Privacy Notice

The Information Services Division (ISD) is a division of National Services Scotland, part of NHS Scotland. ISD provides health information, health intelligence and statistical services that support the NHS and Scottish Government in progressing quality improvement in health and care and facilitates robust planning and decision making.

This Privacy Notice explains how we will use the information we collect about individuals to estimate the prevalence of problem drug use among individuals aged 15-64 in Scotland in 2015/16.

Topics:

1. Why are you collecting information about individuals?
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1. Why are you collecting information about individuals?

A study to produce prevalence estimates of problem drug use (PDU) has been conducted in Scotland every 3 years since 2000. This will be the third time ISD have conducted the study in Scotland, having undertaken the 2009/10 and 2012/13 studies. The work is being commissioned by the Scottish Government, and the results will support delivery of the national drug strategy and the Sexual Health and Blood Borne Virus Framework 2015-2020 Update.

The majority of the problem drug using population in Scotland is ‘hidden’, which simply means that every problem drug user will not necessarily have accessed or come into contact with the services and agencies where data relating to their drug use may be recorded. As a result, there is no basis to obtain a simple count of problem drug users in a way that would reflect the true scale of problem drug use in Scotland.

To get round this, modelling techniques have been developed using the principles of capture/recapture to estimate the size of the hidden population. In Scotland, we do this by obtaining data from three independent sources where we know reliable information is recorded on the drug using behaviours of individuals, namely:

- Individuals registered with specialist drug treatment services
- Drug-related hospital admissions
- Criminal Justice Social Work reports

In the past, ISD have collected data from the Police on individuals detained or arrested under the Misuse of Drugs Act. However, for the current study, data will not be collected from Police Scotland.
We need to capture data at the level of each individual in order to examine the occurrence of those that appear in more than one of these three data sources. It is this extent of multiple contacts (overlaps) across the data sources that will determine the scale of the potential hidden problem drug using population in Scotland.

2. What information will you collect about individuals?

We will be sourcing data from: local alcohol and drug partnerships and all local authority social work departments. Health Board data on individuals admitted to hospital for any reason is already routinely collected by ISD Scotland, so no new data will be collected in that regard. For our purposes, we only require an extract of minimum information on individuals that have come into contact with any of the 

Each data source will be processed by host agency personnel, or by authorised NHS staff from ISD operating on behalf of the host agency, in order to extract a minimum set of identifiers (initials, gender, date of birth and postcode district of residence), and a series of 'yes/no' flags denoting each relevant drug-type category applicable to that particular individual.

3. How will the information be collected?

ISD Scotland, through our Consultancy Services Team, will be coordinating the collection of all data required for the study.

**Individuals registered with specialist drug treatment services**

There are 30 Alcohol and Drug Partnerships (ADPs) across Scotland. They ensure recovery-focused treatment services are available to meet the needs of their respective resident populations. They routinely collect data on individuals accessing their services in order to operationally support the delivery of treatment services to problem drug users.

Authorised staff at the ADP’s will coordinate an extract of the minimum information described above from all their local source systems in accordance with a standardised pro-forma.

The data will be transferred to ISD via either secure file transfer protocols (SFTP) or across the secure NHS network (N3).

**Drug-related hospital admissions**

ISD have been collecting data on individuals admitted to all NHS hospitals in Scotland since the late 1960's through the Scottish Morbidity Recording (SMR) schemes. The current format of the records was launched on 1st April 1996.

SMR01 collects episode level data on individuals discharged from acute specialities (excluding obstetrics and psychiatry), and SMR04 collects episode level data on individuals discharged from mental health specialities across Scotland.
The recording of diagnoses on both SMR01 and SMR04 comprise a main condition and, optionally, up to five further conditions. All conditions on data submissions for hospital discharges are coded according to the 10th revision of the International Classification of Diseases and Injuries (ICD-10).

Authorised staff from ISD’s Consultancy Services Team will extract the minimum information described above from SMR01 and SMR04 using established ICD-10 definitions; these will relate to either poisoning events or mental or behavioural disorders resulting from problem drug use.

**Criminal Justice Social Work reports**

Criminal Justice Social Work Reports (CJSWRs) are compiled by Social Workers, at the request of a sentencing Court, to assist the Court in determining the most appropriate disposal to impose on an offender. The report presents information on the individual, including reference to drug use, where relevant.

Criminal Justice Social Work Reports (CJSWRs) are predominantly being accessed in local authority social work offices where ISD data collectors will act as data processors on behalf of the local authority to code the required dataset. Some local authorities will transfer the relevant (2015/16) CJSW reports electronically to ISD, in order for the data processing function to be performed by ISD on NHS premises. The physical location of the data (Local Authority or NSS Premises) will be stipulated in a signed-off data sharing agreement.

Where data is being processed at local authority social work offices, the final dataset will be transferred to ISD premises on fully encrypted NHS laptop computers.

Where local authorities have requested that the minimum dataset be processed at ISD’s premises, the source reports will be transferred to ISD via a secure file transfer protocol (SFTP).

4. **How will you use the information about individuals?**

We only require individual-level data in order to determine the overlaps (i.e. frequency of individuals appearing in more than one of the WMUHH data sources).

To determine the hidden population of individuals with problem drug use, the individual records from WMUHH data sources will be matched by the identifying variables (initials, gender, date of birth and postcode district of residence) to create overlap tables. Once we have the data in the form of these multidimensional tables of counts (also referred to as contingency tables), we will fit statistical models to them in order to determine the extent of the hidden population. We will then combine the estimates of the hidden population with the known population totals in order to form the overall prevalence estimates. The contingency tables will be constructed using automated methods within our statistical software. We have no need to read the records manually other than to check a small number of records that might be flagged during initial validation and require to be queried with the data provider.

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5. Will the information about individuals be shared with anyone?

Once the information about individuals is supplied to ISD we will validate and then process the data into the format of anonymised contingency tables (counts). All analytical work is being undertaken by ISD, so there will be no need to share the individual-level data or anonymised contingency tables with third-parties.

During validation of the records supplied to us, it may be necessary to query individual cases that we need to reject, with the host agency supplying the initial data. This will be the case if there are missing data items on the initial extract that would otherwise render the record invalid to incorporate as a count within the contingency tables.

All results that are published will be in the form of aggregate tables and charts, showing the estimated number of problem drug users at a geographical level no smaller than local authority.

6. What are you doing to keep the information about individuals secure?

ISD (as part of National Services Scotland) have stringent policies and guidelines in place to protect sensitive information relating to individuals. These include:

- Confidentiality Guidelines
- Corporate Records Management Policy
- Document Storage, Retention and Disposal Policy
- Information Governance Policy
- Information Security Policy
- IT Acceptable Use Policy
- Statistical Disclosure Control Protocol

The study has been approved by the Public Benefit and Privacy Panel for Health and Social Care. The Panel provides a governance structure of NHSScotland, exercising delegated decision-making on behalf of NHSScotland Chief Executive Officers and the Registrar General. The panel operates as a centre of excellence for privacy, confidentiality, and information governance expertise in relation to Health and Social Care in Scotland, providing strategic leadership and direction in this area to NHSScotland Boards, the research community, and wider stakeholder groups.

Data on individuals registering with/receiving specialist drug treatment services will be transferred to ISD via either secure file transfer protocols (SFTP) or across the secure NHS N3 network.

File transfer will not be required for data on drug-related hospital admissions.

For data from Criminal Justice Social Work reports, where these data are being transferred electronically this will be via SFTP. Where these data are being accessed at source, in social work offices, ISD project staff will operate according to the NSS IT Acceptable Use Policy which covers SFTP and Encryption.
All data being shared with ISD from external agencies will be done so in accordance with signed-off Information Sharing Protocols.

All staff authorised to work on the project will have signed the confidentiality guidelines and have undertaken training in secure information handling.

Data on the study will be stored on secure NSS servers and will be accessed by ISD staff from ISD premises at Gyle Square, 1 South Gyle Crescent, Edinburgh, EH12 9EB/2nd floor, Meridian Court, 5 Cadogan Street, Glasgow, G2 6QE.

All software used within NSS must be appropriately authorised, purchased, licensed and installed. All computers that are accessible from the NSS network must be up to date with the latest IT security patches.

7. Can an individual request access to the information you are holding about them?

Yes, we have set out explicit provision in our information sharing protocols for subject access requests.

8. Can an individual request that their personal data is NOT used in the study?

Yes, if any individual notifies us that they do not want their information to be used in this study, their records will be removed.

9. How to contact us

Please contact us if you have any questions about this privacy notice or information we may be holding about you for the purposes of this study.

Please submit your enquiry by email to: nss.isddrugprevalence@nhs.net