

Data Protection Impact Assessment

Learning Disability Statistics Scotland

Information Assurance and Risk 4th August 2017



Introduction

The purpose of this document is to report on and assess against any potential privacy impacts as a result of the *Learning Disability Statistics Scotland* data collection proposed by the Scottish Government.

1. Document metadata

- 1.1 Name of Project: Learning Disability Statistics Scotland
- 1.2 Author of report: Julie Rintoul, Statistician, Health and Social Care Analysis Division, Scottish Government
- 1.3 Date of report: October 2018
- 1.4 Name of Information Asset Owner (IAO) of relevant business unit: Angela Campbell, Deputy Director, Health and Social Care Analysis Division, Scottish Government
- 1.5 Date for review of DPIA On-going during the development of the collection.

Review date	Details of update	Completion date	Approval Date
October 2019			

2. Description of the project

2.1 Description of the work:

Between 2001 and 2007, the Scottish Government collected an annual aggregate return of adults with learning disabilities at both national and Local Authority level in order to monitor 'The same as you?' policy. 'The same as you?' review of services for people with learning disabilities was published in May 2000. This review proposed 29 recommendations for developing learning disability services and set out a programme for change over 10 years, including recommendation 9, which stated that local authorities should keep local records of the number of adults with learning disabilities in the area and the services they use in order to plan services to meet their needs. In 2013, the Scottish Government published Scotland's learning disability strategy 'The Keys to Life' which builds on the success of 'The Same as You?'

Since 2008, the Scottish Commission for Learning Disability (SCLD) has collected individual level data on people with learning disabilities who are known to Local Authorities, on behalf of the Scottish Government. This is now published annually by SCLD as Learning Disability Statistics Scotland (LDSS), which covers information on individuals with a learning disability or autism spectrum diagnosis known to Local Authorities in Scotland.

Individual level data is collected on people with a learning disability or autism spectrum diagnosis aged 16 and 17 who are not in full-time education and on all those aged 18 and over who are known to Local Authorities. This information is collated directly from the authorities' information management systems.

There are 20 data items collected through the LDSS, which are:

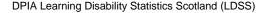
- Person Service Status
- ID number
- Learning disability
- Autism spectrum diagnosis
- Local Authority code / Health board code / out of area placement
- Person current gender
- Person date of birth
- Ethnic group
- Accommodation type
- Lives with family carer
- Number of people with a learning disability living in the same accommodation
- Advocacy
- Personal life plan
- Further education
- Employment opportunities
- Day opportunities
- Local Area Coordination
- Postcode
- CHI
- Social Care ID Number

Commentary forms are also provided to allow Local Authorities to provide additional information on the quality of the data provided.

The Scottish Government has determined the purpose for which this data should be collected is for **statistics and research use only**. As SCLD analyse the data and publish the annual report on behalf of the Scottish Government, they are the **data processor** for this data while the Scottish Government remains **data controller**.

SCLD access and download the data through the ProcXed.net system which provides a secure file transfer facility.

- SCLD receive all of the 20 data items collection through the LDSS.
- the CHI number received by SCLD is encrypted by the ProcXed system before transfer.



SCLD store the data in two separate files.

- One file contains only the personal identifiable data (date of birth, postcode, CHI, unique ID)
- Another file contains all the census data along with age, datazone and other geographies. This second file is a pseudonymised file and therefore contains no data which would allow an individual to be identified.
- all statistical analysis is disclosure controlled to ensure no individual person can be identified in the annual reports.

In summary, the main objectives of Learning Disability Statistics Scotland are to:

- Monitor the progress of the recommendations of 'The same as you?' review.
- Help plan services
- Identify where there are unmet needs
- Compare information across local authority areas and see what is happening nationally.

2.2 Personal data to be processed.

- 1 orderial data to be proceeded.				
Variable	Data Source			
Postcode	Learning Disability Statistics Scotland			
Person date of birth	Learning Disability Statistics Scotland			
Ethnic group	Learning Disability Statistics Scotland			
Person current gender	Learning Disability Statistics Scotland			
CHI number	Learning Disability Statistics Scotland			

2.3 Describe how this data will be processed:

Data Collection

The LDSS data is collected on everyone with a learning disability or autism spectrum diagnosis who is known to Local Authorities. Local Authorities gather the information from their own information management systems and transfer the data to the ScotXed team in Scottish Government by uploading it to the ProcXed.net system, which provides a secure file transfer facility.

SCLD then download the data from the ProcXed.net system which provides them with a secure file transfer facility.

SCLD split the data into two separate datasets:

- (1) **Personal Identifiers:** Postcode, Person date of birth, ID Number, encrypted CHI;
- (2) **Learning Disability data:** a separate pseudonymised file for the learning disability data with no personal identifiable information.

As part of the processing:

- Postcode is converted into geographies Local Authority, Health Board, SIMD, etc the smallest of which will be Datazone.
- Date of birth is replaced by age



Article 4(5) of the GDPR defines pseudonymisation as "the processing of personal data in such a way that the data can no longer be attributed to a specific data subject without the use of additional information." By holding the de-identified carers census data separately from the "additional information", the GDPR permits data handlers to use personal data more liberally without fear of infringing the rights of data subjects. This is because the data only becomes identifiable when both elements are held together.

Analysis files used by Scottish Commission for Learning Disability

Statisticians in SCLD will use a **pseudonymised** Learning Disability file which does not contain any personal identifiable data such as postcode or full date of birth. SCLD will use this data to produce the annual Learning Disability Statistics Scotland national statistics publication.

2.4 Explain the legal basis for the sharing with internal or external partners:

Legal Gateway for sharing:

Social Work (Scotland) Act 1968

www.legislation.gov.uk/ukpga/1968/49/section/8

In the Social Work (Scotland) Act 1968 there are several references for local authorities to provide social welfare data for research purposes. The relevant extract can be found below:

"8 Research

- (1)The Secretary of State may conduct or assist other persons in conducting research into any matter connected with his functions or the functions of local authorities in relation to social welfare, and with the activities of voluntary organisations connected with those functions.
- (2) Any local authority may conduct or assist other persons in conducting research into any matter connected with their functions in relation to social welfare.
- (3)The Secretary of State and any local authority may make financial assistance available in connection with any research which they may conduct or which they may assist other persons in conducting under the provisions of this section."

Lawful basis for processing:

Meets the following conditions for processing Personal Data under:

- Article 6(1) of the GDPR:
- (e) Public task: the processing is necessary for you to perform a task in the public interest or for your official functions, and the task or function has a clear basis in law.
- Article 89(1) of the GDPR:

Processing for ... statistical purposes, shall be subject to appropriate safeguards, in accordance with this Regulation, for the rights and freedoms of the data subject. Those safeguards shall ensure that technical and organisational measures are in place in particular in order to ensure respect for the principle of data minimisation. Those measures may include pseudonymisation provided that those purposes can be fulfilled in that manner. Where those purposes can be fulfilled by further processing



which does not permit or no longer permits the identification of data subjects, those purposes shall be fulfilled in that manner.

when considered with the inferred rights to share data under the legal gateway.

Additionally, this meets the following conditions for processing Special Category Personal Data under:

- Article 9(2) of the GDPR:
- (j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

Statistics & Registration Service Act 2007

www.legislation.gov.uk/ukpga/2007/18/contents

The Scottish Government and Scottish Commission for Learning Disability fully comply with the Code of Practice for Official Statistics.

https://www.statisticsauthority.gov.uk/code-of-practice/

The main pillars and principals are:

Trustworthiness

Confidence in the people and organisations that produce statistics and data:

- T1 Honesty and integrity
- T2 Independent decision making and leadership
- T3 Orderly release
- T4 Transparent processes and management
- T5 Professional capability
- T6 Data governance

Quality

Data and methods that produce assured statistics

- Q1 Suitable data sources
- Q2 Sound methods
- Q3 Assured quality

Value

Statistics that support society's needs for information

- V1 Relevance to users
- V2 Accessibility
- V3 Clarity and insight
- V4 Innovation and improvement
- V5 Efficiency and proportionality



3. Stakeholder analysis and consultation

3.1 List all the groups involved in the project, and state their interest.

Group	Interest
Scottish Government	Data controller. Use data to monitor
	progress of policy recommendations and
	to compare across Local Authorities.
Scottish Commission for Learning	Data processor. Publish national
Disability	statistics report and identify unmet needs
	across different areas.
Local Authorities	Data providers. Use the data to plan
	service delivery and identify unmet
	needs.

3.2 Method used to consult with these groups when making the DPIA.

Discussions were held with the Scottish Commission for Learning Disability. This information is relatively unchanged from the previous Privacy Impact Assessment.

3.3 Method used to communicate the outcomes of the DPIA.

The DPIA is published on the Scottish Government website.

The DPIA was shared with all data providers directly.

4. Questions to identify privacy issues

4.1 Involvement of multiple organisations

The data will be provided by Local Authorities; however, some Local Authorities may contact colleges in their area for information on the number of students attending with a learning disability or autism spectrum diagnosis. Consent is not required from students with a learning disability or autism spectrum diagnosis to provide this information but Privacy Notices are available to let students with a learning disability or autism spectrum diagnosis know how their data will be used.

Because this data is being collected for **statistics and research purposes only**, explicit consent is not required from people with a learning disability or autism spectrum diagnosis, or from their families.

4.2 Anonymity and pseudonymity

Statisticians in SCLD will use a pseudonymised Learning Disability file which does not contain any personal identifiable data such as postcode or full date of birth. SCLD will use this data to produce the annual Learning Disability Statistics Scotland national statistics publication.

4.3 Technology

Not applicable

4.4 Identification methods

We are asking for CHI number if known. CHI is the Health record number issued to NHS patients and could identify someone. CHI numbers are encrypted as they are processed in the ProcXed.net system ensuring that no-one in Scottish Commission for Learning Disability or the Scottish Government has access to the original CHI numbers.

4.5 Sensitive/Special Category personal data

For processing Special Category Personal Data

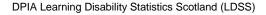
- Article 9(2) of the GDPR:
- (j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or **statistical purposes** in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

The LDSS includes data on Ethnic Group. This will only be used for statistics and research purposes and data will not be published which would allow identification of an individual.

4.6 Changes to data handling procedures

Local authorities are asked to submit and validate individual level data on people with a learning disability or autism spectrum diagnosis who are known to them via ProcXed.Net.

ProcXed.NET is a data collection and validation application. It is designed to hold data only for as long as is required to carry out this function. Once the collection and validation process is complete, data is removed. The application is designed to ensure that the submitter retains control of their data whilst they carry out validation on ProcXed.NET. Scottish Commission for Learning Disability survey administrators and statisticians have no access to the data until the submitter explicitly submits the data.



Data Transmission & Storage

ProcXed.NET uses Transport Layer Security (TLS) encryption in combination with a Server Gated Cryptography (SGC), extended validation certificate to provide the highest available levels of security and trust for data transmission between clients and the ProcXed.NET server. A minimum of 128bit encryption is applied to any data sent between the ProcXed.NET server and the client.

Once data is submitted to ProcXed.NET it is stored in a physically secure location (see below). In addition, data held on the ProcXed.NET servers is encrypted using AES (American Encryption Standard) encryption (SQL server 2008, fips 140-2 compliant as recommended by the Information Commission's Office).

Hosting

ProcXed.NET servers are hosted at Pulsant. Pulsant provide server hosting including physical security, network management, operating system management, power and climate control. Pulsant staff have only limited access to the ProcXed.NET servers and have no access to the ProcXed.NET application.

Pulsant is a secure hosting facility in Edinburgh which is certified to ISO 27001 using a UKAS approved certification body. They provide hosting services to organisations in both the private and public sector. This includes public services such as the NHS and Emergency Services. Many public sector clients hosted by Pulsant have security as a focus and are mandated by the UK government through a Code of Connections (CoCo) (e.g. GSi, GSx, N3 etc) to ensure appropriate security controls are in place. Pulsant has been audited successfully many times by their clients, ISO 27001 auditors, PCI auditors, CESG CLAS consultants and other authorities who advise the UK government on security matters. As part of Pulsant's compliance requirements to ISO 27001, they have implemented an internal audit programme which ensures internal audits are carried out on an ongoing basis and findings are reported to management. Their staff are vetted using processes based on the HMG Baseline Personnel Security standard which also requires Disclosure Scotland checks.

In delivering the service, Pulsant are required to comply with Baseline Personnel Security Standard, adhere to ISO27001 and data protection regulations as well as ensure that employees abide by the provisions of the Official Secrets Act 1911 to 1989.

Application Management

The ProcXed.NET application is managed by the Professional Services Team in the ScotXed unit of the Scottish Government. This team has administrative access to the systems. No other staff in the Scottish Government have administrative access to the systems and data remains under the control of the submitter and becomes available to analysts only when the user submits the data or the data provider, at their own discretion, permits time limited access to their un-submitted data to diagnose data issues .

Backup and Business Continuity

ProcXed.NET servers are protected by a number of built in hardware countermeasures, such as redundant components and RAID storage arrays. In addition, the ProcXed.NET application and data are backed up in order that they may be restored in the event of a catastrophic failure.

All data backups are encrypted and are held onsite at Pulsant for the purposes of system recovery. It is the responsibility of the submitter to ensure that they can resubmit their data in the event of a total loss of the data centre. At the point that the submission is accepted by the Scottish Government, the data is transferred to the Scottish Commission for Learning Disability network and is subject to corporate arrangements for backup and security.

The Scottish Government is a central government department, GSI accredited network accredited to handle Restricted material. We are an ISO27001 compliant organisation and as such have business continuity plans, including a risk incident register. This covers the items listed as they are relevant to our business.

4.7 Statutory exemptions/protection

The personal data that is processed here is for research and statistical purposes only.

Retention & deletion:

Personal Data are to be stored in accordance with Article 5 (1)(e) of the GDPR.

4	\sim	1	
4.	×	Justification	ì
т.	•	ousilibation	ı

Not applicable.			

4.9 Other risks

Ν	lot	t ap	pΙ	ıca	b	e.
---	-----	------	----	-----	---	----

5. General Data Protection Regulation (GDPR) Principles

Principle	Compliant - Yes/No	Description of how you have complied
6.1 Principle 1 – fair and lawful, and meeting the conditions for processing	Yes	Individuals will be told about the use of their personal data through privacy notices. Example privacy notices which can be used are available on the Scottish Government website.
Principle	Compliant - Yes/No	Description of how you have complied
6.2 Principle 2 – purpose limitation	Yes	Under conditions for statistical or research purpose in accordance with Article 89(1). (Additionally see Section 4.7 of this document).



Principle	Compliant - Yes/No	Description of how you have complied
6.3 Principle 3 –	Yes	The information we are asking for is good
adequacy, relevance and		enough quality for the purposes of
data minimisation		statistics and research. We are not
		asking for names of people with a
		learning disability or autism spectrum diagnosis, which could improve data
		linkage. However previous indexing of
		Social Care Survey data has shown that
		good linkage rates can be obtained using
		just postcode, date of birth and gender.
Principle	Compliant – Yes/No	Description of how you have complied
6.4 Principle 4 – accurate,	Yes	Not applicable to this project as data is
kept up to date, deletion		not being used in a manner that would
		impact on individuals. Quality
		assurance processes are built into the
		ProcXed system to validate the data before submitted by the local authority.
		before submitted by the local authority.
Principle	Compliant - Yes/No	Description of how you have complied
6.5 Principle 5 – kept for no	Yes	Section 33 of the Data Protection Act
longer than necessary,		states "Personal data which are processed only for research purposes in
anonymization		compliance with the relevant conditions
		may, notwithstanding the fifth data
		protection principle, be kept indefinitely".
		Article 5(e) of the GDPR requires that
		personal data shall be kept in a form
		which permits identification of data
		subjects for no longer than is necessary
		for the purposes for which the personal data are processed; personal data may
		be stored for longer periods insofar as
		the personal data will be processed
		solely for archiving purposes in the public
		interest, scientific or historical research
		purposes or statistical purposes subject
		to implementation of the appropriate
		technical and organisational measures required by the GDPR in order to
		safeguard the rights and freedoms of
		individuals
		Because data is only for statistical and
		research purposes, the pseudonymised
		Learning Disability data will be kept
		indefinitely.
Principle	Compliant - Yes/No	Description of how you have complied
6.6 GDPR Articles 12-22 -	Yes	Data subject rights do not apply as the
data subject rights		Learning Disability Statistics Scotland file
_		is pseudonymised and analysts are not

		able to identify the data for a particular individual. Privacy notices are available explaining what data is used for.
Principle	Compliant - Yes/No	Description of how you have complied
6.7 Principle 6 - security	Yes	The ProcXed system being used to collect this data is an established system already used to collect official statistics for various parts of Scottish Government including Schools Census.
Principle	Compliant - Yes/No	Description of how you have complied
6.8 GDPR Article 24 - Personal data shall not be transferred to a country or territory outside the European Economic Area.	Yes	Data is held in a secure hosting facility in Edinburgh which is certified to ISO 27001 using a UKAS approved certification body.

6. Risks identified and appropriate solutions or mitigation actions proposed

Is the risk eliminated, reduced or accepted?

Risk	Ref	Solution or mitigation	Result
Data is published which allows identification of an individual	1	All published data will follow statistical disclosure guidance to ensure that no individual person can be identified in any analysis.	Eliminate
Data is shared with other researchers who publish data	2	If there are any applications to link this data then this will be done under the Data Linkage Framework for Scotland ¹ .	Eliminate
allowing identification of an individual		There are six Guiding Principles which should be considered before undertaking a data linkage project. These can be viewed in detail at:	

¹ http://www.scotland.gov.uk/Topics/Statistics/datalinkageframework

DPIA Learning Disability Statistics Scotland (LDSS)

www.scotland.gov.uk/GuidingPrinciplesforDataLinkage.

In summary, the Guiding Principles are:

- 1. Public Interest
- 2. Governance and Public Transparency
- Privacy
- 4. Access and Personnel
- 5. Clinical Trials
- 6. Sanctions

National Services Scotland, National Records of Scotland and NHS Central Register have data linkage services which are modelled on international data linking best practice. A key aspect of both data linkage services are the separation of personal data to the attribute data.

Key features of using National Services Scotland, National Records of Scotland and NHS Central Register data linkage services include:

- The linking of data is for statistical / research analysis only.
- Researchers must apply to the 'Statistics Public Benefit and Privacy Panel' or the 'Public Benefit and Privacy Panel for Health and Social Care' (depending on which datasets are being linked) to gain access to the linked survey data.
- Data will be transmitted and stored in line with Cabinet Office data security requirements.
- Data sharing agreements will be put in place between the data controller (Scottish Government) and the organisation responsible for delivering the data linkage service.
- Linked data for analysis is accessed through a secure safe haven (or from Scottish Government servers) (unless the linked dataset has had Statistical Disclosure Control applied to create an anonymised dataset (i.e. where the risk of identifying a survey respondent is extremely unlikely)).
- Access to data for analysis is only given to accredited analysts for example, they have completed data protection training if they are an



	 academic/NHS Scotland, or they are employed by the Scottish Government. All analytical outputs are checked to ensure they comply with confidentiality requirements, for example by applying Statistical Disclosure Control: The aim of disclosure control is to ensure that any statistical analyses will not reveal the identity of an individual or any private information relating to them. 	
--	---	--

7. Incorporating Privacy Risks into planning

Explain how the risks and solutions or mitigation actions will be incorporated into the project/business plan, and how they will be monitored. There must be a named official responsible for addressing and monitoring each risk.

Risk	Ref	How risk will be incorporated into planning	Owner
Data is published which allows identification of an individual	1	All statistical outputs are subject to statistical disclosure control to ensure that individuals cannot be identified. This is standard practice in statistics team.	Lorne Berkley Evidence & Policy Manager
Data is shared with other researchers who publish data allowing identification of an individual	2	Any requests from researchers will be put to the relevant Privacy panel for approval. Again this is standard practice for team and applies to all data we hold.	Julie Rintoul Statistician

8. Authorisation and publication

The DPIA report should be signed by your Information Asset Owner (IAO). The IAO will be the Deputy Director or Head of Division.

Before signing the DPIA report, an IAO should ensure that she/he is satisfied that the impact assessment is robust, has addressed all the relevant issues and that appropriate actions have been taken.



By signing the DPIA report, the IAO is confirming that the impact of applying the policy has been sufficiently assessed against the individuals' right to privacy.

The results of the impact assessment must be published in the eRDM with the phrase "DPIA report" and the name of the project or initiative in the title.

Details of any relevant information asset must be added to the Information Asset Register, with a note that a DPIA has been conducted.

I confirm that the impact of collecting data for the Learning Disability Scotland Statistics has been sufficiently assessed against the needs of the privacy duty:

Name and job title of a IAO or equivalent	Date each version authorised