

Social Care Survey – Privacy Impact Assessment (Working Document)

Overview

1. This paper outlines the rationale and methodology for collecting individual level social care data for statistical and research purposes. It also explains how this data may be provided to other researchers and how it may be linked to other datasets. Furthermore, it explores the implications around confidentiality and what processes will be in place to ensure that this is protected as far as possible. This paper should be read in conjunction with 'Data sharing review'¹ (Richard Thomas & Mark Walport, July 2008) and the 'Data Sharing Code of Practice'² (Information Commissioner's Office).
2. This paper updates the privacy impact assessment which was conducted for the home care statistical return. Full details can be found here:

<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/HomeCareCensus>

Background

3. It is good practice to review National Statistics output to ensure that they:
 - Meet user needs
 - Maximise the use of existing data
 - Don't place any unnecessary burden on providers

¹<http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/links/datasharingreview.pdf>

²http://ico.org.uk/for_organisations/data_protection/topic_guides/data_sharing

- Continue to be fit for purpose by exploring alternative methodology and technological options
4. Previously, the Scottish Government published two separate National Statistics publications, one presenting data on Home Care clients and one presenting data on Direct Payments clients. All of these people are living in their own homes and receiving Social Care services and some people appeared in both surveys, leading to potential double counting when trying to combine the results from the two surveys. In 2013 the 'Home Care' and 'Self-Directed Support/Direct Payments' returns were combined into a single 'Social Care Survey', following recommendation by the SDS review group and extensive consultation with Local Authorities. See the following link for full results of the consultation:<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/DataSupplier/HSCSCCResults>.
 5. In 2013 Local Authorities were also given the option of submitting individual level data for the 'Respite Care' return as part of the Social Care return. This was previously a separate, aggregate return.
 6. Community Care Statistics Branch regularly meet with various policy colleagues within the Scottish Government to ensure only relevant data is collected in order to evidence policy and planning. Policy areas include; Reshaping Care for Older People, Health & Social Care Integration, Adults with Learning Disabilities, Self-directed Support, Carers, Mental Health, Joint Improvement Team (Telecare, and Outcomes Frameworks).

Data collected in Social Care Survey

7. Information and guidance on the data collected in the Social Care Survey can be found on the Scottish Government website:
<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/SocialCare>

[Survey](#). 'Box 1' (see next page) contains the list of variables detailed in the data specification. In summary, the information found in Box 1 was returned for each client who receives a (community care) service in their own home during the census week.

Box 1: Social Care Survey variables for 2014 (to be provided to the Scottish Government)

Individual Details

- Local Authority code
- Linkage ID
- Postcode
- (Adjusted) Date of Birth (15/MM/YYYY)
- Gender
- Ethnic Group
- Client group
- Type of Housing
- Living alone
- Self-directed Support
- Financial contributors to total care package
- Financial value of total care package for financial year
- Services In receipt Of
- Date of last Care Plan Review
- Date of last Eligibility Criteria category
- Eligibility Criteria Category
- Date of last assessed IoRN score
- IoRN score
- Client has unpaid carer(s)

Home Carer service

- Home Care hours in house – scheduled, actual or both
- Home Care hours from another LA – scheduled, actual or both
- Home Care hours private sector – scheduled, actual or both
- Home Care hours voluntary sector – scheduled, actual or both
- Client needs 2 carers to perform tasks?
- Personal Care hours - scheduled, actual or both

Direct Payment

- Payment start date
- Payment end date
- Value of SDS received in census year (£)
- Assessed needs of client
- How support is being provided

Respite care

- Value of Direct Payment (DP) for respite care
- Respite weeks - Overnight sitter service at home
- Respite weeks - Overnight in a care home
- Respite weeks - Overnight in other accommodation with support
- Respite weeks - Overnight in other accommodation
- Respite hours – in cared for person's normal residence
- Respite hours – in a day centre
- Respite hours – day activities not in a day centre
- Respite hours – other day respite
- Respite hours – in a care home

8. In order to firstly improve the quality of the social care data, for example, by identifying duplicate social care clients (as the social care information tends to be held on multiple management information systems by local authorities), local authorities are asked to provide social client's personal identifiers to National Services Scotland in order to create a 'Linkage ID' based on the Community Health index (CHI) . This enables local authorities to identify possible duplicate records and then subsequently for them to have confidence that they are returning a complete social care record per unique client. Furthermore, this allows the social care data be used in pathways analysis (longitudinal analysis - for example, tracking groups of people who use social care services year after year to see how their support packages change).
9. Secondly, In order to maximize the use of social care data, particularly around evidencing people's health and social care pathways, local authorities have also been asked to provide personal IDs to NHS National Services Scotland (NSS). This is to enable the social care data to be linked to other datasets, for example, health data. An example of a data linkage project which the Social Care Survey is being linked to health data can be found here:

<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Datalinking/HealthSocialCareandHousin>

10. The variables in Box 2 are only required for data linking purposes and will be removed from the final dataset to be used for statistical analysis. In order to maintain social care client's privacy, the personal identifiers are kept separate to the social care data which is returned to the Scottish Government. In addition, the team which handles the personal identifiers at National Services Scotland do not have access to the social care data.

Box 2: Personal identifiers to be provided to National Services Scotland to enable the creation of a linkage ID

Personal Details

- Local Authority code
- Unique ID
- Surname
- Forename
- Postcode
- Date of Birth
- Gender
- Community Health Index (CHI) Number

Legislation

Social Work (Scotland) Act 1968

http://www.opsi.gov.uk/RevisedStatutes/Acts/ukpga/1968/cukpga_19680049_en_3#pt1-pb3-l1g12

11. 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.”

Other pieces of legislation

12. Using individual level data has legislative implications. Outlined below are the main pieces of legislation which will affect the Social Care Survey:

Data Protection Act 1998

http://www.opsi.gov.uk/acts/acts1998/ukpga_19980029_en_1

13. The Data Protection Act (DPA) (1998) provides a set of principals which prohibit the misuse of personal information without

stopping it being used for legitimate purposes. Essentially the principals state that personal data must be:

- Fairly and lawfully processed;
- Processed for limited purposes;
- Adequate, relevant and not excessive;
- Accurate;
- Not kept longer than necessary;
- Processed in accordance with your rights;
- Kept secure;
- Not transferred abroad without adequate protection;

14. According to the act, the personal IDs from the Social Care data which is to be provided to NSS will comprise 'personal data' and the Social Care Data which is provided to the Scottish Government will comprise 'sensitive personal data'.

15. In order for processing of data by NSS and the Scottish Government to be lawful under the Data Protection Act, a condition under Schedules 2 and 3 must be met. For the Social Care Survey the appropriate conditions are:

16. Schedule 2.6: *"The processing is necessary for the purposes of legitimate interests pursued by the data controller or by the third party or parties to whom the data are disclosed, except where the processing is unwarranted in any particular case by reason of prejudice to the rights and freedoms or legitimate interests of the data subject."*³

17. Essentially this means that processing of personal data is allowed if it is in the legitimate interests of the data controller (i.e. the

³ http://www.opsi.gov.uk/acts/acts1998/ukpga_19980029_en_10#sch2

local authority) and the third party to whom those data are disclosed (i.e. Scottish Government and NSS), provided there is no prejudicial consequences to the individual about whom those data relate.

18. Schedule 3.10 - Regulation 9 of the Order ⁴: “*The processing -*

(a) is in the substantial public interest;

(b) is necessary for research purposes (which expression shall have the same meaning as in section 33 of the Act);

(c) does not support measures or decisions with respect to any particular data subject otherwise than with the explicit consent of that data subject; and

(d) does not cause, nor is likely to cause, substantial damage or substantial distress to the data subject or any other person.”

The Social Work (Scotland) Act 1968 lays down a general duty on Scottish Ministers to provide “general guidance” as to how local authorities must perform their functions under the Act (s5(1)). To plan service delivery effectively, the evidence base must be robust and extensive. Nationally for example, questions are being asked of analysts about how care can be provided sustainably in light of funding constraints and demographic pressures (aging population and smaller working population). A key theme of the Reshaping Care programme is to understand the impact of care services – how the introduction of care at an early stage can change the health trajectory of an individual, thus improving the individual’s quality of life and reducing the cost of care long term (longitudinal analysis). Such critical questions cannot be addressed using social care data alone.

19. Part IV, Section 33 (Exemptions) of the Data Protection Act covers statistics and research. Sensitive personal data can be used for research or statistical purposes as long as the following conditions are met:

- (a) *“that the data are not processed to support measures or decisions with respect to particular individuals, and*
- (b) *that the data are not processed in such a way that substantial damage or substantial distress is, or is likely to be, caused to any data subject”.*

20. The DPA states that (sensitive) personal data can be processed for research or statistical purposes even if that was not the original intention of the information. The data *may* be kept indefinitely if it is for research or statistical purposes. Furthermore, the DPA states that (sensitive) personal data can be exempt from Section 7 - Right of access to personal data if “(a) they are processed in compliance with the relevant conditions, and (b) the results of the research or any resulting statistics are not made available in a form which identifies data subjects or any of them.”

21. Thomas & Walport (2008) discuss the issue of sharing personal data in the context of research and statistical analysis and how this fits with legislation in their ‘Data Sharing Review’ paper. An extract of their findings can be found below which are particularly relevant to the proposed home care individual statistical return:

22. *“Research and statistical analyses represent important opportunities for using and sharing information.....Developing an evidence base to improve health and social policy in many areas depends on using data derived from collections of personally identifiable material. Wherever possible, such data should be anonymised, but creating anonymised information involves accessing and processing personal information to remove identifiers from it. Many research questions also require the use of coded datasets that no longer contain explicit identifiers, but ultimately allow the data to be linked to a particular individual. Such data are often described as*

‘pseudonymised’; and preserving these potential identifiers may be vital, for example, to allow linkage of pseudonymous data about the same person to facilitate a longitudinal study, or for postcode data in cases involving geographically sensitive research questions.”

23. *“The aim here is to allow this important statistical and research analysis to proceed, while minimising the risk of identifying individuals from within datasets. In our view, the approach of creating and using coded data should be recognised as a legitimate way of safeguarding people’s identities, and data handled in this way should not constitute a breach of the Data Protection Act.....” Thomas & Walport (2008).*

Statistics & Registration Service Act 2007

<http://www.scotland.gov.uk/Topics/Statistics/About/StatisticsReform/Legislation>

24. The Scottish Government fully comply with the Code of Practice for Official Statistics. The main principals are:

- Meeting user needs
- Impartiality and objectivity
- Integrity
- Sound methods and assured quality
- Confidentiality
- Proportionate burden
- Resources
- Frankness and accessibility

<http://www.statisticsauthority.gov.uk/assessment/code-of-practice/code-of-practice-for-official-statistics.pdf>

An extract of ‘Principle 5: Confidentiality’ can be found on the following page along with an explicit protocol around using administrative sources for statistical purposes.

Principle 5: Confidentiality

Private information about individual persons (including bodies corporate) compiled in the production of official statistics is confidential, and should be used for statistical purposes only.

Practices

1. Ensure that official statistics do not reveal the identity of an individual or organisation, or any private information relating to them, taking into account other relevant sources of information.
2. Keep confidential information secure. Only permit its use by trained staff who have signed a declaration covering their obligations under this Code.
3. Inform respondents to statistical surveys and censuses how confidentiality will be protected.
4. Ensure that arrangements for confidentiality protection are sufficient to protect the privacy of individual information, but not so restrictive as to limit unduly the practical utility of official statistics. Publish details of such arrangements.
5. Seek prior authorisation from the National Statistician or Chief Statistician in a Devolved Administration for any exceptions, required by law or thought to be in the public interest, to the principle of confidentiality protection. Publish details of such authorisations.
6. In every case where confidential statistical records are exchanged for statistical purposes with a third party, prepare written confidentiality protection agreements covering the requirements under this Code. Keep an operational record to detail the manner and purpose of the processing.

Protocol 3: The use of administrative sources for statistical purposes

Administrative sources should be fully exploited for statistical purposes, subject to adherence to appropriate safeguards.

Practices

1. Observe all statutory obligations and relevant codes of practice in relation to the protection of confidentiality and the handling of personal data.
2. Only base statistics on administrative data where the definitions and concepts are good approximations to those appropriate for statistical purposes.
3. Maximise opportunities for the use of administrative data, cross-analysis of sources and for the exchange and re-use of data, to avoid duplicating requests for information. Where possible, use common information technology and information management systems that facilitate the flow of information between producers of statistics.
4. Ensure that no action is taken within the producer body, or public statement made, that might undermine confidence in the independence of the statistics when released.
5. Prepare, in consultation with the National Statistician, a Statement of Administrative Sources which identifies the following.
 - a. The administrative systems currently used in the production of official statistics.
 - b. Procedures to be followed within the organisation to ensure that full account is taken of the implications for official statistics when changes to administrative systems are contemplated.
 - c. Information on other administrative sources that are not currently used in the production of official statistics but have potential to be so used.
 - d. Arrangements for providing statistical staff, whether inside the producer body or elsewhere, with access to administrative data for statistical purposes.
 - e. Arrangements for auditing the quality of administrative data used for statistical purposes.
 - f. Arrangements for ensuring the security of statistical processes that draw on administrative data.

Data issues 1: Using administrative data as opposed to survey data

25. Maximising existing administrative data has many strengths over introducing a new sample survey to monitor and inform future policy. Data from sample surveys can contain small numbers for particular variables, for example ethnicity, and as such can be prone to sampling error (as the sample may be a small proportion of the entire population). In order to achieve meaningful statistical analysis, the sample survey would need to be large and complex and therefore

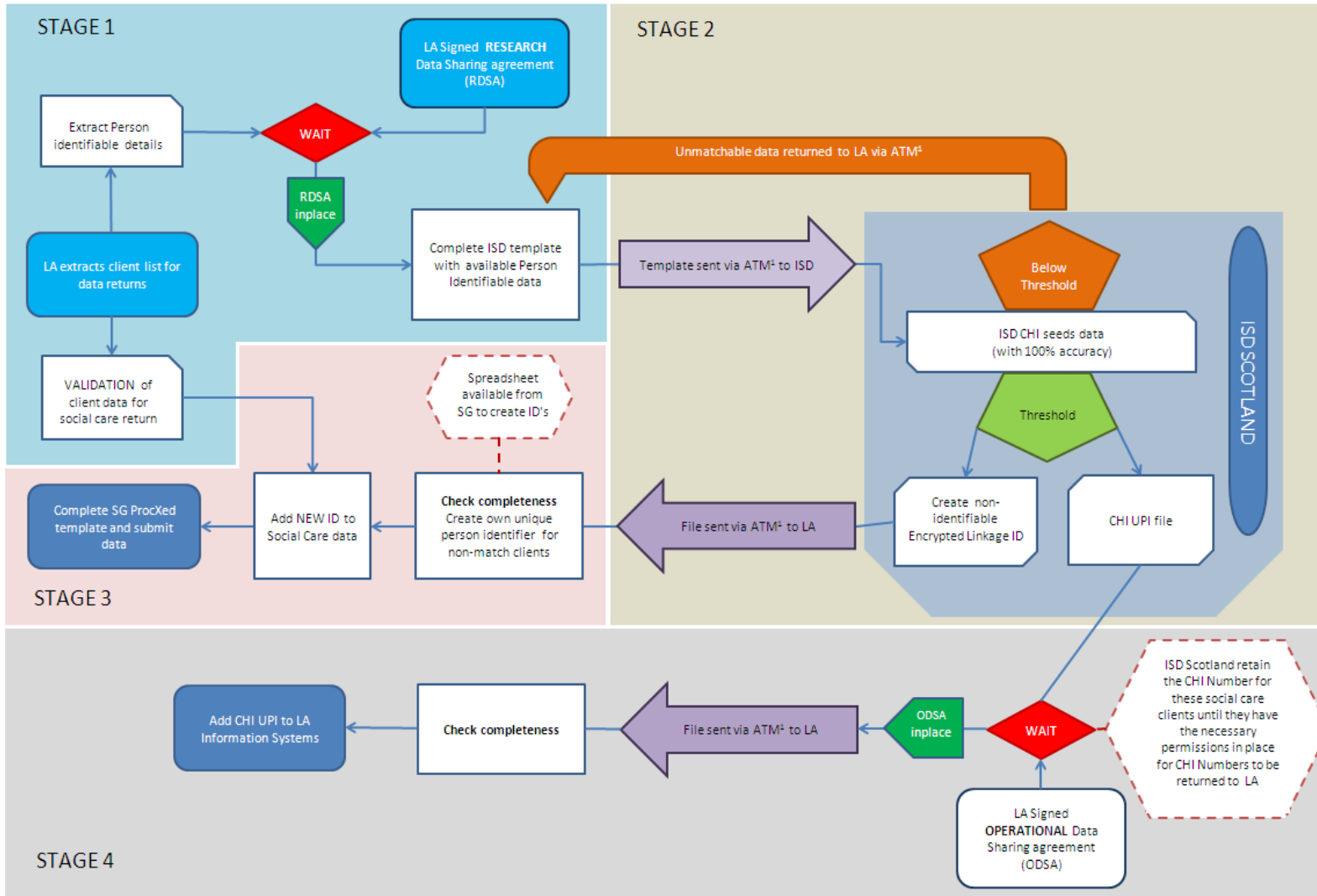
prone to greater respondent error due to the increased administrative burden placed on them. Administrative data collected for the purpose of service provision is more accurate and less influenced by survey questions and length.

Data issues 2: Using individual level data as opposed to aggregate data

26. A further important consideration for using existing individual level administrative data over aggregate data is to do with the identification of clients from aggregated tables. Asking local authorities to provide several slightly different aggregate tables increases the risk of personal identification from table differencing. This is because it would be extremely difficult to manage the volume of tables from 32 local authorities. The collection of individual level information would allow more control over producing aggregate tables as statistical disclosure control can be applied to the dataset before it is used for analysis (see 'Dissemination' section). Individual level data allows better analysis as aggregated data inherently limits the ability of analysts to respond flexibly to policy needs – a good example is age related data, often returned in age bands in aggregate tables you are restricted to set age bands (and indeed in monitoring change over time). Furthermore, without individual level data, longitudinal analysis would not be possible.

27. Further details are provided on the following pages explaining the proposed data collection/validation processes, and the steps in place to maintain confidentiality as far as possible. This is in order for the home care data collection to comply with the DPA and the Statistics & Registration Service Act 2007.

Data collection process



1 - ATM = Agreed Transfer Method

Stage 1. Submitting personal IDs to NSS

28. Once data sharing agreements are in place, Local Authorities are asked to complete the following template with the personal identifiers for their social care clients they intend to include as part of the Social Care Survey. Note no social care data is shared at this stage.

<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Datalinking/HealthSocialCareandHousin/HSCHDdatasupplier/HSCHDSTemp1>

29. Local Authorities can provide further clients if they wish, for example:

- To receive the CHI number from National Services Scotland at a later date (once a data sharing agreement is in place covering the use of CHI for operational purposes e.g. direct client care under health and social care integration).
- To link other social care data which is not included as part of the Scottish Government's Social Care Survey to other datasets.
- To link other local authority data to (for example) health data.

30. Local Authorities are asked to send the completed template via Globalscape. This is a secure data transfer method - further details about Globalscape can be found in [Annex 1](#).

31. National Services Scotland (CHI Indexing Team) will create a 'Linkage ID' based on matching the personal identifiers to the personal identifiers held on the CHI database. The CHI Indexing Team will return the newly created 'Linkage ID', a 'project code' and the local authority's original 'unique person ID' to the local authority by Globalscape.

Stage 2: Submitting Social Care Survey return to ScotXed

32. Since 2010, the Community Care Statistics team have received individual level Home Care and Direct Payments data from Local Authorities via ProcXed. This has resulted in a more flexible and detailed data set that has been used to produce the Home Care and Direct Payments publications. In 2013, the Home Care and Self-Directed Support/Direct Payments surveys were combined into a single 'Social Care Survey': <http://scotland.gov.uk/Publications/2013/11/8713>
33. Local authorities are asked to submit and validate individual level social care data via ProcXed.Net (Stage 3, Diagram 1). ProcXed.NET is designed to ensure that the submitter retains control of their data whilst they carry out validation checks. Scottish Government survey administrators and statisticians have no access to the data until the local authority explicitly submits it to the Scottish Government. ProcXed.NET uses Secure Sockets Layer (SSL) 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.
34. Local authorities are able to view aggregate tables of their data before it is submitted to the Scottish Government. This will also help with validation purposes.
35. 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 are encrypted using AES (American Encryption Standard) encryption (SQL server 2008, fips 140-2 compliant as

recommended by the Information Commission's Office⁵). At this point, the Scottish Government become the data controllers.

36. ProcXed.NET servers are hosted at Scolocate. Scolocate provide physical server hosting including physical security, power and climate control. Scolocate staff have only limited⁶ physical access to the ProcXed.NET servers and have no access to the systems. Compliance audits for Scolocate are available on request from SWStat@scotland.gsi.gov.uk.

37. ScoLocate 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 ScoLocate 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. ScoLocate 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 ScoLocate's compliance requirements to ISO 27001, they have implemented an internal audit programme which ensures internal audits are carried out on an on-going 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..

38. 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

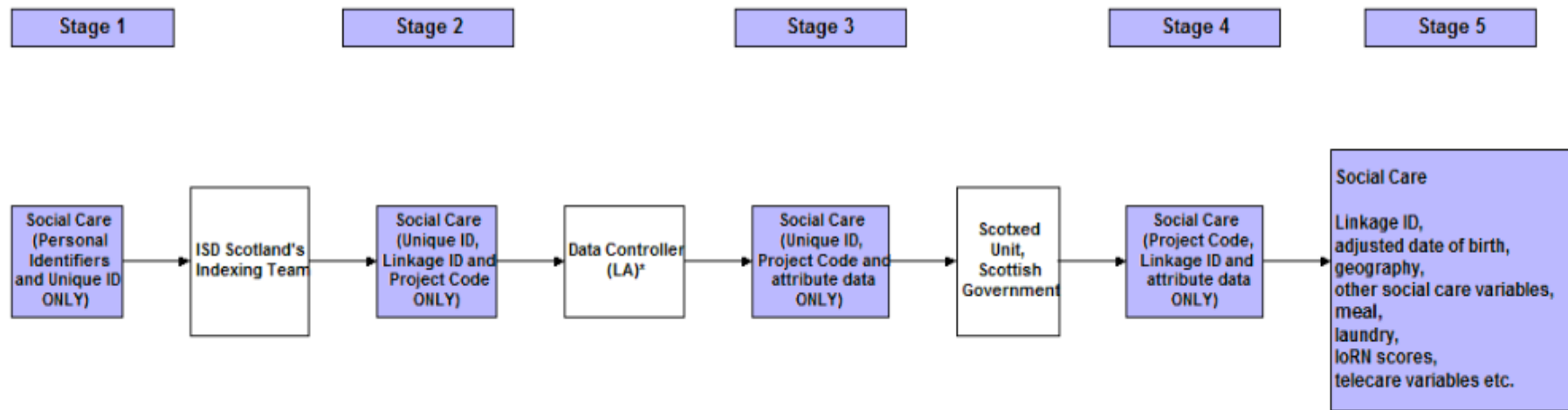
⁵http://www.ico.gov.uk/about_us/news_and_views/current_topics/Our%20approach%20to%20Encryption.aspx

⁶ Only key staff have access under certain circumstances and all access is recorded.

Scottish Government have administrative access to the systems and data remains under the control of the submitter and becomes available to Scottish Government staff only when the user submits the data to the Scottish Government.

39. 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 is backed up in order that it can be restored in the event of a catastrophic failure.
40. User data held on ProcXed.NET is not backed up. This ensures that no additional copies of users data are made. It is the responsibility of the submitter to ensure that they can resubmit their data in the event of a system failure. At the point that the submission is accepted by the Scottish Government, the data is transferred to the Scottish Government network and is subject to corporate arrangements for backup and security.
41. 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.

Diagram 1 – Data linking process



Note: Full post code is stored separately to the dataset used for statistical analysis.

42. The resultant linked dataset will then be anonymised before Scottish Government statisticians analyse it, i.e. full postcode will be removed but geographical indicators (e.g. datazone, health board) are included instead (Stage 4, Diagram 1).
43. The anonymised home care dataset will be stored in a restricted SAS® library. Named individuals will have access to the dataset only with Senior Statistician approval. IT System Administrators have access to all SAS® datasets.

Retention Schedule

44. “Personal data processed for any purpose or purposes shall not be kept longer than is necessary” (Fifth principle, Data Protection Act, 1998). Section 33 of the Data Protection Act states *“Personal data which are processed only for research purposes in compliance with the relevant conditions may, notwithstanding the fifth data protection principle, be kept indefinitely”*.

Consent

45. In accordance with the Code of Practice for Official Statistics⁷ the Scottish Government have a duty to abide by Principle 5 which covers data confidentiality (as well as to the Data Protection Act 1998). In addition to the processes which will be in place surrounding the transmitting, storing and accessing the data (see above), local authorities will be asked to update their fair processing notices for clients and inform them at reviews of how their data will be used by the Local Authority and Scottish Government. Clients (or their carer) “*have a right to expect that they will be told the purposes for which their information will be used, who will use it, with whom it will be shared, how long it will be retained, and how it can be updated. They further have a right to expect that their information will be handled fairly and securely, and that they will be told all this in a clear and straightforward manner, free from excessively legal or confusing language*” (Thomas & Walport, 2008⁸). Suggested text to be incorporated by local authorities into their fair processing notices can be found in Box 3.

⁷<http://www.statisticsauthority.gov.uk/assessment/code-of-practice/code-of-practice-for-official-statistics.pdf>

⁸<http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/links/datasharingreview.pdf>

Box 3: Privacy Notice – suggested text for local authorities (see Annex 2 for easier to read version)

Your personal details and support package may be shared with the Scottish Government and NHS Scotland for statistical and research purposes only.

- This information will help the Scottish Government, your Local Authority and NHS Scotland to plan for future care services. This will help improve services for you and others.
- Every effort will be made to ensure that your information is kept safe at all times.
- Only people in the Scottish Government and NHS Scotland who need to see your personal information will be able to access it.
- All pieces of information which could identify you, such as names, dates of birth and postcodes, will be removed before the data is used by statisticians/researchers.
- Social Care data will be used to produce statistical information. It will not be possible to identify you from this information.

The latest 'Social Care Services' statistics publication can be found at:
<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Publications>

If you would like more information, please get in touch with the following people:

Local authority contact:

Scottish Government contact:

Statistician
Community Care Statistics
Basement Rear
St Andrews House
Regent Road
Edinburgh
EH1 3DG
0131 244 3777

46. It is proposed that explicit consent will not be asked of the social care clients. This is due to several reasons. Firstly, the scale of the data collection (based on *existing* Management Information) makes this an incredibly large exercise to audit, and furthermore may result in incomplete datasets and bias – which is of particular importance in statistical analysis. Secondly, although personal data is being collected for linking to other datasets, the end result is an anonymised dataset which will only be used for statistical purposes by statisticians and researchers. The data will

therefore not be used to influence decisions or actions in respect to an individual or be used to cause substantial damage or distress for that individual. Finally, people who receive social care services are often very vulnerable and the local authority, the Scottish Government and NHS Scotland would not be in a position to verify that the client has fully understood the request for consent and the implications.

47. As part of the 'Data Sharing Review' by Thomas and Walport (2008) they discuss the need for consent in different contexts an extract can be found below which is of particular relevance in the context of the individual home care dataset:

48. *"A prominent and recurring theme throughout the review was the degree to which people should be able to exercise choice and control over information about themselves. The debate over consent was polarised and complex, and no consensus emerged. This is not surprising."*

49. *"We support the instinctive view that wherever possible, people should give consent to the use or sharing of their personal information, allowing them to exercise maximum autonomy and personal responsibility. However, achieving this in practice is not so simple. It is unrealistic to expect individuals ever to be able to exercise full control over the access to, or the use of, information about them. This is because of a number of factors, not least practical difficulties in seeking and obtaining consent in many circumstances. Moreover, there are many circumstances in which it is not useful, meaningful or appropriate to rely on consent, or indeed to obtain fresh consent at a later stage for the reuse of personal information for a different purpose."*

50. *".....there are strong arguments that for research and statistical purposes, where the identity of individuals is not material to the research, a requirement to obtain consent could prevent or impede worthwhile studies [and so damage the development of healthcare provision, for*

example]. In this area, relying on individual consent to share data does not seem to be appropriate.” Thomas and Walport (2008).

51. The social care data is extracted from administrative systems. The purpose of collecting this data is not to influence decisions or actions in respect to an individual. The purpose of collecting person identifiable information is purely to link datasets to create anonymised datasets for statistical and research purposes only.

52. As part of the full Privacy Impact Assessment, the ‘Fair Processing Notice’ was tested through focus groups.

Dissemination

53. Even though personal identifiers will have been removed from the final home care dataset, the dataset can still be disclosive. For example, if the home care information is used in conjunction with local knowledge then a client *may* be identified. To reduce the risk of this occurring, statistical disclosure control will be applied to all analyses based on the social care data. 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. New disclosure control guidance has been issued to Scottish Government statisticians which will be adhered to. Moreover, this is in line with the ‘Code of Practice for Official Statistics, Principle 5’ which the Scottish Government and NHS National Services Scotland will be assessed against.

54. The social care dataset is used to produce an annual ‘National Statistics’ publication⁹ and to provide analysis for numerous ad hoc requests by internal (Scottish Government) and external stakeholders (e.g Care Inspectorate, Association of Directors of Social Work, home care

⁹ <http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Publications>

providers, voluntary organisations, private sector and other local authorities and Government Departments)¹⁰. Additional analysis by Local Authority and background to the social data collection will be available on our website¹¹.

55. Detailed individual level national social care data is being made available to non-Scottish Government and National Services Scotland analysts for the first time from 2014 for statistical/research purposes. The national social care datasets should be accessed via the Farr Institute safe havens¹², Scottish Government, National Services Scotland (NHS Scotland). Any exceptions to this must have approval from the Scottish Government (as data controller of the Social Care Survey). Further information about applying to access the detailed individual level national social care data can be found here:

<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Datalinking/HealthSocialCareandHousin/HSCCHA2D>

Audit

56. National statistics are assessed by the Statistics Authority¹³ against the 'Code of Practice for Official Statistics' (this includes against the principle concerning confidentiality).
57. Data sharing agreements will be in place prior to any sharing of personal IDs to NSS. These agreements will be reviewed and signed annually by all organisations involved in this data collection process (local authority, National Services Scotland and Scottish Government).

¹⁰ <http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Data>

¹¹ <http://www.scotland.gov.uk/Topics/Statistics/Browse/Health>

¹² http://www.farrinstitute.org/centre/Scotland/27_EInfrastructure.html and <http://www.isdscotland.org/Products-and-Services/eDRIS/Becoming-an-eDRIS-User/#Safe-Havens>

¹³ <http://www.statisticsauthority.gov.uk/assessment/index.html>

Conclusion

58. In order to plan social care services effectively requires good quality social care information. It has been demonstrated in the pilot of the 'Linked social care, housing and health data project', that matching social care clients to the CHI database improves the quality of the social care data by identifying possible duplicate records. Furthermore, to maximise the social care data, matching the social care clients to CHI enables the future linkage of the social care data to other datasets, such as health data. In this example, it helps us evidence people's interactions and pathways across health and social care.

Spring 2014 (Version 1)

Annex 1: Globalscape

1. Transfer of demographic/indexed data from/to data providers uses Globalscape Secure File Transfer. This is certified as part of the eDRIS solution. Temporary account credentials are machine generated by the Globalscape platform for the upload/download of data. Individual secure drop zones set up for each local authority.

2. Globalscape server infrastructure (HTTPS):
 - Web based access to the application encrypted using Secure Socket Layer (SSL)
 - Encryption standard SSL 2048 key
 - Connection via port 443.

Further details to be published soon.

Local Authorities have been provided specific details directly. Please contact SWStat@scotland.gsi.gov.uk for further information.

Annex 2: Privacy Notice - Easy Read Version



The Scottish Government is collecting information about people who use a social care service. Social Care Services are defined as Home Care (where someone gives you help to live in your own home), Community Alarm/Telecare, Housing Support, Meals Services and Direct Payments.

- You do not have to do anything. The Scottish Government will ask for information like your personal details and support package from your Local Authority.
- The information they collect will help the Scottish Government and your Local Authority to plan for care services in the future. This will help to make services better for you and others.



- The Scottish Government will try to make sure that the information they get about you is always kept safe.
- Only people in the Scottish Government who need to see your information will be able to look at it.
- The information that is collected will be used to write a report containing lots of numbers. We call these numbers 'statistics'.
- No one will know the information that is in the report is about you. Personal information like your name, date of birth and postcode will not be put in the report.





You can look at the home care services statistics reports by going to this website:

<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Publications>

If you would like to know more or have any questions, you can contact the following people:

Local authority contact:



Statistician
Community Care Statistics
Basement Rear
St Andrews House
Regent Road
Edinburgh
EH1 3DG



0131 244 3777



SWStat@scotland.gsi.gov.uk



Scottish Government contact:



Statistician
Community Care Statistics
Basement Rear
St Andrews House
Regent Road
Edinburgh
EH1 3DG



0131 244 3777



SWStat@scotland.gsi.gov.uk

Annex 3 - Glossary of terms

Administrative Data - Data derived from information collected and maintained as part of an administration system, such as health records, social care records.

ADSW – Association of Directors of Social Work

Aggregate Statistics - Statistics that relate to, and provide information about, an entire group and do not differentiate individuals within that group.

Anonymous - Data or records are anonymous when the data subject's identity is obscured by lack of name and similar information that would make the identity of the subject obvious. Under some circumstances it may be possible to re-identify a data subject using even when the dataset has been anonymised, statistical disclosure control reduces the risk of this happening.

Attribute data – Information about the service the client/patient has received (in the context of this project). For example, hours of home care, length of stay in hospital, number of prescriptions. Sometimes called 'payload data'.

Caldicott Guardian - oversees the arrangements for the use and sharing of NHS patient identifiable information:

(<http://www.scotland.gov.uk/Publications/2011/01/31115153/12>).

CHI – The Community Health Index (CHI) is a population register, which is used in Scotland for health care purposes. The CHI number uniquely identifies a person on the index:

CHIAG – Community Health Index Advisory group advises the Director for Public Health for each Health Board and the Chief Medical Officer on use of the CHI number:

(<http://www.shsc.scot.nhs.uk/shsc/default.asp?p=108>).

Consumer panel – discussion group to share views on a topic.

COSLA – Convention of Scottish Local Authorities

Data controller – a person who (either alone or jointly or in a common with other persons) determines the purposes for which and the manner in which any personal data are, or are to be, processed.

(Page 49, Data sharing code of practice, ICO

http://www.ico.gov.uk/for_organisations/data_protection/topic_guides/data_sharing.aspx).

Data processor – any person (other than an employee of the data controller) who processes the data on behalf of the data controller.

(Page 49, Data sharing code of practice, ICO
http://www.ico.gov.uk/for_organisations/data_protection/topic_guides/data_sharing.aspx).

Data linking – Joining up information from different sources about the same person.

Data sharing – the disclosure of data from one or more organisations to a third party organisation or organisations, or the sharing of data between different parts of an organisation.

(Page 49, Data sharing code of practice, ICO
http://www.ico.gov.uk/for_organisations/data_protection/topic_guides/data_sharing.aspx).

Data sharing agreements/protocols – [the] set out [of] a common set of rules to be adopted by the various organisations involved in a data sharing operation.

(Page 49, Data sharing code of practice, ICO
http://www.ico.gov.uk/for_organisations/data_protection/topic_guides/data_sharing.aspx).

Data zone – The data zone geography covers the whole of Scotland and nests within local authority boundaries. Data zones are groups of Census output areas which have populations of between 500 and 1,000 household residents, and some effort has been made to respect physical boundaries. In addition, they have compact shape and contain households with similar social characteristics. There are 6505 data zones.

<http://www.scotland.gov.uk/Topics/Statistics/scotstat/snsgroup/geography>

Decrypt – Opposite of encryption (see below); to decode.

DOB – Date of Birth

DPA – Data Protection Act

Encryption – to convert (information or data) into a code, especially to prevent unauthorised access.

(Oxford University Press
http://oxforddictionaries.com/definition/encrypt#m_en_gb0264750.004)

EPRs – Electronic Patient Records

HRG – Health Resource Group

ICO – Information Commissioner’s Office

(CHI) Indexing (or seeding) – Population reference based on CHI dataset. Personal identifiers from other datasets are matched to the CHI dataset and a linkage identifier is created.

IORN – Indicator of Relative Need

(<http://www.jitscotland.org.uk/toolkits/information-resources/iorn/>)

ISD Scotland - The Information Services Division (ISD) is a division of National Services Scotland, part of NHS Scotland. ISD provides health information, health intelligence, statistical services and advice that support the NHS in progressing quality improvement in health and care and facilitates robust planning and decision making. (<http://www.isdscotland.org/>)

LAs – Local authorities

Longitudinal Survey - A survey in which information is collected from the same group of individuals on more than one occasion. This allows changes to be tracked through time.

Linkage agent – Overseen by the data linking team. Secure area where datasets for linking are received from the data controllers, plus the linkage key from the Indexing Team. The linkage key decrypts the linkage IDs contained on the datasets to be used in the project. The datasets are then stored in a secure area for access from the researcher via a safe haven. The linking and storing of data is an automated process.

Linkage ID – Linkage Identifier - Information that can be used to join something to something else. Sometimes referred to as ‘study number’.

Linkage key – Look up table to decrypt the linkage ID (in the context of this project).

NHS – National Health Service

NRS – National Records of Scotland

ONS – Office for National Statistics

PA – Personal Assistant

PAC – Privacy Advisory Committee

(<http://www.isdscotlandarchive.scot.nhs.uk/isd/2466.html>)

Payload data - Information about the service the client/patient has received (in the context of this project). For example, hours of home care, length of stay in hospital, number of prescriptions. Sometimes called 'attribute data'.

Personal data – data which relates to a living individual who can be identified-

(a) from those data, or (b) from those data and other information which is in the possession of, or is likely to come into possession of, the data controller,

and includes any expression of opinion about the individual and any indication of the intentions of the data controller or any other person in respect of the individual.

(Page 50, Data sharing code of practice, ICO

http://www.ico.gov.uk/for_organisations/data_protection/topic_guides/data_sharing.aspx).

Personal identifiers – Information that identifies a person such as name and date of birth.

Privacy Impact Assessment (PIA) – is a comprehensive process for determining the privacy, confidentiality and security risks associated with the collection, use and disclosure of personal data:

(http://www.ico.gov.uk/for_organisations/data_protection/topic_guides/privacy_impact_assessment.aspx)

Privacy notice – Explanation of how your personal information may be used.

Processing of data – in relation to information or data, means obtaining, recording or holding the information or data or carrying out any operation or set of operations on the information or data, including:

(a) organisation, adaptation or alteration of the information or data,

(b) retrieval, consultation or use of the information or data,

(c) disclosure of the information or data by transmission, dissemination or otherwise making available, or

(d) alignment, combination, blocking, erasure or destruction of the information or data.

(Page 50, Data sharing code of practice, ICO

http://www.ico.gov.uk/for_organisations/data_protection/topic_guides/data_sharing.aspx).

ProcXed.Net - Secure service for collecting data for statistical analysis by the Scottish Government.

<https://www.scotxed.net/Public%20Web%20Part%20Pages/ProcXed.NET.aspx?PageView=Shared>

Project code – Unique reference number assigned to each project.

Safe haven – Refers to both a physical location and to an agreed set of administrative arrangements to ensure the safety and secure handling of [person] identifiable information.

<http://www.datadictionaryadmin.scot.nhs.uk/isddd/2125.html>

Sensitive personal data - means personal data consisting of information as to -

- (a) the racial or ethnic origin of the data subject,
- (b) his political opinions,
- (c) his religious beliefs or other beliefs of a similar nature,
- (d) whether he is a member of a trade union (within the meaning of the Trade Union and Labour Relations (Consolidation) Act 1992),
- (e) his physical or mental health or condition,
- (f) his sexual life,
- (g) the commission or alleged commission by him of any offence, or
- (h) any proceedings for any offence committed or alleged to have been committed by him, the disposal of such proceedings or the sentence of any court in such proceedings.

(Page 51, Data sharing code of practice, ICO

http://www.ico.gov.uk/for_organisations/data_protection/topic_guides/data_sharing.aspx)

SDS – Self-Directed Support

<http://www.scotland.gov.uk/Topics/Health/care/adult-care-and-support/independent-living>)

SG – Scottish Government

SHIP – Scottish Health informatics Programme (<http://www.scot-ship.ac.uk/>)

SMR – Scottish Morbidity Record

<http://www.datadictionaryadmin.scot.nhs.uk/isddd/9036.html>)

SOLAR – Society of Local Authority Lawyers & Administrators in Scotland

<http://www.SOLARScotland.org.uk/>

Statistical Disclosure Control – Methods to reduce the risk of disclosure of individual people/households/companies etc. This may involve removing or reducing information (e.g. replace date of birth with broad age category).

Study number - Information that can be used to join something to something else. Sometimes referred to 'Linkage ID'.

UniqueID – **Unique Identifier** – Reference number unique to an individual.

Variables - an expression that can be assigned any of a set of values (<http://dictionary.reference.com/browse/variable>)