

# **Suicide by people in contact with substance misuse services in the UK: a feasibility study**

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## ABBREVIATIONS

<b>ADP</b>	Alcohol and Drug Partnership
<b>APB</b>	Area Planning Board
<b>CQC</b>	Care Quality Commission
<b>CGL</b>	Change Grow Live
<b>DACT</b>	Drug and Alcohol Coordination Team
<b>DAISy</b>	Drug and Alcohol Information System
<b>DATWT</b>	Drug and Alcohol Treatment Waiting Times
<b>HSCB</b>	Health and Social Care Board
<b>HSCT</b>	Health and Social Care Trust
<b>HQIP</b>	Healthcare Quality Improvement Partnership
<b>HRA CAG</b>	Health Research Authority Confidential Advisory Group
<b>HRA REC</b>	Health Research Authority Research Ethics Committee
<b>HEI FEC</b>	Higher Education Institution Full Economic Costing
<b>ISD</b>	Information Services Division
<b>IA</b>	Integration Authority
<b>NCISH</b>	National Confidential Inquiry into Suicide and Safety in Mental Health
<b>NDTMS</b>	National Drug Treatment Monitoring System
<b>NHSSMPA</b>	NHS Substance Misuse Provider Alliance
<b>NRS</b>	National Records of Scotland
<b>NISRA</b>	Northern Ireland Statistics and Research Agency
<b>ODR</b>	Office for Data Release
<b>ONS</b>	Office for National Statistics
<b>PBPP</b>	Public Benefit and Privacy Panel
<b>PHIRB</b>	Public Health Information and Research Branch
<b>RQIA</b>	Regulation and Quality Improvement Authority
<b>R&amp;D</b>	Research and Development
<b>SDMD</b>	Scottish Drug Misuse Database
<b>SMD</b>	Substance Misuse Database
<b>TOP</b>	Treatment Outcome Profile
<b>WNDSM</b>	Welsh National Database for Substance Misuse

## SUMMARY

### Why did we carry out the study?

People with substance misuse and dependence problems are at increased risk of co-occurring mental illness and suicide. Over half of people who die by suicide who are in recent contact with mental health services have a history of alcohol or drug misuse. In the UK, substance misuse services were historically provided by the NHS alongside specialist mental health care. Following 10 years of NHS reforms they have been significantly reshaped, with third sector organisations playing a greater role. This has made national investigations of people in contact with substance misuse services potentially more challenging to complete.

### What did we do?

We carried out a one-year study into the feasibility of establishing a clinical investigation into the frequency and nature of contact with substance misuse services prior to suicide. Our aims were to:

- (1) Understand how substance misuse services in the UK are commissioned and provided;
- (2) Explore whether we can map these services across the UK;
- (3) Explore what data are available for use in a study of suicide by people in contact with substance misuse services in the UK;
- (4) Examine the feasibility of an investigation into substance misuse service contact prior to suicide, including ethical, governance and costing implications, either by:
  - Adapting the existing methodology of the National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH) used to identify patient suicides, OR
  - Using alternative existing data sources.

To do this, we (1) engaged with relevant stakeholders, including representatives from public health governing bodies, commissioning groups, planning boards, local authorities, service providers, and front-line practitioners in all four UK nations; (2) explored relevant sources of data that could be used, including via data linkage, to establish a national study investigating suicide by people in contact with substance misuse services.

### What did we find?

We found that substance misuse service provision varies between UK countries, and within local authorities (or their equivalent); services are run by health services, third sector organisations, or jointly commissioned. The complexity of the landscape and the frequent re-commissioning of these

services has made it difficult to track trends of suicide by people in contact with these services. Extrapolating from ONS data on deaths related to drug poisoning and NCISH data on suicide by people in contact with NHS specialist services, we estimate that there are around 400 suicide deaths per year by people in contact with substance misuse services.

We are satisfied that a study of suicide by people in contact with substance misuse services is feasible, and determined three options for obtaining national clinical data on people in contact with services prior to their death (below). This work carries a higher risk than the established core NCISH work, due to changing service provision, potential technical issues of data linkage, and the fact that we would need to establish relationships with substance misuse service providers. We would expect lower response rates. If our preferred option were to be developed into a study, we propose that the next stage would be to liaise with national data providers to develop a detailed proposal following exploration of technical issues.

### **Proposals for data collection**

Based on the views of stakeholders, we suggest three options for obtaining national data on people in contact with substance misuse services prior to suicide:

#### **Option 1: Using NCISH methodology**

Utilising existing NCISH methodology to capture information on the circumstances and care of people in contact with substance misuse services prior to their death.

#### **Option 2a: Linking mortality data with national substance misuse databases**

First linking national mortality data with existing databases of substance misuse service clients in England (the National Drug Treatment Monitoring System), Wales (the Welsh National Database for Substance Misuse), and Scotland (the Scottish Drug Misuse Database and the Drug and Alcohol Waiting Times database) to identify people who died by suicide within 12 months of substance misuse service contact, and then collecting clinical data on these people via questionnaires.

#### **Option 2b: Linking mortality data with leading third sector organisation databases**

Collecting clinical information from centrally-held records of the three main third sector organisations providing substance misuse care and treatment in England, Scotland and Wales.

**We propose that the preferred option for a national investigation into deaths by suicide in substance misuse services in the UK is option 2a in England, Wales and Scotland. Linking with existing datasets would be the most comprehensive and robust method to identify people who died by suicide in recent contact with substance misuse services. Collecting additional clinical data via a questionnaire developed for this purpose would ensure that relevant factors associated with suicide are identified. This would be less resource intensive than using the NCISH model but would collect similarly rich data. Northern Ireland does not have an identifiable national database for substance misuse treatment and therefore the NCISH model would be the preferred option.**

## BACKGROUND

Suicide rates in the UK have declined steadily over recent years<sup>1</sup> but certain sub-groups remain at heightened risk, including people with substance misuse and dependence problems.<sup>2,3</sup> Almost a quarter (22%) of drug-related deaths receive a conclusion of suicide or undetermined intent at coroner's inquest,<sup>4</sup> and this figure may be an underestimate due to the considerable overlap or relationship between reported accidental overdoses and suicide attempts.<sup>5</sup> Tackling substance misuse as a driver for suicide prevention is a Government priority.<sup>6</sup> This is a particular priority for high-risk groups where substance misuse is known to be a common risk factor for suicide, including middle-aged men, who have the highest rates of suicide,<sup>7</sup> and young people, in whom rates are increasing.<sup>8</sup> In 2016/17, the Care Quality Commission inspected 68 independent units offering residential detoxification from drugs and/or alcohol, and took action to require that 49 of these units make improvements as they had failed to reach fundamental standards of care.<sup>9</sup> CQC recommendations will improve the care of all people under these services, though these inspections related only to independent residential detoxification services, and did not specifically address the factors associated with suicide in this vulnerable group.

The relationship between substance misuse and suicide is complex as mental health problems often co-occur; 80% of people receiving treatment for alcohol misuse and around 70% of those receiving drug treatment are thought to have coexisting mental health problems.<sup>10,11</sup> In a national consecutive case series of all deaths by suicide in the UK, over half (56%) of patient suicides (i.e. people in contact with mental health services within 12 months of suicide) had a history of alcohol or drug misuse. Of those, only a minority were in contact with specialist substance misuse services.<sup>12</sup> In England, the National Drug Treatment Monitoring System (NDTMS) reports that only around half of substance misuse service clients with a mental health treatment need receive the required treatment from mental health services.<sup>13</sup> NDTMS also reports that the number of people receiving treatment for alcohol alone has decreased by 17% from 2012/13 to 2017/18, though estimates of alcohol dependency have remained relatively stable, suggesting that only one in five people in need of treatment are receiving it. Substance misuse service providers have indicated that supporting people with coexisting mental illness is increasingly challenging due to scarce resources.<sup>14</sup>

Historically, substance misuse services were provided alongside specialist mental health care by local mental health trusts/health boards. In the past 10 years, NHS reforms across the UK have reshaped substance misuse services, with third sector and voluntary organisations playing a greater role.<sup>15</sup> These organisations now bid to local authorities for the contract to provide specialist substance

misuse treatment services, and these services are re-commissioned around every three years. Recent changes to the commissioning of substance misuse services across the UK are detailed on pages 12-13 of this report. This significant reshaping of substance misuse services has made it difficult to track trends and identify factors associated with suicide in this vulnerable population. Without the data to accurately record the frequency and nature of contact with substance misuse services prior to suicide, meeting the Government's priority of tackling substance misuse as a driver for suicide prevention is challenging.



## AIMS OF THE FEASIBILITY STUDY

The National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH) was commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England, NHS Wales, the Scottish Government Health and Social Care Directorate, and the Northern Ireland Department of Health to examine the feasibility of establishing an investigation into the frequency and nature of contact with substance misuse services prior to suicide. This study was selected as a topic for investigation by our Independent Advisory Group (IAG), who will assess whether a full study will be commissioned by HQIP. Specifically, the objectives of this study are to;

- (1) Understand how substance misuse services in the UK are commissioned and provided;
- (2) Explore whether we can map these services across the UK;
- (3) Explore what data are available for use in a study of suicide by people in contact with substance misuse services in the UK;
- (4) Examine the feasibility of an investigation into substance misuse service contact prior to suicide, including ethical, governance and costing implications, either by:
  - Adapting the existing methodology of the National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH) used to identify patient suicides, OR
  - Using alternative existing data sources.

In addressing these objectives, we have:

- Interviewed six practitioners working in NHS, third sector and jointly funded substance misuse services about treatment pathways, management of dual diagnosis, and the incidence and investigation of suicide deaths in their service. Interviewees were also asked whether they would engage with an investigation into contact with substance services prior to suicide, and whether and how it might inform their practice;
- Engaged with relevant stakeholders across the UK, including:
  - People who receive care:** organisations representing people with substance misuse problems;
  - People who deliver care:** service providers, front-line practitioners;
  - People who commission care:** commissioning groups, planning boards, local authorities;
  - Other key stakeholders:** Public Health England, Scottish Government, Public Health Wales, Public Health Authority, the Care Quality Commission, the National Drug Treatment Monitoring System (NDTMS), the Welsh National Database for Substance Misuse (WNDSM), the Scottish Drug Misuse Database (SDMD), relevant academic bodies;
- Identified existing databases of people in contact with substance misuse services;

- Established whether the NCISH methodology could be used to examine contact with substance misuse services, including highlighting any barriers to data collection;

## **Structure of this report**

This report summarises:

- (1) Information from key stakeholders about who provides alcohol and drug treatment services in the UK, and whether these services can be mapped;
- (2) Available national sources of data on the frequency and nature of contact with substance misuse services in the UK, and whether any clinical data are routinely collected;
- (3) How NCISH operates, and how this methodology could be used to establish an investigation into the frequency and nature of contact with substance misuse services prior to suicide;
- (4) Options for potential methodology for collecting data on the rate and nature of contact of substance misuse services prior to suicide, including considerations and our preferred option;
- (5) Indicative costings for the options proposed.

## SUBSTANCE MISUSE SERVICES IN THE UK

### Substance misuse service providers

Substance misuse services in the UK are provided by (1) third sector charitable organisations, and (2) NHS providers. There is little published data about the number of contracts awarded to third sector organisations. In 2014, Public Health England estimated around 50% of substance misuse services were provided by third sector organisations.<sup>16</sup> Key stakeholders told us that the current situation is estimated nearer 75% of substance misuse services in England being provided by third sector organisations as specialist NHS service providers diminish.

### Third sector substance misuse services

Third sector organisations are registered charities funded via (1) contracts from local authorities, NHS trusts or similar institutions; (2) grants; (3) individual beneficiaries; (4) trading incomes, or (5) a combination of these funding streams. There are three leading third sector organisations that provide substance misuse treatment services in the UK (excluding Northern Ireland): Change Grow Live (CGL), Addaction, and Turning Point. All three national providers are centrally managed with regional offices. In Wales, the main third sector provider is Kaleidoscope. There are also a number of smaller third sector organisations who co-provide substance misuse services often with the three leading providers (e.g. Blenheim alcohol and drug charity work in partnership with Turning Point). Collective Voice, a group of eight third sector substance misuse organisations (including CGL and Turning Point), work together to represent the interests of individuals who use their services.

### NHS substance misuse services

NHS substance misuse services are delivered by NHS providers and are subject to tendering for funding from local authorities. Some NHS providers with well-established substance misuse services deliver these more widely to other mental health providers (e.g. Midlands Partnership NHS Foundation Trust's Inclusion provides alcohol and drug services nationally). Most NHS providers deliver care for several local authorities; this means some geographical areas of a local authority can have their substance misuse services provided by either their host trust, a different NHS provider, a third sector organisation, or a combination. The NHS Substance Misuse Provider Alliance (NHSSMPA) is a group of 11 NHS Trusts who provide substance misuse treatment services across England. The NHSSMPA works collaboratively with service users, stakeholders and other organisations to contribute to the development of research and to help shape alcohol and drug policy.

## Commissioning of substance misuse services

The commissioning of substance misuse services has become more complex over the last decade. We have summarised relevant information relating to commissioning of these services from our discussions with key stakeholders.

### England

Prior to 2012, substance misuse services in England were jointly commissioned by the NHS and local authorities. Following the introduction of the Health and Social Care Act in 2012,<sup>17</sup> the commissioning of substance misuse services became the responsibility of local authorities. The 152 upper tier local authorities in England are allocated a Government budget overseen by Public Health England. Services are commissioned through a competitive tendering process in conjunction with Health and Wellbeing Boards, with an average time frame for re-tendering of three years with regional differences. Contracts are awarded to the NHS, large third sector charitable organisations, and smaller charities or, in some areas, a combination of these. Several services provide care across multiple regions and funding may be pooled from multiple local authorities. Service contracts are often divided between providers: it is not uncommon to have NHS services delivering prescribing treatments, and third sector services providing psychosocial interventions within the same locality.

In 2014, the NDTMS conducted a national survey of substance misuse services in England, and recorded 1,172 service sites.<sup>18</sup> This number is constantly fluctuating – the current estimate being around 900<sup>13</sup> - as the larger organisations take on more contracts and smaller charities become absorbed into larger organisations.

### Scotland

In 2014, the governance, planning and resourcing of adult social care and key health services were brought together by the introduction of The Public Bodies (Joint Working) (Scotland) Act.<sup>19</sup> The Act created Integration Authorities (IAs); partnerships between local authorities and Health Boards. IAs are allocated funding from the Scottish Government, some of which is then distributed to 30 Alcohol and Drug Partnerships (ADPs), multi-agency strategic partnerships responsible for planning and commissioning services to deliver substance misuse treatment in local areas. In total, there are 31 IAs which are aligned to the 30 ADPs (the local authorities Stirling and Clackmannanshire share an IA and an ADP, and Mid and East Lothian share an ADP but have separate IAs). We found that medical treatment and harm reduction interventions are most often provided by NHS providers, whilst follow-up care and psychosocial interventions are provided by charitable organisations. However, as in England, this is a constantly changing landscape.

## Wales

In Wales, seven Area Planning Boards (APBs) align to the seven NHS Health Boards to commission substance misuse services. These APBs were established in 2010 as part of plans for the delivery of the Welsh Government’s Substance Misuse Strategy ‘Working Together to Reduce Harm’.<sup>20</sup> Each APB is responsible for the strategic direction and work programme for the local area, and services are provided based on the needs of the population. Substance misuse services are provided by NHS Health Boards, third sector organisations or a combination of both. As in England, services in Wales are also subject to tender approximately every three years.

## Northern Ireland

Substance misuse services in Northern Ireland are commissioned by the Health and Social Care Board (HSCB), and delivered by the five NHS Health and Social Care Trusts (HSCTs). Each HSCT has a Drug and Alcohol Coordination Team (DACT); a multi-agency partnership comprising all key organisations (statutory, community, and voluntary) with an interest in addressing drug and alcohol related issues and concerns in the local area. The work of the DACTs is supported by the Public Health Agency whose local lead for drug and alcohol facilitates the work of the team. DACTs promote and support a coordinated approach to addressing alcohol and drug-related issues across each Health and Social Care Trust area. DACTs do not directly commission services, hold a budget or hold clinical record systems.

## Exemplar substance misuse service provision: Greater Manchester

Service provision varies within local authorities. Here we use the county of Greater Manchester as an example of this complexity, with services variously provided by (i) the NHS, (ii) the third sector, and (iii) jointly commissioned care.

### Map of Greater Manchester’s local authorities and sector substance misuse providers.



Local Authority	NHS Mental Health Trust	Substance Misuse Service Provider
1	B	Third sector-Addaction
2	A	NHS home trust
3	A	NHS home trust
4	A	NHS home trust
5	A	Third sector -CGL
6	C	Third sector -ADS
7	C	Third sector -Turning Point
8	C	Third sector -Turning Point
9	C	Third sector -CGL
10	C	NHS home trust and third sector -CGL

## **What do these complexities mean for care?**

We interviewed six frontline practitioners and 31 stakeholders about the complexities of current substance misuse service provision in the UK and how this impacts on care. The following themes emerged from these discussions:

### **Care pathways**

Staff told us that there is often no clear treatment pathway for clients with substance misuse problems. Some services offered a central hub of mental health, substance misuse, harm reduction, and rehabilitation services, whereas in more rural areas, services were often delivered by GP surgeries. We were told that the frequent re-tendering of substance misuse services was experienced as disruptive by some clients.

### **Non-alignment of service provision**

The footprints of NHS services and third sector substance misuse services are not always aligned. This can mean individuals with coexisting mental illness and substance misuse might receive mental health support from one service area, and substance misuse support from another. For these people, their medical records may not be linked unless an agreement is in place between services; this could lead to poor communication and information sharing, and disjointed and uncoordinated care.

### **Mental health service access**

We were told that substance misuse service clients often had difficulty in accessing adequate mental health care. Those under mental health services in addition to substance misuse services experienced poor information sharing with little in the way of joint care planning, case management and few joint reviews.

### **Risk assessment**

Risk assessments are often duplicated if there are multiple providers involved in a client's care. Our discussions highlighted concerns around inadequate communication of suicide risk – a theme also identified in our recent report on the assessment of clinical risk in mental health services.<sup>21</sup>

## CAN SUBSTANCE MISUSE SERVICES BE MAPPED ACROSS THE UK?

There is no definitive record of the total number of NHS and third sector substance misuse services across the UK (with the exception of Northern Ireland where all services are provided by the five Health and Social Care Trusts). Current informed estimates are of 900 individual substance misuse services in England alone,<sup>13</sup> around 60% of which are provided by the three leading third sector organisations; CGL, Addaction and Turning Point. Several organisations have made efforts to maintain a list of substance misuse services across the UK and these are detailed below.

### England

#### (i) Care Quality Commission (CQC)

The CQC, a non-departmental public body of the Department of Health and Social Care, holds a database of all registered providers of substance misuse services in England. This resource covers details of regulated and registered services by provider type. The CQC database, however, does not hold comprehensive information on all substance misuse services in England. The database is updated following any CQC service inspection, but not updated following the re-tendering of services if this falls outside of the inspection timeframe.

#### (ii) Commissioners

Each of the 152 upper tier local authorities in England holds details of the substance misuse services they commission. Many providers offer services across multiple authorities and many authorities have multiple providers.

#### (iii) National Drug Treatment Monitoring System (NDTMS)

The NDTMS collects information from all publicly-funded substance misuse services in England, including the names of the providers of these services. This information is over-seen by Public Health England and is not publically available. Access to this list of substance misuse service providers would be via a Freedom of Information Act request.

#### (iv) Online resources, e.g. Talk to Frank

Talk to Frank is an online resource for substance misuse information, including information on how to access services and where these services are available (by a postcode search). However, information on which services are available in which areas is not regularly updated.

## Scotland

### (i) Commissioners

The 30 Scottish ADPs currently coordinate 268 substance misuse services across Scotland. Information on which services are commissioned is held and maintained by the ADPs and would be available on request.

### (ii) Scottish Drug Misuse Database (SDMD) and Drug and Alcohol Treatment Waiting Times (DATWT) database

The SDMD collects information from all drug (including alcohol and drug) misuse service providers in Scotland. The DATWT database collects information on individuals referred for drug *or* alcohol treatment. This information is managed by the Information Services Division (ISD) of NHS National Services Scotland. The SDMD and DATWT service list includes contact details of the service providers across Scotland, which we obtained on request. From this, we know there are currently 268 active substance misuse services providing data for SDMD and DATWT in Scotland.

### (iii) Online resources, e.g. Know the Score

Similar to Talk to Frank, Know the Score's website provides information on substance misuse, including a (postcode searchable) service directory on local substance misuse services. As with England, this information is not regularly updated.

## Wales

### (i) Commissioners

The NHS Wales Informatics Service website<sup>22</sup> previously published a map of substance misuse services across Wales, provided by the Substance Misuse Advisory Regional Team of Welsh Government. This has now been removed from the website, and to our knowledge this has not been updated since 2013.

### (ii) Welsh National Database for Substance Misuse (WNDSM)

The WNDSM collects information from all substance misuse service providers in Wales in receipt of Welsh Government funding, including the names of the providers of these services. This information is controlled by The NHS Wales Informatics Service and is not publically available. We have been provided with this information, on request. From this, we know there are currently 48 substance misuse providers over 138 sites across Wales.



### (iii) Online resources e.g. Dan 24/7

As with online resources in England and Scotland, Dan 24/7 is a website that offers users the option to search online for local and national substance misuse services (either by postcode or type of service). This information is not regularly updated.

## Northern Ireland

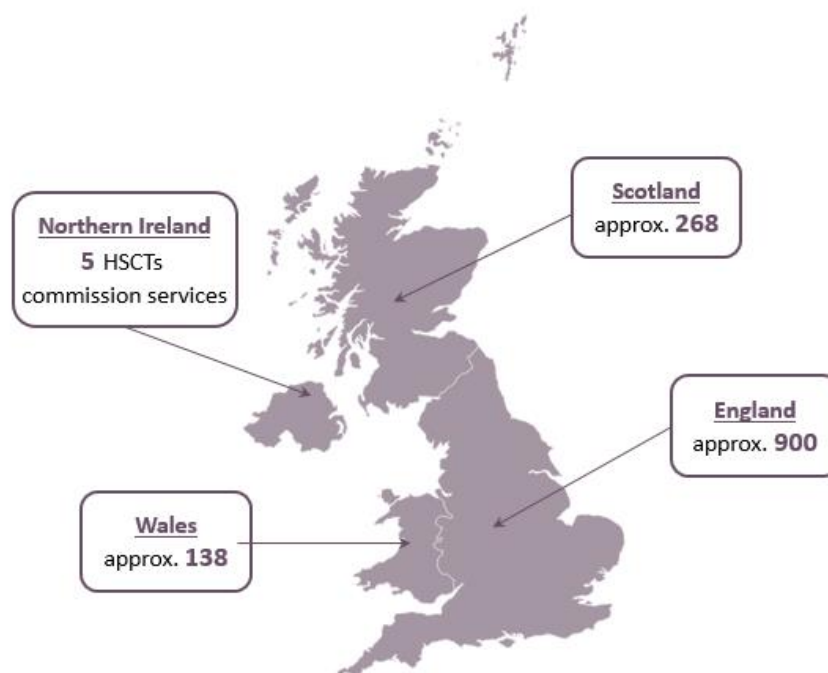
### (i) Commissioners

All five Health and Social Care Trusts (HSCTs) provide substance misuse care and treatment through commissioned secondary and tertiary services across Northern Ireland. The Health and Social Care Board (HSCB) has recently developed a document detailing substance misuse services across the country. This information is not publicly available, and has been provided to us on request.

## Mapping services across the UK

It is theoretically possible to devise a map of substance misuse services across the UK based on information from commissioners and/or a combination of the organisations listed above. However, due to the complexity of the landscape and the frequent re-commissioning of substance misuse services, this would be a challenging process requiring constant administrative support to keep the information valid and up-to-date. Indicative numbers of individual services by nation are shown below, with many of these provided by national organisations.

### Approximate number of substance misuse service providers in the UK



## AVAILABLE DATA

We asked six practitioners working in NHS, third sector and jointly-funded substance misuse services for their views on the importance of an investigation into the frequency and nature of contact with substance misuse services prior to suicide. They cited an interest in examining (1) changes in suicide rates following re-commissioning of services, (2) overall trends, and (3) factors associated with suicide (particularly engagement with services, and family and life history of clients), and (4) problems associated with caring for people with coexisting mental illness and substance misuse.

We have developed a preliminary questionnaire to establish if variables identified from the literature are available from the centrally-held clinical records of the three leading organisations providing substance misuse services in the UK. Our proposed data collection would allow us to identify factors associated with suicide in this group, and details of the care received. It would be possible to analyse sub-groups, including people with solely alcohol or drug dependence, or both, to identify common factors unique to each group.

In the event that a study of suicide by people in contact with substance misuse services is established, we suggest that key stakeholders should be invited to review the questionnaire and provide feedback on the contents; this should include people with specialist expertise in the area of substance misuse, as well as representatives from relevant service user organisations, and people with lived experience.

### **Existing substance misuse databases**

When someone receives treatment from a substance misuse service in England, Scotland or Wales, standardised information is recorded by the health worker and shared, if consent is given, with relevant Government agencies (e.g. Public Health England) for collection in a national database. It is mandatory for substance misuse services to update national databases with information on an individual's treatment every 12 weeks, following discharge from the service, or if the person disengages from treatment. Each agency offering substance misuse treatment is assigned a unique code within the database. Identifiable databases are available in England, Scotland and Wales, but not in Northern Ireland. Voluntary organisations, although a source of support for many, that are not funded by contract do not consistently hold identifiable data, and are therefore excluded from this feasibility investigation.

### **National Drug Treatment Monitoring System (NDTMS) (England)**

The NDTMS is managed by Public Health England and collects information on all individuals who are assessed and accepted into treatment from all publicly-funded substance misuse services in England. As well as collecting information on the types of substances used, the treatment received, and the length of time in treatment, the NDTMS use Treatment Outcome Profiles (TOP), an outcome monitoring tool for substance misuse services. Basic data are gathered in four areas: (1) current substance use; (2) injecting behaviour; (3) crime; and (4) health and social functioning. Data held by the NDTMS can be requested via the Office for Data Release (ODR).

### **Welsh National Database for Substance Misuse (WNDSM)**

The WNDSM is managed by NHS Wales Informatics Service. All substance misuse service providers in Wales in receipt of Government funding submit their data to the WNDSM, which, like NDTMS, uses Treatment Outcome Profiles.

### **Scottish Drug Misuse Database (SDMD)**

The SDMD is managed by the Information Services Division (ISD) Scotland (part of NHS Scotland), and gathers similar information to the NDTMS and the WNDSM. The SDMD gathers data on individuals assessed for specialist drug treatment and does not collect data on individuals presenting for alcohol treatment only.

### **Drug and Alcohol Treatment Waiting Time (DATWT) database (Scotland)**

The DATWT database is managed by ISD Scotland and collects data on individuals who are referred for specialist drug or alcohol treatment. This information includes personal, referral, assessment and treatment details. We have been informed that information held within DATWT includes the name of the service where the initial treatment was provided. The Drug and Alcohol Information System (DAISy) is being developed to collect data from services providing specialist drug and alcohol treatment services (amalgamating data currently held in the SDMD and DATWT) and is due to be launched in late 2019. Until DAISy is operational, data will continue to be gathered and held in the SDMD and DATWT.

### **Substance Misuse Database (SMD) (Northern Ireland)**

The Northern Ireland Substance Misuse Database (SMD) is overseen by the Public Health Information Research Branch, and collects data on substance misuse service users in Northern Ireland. This information is not identifiable.

## **Clinical data held by third sector organisations**

Third sector organisations Change Grow Live, Addaction, and Turning Point collectively provide around 60% of substance misuse services in England, Scotland and Wales (NB: a conservative estimate provided by key stakeholders). Proportionally, the majority of these services are in England, with smaller provision in Scotland and Wales. They hold central clinical databases, including information on demographic factors, social circumstances, coexisting mental illness, physical illness, and treatment received. Stakeholders from the three leading organisations have reviewed the proposed NCISH questionnaire (see page 18 of this report) and indicated that similar variables are collected in their databases.

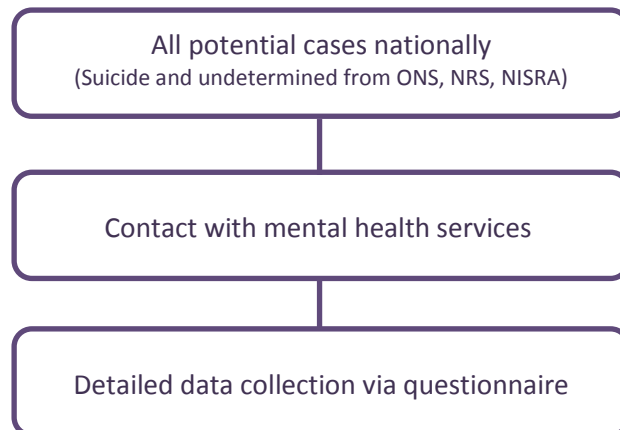
## **The National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH)**

NCISH has collected in-depth information on all suicides by people in contact with mental health services in the twelve months prior to their death in the UK for over 20 years. Our recommendations have improved patient safety in mental health settings and reduced patient suicide rates, contributing to an overall reduction in suicide in the UK.<sup>23</sup> Our evidence is cited in national policies and clinical guidance and regulation across the UK. The NCISH has three broad aims:

- To examine the circumstances leading up to and surrounding the deaths by suicide of people under the recent care of, or recently discharged from, specialist mental health services;
- To identify factors in the management and care of patients which may be related to suicide;
- To recommend measures to reduce the number of suicides by people receiving specialist mental health care.

NCISH collects information on all deaths in the UK allocated a suicide or undetermined conclusion at coroner's inquest. Further detailed demographic, behavioural and clinical information is then collected on all those who were in contact with mental health services in the year prior to death. Our core data collection process is summarised below. NCISH has the overall aim of improving safety of mental health services for all patients, which in turn contributes to a reduction in patient suicide rates and an overall decrease in suicide rates nationally.

## NCISH methodology



NCISH have (1) a limited dataset on all general population suicides, covering basic demographics and geography, and (2) a detailed dataset on suicide by mental health patients, covering key aspects of health and social care. Prior to NHS reforms introduced over the last 10 years, treatment for substance misuse problems was delivered by mental health services. This meant NCISH previously had access to the epidemiological data on all individuals who died by suicide within 12 months of contact with substance misuse services. Currently, information is available to NCISH only on people in contact with NHS-based substance misuse services. This is complicated by instances where people had been seen by both mental health and substance misuse services prior to suicide – clinical data are only collected from the service that had the most recent last client contact.

Given our long-standing and well-established methodology for collecting in-depth information on all suicides of mental health patients in the UK and our history of handling confidential and sensitive data, we would be well-placed to collect data from substance misuse services in addition to our existing work programme. This would allow the possibility of data linkage with the current NCISH database of suicides by mental health patients to compare specific characteristics and trends.

## SUICIDE BY PEOPLE IN CONTACT WITH SUBSTANCE MISUSE SERVICES: PROPOSAL

We have explored the possibility of three options for a study examining substance misuse service contact before suicide across the UK.

### Option 1: Using NCISH methodology

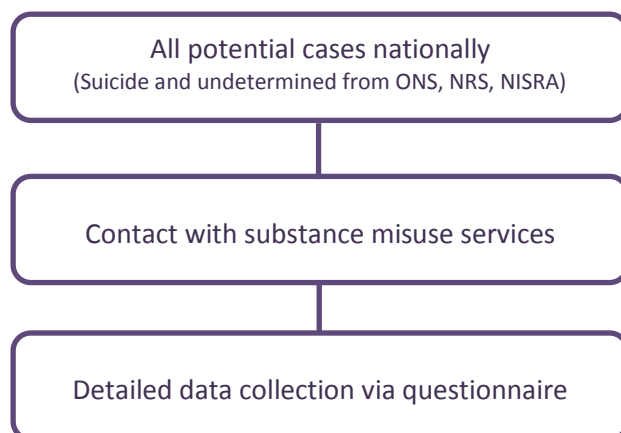
NCISH methodology, as described on pages 20-21 of this report, could be adapted as follows:

**Stage 1:** Information about people who died by suicide and probably suicide (undetermined deaths), including the district of residence and death, would be obtained from general population mortality data collected quarterly from national data providers (ONS for deaths registered in England and Wales; National Records of Scotland (NRS) for deaths registered in Scotland; and the Northern Ireland Statistics and Research Agency (NISRA) for deaths registered in Northern Ireland).

**Stage 2:** Details of each person would then be submitted to organisations providing substance misuse care and treatment in each individual's district of residence, district of death and adjacent districts, to identify those who had service contact in the 12 months before death.

**Stage 3:** If service contact is confirmed in stage 2, detailed clinical data would be obtained via an online questionnaire sent to the clinician responsible for the patient's care.

### Methodology for option 1



### Considerations for option 1

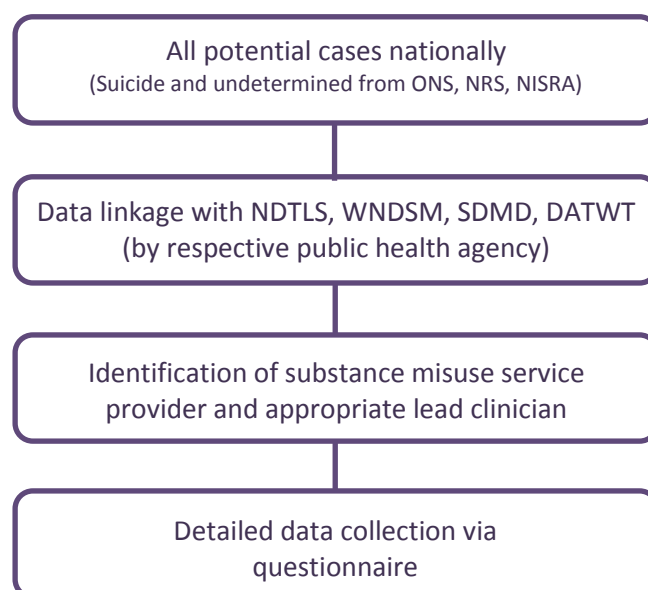
- (1) The clinicians we interviewed all agreed that completing a questionnaire following the death of a client in receipt of substance misuse treatment would be feasible within their workload and that because comprehensive client notes are kept these would be sufficient for completion of the questionnaire by any member of the care team;
- (2) Interviewees informed us that clinical notes stay with the client's care provider regardless of staff turnover and re-commissioning;
- (3) Local authorities (or their equivalent) will need to be contacted prior to data collection to determine which substance misuse services they commission. Alternatively, organisations providing substance misuse treatment services across the UK would need to be mapped;
- (4) In many areas substance misuse services will be provided by national organisations (e.g. CGL), whilst some areas will have services provided by a combination of NHS and third sector providers;
- (5) Multiple substance misuse services would need to be sent a list of named individuals to identify potential contact in the 12 months prior to death, to allow for the complexities detailed above. This may result in multiple questionnaires being received from a number of providers on one individual. Detailed protocols would need to be in place prior to data collection including information on how to respond to conflicting data;
- (6) A named administrative contact would be required in over 900 substance misuse service sites in England, 268 in Scotland, 138 in Wales and from the five HSCTs in Northern Ireland;
- (7) Substance misuse service providers change frequently due to the re-tendering process. This usually happens every three years, but we found examples of contracts lasting from one to ten years;
- (8) Local authorities can fund more than one substance misuse service which can provide different treatments to the same patient;
- (9) Not all services will have their patient records digitalised; some may still be paper based. This may have resource implications for these services, and also implications for the potential loss of data;
- (10) We have been informed that questionnaires from larger third sector organisations would be completed from centrally-held databases, not by the individual who treated the client;
- (11) Some smaller substance misuse services may not have the capacity to complete the questionnaires;
- (12) Services may be unaware that a client had died by suicide until receiving notification as detailed above.

## Option 2a: Linking mortality data with national substance misuse databases

Option 2a would use national databases in England, Scotland and Wales to establish whether a person who died by suicide had contact with substance misuse services. These databases (detailed on pages 18-19 of this report) could be linked to general population mortality data from national data providers to identify people who had died by suicide within 12 months of contact with substance misuse services. Both the Scottish and Welsh national databases have previously been successfully linked with national mortality data.<sup>24,25</sup> From consultation with key representatives at relevant public health agencies, we have been informed that individual-level, identifiable information available on these databases includes: first name or initial, surname or initial, date of birth, gender, and local authority area of residence.

In order to ensure compliance with the Data Protection Act 2018 we propose only personal identifiers relevant to correctly and accurately match mortality data with substance misuse treatment data will be used. Identifiable information would be linked (by one-way data linkage) using OpenPseudonymiser software<sup>26</sup> in England (discussions would need to be held with Public Health colleagues in Scotland and Wales to identify a suitable linkage process). Once the data were linked, information could be gathered about the service in which the client was last treated, including contact information, via their respective agency code. We then propose contacting the relevant service provider (by letter) to identify the responsible clinician to complete an online questionnaire about their care and treatment.

### Methodology for option 2a





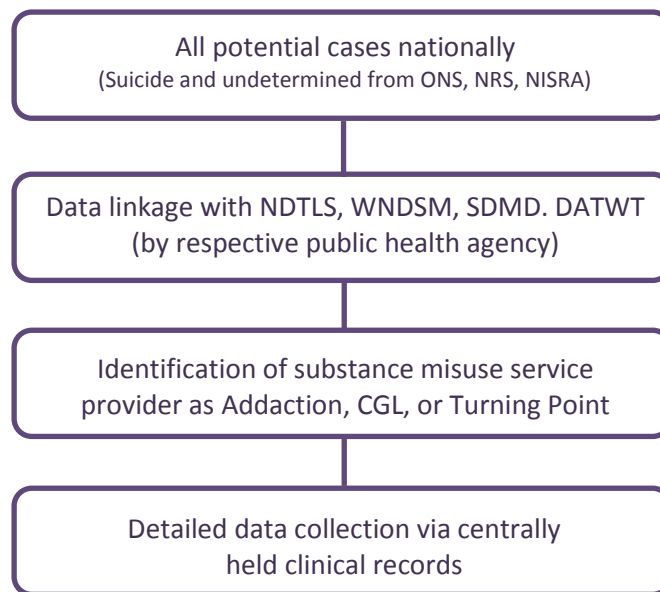
### Considerations for option 2a

- (1) As in option 1, clinicians confirmed that completing a questionnaire following the death of a client in receipt of substance misuse treatment would be feasible within their workload and comprehensive client notes would allow completion of the questionnaire by any member of the care team;
- (2) There are cost implications for the linkage of national mortality data with the NDTMS, SDMD and DATWT database (see page 30 of this report);
- (3) Northern Ireland does not have an identifiable national substance misuse database; therefore, option 2a would not be available for establishing the frequency of contact with substance misuse services in Northern Ireland;
- (4) There may be data quality issues, including linkage errors which may miss or duplicate service contact;
- (5) The NDTMS, WNDMS SDMD and DATWT only record information for clients who have given their consent for their information to be shared. These databases do not include information on all people who receive treatment from substance misuse services. However, NDTMS have reported their current consent refusal rate as under 1%.<sup>27</sup>

### Option 2b: Linking mortality data with leading third sector organisation databases

Option 2b would gather data from the centrally-held clinical records of the three leading third sector organisations providing substance misuse treatment services in the UK – Change Grow Live, Addaction and Turning Point. These three organisations, who provide around 60% of services in the UK, have indicated that direct linkage of mortality data with their databases would not be feasible. Therefore, this option would still require linkage to national databases in England, Scotland and Wales to establish whether a person who died by suicide had contact with substance misuse services, as in option 2a. Where contact with the three organisations was established, a pro forma would then be completed from the routinely-collected data. During our discussions, stakeholders from these organisations indicated that a research team could visit their central offices to extract the data.

## Methodology for option 2b



## Considerations for option 2b

- (1) This option would avoid a reliance on questionnaire completion by clinicians, who already have significant workloads;
- (2) There are cost implications for the linkage of national mortality data with the NDTMS, SDMD, and DATWT database (see page 30 of this report);
- (3) In order to progress this option, we would need to identify what clinical information is collected centrally, whether this is robust and consistent across each of the three providers, and whether this would be comparable to data collected via questionnaire;
- (4) Data collection would be from standardised records, and not from a clinician who knew the person;
- (5) This option would only collect information from the three main service providers Addaction, CGL, and Turning Point.

## ETHICS AND GOVERNANCE

This proposed study would require various approvals and data sharing agreements, given the handling of sensitive personal data. We have summarised the organisations that would need to be contacted for the study to commence in each of the four nations, and related governance considerations.

### England and Wales

- The Health Research Authority (HRA) Research Ethic Committee (REC);
- The Health Research Authority (HRA) Confidentiality Advisory Group (CAG) (for exemption under Section 251 of the NHS Act 2006 enabling access to confidential and identifiable information without consent in the interest of improving care);
- NHS Research and Development (R&D) sites;
- ONS to enable access to mortality data;
- Data release permissions will be required from the NDTMS (England);
- Data release permissions will be required from the WNDSM (Wales).

### Scotland

- NHS Scotland Public Benefit and Privacy Panel (PBPP) (for permission to access NHS Scotland health data without consent);
- HSC Research and Development (R&D) sites;
- NRS to enable access to mortality data;
- Data release permissions will be required from the SDMD and the DATWT database.

### Northern Ireland

There is currently no statutory gateway for setting aside the common law duty of confidentiality in Northern Ireland, such as is provided by Section 251 of the NHS Act 2006 in England and Wales and the PBPP in Scotland. This means that no patient identifiable information can be transferred outside Northern Ireland. NCISH have established a collaborative data collection of patient suicides in Northern Ireland with the Regulation and Quality Improvement Authority (RQIA), in order to maintain these confidentiality standards. The RQIA (i) receive national mortality data from NISRA; (ii) liaise directly with the HSCTs to identify those individuals in contact with mental health services in the 12 months prior to their death; and (iii) request the senior clinician responsible for the patient's care complete an electronic questionnaire. This pseudoanonymised patient information is then accessed, stored and analysed by NCISH. In order to establish a similar partnership with RQIA for a

study of suicide within 12 months of substance misuse service contact, the RQIA would need to liaise with NISRA (for mortality data), and the Privacy Advisory Committee in Northern Ireland.

### **Third sector organisations**

Currently third sector organisations do not have a streamlined single system for applying for the ethical permissions and approvals for health research in the same way as the NHS Integrated Research Application System (IRAS). We have been informed that obtaining NHS REC/PBPP/ Northern Ireland Privacy Advisory Committee approval and exemption under Section 251 of the NHS Act 2006 would be sufficient for these organisations to participate in the study, though individual organisations may have their own governance requirements.

## TIMESCALE AND COSTS

In order to determine approximate timescales and costs, we have estimated the number of deaths by suicide in substance misuse services. There are no suicide data specific to this population – this is something that the proposed study of suicide by people in with substance misuse services would provide. Given the lack of available appropriate data, we used two approaches to determine the crude approximate number of suicides by people in contact with substance misuse services: (1) forecast modelling of ONS data on deaths related to drug poisoning in England and Wales,<sup>4</sup> and (2) extrapolating from NCISH data of people in contact with specialist substance misuse services.

- (1) We used forecast modelling based on 7 years of ONS data on deaths related to drug poisoning to estimate expected numbers of deaths for 2018 and 2019. Our models suggest a stable trend with relatively wide prediction intervals reflecting variation in historical data. We estimate just under 800 intentional or undetermined deaths by drug poisoning in which drug misuse was involved in the two year period, around 400 deaths per year;
- (2) We know that around 1,600 deaths by suicide occur in people in contact with mental health services in the year before death.<sup>12</sup> Of those, we know that around half (~800) had a history of drug or alcohol misuse, and only 20% (~160) were in contact with specialist mental health services. This figure only refers to people in contact with mental health services AND substance misuse services; we would expect a higher number of suicides when taking into account people in contact with substance misuse only. The estimated figure of around 400 deaths per year from ONS data seems reasonable when extrapolating from NCISH suicide data.

Precise timescales and costs would be negotiated between the eventual provider and funders of the substance misuse study. NCISH would be well-placed to conduct the study, as we have established relationships with many of the key stakeholders via this feasibility investigation. We estimate that NCISH could conduct a study of this type within 18 months to 2 years, covering data collection relating to one year of deaths. Another provider may require additional time for initial set-up. We provide some indicative annual costs below. Please note that costs do not include any country-specific additional work, overheads, or the cost of setting up and maintaining an advisory group.

### **Option 1: Using NCISH methodology**

The main costs for option 1 are for a small project team including project management; senior clinical leadership; mid-grade or senior-grade research staff and administrative support. Sessional

input on statistics and IT will also need to be included. Other costs would include consumables (e.g. IT equipment, office costs), and travel costs to meetings etc. It is possible that initial costs will be lower as the project is established. Using NCISH as an example, we estimate that £180,000 to £200,000 would be needed to implement option 1. This sum does not include overheads or Higher Education Institution Full Economic Costing (HEI FEC).

### **Option 2a: Linking mortality data with national substance misuse databases**

Costs for option 2a would relate to data linkage costs (see below) and the operational costs of a small project team, which would be in the region of £120,000 to £150,000 (on the basis of a team comprising administrative support, one senior researcher/project manager, one clinical lead at professorial level working 1 day/week, and sessional input on statistics and IT).

### **Option 2b: Linking mortality data with national substance misuse databases**

Costs for option 2b would be in the region of £100,000 to £130,000 and would comprise data linkage costs, operational costs for a small project team (a smaller team than detailed for options 1 and 2 as administrative workload would be less), and possible additional charges to recover full staff costs incurred by CGL, Addaction and Turning Point in extracting data from their centrally held clinical records. At the time of reporting, we are unable to confirm if this would be the case.

## **Data linkage costs**

### **NDTMS (England)**

All requests to access Public Health England data are charged on a project-by-project basis to reflect the amount of work required to facilitate access to the data. The NDTMS have indicated estimated costs of £1,500 to £2,000 for the initial development of the process of linking NDTMS data with ONS mortality data and approximately £800 for ongoing costs per linkage. We suggest linkage would occur on a quarterly basis.

### **WNDSM (Wales)**

We have been advised that there are no costs associated with linking ONS mortality data with the WNDSM depending on who makes the request. University-based researchers are not charged for access to WNDSM data.

### **SDMD and DATWT database (Scotland)**

Charges are based on a full cost recovery plus overhead rate e.g. per diem rate + overhead rate x days worked. This allows ISD Scotland, data controllers for the SDMD and the DATWT database, to recover full staff costs incurred in the development, production and quality assurance of the required analysis. It is estimated that costs will be in a similar region to the NDTMS.

## CONCLUSION

The significant reshaping of substance misuse services over the last decade has made it difficult to track trends and identify factors associated with suicide in this vulnerable population; provider complexity is a key finding from our investigation. Key stakeholders have indicated that an investigation of suicide by people in contact with substance misuse services would be welcomed, and this work could help inform future national policy and guidance.

We are satisfied that a study of suicide by people in contact with substance misuse services is feasible, and estimate that there would be around 400 such deaths per year. We have determined three options for obtaining national clinical data on people in contact with substance misuse services prior to their death (below). NCISH would be well-placed to collect this data from substance misuse services. This work carries a higher risk than our existing work programme, due to (1) the complex and changing nature of service provision, (2) potential technical issues when relying on data linkage, and (3) the fact that we would need to establish relationships with substance misuse service providers, including independent providers. A study of suicide by people in contact with substance misuse services would not achieve response rates comparable to the core NCISH work (~95%). To establish a study of suicide by people in contact with substance misuse services using our preferred option, we propose that the next stage would be to liaise with national data providers to develop a detailed technical proposal for data linkage, exploring data quality, and setting out specific risks, costs, and timescale.

## Proposals for data collection

Based on the views of stakeholders, we suggest three options for obtaining national data on people in contact with substance misuse services prior to suicide:

### **Option 1: Using NCISH methodology**

Utilising existing NCISH methodology to capture information on the circumstances and care of people in contact with substance misuse services prior to their death.

### **Option 2a: Linking mortality data with national substance misuse databases**

First linking national mortality data with existing databases of substance misuse service clients in England (the National Drug Treatment Monitoring System), Wales (the Welsh National Database for Substance Misuse), and Scotland (the Scottish Drug Misuse Database and the Drug and Alcohol Waiting Times database) to identify people who died by suicide within 12 months of substance misuse service contact, and then collecting clinical data on these people via questionnaires.

### **Option 2b: Linking mortality data with leading third sector organisation databases**

Collecting clinical information from centrally-held records of the three main third sector organisations providing substance misuse care and treatment in England, Scotland and Wales.

**We propose that the preferred option for a national investigation into deaths by suicide in substance misuse services in the UK is option 2a in England, Wales and Scotland. Linking with existing datasets would be the most comprehensive and robust method to identify people who died by suicide in recent contact with substance misuse services. Collecting additional clinical data via a questionnaire developed for this purpose would ensure that relevant factors associated with suicide are identified. This would be less resource intensive than using the NCISH model but would collect similarly rich data. Northern Ireland does not have an identifiable national database for substance misuse treatment and therefore the NCISH model would be the preferred option.**



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