatment.
4. Key stakeholders aware of these issues and also concerned about ongoing sexual exploitation and control of women in these communities.
5. Services for women were disconnected, inadequate, and not women centred.
6. Responsibility for care of children was important.
7. Gender-sensitive treatments that support women-specific services in maternity, childcare, and domestic violence are needed.
8. Peer-led support was seen as particularly successful when attempting to engage women.
9. Participants shared their vision for recovery-based community services. Shared spaces brought together a range of biopsychosocial services.

5.8.4 Conclusion

- This report aims to inform policy and practice for women who use drugs at local and national level in Ireland.
- Develop an adequate trauma-informed response.
- Establish gender transformative, integrated treatment and support services.
- Establish working groups between Local Drug and Alcohol Task Forces and child/family agencies.
- Develop pathways for women to sustain recovery.
- Expand pathways to education and training for women.
- Support women to rebuild and sustain healthy family relationships.

5.9 Summary

In this section we summarise the main findings from reviewing the Irish studies. It should first be noted that many of the studies above did not appear within the formal review of the literature, however the specific focus of this exercise on Ireland resulted in them being included in this section. Some may be smaller than the findings identified internationally (or through the formal review), however this appears to indicate a willingness for treatment providers in Ireland to critically examine their provision and the experiences, including outcomes, of patients and clients. The ROSIE study was a national study, however, there does not appear to have been any move towards some of the more recent developments such as LiR or PROMs.

6 Recommended approach to studying rehabilitation outcomes in Ireland

6.1 Introduction

In this section we outline the recommended approach to studying rehabilitation outcomes in Ireland. The findings from the evidence map and the examination of Irish health information systems and evaluation studies were considered an appropriate research design for evaluating rehabilitation impacts and outcomes in Ireland, however a clear recommendation from this report is that outcome measurement should be embedded in existing systems such as the data currently collected by services across Ireland and the information collated centrally by HRB via the NDTRS. To be clear, it is felt that a new 'research' study, such as those previously carried out in Ireland and elsewhere in Europe is not warranted, despite these being the type of study that appear within a mapping exercise like the one above that focused on papers published in the scientific literature.

As previously noted, there is a range of services, including community-based and residential rehabilitation services, in Ireland. While historically perhaps the focus has been more on treatment, there is increasing recognition that recovery is an important part of the journey. A detailed discussion on the role of recovery is beyond the remit of this report. However, recovery is seen as more of a person-centred, individual phenomenon (as opposed to a service). SAMHSA defines recovery as "a process of change through which people improve their health and wellness, live self-directed lives, and strive to reach their full potential" SAMHSA (2012). As Neale *et al.* (2016) note, recovery has moved from being almost exclusively associated with 12-step fellowships and abstinence to being part of the wider treatment and rehabilitation landscape, including housing, health, employment, offending, and relationships. Citing Laudet (2009), Neale *et al.* highlight the need for a way of measuring outcomes that reflects the multidimensional aspects of recovery. The national drugs strategy, *Reducing Harm, Supporting Recovery. A health-led response to drug use and alcohol use in Ireland 2017- 2025* (Department of Health, 2021) refers to the journey of recovery as something highly personal, with different priorities and goals for each individual. This multifaceted and person-centred approach should be reflected in outcomes monitored by assessing a broader and more holistic range of outcomes for each individual. These may include harm reduction and quality of life measures as well as abstinence.

In tandem with the increasing acceptance and promotion of recovery (which is person-centred), researchers and health professionals have highlighted the benefits of PROMS across a range of health issues (Neale *et al.* 2016). This is perhaps a move away from clinicians and services 'assessing' the outcomes that individuals have achieved to an approach where the individual considers their own specific outcomes.

PROMS can be defined as "any report of the status of a patient's health condition that comes directly from the patient without interpretation of the patient's response by a clinician or anyone else" (FDA, 2009). They can provide critical information for patients and service providers and are especially useful when externally observable outcomes are not available or appropriate (Cochrane, 2022) and can provide the only reasonable approach to treatment evaluation for emotional function. They can evaluate patients' experiences of symptoms, functional status and health-related quality of life (Cochrane, 2022)

PROMS are instruments which can be used to measure patient reported outcomes. For substance use, treatment outcomes beyond survival, major morbid events and biomarkers can be collected using PROMs. Patient perspectives are not accurately captured using only traditional outcome measures, so it is important to explore other ways of measuring treatment outcomes. Unlike other outcome measures,

PROMs focus on capturing improvements to the patient's health and well-being and can assess a broader spectrum of well-being related outcomes such as mood, experiences of symptoms, functional status and health-related quality of life (Cochrane 2016; Commonwealth Fund, n.d). Research suggests that outcome measurement for substance use should go beyond measuring substance use and look at wider variables including bio- psycho- social factors (Alves et al, 2017).

As discussed earlier in this section, recovery can be defined in many different ways, although it is generally associated with improvements in different domains of one's life, including relationships and social structures, selfcare, housing, health and employment (Neale et al, 2016). Any evaluation of treatment outcomes should take this into account, and include patient measured outcomes on these multiple domains. The recovery movement as well as a broader movement within health services and research to recognise the importance of lived experience both highlight the importance of a patient centred approach to both treatment and research. PROMs place the voice of the patient at the heart of any evaluation. It has been demonstrated that patient-set treatment goals and outcomes are often incongruent with those of substance use treatment providers and services (Marchand et al, 2019), highlighting the need for a reprioritisation of stakeholders and approaches to outcome measurement. Using PROMs can identify discrepancies between clinician and patient perspectives and collect more relevant data to assess the effectiveness of treatment for the individual as well as the service. Research by Alves et al (2017) suggests that patients in treatment for substance use have a much greater diversity of concerns than have previously been included when designing outcome measures. Identifying these concerns may facilitate a better understanding of treatment approaches and improve outcomes.

The involvement of people with lived experience through various types of engagement and collaboration has gained support and recognition as an important aspect of research and service development, as well as delivery and evaluation. Lived experience is defined as "personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people" Graham et al (2019). Increasingly, this has been employed in the substance use field and when exploring recovery outcomes, and therefore it is not surprising that the use of PROMs has been considered when measuring recovery outcomes.

SURE was co-developed with service users in London, with academic input from the UK's National Addiction Centre at King's College London. Initially a paper-based tool, it was developed following requests from those using it into an app which also included a separate assessment tool, the Substance Use Sleep Scale. It was suggested that this was a different approach as it was developed in collaboration with community members and therefore different to other assessment tools such as the Addiction Severity Index or the Treatment Outcomes Profile. Co-development or co-production was at the heart of this initiative, which benefited from the National Addictions Centre having a long-established service user group in conjunction with a local peer-led recovery group.

6.2 Recommendation

As previously discussed, the involvement of people with lived experience has been increasing in popularity in research and services. This has been utilised to great advantage in studies such as SURE and suggests that this could be a key development in the updating of substance use outcome measures. The involvement and input of people with lived experience can offer a more person-centred and tailored approach, which more accurately reflects the experiences and outcomes of substance use treatment.

There are many ways of involving people with lived experience (PWLE) in research, and all have some value. The concept of co-production is about the development of equal partnerships between PWLE and researchers or professionals. The traditional hierarchy is challenged and the value of lived experience is

emphasised as being as important as professional or academic knowledge and skills. Co-production in its purest form involves a shift to shared power and joint decision-making, with all participants working together as equals, from inception to completion (NIHR Involve, 2019). There is a continuum of co-production, which should be acknowledged. Pure co-production is not always possible or appropriate, but this does not mean that PWLE should not be involved in a significant and meaningful way. Rather than using stringent criteria for defining co-production, it is more important that key values be employed. The Social Care Institute for Excellence (SCIE) (2015) defines these key values as: equality, diversity, accessibility and reciprocity. NIHR Involve states: “Co-producing a research project is an approach in which researchers, practitioners and the public work together, sharing power and responsibility throughout the life of a project, from start to finish” (NIHR Involve, 2019). These are just two definitions which begin to explain how important and how beneficial co-production is and can be to a research project or service evaluation. Involving PWLE in projects such as this can have many benefits, including increased relevance, usefulness, usability, and use of research outputs (Graham et al 2019). Co-production has the potential to improve the quality and relevance of research, as well as its effect on policy and practice (Redman et al, 2021). Because of this, we recommend that PWLE should be key contributors and collaborators in any forthcoming research or collection of outcome measures, at least in the spirit of co-production.

We recommend a system or process that augments data collected by existing service and collated, in part, by the HRB within the NDTRS, augmented by opportunities for those leaving treatment or rehabilitation to provide outcomes, under the general ethos that this should be voluntary, agreed in co-production with PWLE and are considered as PROMS. While all research collected within research studies could be considered as ‘voluntary’ given the need for informed consent, it is suggested that any additional data collected on individuals is given by them in a truly voluntary way in that there is no expectation or obligation that people need to provide data, they should only be comfortable providing data and are able to opt out, particularly (for example) if they no longer want to be associated with previous treatment or they feel they have ‘moved on’. While this approach may be criticised as potentially lowering response rates, it has often been seen in previous research into substance use, particularly ‘epidemiological’ research that an over-reliance of getting high response rates or complete data are not needed. In other words, for the important issue of finding out what works the best across Ireland’s diverse treatment and rehabilitation landscape, perfection could be seen as the enemy of the good.

Treatment (particularly residential rehabilitation) works. It is a human right. Despite that, there can be the counter argument that money invested in support, treatment and residential services is wasted as problems due to alcohol or other drugs is ‘self-inflicted’, as well as concerns that prioritising spending on drug or alcohol treatment reduces funds available for other healthcare issues. There are parts of the world where treatment is not available and where the use of drugs is primarily seen as a criminal justice issue. Therefore, there can sometimes be the perception that any request to evaluate treatment (or in a broader sense, examine if it is working or if it can work better), can be seen as the thin end of the wedge where (for financial, moral or political reason) access to support, treatment and rehabilitation is restricted.

Because of this, the recommended enhanced monitoring needs to take those who advocate for those who use alcohol or other drugs with them. This brings us to public and patient involvement (PPI). In the area of alcohol and other drugs, the term PPI can be problematic. The ‘public’ aspect of PPI can be particularly problematic as surveys (UK Drug Policy Commission, 2010) show that the public’s perception of those who have problems with alcohol or other drugs can be negative or stigmatising. Also classing those affected by drugs or alcohol as ‘patients’ can be problematic. It is far better to look at this as co-production.

We are not talking about co-production of drug or alcohol treatment services (which should be promoted as a matter of course) we are talking about co-production of one aspect of any well-functioning support, treatment or rehabilitation service which is the monitoring of outcomes for individuals. In one sense, it is making sure that the internal data collection (whether that is data collected for clinical assessment or working out the best way to support the individual, or data collected to examine whether the service is meeting its aims and objectives) can be used effectively (and with the support of the services and the individuals using such services) in a wider national enhanced monitoring system.

For the purposes of this report, we have named the proposed research approach *Tuairisciú ar Thorthaí Téarnaimh (TTT)* or Reporting of Recovery Outcomes. It is important to emphasise here that the name is only to assist in the writing of this report, as the name, as well as the rest of the project, should be developed using a co-production approach. The writer of this report only speaks English and has no knowledge of how an acronym (albeit only created for ease of discussion in this report) would be received.

Providing support for those who use alcohol and other drugs problematically is not a new thing. It could be argued that there is no longer a need for evaluating whether treatment, support or rehabilitation is effective or should be in place, nor whether it is cost-effective. Supporting individuals to address issues with alcohol or other drugs not only improves the life of the specific individual, but also to that individual's family, friends, communities and wider society.

There will always be a need to continually improve the provision of support, treatment or rehabilitation for those experiencing problems due to their use of alcohol or other drugs. Therefore, if the research questions are not relating to 'does it work', but how can it be ensured that it is working well (primarily in terms of meeting the needs of individuals in treatment or rehabilitation, but also in terms of being cost effective) and can be made to work better. In order to do this, we propose a co-production approach that ensures people with lived experience (PWLE) are involved in a meaningful way.

As previously mentioned, TTT will be voluntary not mandatory (either at the individual level or the service level). 100% coverage would be good, but we must not let perfection be the enemy of progress. One aspect of this will be the use of a mobile phone app which will allow those who are either in (or have been in), support, treatment, or rehabilitation to report their outcomes in a way that they are comfortable with. This does recognise that not everybody will have access to a mobile phone, but it is thought that many people do. Alternatives to a mobile phone app (such as a secure website, and the option to have a phone call) will be on offer. Those who are in treatment (or still in contact with treatment – including those classed as graduates or in step down, or in other words still in active contact with the treatment provided) will be given the opportunity to participate through that provider. Language is important here; it is about being 'given the opportunity' or 'asked to' participate rather than it being seen as something mandatory.

We would recommend that an integral part of TTT would be an Irish Equivalent of Capital Card (although it should be administered separately from HRB or Government). As with everything in this report, it is only a suggestion which should be seen as a starting point for the co-production and any research into 'what works'. Some 'pushback' for this idea would be expected so it may be worthwhile engaging with an organisation such as WDP to see how this could be handled.

For those out of treatment (or those not in regular contact with their original treatment provider) then the outcomes monitoring will be through invitations to contact. For this, as well as other aspects of the data collection, peer researchers could be utilised. As well as being effective in reducing barriers between service users and providers, this can offer a meaningful way for PWLE to get involved and learn new skills, and to take ownership of the research.

6.2.1 Data collection

Most of the recommended approach to studying treatment outcome is focused on better using data currently collected by treatment and rehabilitation service and supplementing data with opportunities for those who have left treatment or rehabilitation to provide data, similar to PROMS such as Life in Recovery or those using the SURE app as part of their recovery. Currently, the NDTRS reports at the episode level and does not employ any techniques to identify individuals accessing services at different times (or episodes). A system will be devised to allow linkage within the NDTRS to build up a history for individuals. This will be based on the existing (and any proposed) identifiable data collected within the NDTRS. It is recognised that the NDTRS has not been set up to record information at the individual level and it would be wrong (for various reasons, including reporting to the EMCDDA) to assume that any linkage techniques would be robust enough to accurately identify individuals and use such linked information to make any inferences about any 'presumed' individuals or generate summary statistics (e.g. the number of individual in treatment or the number of individuals in receipt of any particular type of treatment). This history can then be used to add to an epidemiological profile for each presumed individual which can be used within any outcomes analyses. A flowchart and a more detailed description of data collection points is given in Appendix 2. Support will be needed and will be given to the HRB to allow this (anticipated 3 months FTE of an experienced researcher, see below for a more detailed discussion of resource implication), with the aim of processes being automated or documented to the extent that the HRB could assume this work without additional costs after the 3 months). It is recognised that due to issues in linking data then it will either be 1) not possible to provide background information on a certain proportion of individuals; or 2) each linkage will be assigned a probability (or measure of confidence) that it is a particular individual, and this uncertainty can be included in any future analyses). Indeed, any information from this linkage is likely to be corroborated with information collated within TTT (the individual's age, gender, substances used, injecting status, health and employment information, etc.). On entering TTT, consent will be sought to use previous NDTRS data in such a manner (with clear mechanisms to enable those who do not consent to that part of TTT to still remain). This is over and above the consent to participate in TTT. As will every part of TTT it is voluntary, so for this stage the exclusions will be:

1. Those who opt out of TTT
2. Those who opt out of using their current episode's NDTRS data to inform TTT
3. Those who opt out of using their previous data within the NDTRS to inform TTT
4. Those for whom there is not sufficient information to link any previous NDTRS data.

Exit point from the clearly defined treatment episode (EP)

As with all additional data collection, this will be agreed following a process of co-production. The general ethos will be that the agreed data (which will be collated centrally in a similar manner to the NDTRS as in it will be presumably coordinated or managed by the HRB, perhaps using eCASS and will build upon any existing data on people 'leaving' treatment that is being collected by the service as part of the usual data recording processes they employ. It is recognised that 'treatment' is a journey therefore this point needs to be clearly defined (and agreed), e.g. if someone has a period of residential detoxification, then moves to residential rehabilitation is that one episode of treatment). This is important, and care should be taken to avoid encouraging premature discharge as sometimes happens in the UK and ending up with the situation where people are re-appearing several times within treatment monitoring systems. The exit point data form will be one page (perhaps in a similar manner to TOP in England). Within the data recording for the exit point data, consent will be sought along with an agreed identified code, which would allow further episodes within the NDTRS to be identified. Also, when leaving treatment, they would

be asked for contact details that they are happy to be used to facilitate contact for follow-up, such as phone, mobile phone, email or details of trusted friends/family members.

It is proposed that there are up to four points where those leaving treatment are invited to provide data. These would be:

Follow-up 1 (FU1)

This will take place three months after leaving the ‘trigger’ treatment episode. The process for collecting data will depend on the individual’s situation and whether informed consent has been given to follow-up and invite to give data. All people leaving treatment will be given details of how they can contribute to data collection regardless of them receiving an invite therefore those who had not initially given consent, but later wish to contribute, can. These details will include telephone, app based and web-based methods of data collection and a suggested date for making contact will be provided.

If someone is in contact with a service that contributes to the NDTRS and has had an NDTRS form completed on them then these data would be used instead of any additional data collection (if it possible to link with previous data collecting when leaving the trigger episode and appropriate consent given).

If the individual has not made contact, or relevant data could not be gathered from another NDTRS episode then the following approach to inviting someone to provide data will be followed. Using the contact details provided (included a trusted friend or family member if direct contact was not successful) the individual will be invited to provide an update of their situation. The nature of this would be up to the individual and would take the form of either a one-page (or equivalent) update collected via an app or web-based form, or a brief telephone call. They will also be given an option to provide a more detailed set of data (again via app or web-based form or telephone interview). Equally valid responses to this attempt to contact will be the individual stating that they are unable to provide information at that time (and this will be respected, with no questions asked or any attempt to persuade the individual to change their mind and provide information) or saying that they would welcome a call back or contact in the near future if immediate circumstances mean it is difficult to make contact.

Follow-up 2 (FU2)

This will take place 6 months after leaving the ‘trigger’ treatment episode and follow the general approach for FU1, provided that informed consent has been obtained. If consent was in place, yet a successful attempt at collecting data at FU1 was not possible, an attempt at collecting data for FU2 would still be made.

Follow-up 3 (FU3) and Follow-up 4 (FU4)

These will take place 12 and 24 months after leaving the ‘trigger’ treatment episode. The extended period after first data collection will allow an assessment of how the process is working, and whether any additional data items should be added to the data collection (or dropped).

As previously mentioned, the scope for examining previous contacts within the NDTRS and any other readily available (to HRB) data that can be linked should be examined, possibly providing a data profile prior to that treatment/rehabilitation episode. Funding should be made available to services for any additional costs associated with the Exit Form. Separate funding should be made available to services for support in FU1, FU2, FU3, FU4 – e.g. if the service operates a ‘graduate’ or ‘continuing care’ ethos then use additional funding to support this (either the service collecting the data or signposting/encouraging the individual to submit data by other methods – app, website, telephone interview). As stated above, this is a suggested proposal that needs agreement from services, and more importantly, co-production with people with lived experience.

In an ideal monitoring or surveillance system, there would be 100% compliance with any reporting demands/requests. There will always be accommodation for those who, perhaps due to confidentiality or data protection concerns, would prefer not to give consent for their data (including any data that could be deemed to be patient identifiable) to be used for monitoring purposes. There can be systems where this desire for confidentiality can be overridden for public health or other reasons, however it is recommended that this new monitoring system takes a person-centred approach and respects the rights of the individuals involved. To do this, and still ensure good compliance with data collection, we recommend the co-production approach is utilised, to find the most effective and most acceptable means of collecting such data. Individuals should feel like their contributions are valued and their privacy respected, rather than feeling coerced into sharing information. It may be that exploring the uses of the data and explaining the need for its collection is justification enough for individuals to want to contribute.

Whilst there are issues regarding the validity of self-reported data, it could be argued that a non-intrusive collection method such as asking patients to self-report would be more acceptable and therefore more likely to be completed. Again, this should be developed in partnership with PWLE in order to balance the desire for comprehensive monitoring and the rights and preferences of the individuals using the services.

It is worth considering the appropriateness of linking with other government datasets, including those related to employment and social support. Despite the roll-out of a unique identifier number (either the personal public service number or individual health identifier), it is thought highly unlikely that there can be any linkage between the NDTRS and other datasets. In effect, this is ruling out a version of the Drugs Data Warehouse (a large record linkage project carried out with English data sets, Pierce et al 2015). However, any 'rejection' of this at the moment should not be seen as discouragement from working towards a situation where data linkage can be facilitated, not just with the use of a unique identification number but also strengthened consent for linkage (both at the individual and societal level).

6.2.2 Process evaluation

While we are not suggesting a formal research study akin to those which have 'evaluated' drug treatment or rehabilitation services in the past, we are suggesting that there should be some element of research examining the roll-out of additional data collection and better use of existing data collected by services and this would be more of a process evaluation, examining whether the intended outcomes of the new reporting are being met and that it is working well for all stakeholders, including services and service users. For the process evaluation, we recommend a bottom up instead of top-down approach. In other words, what is recommended is a study that treats individuals and services providers as participants in research, rather it is building upon a system that puts the change and recovery (and measuring both) at the heart of the therapeutic journey of each patient, client or service user should have.

6.2.3 Co-production

"Community members have traditionally been excluded from the production of academic knowledge and have had little or no decision-making power in this regard.

By democratising knowledge production by including community members in the research process, power is distributed through more equitable community-academic relationships...

Inclusion of community members in the research process can be enhanced by valuing their lived experience, providing training and mentoring opportunities, financial compensation, building trust and accommodating their needs." (Belle-Isle et al, 2014)

Co-production is a concept which is hard to define. Many definitions exist, but the core of these relates to the equal value of those with lived experience and those with professional experience. INVOLVE (2018)

defines it as follows: “Co-producing a research project is an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge.” (INVOLVE, 2018, p. 4). The INVOLVE definition incorporates five key principles: 1) power sharing; 2) respecting and valuing others; 3) including all perspectives; 4) reciprocity; and 5) building relationships.

There are benefits to be had for all by utilising a co-production approach: for the research itself, for those using services (or taking part in research) and those involved in the research process. Four main reasons for involving PWLE have been identified: policy imperative (funders, etc. often require evidence of collaboration); moral approach (those affected by an issue have a right to be involved in research which affects them); theories of knowledge (the recognition that PWLE have valuable knowledge and information); and results based (Neale et al, 2017). Results-based reasoning suggests a range of potential benefits for the research, the researchers and those affected by the issue; in addition, the project can be given greater credibility.

In a Public Health England (United Kingdom) evidence review on drug treatment outcomes (Public Health England, 2017), participants overwhelmingly felt that 6 months was insufficient time to be able to demonstrate stable recovery and therefore the ‘non-re-presentation window’ in the successful completion definition for people returning to treatment should be longer than 6 months. Many participants felt that the length and speed of a recovery journey were vital factors; in addition, they said they would have welcomed much longer periods of support after treatment, with 2 and 5 years being mentioned. Many participants emphasised that recovery should be understood to consist of progress across a broad range of issues. They described the things that were important to them – not just addressing substance misuse, but also improving their housing situation, physical and mental health, their social situation and relationships with their families, and their employment and training opportunities. One male participant noted: “You should measure use; stable accommodation; education; training and employment; if life feels good; health issues are dealt with – mental and physical; is there family contact, and money?” Many participants emphasised that improving their quality of life while remaining healthy and stable on a methadone script should be considered a successful outcome and acknowledged as such.

Co-production can be challenging to implement, as it is a new way of working for many. For researchers, it can be difficult to understand how to do it in a meaningful way, to avoid tokenism and ensure the project moves ahead smoothly. By sharing control of the research design, implementation and dissemination, researchers give up power and the usual dynamics are shifted. Although co-production is gaining in popularity, it does require work to make sure that it is done well. PWLE should be treated as equal partners in the research, and any barriers to their involvement should be addressed to ensure they are able and comfortable to be fully involved. These may include issues around language used, unfamiliarity around methods and approaches, challenges around safeguarding or relationship management. Time and financial costs can also add up, as PWLE should be appropriately remunerated for their involvement. For PWLE, challenges of being involved in this way can include stigma, risks to well-being, an intimidating or unfamiliar environment, or with research methods. It can also be an unfulfilling experience if not managed well, leading to feelings of being undervalued.

Despite these challenges, co-production offers many benefits. For PWLE, it can offer new experiences and opportunities to learn and be involved with research; to influence healthcare delivery or design; improved confidence and skills; an opportunity to have their voices heard and feel valued for their contribution. For many, recognising personal experiences as a strength rather than a thing to be fixed or treated can be life changing.

For researchers, it can also be a learning experience and offer opportunities to explore new ways of working and to learn from others. It also lends to the research credibility among stakeholders and can provide unexpected ways of working or outcomes. It is an opportunity to engage with those using services and to ensure that services are fit for purpose. Co-production can mean being open to developing a wider skillset and different outlook. It can help professionals to reflect and think about their role and approach in new ways and reinforce and refresh their passion and motivation for their work.

Co-production is not just an ethically sound concept, but it can provide value for money and improve outcomes.

The review should consider the evidence available from the examination of Irish information studies and published evaluations and data from the evidence map of the international literature. Some countries have completed treatment outcome [impact] studies while other countries have completed treatment and rehabilitation studies. Some studies examined the experience of those with opiates as their main problem drug while others have examined a broad spectrum of psychoactive substances, including alcohol. Studies are generally implemented over a five-year period. Ireland has completed one major cohort study and the review should identify lessons from this study and other evaluations in considering the questions below.

6.2.4 Practical implication of using proposed evaluation method

The evaluation study of rehabilitation outcomes will involve substantial investment in the research study, possible changes to information systems and other infrastructural costs. It will require careful navigation of the policy and service environments to ensure that there is buy in from all stakeholders.

6.2.4.1 Costs

As TTT will not be a formal research study, and will be a result of co-production, the costs associated with the approach will be more speculative. Actual costs and methods for reimbursement will need to be considered centrally by a lead organisation (e.g. HRB) who may, or may not, be in a position to commission any required additional work within existing services. Costs could also be broken down by expected number of patients/clients enrolled (which at this stage can only be estimated using data that HRB may have but do not make publicly available).

It is assumed that all such services are contributing to the NDTRS or using a recording system such as eCASS. Funded support will be made available to such services to augment their data collection to have an exit form to be completed.

Proposed costs:

- HRB data linkage support 3 months research
- App/website development
- HRB additional analysis support (36 months in first instance)
- HRB part-time telephone interviews (again 36 months in first instance). Includes Freephone number – not recording incoming call number, etc. For example, all the issues that would be faced for data protection, data security within ethics
- Additional support to agencies to facilitate FU1-FU4 (for relevant agencies who can justify needing additional costs).
- Possibly this could be done in conjunction with the drug taskforce infrastructure
- Project lead (full-time 36 months)

- Process evaluation – 12 months
- Co-production lead – 12 months
- Costs associated with co-production.

The point of this document is to make suggestions. It is for others to consider whether they are feasible, or costs can be made available.

6.2.4.2 Cost-effectiveness

Often data are collected in order to enable health economists to establish whether any treatment or intervention is cost-effective, either in terms of saving lives, improving the quality of lives (e.g. by considering QALYs). There is also an approach where the social and economic costs of alcohol and other drugs is considered. While estimating the social and/or economic costs of alcohol other drug use is far from an exact science, it is clear that the costs to society are substantial and that helping people move from a position where they can be considered as ‘contributing’ to those costs into a situation where change has been positive does result in decreases in social and economic costs. There is, for example, the often-quoted example in England where it was often claimed that £1 invested in treatment resulted in £9 savings in social and economic costs. This simple equation masks quite a complex set of calculations, for example there are different costs associated with different types of treatment and it is clear that longer-term treatment and residential treatment will be more costly than one off psycho-social interventions. Provision of support, treatment and rehabilitation services should not be based on cost, rather on what is best for the individual taking into account their personal circumstances and clinical need.

The data collected within the proposed outcomes monitoring are not anticipated to be able to allow a formal cost-effectiveness analysis of whether treatment is cost effective or examine which specific types of treatment are more cost-effective than others. If it was felt necessary that the cost-effectiveness of treatment is to be examined then that would take a specific study, although previous studies have found it difficult to assign costs (and cost benefits) within this area. However, when carrying out the co-production to see what data are acceptable to services and primarily those who use them, it should be borne in mind that when there is no strong consensus about whether or not particular data field are included, they should perhaps err on the side of collecting data that could be used within a formal cost-effectiveness analysis. Given issues relating to carrying out formal cost-effective analyses, consideration should be made as to whether the additional data collected within TTT (and any data that can be used from the NDTRS, eCASS or any centrally held ‘administrative’ data can be used within a Social Return on Investment (SROI) analysis, either for any national analysis or any local analyses (or evaluation of any particular service, or decision-making during commissioning).

6.3 Conclusions

This document has set out recommendations for carrying out research into rehabilitation and treatment outcomes in Ireland. A scoping review was carried out looking at published literature on the effectiveness of treatment and rehabilitation, however the outputs from many of the studies were not of immediate use for developing recommendations for future research, e.g. in terms of outcomes measured. A review of recent international studies and Irish studies was also undertaken, and this was more informative for developing recommendations, particularly more recent studies based on PROMS and studies that make full use of technological developments such as the SURE app. It is recommended that this type of approach is carried out in Ireland, an approach that builds upon existing data collected by drug treatment and rehabilitation services, including data collated by the HRB but augmented by data collected directly from those leaving treatment or rehabilitation services. Approaches to setting up additional data

collection should be agreed on a co-production basis, with input from those who could be seen as participants in the research to ensure that data are collected in a way that is appropriate and convenient and which would therefore maximise buy-in and coverage of data. While there have been large research studies both in Ireland and elsewhere which used traditional methods of following up participants in a cohort study design (often involving detailed questionnaires), it is felt that a move to using PROMS is more appropriate.

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Appendix 1 Search strategies

MEDLINE via Ovid search (run in Advanced tab)

#	Search terms	
1	exp substance-related disorders/	281,528
2	((drug or substance* or alcohol or opioid or opiate or heroin) adj (dependen* or user* or misuse or abuse* or abstinen* or (use* adj (disorder*))))).tw.	108,575
3	addiction.tw.	37,411
4	1 or 2 or 3	327,545
5	exp substance-related disorders/rh, th	50,384
6	Substance Abuse Treatment Centers/	5,307
7	Methadone/tu or Buprenorphine/tu or Narcotics/tu	10,826
8	(Treatment or rehabilitation or recovery).tw.	4,182,985
9	5 or 6 or 7 or 8	4,208,068
10	Cohort studies/ OR Longitudinal studies/ OR Prospective studies/ OR Follow-Up studies/	1,415,792
11	Epidemiologic Methods/	31,435
12	((cohort OR longitudinal OR prospective) adj study).tw.	326,426
13	10 or 11 or 12	1,518,085
14	Treatment Outcome/	994,060
15	(outcome* or "follow up" or follow?up or evaluation or effectiveness).tw.	3,186,035
16	Quality of Life/	200,091
17	14 or 15 or 16	3,757,988
18	Multicentre Studies as Topic/	18,871
19	exp Geographic Locations/	4,365,248
20	17 or 18	3,768,352
21	4 and 9 and 13 and 17 and 20	8,695
22	limit 21 to (English language and yr="2000 -Current")	6,075

CINAHL Plus with full text via EBSCOHost

#	Search terms	
S1	MH ("substance use disorders+")	166,961
S2	TI (drug or substance* or alcohol or opioid or opiate or heroin) N1 (dependen* or user* or misuse or abuse* or (use* N1 (disorder*))) or AB (drug or substance* or alcohol or opioid or opiate or heroin) N1 (dependen* or user* or misuse or abuse* or (use* N1 (disorder*)))	59,581
S3	TI (addiction) or AB (addiction)	20,341
S4	S1 or S2 or S3	194,600
S5	MH ("substance use disorders+/RH/TH" or "Substance Use Rehabilitation Programs+" or "Methadone/TU" or "Buprenorphine/TU" or "Narcotics/TU")	36,021
S6	TI (treatment or rehabilitation or recovery) or AB (treatment or rehabilitation or recovery)	998,066
S7	S5 or S6	1,015,134

S8	MH ("Nonexperimental Studies+" or "Epidemiological Research")	790,223
S9	TI (cohort OR longitudinal OR prospective) N1 study) or AB (cohort OR longitudinal OR prospective) N1 study)	194,937
S10	S8 or S9	857,045
S11	MH ("Treatment Outcomes+" or "Quality of life+")	481,854
S12	TI (outcome* or "follow up" or follow?up or evaluation or effectiveness) or AB (outcome* or "follow up" or follow?up or evaluation or effectiveness)	1,120,331
S13	S11 or S12	1,392,024
S14	MH ("Multicentre Studies" or "Geographic Locations+")	2,172,777
S15	S4 and S7 and S10 and S13 and S14	3,341
	WITH LIMITS	3,148

[Used the 'Limit your results' (via Edit) to limit published dates to 2000-2020, select 'Exclude MEDLINE records' and English in Language. Click Save]

PsycInfo AND PsycArticles via ProQuest

Select both databases and run in Advanced Search, Command Line. Copy & paste all text below

(MAINSUBJECT.EXACT.EXPLODE("Substance Related and Addictive Disorders") OR ab,ti((drug OR substance* OR alcohol OR opioid OR opiate OR heroin) NEAR/1 (dependen* OR user* OR misuse OR abuse* OR (use* NEAR/1 (disorder*)))) OR ab,ti(addiction)) AND (MAINSUBJECT.EXACT.EXPLODE("Addiction Treatment") OR ab,ti(treatment or rehabilitation or recovery)) AND (MAINSUBJECT.EXACT.EXPLODE("Prospective Studies" OR "Longitudinal Studies") OR ab,ti((cohort PRE/1 study) OR (longitudinal PRE/1 study) OR (prospective PRE/1 study))) AND (MAINSUBJECT.EXACT.EXPLODE("Treatment Outcomes" OR "Quality of Life") OR ab,ti(outcome* OR "follow up" OR follow?up OR evaluation OR effectiveness)) – **1,721**

[Add 2000-2020 Publication date limits in the left-hand column] – **1,382**

Social Sciences Citation Index via Web of Science

#	Search terms	
1	TS=((drug or substance* or alcohol or opioid or opiate or heroin) NEAR/1 (dependen* or user* or misuse or abuse*) OR TS=((drug or substance* or alcohol or opioid or opiate or heroin) NEAR/1 (use* NEAR/1 disorder*)))	80,972
2	TS=(treatment or rehabilitation or recovery)	441,618
3	TS=(prospective or longitudinal or cohort)	252,789
4	TS=(outcome* or "follow up" or follow?up or evaluation or effectiveness)	813,754
5	#4 AND #3 AND #2 AND #1	3,273

[Limit publication dates in Timespan for each search line. Check under 'Web of Science Core Collection: Citation Indexes' that only Social Sciences Citation Index (SSCI) --1970-present is selected]

Note

We note that there was a relatively recent systematic review carried out by de Andrade et al (2019) which published their search strategy which has an exclusion as part of their search. They also searched MEDLINE, CINAHL, PsycInfo and PsycArticles, but did not search the Social Sciences Citation Index. We

have tried to replicate their search strategy to use with the Social Science Citation Index, coming up with the following results:

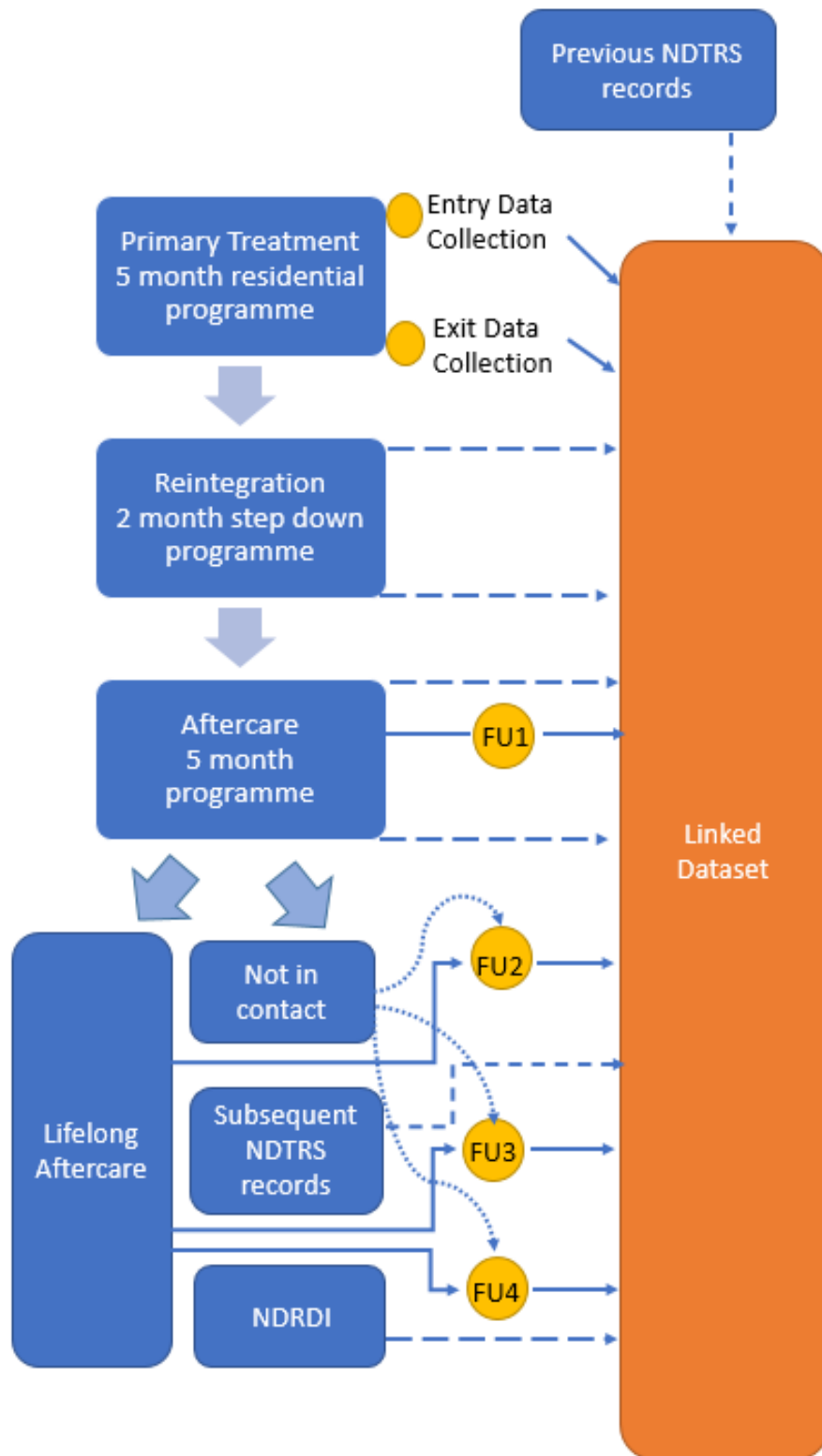
#	Search terms	
1	TS=((drug or substance* or alcohol or opioid or opiate or heroin) NEAR/1 (dependen* or user* or misuse or abuse*) OR TS=((drug or substance* or alcohol or opioid or opiate or heroin) NEAR/1 (use* NEAR/1 disorder*))	81,129
2	TS = (residential OR therapeutic communit*)	41,568
3	TS = (intervent* OR treat* OR rehabilitat* OR *therap* OR counsel*)	874,389
4	TS = (effect* OR impact* OR outcome*)	1,685,008
5	#4 AND #3 AND #2 AND #1	1,760
6	TS = (child* OR adolescent* OR teen* OR juvenile* OR meta* OR review)	994,497
7	#5 NOT #6	1,179
8	TS=(treatment or rehabilitation or recovery)	442,578
9	#5 AND #8 NOT #6	1,139

[Limit publication dates in Timespan for each search line. Check under 'Web of Science Core Collection: Citation Indexes' that only Social Sciences Citation Index (SSCI) --1970-present is selected]

This gives a more manageable amount of hits compared to the original search, but it is noted that they included the term 'review' in the exclusion. While this search strategy used by de Andrade et al (2019) was not formally included in this current review, the results from this search were informally reviewed along with grey literature.

Appendix 1 Data Collection Flowchart

Figure 3: Data collection flow chart



Introduction

In this appendix, we outline the various points where data that are already being collected as part of the treatment/rehabilitation journey, or additional data can be used to inform an outcomes study. We include a flowchart as Figure 3. The data all feed into a central linked dataset which can be interrogated and analysed to examine treatment outcomes. As with many 'epidemiological' datasets, there may, or will be, issues with the data collection that arise from missing data; for example, at one point where follow-up data were sought it was not possible to locate or identify the individual (or the individual chose not to opt into that particular data collection point for valid reasons). This can be handled using commonly used statistical methods. There will be another key issue with this process which, up until now, has been seen as a barrier to maximising the benefits of data collection on drug treatment or rehabilitation in Ireland. That issue is the lack of unique identifiers used within the NDTRS. Again, this can be dealt with using increasingly common statistical/data linkage methods.

Data collection points

There are two main data collection points associated with a treatment/rehabilitation episode. These are the data collected on entry to the service and the data collected on exit. All services will be collecting data on entry, whereas data collection on exit may be new. Under the main co-production ethos of the recommended approach, if additional data collection at the end of the treatment/rehabilitation episode is to be instigated, then such data should be that which service users are happy to provide and services are happy to collect. It is likely that these data will be readily available from within any data recording systems used by the services. The data collected when entering the service and when leaving the main service episode can be used directly within the linked dataset. There would be no problems in relation to linking data with reduced identifiers (as a unique identifier will be used) and it is likely that missing data will be minimal, possibly only due to individuals choosing to opt out.

The four main follow-up data collection points are described as happening at 3, 6, 12 and 24 months (FU1, FU2, FU3 and FU4) following the exit data collection at the end of the main treatment/rehabilitation episode. It should be noted that a discussion of what constitutes this main episode may be warranted, with an agreement as to whether this includes step-down or reintegration services. This may differ between services and an initial stage of setting up a new outcomes study based on the linkage of data will be to broadly map out the data collection points and how they fit into the offer of any particular service. For example, the 2020 Coolmine Annual Report (Coolmine, 2021) describes a main (minimum) 5-month residential primary treatment episode followed by a (minimum) 2-month reintegration period, followed by a (minimum) 5-month aftercare period, which in turn is followed by lifelong aftercare, run by graduates for graduates with the support of a graduate co-ordinator. While the flowchart in Figure 3 follows the broad offer from Coolmine, other treatment or rehabilitation services may also have the services they provide mapped out in a similar manner. It is therefore possible that some (possibly all) of the follow-up data collection will be carried out when the individual is still in contact with the treatment/rehabilitation provider.

It is possible that those who completed the initial part of treatment may no longer be in contact with the service provider at follow-up. In such circumstances, the other approaches for collecting data, which are not based on the individual being in contact with the service, can be used.

In Figure 3, the entry and exit data collection points, as well as any of the four follow-up data collection points completed when the individual is still in contact with the service (i.e., data collection, at least in part, facilitated by the service) are shown as solid lines. Where the individual is not in contact, the same follow-up data collection is shown as a dashed line.

Other direct data linkage

A range of data collection activities will be carried out internally within a specific treatment or rehabilitation service, or with larger providers such as Coolmine, Cuan Mhuire, or the Tabor Group. An example of the breadth of services provided by a larger provider is set out in the 2020 Coolmine Annual Report (Coolmine, 2021). Many, if not all, of the various services provided, including community outreach, community detoxification, day programmes and housing/employment support services will be collecting data on clients at various points and, if in agreement with the individual, should be able to share suitably anonymised/protected data to allow the linked dataset to be able to exploit such information. This data collection is shown with a dashed arrow. In line with the wider ethos of this new approach to evaluating outcomes, involvement in the process should be voluntary and the data to be collected/shared should be agreed, with the expectation that they should be both brief and patient-centred.

Indirect data linkage

As described in this report, it should be possible to create linkages between existing datasets (primarily the NDTRS, but also possibly the NDRDI post-treatment) in order to augment the data collected directly from the individual/services as part of the main outcomes study (entry and exit data collection, FU1, FU2, FU3 and FU4). This may need additional research support, working in partnership with the organisation that is carrying out the residential outcomes evaluation. This data collection is shown (for the NDTRS) as a dashed line in Figure 3. As it may be easier to link from NDRDI data, this is shown as a different type of dashed line.

It is important to recognise that such linkage between previous NDTRS episodes and any subsequent episodes carried out by other services within a relevant time period will not be 100% complete. While this would be a major issue for a monitoring or surveillance system, it is an issue that can be dealt with using statistical methods within an epidemiologically based outcomes study. The issue would be more about engaging with service providers and people who use their service to agree what can be shared/linked, both in terms of informed consent and the particular data items. There may be additional data within the NDTRS that can facilitate the linkage, or data that can be quite easily collected within this new study (including readily available data) that can enhance the linkage, e.g. geographical location or contact with previous services. The key to this approach is maximising the data that can be easily collected, thus ensuring that the individuals who the data pertain to are happy to give informed consent for this to happen (either retrospectively or prospectively) and that the new study recognises that previous large-scale cohort studies with people who access drug treatment or residential services rarely meet the gold standard of randomised controlled trials in terms of very high follow-up rate and low rates of other loss to follow-up.