

Linking social care, housing support & health data for statistics

Project Plan and Privacy Impact Assessment (PIA)

Executive Summary

Overview

This paper outlines the rationale, legal requirements, and methodology for linking social care, housing support and health data for statistical/research purposes only. Furthermore, it details how people's privacy and confidentiality will be maintained and protected as far as possible. Full project details are available at:

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

Background

It is widely felt that better evidence is needed around the interactions between social care, housing support and health which enable people to live independently in their own homes for as long as possible. Collecting individual level data on social care, housing support and health, provides an opportunity to link this data for statistical/research purposes. This will ultimately enable service providers, planners and policy to gain an improved understanding of these interactions which have been limited to date.

Research questions (summary)

In summary, this project aims to provide evidence around the following research areas:

- Evidencing people's social care, housing support and health service pathways including;
 - An improved understanding of planned and unplanned hospital admissions/attendances
 - An improved understanding of polypharmacy and medications associated with higher risk to patients
 - An improved understanding of multiple morbidities and complex needs

- An improved understanding of social care, housing support and health service resource use
- An improved understanding of the outcomes for people who use social care, housing support and health services.
- An improved understanding of social care, housing support and health service use for those who have died by probable suicide.
- Using a combination of data sources to improve the quality of data which can then be used in analysis, for example:
 - Using various health datasets to identify those who have been diagnosed with long term conditions (for example dementia) and are in receipt of social care, housing support and health services.
 - Using various social care, housing support and health datasets to identify those with mental health problems and are in receipt of social care, housing support and health services.

Legal & ethics

Ultimately, it will be up to the data controllers to decide whether they can pass the information requested to ISD Scotland without breaching any legislation.

The project has to go through the following stages to gain approval prior to any data linking being able to take place:

- Permission from data controllers,
- Permission from health research ethics if the project is deemed 'research' as opposed to 'audit' or 'service evaluation',
- Permission from the CHI (Community Health Index) Advisory Group,
- Permission from the Privacy Advisory Committee.

The project has been developed with the assistance of the Information Commissioner's Office.

In addition, a full Privacy Impact Assessment (PIA) has been carried out which includes discussion groups with social care clients and health service users

on their views of sharing and linking data, particularly for research. The findings from the discussion groups have been published (<http://www.scotland.gov.uk/Publications/2011/09/20085846/0>). The PIA is a working document and will be updated to reflect any changes to the project.

Methodology

The proposed methodology is based on international data linking best practice and advice from the Information Commissioner's Office. The Farr Institute in Scotland and ISD Scotland will be used to undertake the data linking, secure storage, restricted access, checking analytical outputs and destruction of data. Key aspects of the methodology include:

- The linking of data is for statistical / research analysis only.
 - Personal identifiers and attribute information (the information about the service the person is receiving and their condition) is never transmitted and stored together.
 - One team within ISD Scotland access the personal identifier data and a completely separate team within ISD Scotland access the attribute data.
 - Minimal data travel.
 - The attribute data to be used is what is already provided to either the Scottish Government or ISD Scotland through routine national data collections.
 - Data will be transmitted and stored in line with Cabinet Office and NHS Scotland data security requirements.
 - Data sharing agreements will be put in place between the data controller and ISD Scotland.
 - ISD Scotland will become an additional data controller of all data that is passed to them and as such they will be responsible for complying with relevant legislation, including the Data Protection Act (1998).
 - Access to data for analysis is only given to approved analysts for example they have completed data protection training if they are an academic, and/or they are employed by the Scottish Government, local authority or NHS Scotland.

- Data is accessed through a secure safe haven or via NHS National Services Scotland (ISD Scotland). No copies of the datasets are allowed to be made onto removable media.
- All analytical outputs are checked to ensure they comply with confidentiality requirements (for example by applying Statistical Disclosure Control).

Timescales

The sharing and linking of data for the pilot project occurred between late 2012-early 2014. 12 local authorities participated in the pilot project which was conducted in 3 phases. Further information about the pilot is available here: <http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Datalinking/HealthSocialCareandHousin> *{still to publish review and pilot analysis}*. All local authorities will be invited to take part in the project from 2014.

Conclusion

There is strong support to improve the analytical evidence of how social care, housing and health interact and contribute to enabling people live at home for as long as possible. The linking of social care, housing and health data will provide analysis on the outcomes for clients who are receiving different combinations of services at different points in their care paths. Furthermore, the analytical evidence from using linked social care, housing and health data will be pivotal for central government, local authorities, health boards, private and the voluntary sector in the planning and evaluating of services/policies.

As a consequence of handling and linking sensitive personal information, appropriate security procedures will be put in place to ensure that the project is compliant with legislation and the recommended procedures in the Information Commissioner's Office's 'Data sharing code of practice'.

Linking social care, housing support & health data for statistics

Project Plan and Privacy Impact Assessment (PIA)

Overview

1. This paper outlines the rationale, legal requirements, and methodology for linking social care, housing support¹ and health data for statistical/research purposes only. Furthermore, it details how people's privacy and confidentiality will be maintained and protected as far as possible. This paper builds on the first stage of the data linking project – moving the Home Care Statistical Return from an aggregate to an individual level data return which was implemented in 2010, and then the subsequent merging of the Home Care Statistical Return with the Self-Directed Support (Direct Payments) Return into a single 'Social Care Survey'. Further details about this project, including a full Privacy Impact Assessment is available from the links below:

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

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

2. Further papers related to the 'Linking social care, housing support and health data' project – including a literature review of international data linkage projects and examples of best practice – can be found here:

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

¹ Note: Detailed housing data will not be linked to initially as there is currently a review of the housing support statistical return (further information on this review can be found in Annex 1). Limited housing support data is collected via the Home Care Statistical Return (Scottish Government). It is the long term aim to link social care and health data to housing and so, references to housing data have been included in the project plan where appropriate.

3. This Project Plan and Privacy Impact Assessment is a working document. The latest version of this document can be found here:

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

Background

4. As part of the review of home care statistics (now known as the Social Care Survey) (which is collected and published annually by the Scottish Government), it was widely felt – both within and out with the Scottish Government - that the data did not provide sufficient evidence on the important interactions between social care, housing and health which enable people to live independently in their own homes for as long as possible. In order for services from all sectors be able to plan effectively, they need to have a robust evidence base to inform decision making. This is especially important in light of financial pressures and an ageing population. Collecting individual level data on social care, housing support and health, provides an opportunity to link this data for statistical/research purposes. This will ultimately enable service providers and planners to gain an improved understanding of the relationships between social care, health and housing support, which have been limited to date.
5. A cross organisational working group was established to take this project forward. Organisations represented include; the Scottish Government, NHS Scotland, COSLA (Convention of Scottish Local Authorities), ADSW (Association of Directors of Social Work) and National Records of Scotland (NRS) (formally GROS (General Register Office for Scotland). These organisations (except NRS) are now represented via the project Reference Group and the project Governance Group. Further details about the existing working group can be found in Annex 4² and details about the

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

'Reference Group' and the 'Governance Group' can be found from the following webpage:

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

Data linking best practice

6. Prior to any data linkage being undertaken for statistics/research there are a number of criteria which need to be met:

- **Clear justification**
- **Satisfy legal requirements**
- **Undertake a Privacy Impact Assessment**
- **Ethics (if applicable) / Privacy Advisory Committee / CHI Advisory Group approval (if applicable)**
- **Only link what is absolutely necessary**
- **Separate data linking team**
- **Secure environment for the data to be held and transferred**
- **Clear barrier between data providers and the linked data to ensure it can't be used for operational purposes**
- **Clear barrier between the data linking team and those undertaking analysis**
- **Arrangements for data governance**
- **Retention policy**
- **Disclosure policy**
- **Transparency**

The following pages will address each criterion in turn. The document will evolve as the project progresses.

Evidence for social care, health & housing policy

7. This project will provide analytical evidence to help shape social care, health and housing policy and service planning. The analysis from the project will support the following Scottish Government National Outcomes³:

- *We live longer, [healthier lives](#)*
- *We have tackled the significant [inequalities](#) in Scottish society*
- *We live in well-designed, [sustainable places](#) where we are able to access the amenities and services we need*
- *Our people are able to maintain their [independence as they get older](#) and are able to access appropriate support when they need it*
- *Our [public services](#) are high quality, continually improving, efficient and responsive to local people's needs*

The following policy areas are responsible for contributing to meet these objectives:

- A Route Map to the 2020 Vision for Health and Social Care⁴
- Shifting the Balance of Care⁵
- Reshaping Care for Older People⁶⁷⁸⁹
- Change Fund¹⁰
- Integrated Resources Framework¹¹
- Health & social care integration¹²
- Self-Directed Support¹³¹⁴
- Dementia Strategy¹⁵
- Delivering for Mental Health¹⁶

³ <http://www.scotland.gov.uk/About/Performance/scotPerforms/outcome>

⁴ <http://www.scotland.gov.uk/Topics/Health/Policy/Quality-Strategy/routemap2020vision>

⁵ <http://www.shiftingthebalance.scot.nhs.uk/>

⁶ <http://www.scotland.gov.uk/Topics/Health/care/reshaping>

⁷ <http://www.jitscotland.org.uk/action-areas/reshaping-care-for-older-people/>

⁸ <http://www.jitscotland.org.uk/action-areas/intermediate-care/>

⁹ <http://www.jitscotland.org.uk/action-areas/reshaping-care-for-older-people/workstream-c---care-at-home/>

¹⁰ <http://www.scotland.gov.uk/Topics/Health/care/reshaping/changefund>

¹¹ <http://www.shiftingthebalance.scot.nhs.uk/initiatives/sbc-initiatives/integrated-resource-framework/>

¹² <http://www.scotland.gov.uk/Topics/Health/Policy/Adult-Health-SocialCare-Integration>

¹³ <http://www.scotland.gov.uk/Publications/2010/11/05120810/0>

¹⁴ <http://www.selfdirectedsupportscotland.org.uk/>

¹⁵ <http://www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/Dementia>

- Telecare¹⁷
- Long Term Conditions Collaborative¹⁸

8. Furthermore, Scottish Government Ministers have committed to introducing a single system of health and social care in this Parliament¹⁹, recognising that better integrated services are required to provide appropriate support for people at vulnerable points in their lives.

9. Essentially, a shift is required in how services are provided in order to meet “*the changing needs and aspirations of individuals and their families*”²⁰. Greater emphasis is required on services being provided in the community and in people’s homes, rather than in hospitals and/or care homes - where appropriate. Furthermore, with demographic changes and greater financial constraints, social care, health and housing policies, services, and providers, all need to work in collaboration in order to make effective use of resources and skills, whilst still providing services which meet the needs and aspirations of individuals as far as possible. All the policies and initiatives mentioned in the above bullet points have adopted this approach.

10. An example of how the linked data from this project can be used to evaluate policies, improve initiatives, help with service planning and improve outcomes for people, can be seen in the Dementia Strategy. ‘Scotland’s National Dementia Strategy’ was published by the Scottish Government in 2010. The Dementia Strategy outlines the commitment of the “*Scottish Government and its partners in local government, and the voluntary and private sectors..... to delivering world-class dementia services in Scotland*”. Below is an extract of some of the strategy aims which the analysis from the data linking project can support:

¹⁶ <http://www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/DFMH>

¹⁷ <http://www.jitscotland.org.uk/action-areas/telecare-in-scotland/>

¹⁸ <http://www.improvinghsscotland.scot.nhs.uk/programmes/long-term-conditions/Pages/About.aspx>

¹⁹ <http://www.scotland.gov.uk/Topics/Health/Policy/Adult-Health-SocialCare-Integration>

²⁰ <http://www.shiftingthebalance.scot.nhs.uk/>

- *“Providing integrated support for local change, including through implementation of the dementia care pathway standards and through better information about the impact of services and the outcomes they achieve;*
- *Continuing to increase the number of people with dementia who have a diagnosis to enable them to have better access to information and support; and*
- *in general hospital settings, by improving the response to dementia, including through alternatives to admission and better planning for discharge”.* (Page 8, Scotland National Dementia Strategy, 2010)

11. Furthermore, there is an explicit action (page 49) from the strategy on improving management and outcome information.

“At the moment the information that we have to monitor, plan and develop dementia services is often poor. We have seen good improvement in local information sources and the use of information in connection with the current NHS [H.E.A.T] dementia target²¹. However, a constant theme throughout the development of the Dementia Strategy has been the need for better information on what is or isn't working. This has to include data on care outcomes, the experience of using services and the efficiency of service provision. Central to delivering this are:

- *....At a National level, a system for producing relevant comparative information;*
- *Developing the skills of analysts and managers to ensure effective reporting and interpretation of data.....”*

12. As a specific example, part of the strategy mentions improving access to services such as “telecare, intermediate care services and reablement” in

²¹ <http://www.scotland.gov.uk/About/scotPerforms/partnerstories/NHSScotlandperformance/Dementia>

order firstly, to help people with dementia live in their own homes for as long as possible and, secondly, to help reduce unplanned hospital admissions. Linking social care (home care telecare data) and health data (SMR01 (acute inpatients) and SMR04 (mental health inpatients)) can provide individual level information on client pathways to use as evidence to assess whether these aims are being met nationally and locally. Without data linkage, this would not be possible.

13. In addition, this data linking project will potentially provide improved analytical evidence to support various measures/targets in the following areas of work:

- Scotland Performs²²
- H.E.A.T²³
- Single Outcome Agreements²⁴
- Scottish Community Care Benchmarking Network²⁵

14. In summary, this data linking project will provide analytical evidence to support central government, local authorities, health boards, private and voluntary sector in the planning and evaluation of services/policies. It will additionally, provide analysis on the outcomes for clients who are receiving different combinations of services at different points in their care paths. For example, it will be possible for the first time to assess the impact of different service interventions on unplanned hospital admissions through the linkage of social care and health data.

²² <http://www.scotland.gov.uk/About/scotPerforms>

²³ <http://www.scotland.gov.uk/About/scotPerforms/partnerstories/NHSScotlandperformance>

²⁴ <http://www.scotland.gov.uk/Topics/Government/local-government/SOA>

²⁵ <http://www.communities.idea.gov.uk/comm/landing-home.do?id=1519248>

Research questions to be answered through data linkage

15. This project aims to provide analytical evidence around the following areas (specific details of the research will be able to be found here once they have been fully specified):

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

- Evidencing people’s social care, housing support and health service pathways including;
 - i. An improved understanding of planned and unplanned hospital admissions/attendances
 - ii. An improved understanding of polypharmacy and medications associated with higher risk to patients
 - iii. An improved understanding of multiple morbidities and complex needs
 - iv. An improved understanding of social care, housing support and health service resource use
 - v. An improved understanding of the outcomes for people who use social care, housing support and health services.
 - vi. An improved understanding of social care, housing support and health service use for those who have died by probable suicide.
- Using a combination of data sources to improve the quality of data which can then be used in analysis, for example:
 - i. Using various health datasets to identify those who have been diagnosed with long term conditions (for example dementia) and are in receipt of social care, housing support and health services.
 - ii. Using various social care, housing support and health datasets to identify those with mental health problems and are in receipt of social care, housing support and health services.

16. Full datasets, time periods and variable lists to be included in the project can be found here:

<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Datalinking/HealthSocialCareandHousin> . In summary, the project will aim to use information from the following areas:

- Social care / housing support data for people who receive care and support:
 - i. In their own home (including sheltered housing),
 - ii. in a care home.
- Health data for people:
 - i. Who have received treatment from a hospital,
 - ii. who have received a prescription dispensed in the community.
 - iii. *[This section will be updated as further health data becomes available e.g. community health data and intermediate care data].*
- Deaths data including:
 - i. Date of death,
 - ii. cause of death (if probable suicide only).
- Demographics data
- Geography data
- GP practice
- Care home

Consultation

17. This data linking project has consulted (and will continue where appropriate) with the following organisations/committees/people for approval/support

- **Support from Association of Directors of Social Work (ADSW)**
- **Approval from data controllers (i.e. Local Authority and Caldicott Guardian at ISD Scotland)**
- **Presented project to LA Information Security Group – data protection officers and information security officers**
- **Support from Information Commissioner’s Office**
- **Ethical approval (if deemed ‘research’ as opposed to ‘audit’ or ‘service evaluation’)**
- **Approval from the CHI Advisory Group**
- **Approval from the Privacy Advisory Committee (PAC)**
- **Consumer panels (focus groups) with those either working in the field of providing social care, housing support or health services, or are users of these services.**

Legislation

Social Work (Scotland) Act 1968

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

18. In the Social Work (Scotland) Act 1968 there are several references to provision of social welfare data by local authorities for research purposes. The relevant extracts 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.”

19.The relevant extracts from the Mental Health (Care and Treatment) (Scotland) Act 2003 and the National Health Service (Scotland) Act 1978 with regards to research can be found below:

Mental Health (Care and Treatment) (Scotland) Act 2003

<http://www.legislation.gov.uk/asp/2003/13/contents>

“279 Information for research

(1)A person having functions by virtue of this Act shall, on being required to do so by the Scottish Ministers—

(a)provide them or any other person specified in the requirement with such relevant information as is so specified; and

(b)do so in any such form as may be so specified.

(2)The Scottish Ministers may, under subsection (1) above, require the provision of relevant information only if, in their opinion, it is needed by them (or, as the case may be, the other person specified in the requirement) for research purposes within the meaning given by section 33 of the Data Protection Act 1998 (c. 29) (research, history and statistics).

(3)Information need not be provided under this section if, were it evidence which might be given in proceedings in any court in Scotland,

the person having that evidence could not be compelled to give it in such proceedings.

(4)Where information required under subsection (1) above—

(a)is, or refers to, information about a natural person and would identify or enable the identification of the person; and

(b)can reasonably be provided under subsection (1) above so as not to identify or enable the identification of the person,

it shall be so provided.

(5)Where—

(a)the person required under subsection (1) above to provide the information is under a duty of confidentiality in respect of that information; and

(b)the person cannot provide the information without breaching the duty,

the information shall not be provided unless the person to whom the duty is owed has consented to its provision. [Subsections 4 and 5 are discussed further on pages 64-65].

(6)On receipt of information provided under this section, the Scottish Ministers (or any other person provided under this section with the information) may, for the purposes referred to in subsection (2) above, do any, or all, of the following—

(a)process the information;

(b)collate it;

(c)publish it or reports based on it.

(7)Regulations may provide as to the procedure to be followed in making requirements under this section for information and in providing it.

(8)Where information recorded otherwise than in legible form is required to be provided under this section, it shall be provided in legible form.

(9)For the purposes of this section—

(a)information is “relevant” if it is information as to the operation of this Act; and

(b) a person is under a duty of confidentiality in respect of information although the person could notwithstanding that duty be compelled to give evidence as to that information in proceedings in a court in Scotland.”

National Health Service (Scotland) Act 1978

<http://www.legislation.gov.uk/ukpga/1978/29>

“47 Educational and research facilities.

(2) Without prejudice to the general powers and duties conferred or imposed on the Secretary of State under the Scottish Board of Health Act 1919, the Secretary of State may conduct, or assist by grants or otherwise any person to conduct, research into any matters relating to the causation, prevention, diagnosis or treatment of illness, or into such other matters relating to the health service as he thinks fit.”

Other pieces of legislation

20. The linkage of social care data with housing and health data is affected by other pieces of legislation. Outlined below are the main pieces of legislation which the Scottish Government and ISD Scotland will be satisfying before any data linkage is undertaken:

Data Protection Act 1998

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

21. The Data Protection Act (DPA) (1998) provides a set of principles which prohibit the misuse of personal information without preventing its use for legitimate purposes. The principles 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 individuals' rights;
- Kept secure;
- Not transferred abroad without adequate protection;

22. According to the Act, the health and social care data to be linked is 'sensitive personal data'.

23. In order to meet the requirements of the first data protection principle under the Data Protection Act (which requires personal data to be processed fairly and lawfully) a condition under each of Schedules 2 and 3 must be met. For this statistical data linkage project the applicable conditions are:

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."*²⁶

24. Essentially this means that processing of personal data is allowed if it is in the legitimate interests of the data controller (i.e. the local authority and the Health Board) and the third party to whom those data are disclosed (i.e. ISD Scotland and then in an anonymised format to approved researchers – for example Scottish Government Statisticians, academics), provided there is no prejudicial consequences to the individual about whom those data relate.

Schedule 3.10 - Regulation 9 of the Order²⁷: *"The processing -*
(a) is in the substantial public interest;

²⁶ http://www.opsi.gov.uk/acts/acts1998/ukpga_19980029_en_10#sch2

²⁷ <http://www.opsi.gov.uk/si/si2000/20000417.htm>

(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.”

25. 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)²⁸. A key theme of the Reshaping Care programme is to understand reablement – 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 (see page 8 for research questions).

26. Furthermore, there is a shift in how local authorities and health boards will provide care in the future. As part of the draft 2011-12 budget, it was announced that the “*Scottish Government has allocated £70 million in 2011-12 within the NHS Budget to a Change Fund for NHS Boards and partner local authorities to redesign services to support the delivery of new approaches to improved quality and outcomes*”²⁹. In practice this means that Health Boards and local authorities will have to work together with the joint aim of trying to keep (older) people living independently in their own homes. To help achieve this, Health Boards and local authorities will have “*to focus on reducing unnecessary hospital admissions and speeding discharge after a crisis. This will result in better outcomes for older people*

²⁸ <http://www.scotland.gov.uk/Topics/Health/care/JointFuture/Outcomes>

²⁹ <http://www.scotland.gov.uk/Publications/2010/11/17091127/9>

*and ease the pressure on acute hospital provision*³⁰. The necessary analytical evidence to demonstrate the balance of where, and how care is provided between Health Boards and their partner local authorities can only be provided by data linkage. Health Boards, local authorities, the Scottish Government, and other organisations involved in providing/directing health and care will use the analytical evidence for service planning and shaping future health & care policy.

27. More broadly, Scottish Ministers have committed to introducing a single system of health and social care during this Parliament. The objectives of integration – to deliver better outcomes via services that are more effectively joined up – will only be possible with access to what is currently identified as health and social care data, but which represents a continuum of experience for the patient or service user regardless of the provenance of services.

28. In summary, linking specified social care, housing and health data will enable statisticians/researchers to provide important analytical evidence to policy makers and service planners in the public, voluntary and private sectors. The processing (data linking) is necessary in order to enable Scottish Ministers to provide the general guidance required under the Social Work (Scotland) Act 1968 and the National Health Service (Scotland) Act 1978.

29. Part IV, Section 33 (Exemptions) of the Data Protection Act covers statistics and research. Where the processing of personal data (including sensitive personal data) is carried out for research or statistical purposes, section 33 makes special provision relaxing, or exempting, certain DPA requirements, provided the following conditions are met:

(a) “that the data are not processed to support measures or decisions with respect to particular individuals, and

³⁰ <http://www.scotland.gov.uk/Publications/2010/11/17091127/9>

(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”.

30. In particular, section 33 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.”
31. Thomas & Walport (2008)³¹ 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. Two extracts of their findings can be found below; these are of particular relevance to the proposed social care, housing and health linked data:
32. *“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*

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

the same person to facilitate a longitudinal study, or for postcode data in cases involving geographically sensitive research questions.”

33. *“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 Protect Act.....” Thomas & Walport (2008).*

Statistics & Registration Service Act 2007

<http://www.scotland.gov.uk/Topics/Statistics/RegulationOfficialStatistics>

34. The Statistics & Registration Service Act (2007) provides for the creation of a new Statistics Board *“operating at arm’s length from Ministers, with a statutory responsibility to promote and safeguard the production and publication of official statistics that serve the public good”* (Extract from ‘Explanatory Notes to the Statistics & registration Service Act 2007³²). Part of the Statistics Board’s responsibilities, was to draw up a Code of Practice for Official Statistics which all National Statistics products are assessed against.

35. The Scottish Government and ISD Scotland fully comply with the Code of Practice for Official Statistics. The main principles are:

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

³² <http://www.statisticsauthority.gov.uk/about-the-authority/uk-statistical-system/legislative-background/key-legislative-documents/index.html>

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

Extracts of ‘Principle 5: Confidentiality’ and Protocol 3: ‘The use of administrative sources for statistical purposes’ are shown below.

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 data linkage instead of carrying out a survey

36. Maximising the use of existing administrative data has many advantages over introducing a new sample survey to monitor and inform future policy. Data from sample survey questionnaires may contain small numbers for particular variables, for example, ethnicity, and 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, a survey of sufficient size to draw accurate conclusions both at local authority, health board and Scotland level would be very expensive (£ms). In addition, the sample

survey questionnaire would need to be large and complex and therefore prone to greater respondent error due to the increased administrative burden placed on the survey respondent. Administrative data collected for the purpose of service provision is more accurate and less influenced by survey questionnaire design. Moreover, many of the people who receive social work services may not be able to fully understand and complete a questionnaire. This could lead to poor quality data overall and a lack of responses from important population subgroups who may have quite different needs from social care, housing and health policy/planning. Finally, it may not be possible to capture all the data required from a survey, for example, somebody's level of care prior to death.

37. Further details are provided on the following pages explaining the proposed data linking processes, and the steps in place to maintain confidentiality. This will ensure that the social care, housing and health data linking project complies with the Data Protection Act (1998), the Statistics & Registration Service Act 2007 and the Mental Health (Care and Treatment) (Scotland) Act 2003.

The data linking process

The Farr Institute³³

38. The Farr Institute in Scotland is a collaboration between six Scottish Universities and NHS National Services Scotland to harness health data for patient and public benefit by setting the international standard for the safe and secure use of electronic patient records and other population-based datasets for research purposes.

39. Clinical, population and computer scientists will combine their expertise to interpret large and complex health datasets in research environments that safeguard patient confidentiality. Researchers will develop methods for safely sharing, combining and analysing diverse datasets across

³³ http://www.farr-institute.org/centre/Scotland/3_About.html

boundaries, enabling new discoveries and validating research findings with a speed and scale not previously possible.

The Farr Institute in Scotland builds on the work undertaken by the Scottish Informatics Programme (SHIP)³⁴ from 2009 to 2012. SHIP developed and agreed ideas and governance for the collation, management, dissemination and analysis of anonymised electronic patient records³⁵.

40. The governance model established by SHIP is similar to well established data linkage systems worldwide (e.g. the Western Australia Data Linkage Service³⁶, Manitoba Centre for Health Policy³⁷). Diagram 2 below gives a schematic view of the SHIP protocol.

Currently, Farr Scotland has regional 'Safe Havens' located within Aberdeen, Dundee, Edinburgh and Glasgow, and a National 'Safe Haven' at NHS National Services Scotland (NSS). This Federated Model of Safe Havens is concerned with optimising the flow of data between these different Safe Havens, in a safe and secure manor to efficiently provide data and services to enable research. All data remains under the control of the NHS and complies with all legislative and NHS policies.

41. The 'Social Care, Housing & Health data linking project' will use the governance procedures agreed by SHIP and the Farr infrastructure to:

- Put in place any data sharing agreements between the data controller and ISD Scotland;
- Transfer individual identifiers between data controller and ISD Scotland securely;
- ISD Scotland will index the identifier data and return to the data controllers

³⁴ <http://www.scot-ship.ac.uk/>

³⁵ http://www.scot-ship.ac.uk/sites/default/files/Reports/Guiding_Principles_and_Best_Practices_221010.pdf

³⁶ <http://www.datalinkage-wa.org/>

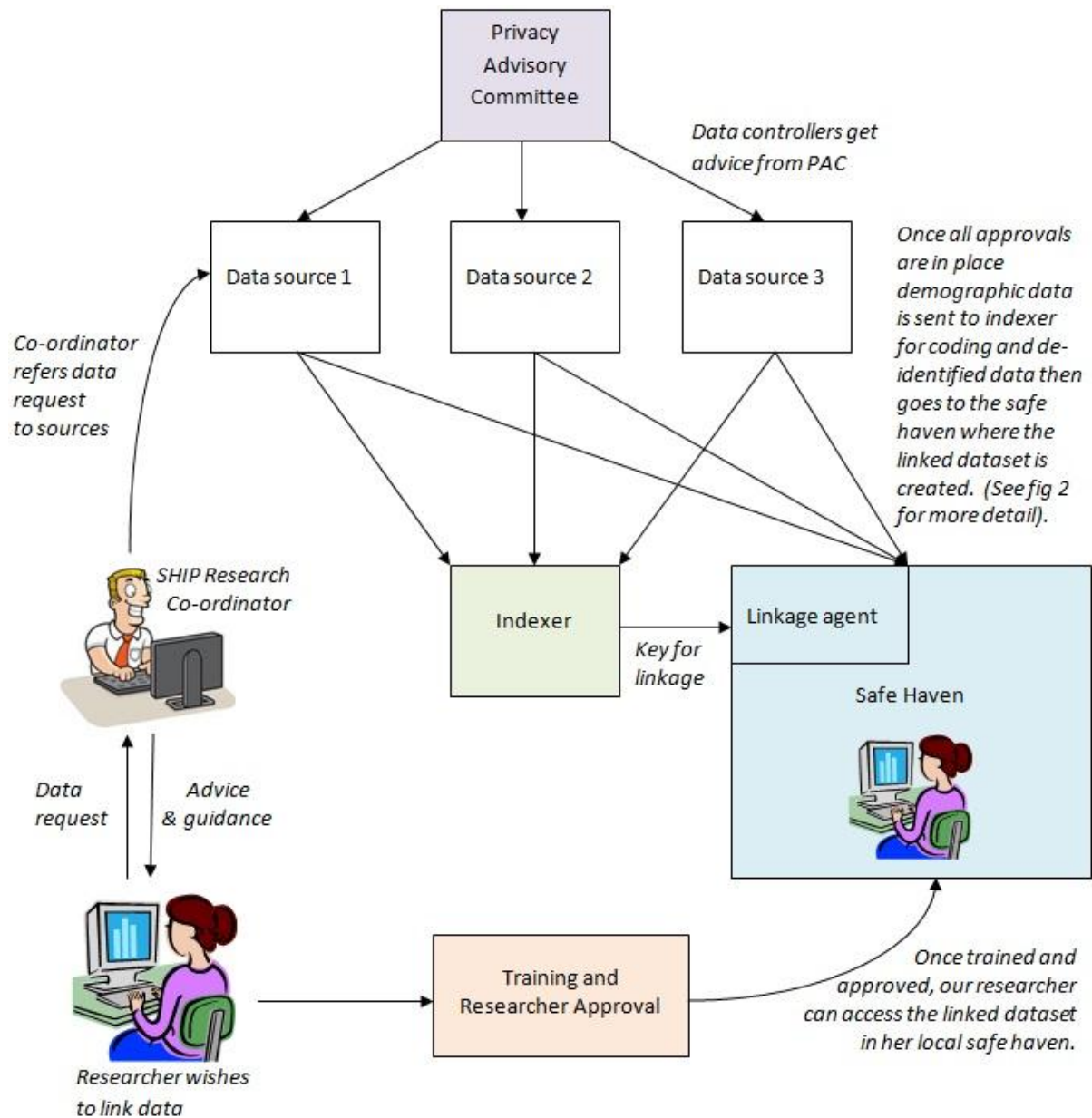
³⁷ <http://umanitoba.ca/faculties/medicine/units/mchp/resources/index.html>

- Transfer attribute or content data (de-identified) between the data controller and ISD Scotland
- Undertake the linkage;
- Store all data securely;
- Provide a safe data haven for approved analysts to access the anonymised linked data.
- Store the data securely for as long as is agreed with the 'Social Care, Housing & Health Data Linking Project Governance Group'.
- Delete data in line with ISD Scotland's protocols.

42. In addition, the 'Social Care, Housing & Health data linking project' will use ISD Scotland (part of NHS National Services Scotland) to:

- Store a copy of the linked data securely on ISD Scotland servers to enable a second access route for NHS, local Authority, Scottish Government analysts;
- Caldicott Guardian approval must be in place before any NHS, local authority or Scottish Government analyst can access the anonymised linked data.
- Store the data securely for as long as is agreed with the 'Social Care, Housing & Health Data Linking Project Governance Group'.
- Delete data in line with ISD Scotland's protocols.

Diagram 2 – [Extract of] SHIP/Farr Institute process



43. Definitions of terms used in the above diagram and over the following pages (also found in annex 2, page 53):

- **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 ‘content data’ or ‘payload data’.

- **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, processed³⁸.
- **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 operation³⁹.
- **Data linking** – Joining up information from different sources about the same person.
- **Encryption** – to convert (information or data) into a code, especially to prevent unauthorised access⁴⁰.
- **(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.
- **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).
- **Personal identifiers** – Information that identifies a person such as name and date of birth.

³⁸ (Page 49, Data sharing code of practice, ICO
http://www.ico.gov.uk/for_organisations/data_protection/topic_guides/data_sharing.aspx)

³⁹ (Page 49, Data sharing code of practice, ICO
http://www.ico.gov.uk/for_organisations/data_protection/topic_guides/data_sharing.aspx)

⁴⁰ (Oxford University Press
http://oxforddictionaries.com/definition/encrypt#m_en_gb0264750.004)

- **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 information⁴¹.

44. The process for indexing and linkage are described in detail in following paragraphs and diagram 3. All indexing and linkage activities take place on servers run by NHS Scotland or run to agreed standards on behalf of NHS Scotland. Data transfer between ISD and LAs will take place using Globalscape (see Annex 4). This will be the use of individual secure drop zones set up for each local authority. One of the drop zones will be used for file transfer connected with the indexing process (stages 1 and 2); another drop zone will be used for file transfer connected with the linkage process. This ensures that personal identifiers are always kept separate from attribute data.

45. A research coordinator will be responsible for overseeing the project from start to finish. This will include provision of assistance with data sharing agreements and any other paperwork, arrangements for data transfer to enable indexing and linkage, access to the safe haven to carry out analysis and, finally, disclosure control of outputs.

46. The data linkage process falls into three distinct phases (shown as stages 1-3 in diagram 3). Stages 1 and 2 provide a unique linkage ID for each record to be linked. This involves transfer of personal identifiers from the data controller to ISD's indexing team and the return of (encrypted) linkage IDs to the data controller. No attribute data is transferred in stages 1 and 2.

47. In stage 3 the attribute data is sent to ISD's data linking team together with the project code and (encrypted) linkage ID for each record. Different

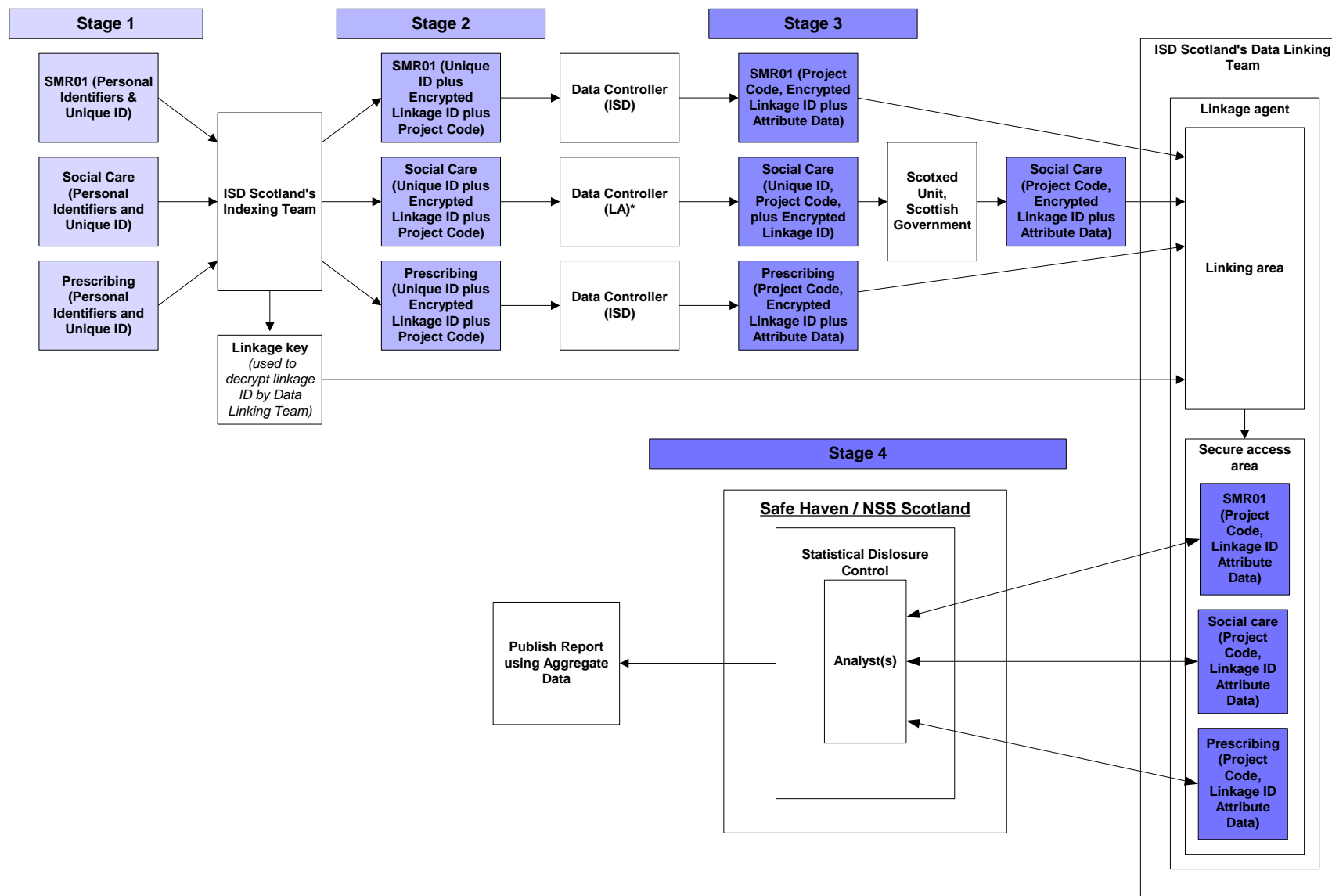
⁴¹ <http://www.datadictionaryadmin.scot.nhs.uk/isddd/2125.html>

teams in ISD handle the indexing (stages 1 and 2) and the linkage (stage 3). Datasets used in the indexing and linkage processes are stored in separate secure areas. Access to these areas is restricted to members of the appropriate teams. All such access is subject to confirmation twice a year and all members of staff sign the NSS (National Services Scotland (part of the NHS)) confidentiality statement on an annual basis.

48. The linkage agent is overseen by ISD's data linking team. The linkage agent receives the datasets to be linked from the data controllers. In addition, the linkage agent receives the linkage key from ISD's Indexing Team which is used to decrypt the linkage IDs. The datasets to be used for analysing are stored in a secure area within the linkage agent. This is all an automated process (unless there are any errors with regards to the linkage IDs which may require further checks by the data linking team). Approved researchers access the data via a safe haven and use dedicated project specific secure workspace in the safe haven to perform their analyses and to store their outputs, Security will be maintained by secure logon and the use of software (Citrix) that ensures data cannot be saved or emailed outwith the safe haven. Physical access to the safe haven will also be restricted and must be booked in advance. When the analysis is complete the research coordinator attached to the project will check the proposed outputs for disclosure risks and may require amendments if, for example, some of the tabular output contains very low frequencies in certain cells. The level of disclosure control to be applied is agreed with the data controllers in advance (in the case of this social care, housing support and health data linking project, the 'Governance Group' will agree the level of statistical disclosure control with ISD Scotland on behalf of local authorities. This will ensure that statistical outputs are in alignment with previously published social care statistical publications by the Scottish Government, which are based on local authority data) .

49. A more detailed description of the process for this specific project can be found over the following pages.

Diagram 3: The Local Authority – ISD Scotland – Scottish Government - data linking process for linking social care, housing and health data for statistics (example with selected datasets only)



* Or the Scottish Government if the local authority used the Scottish Government to undertake home care and Direct Payments data linking for historic 2010-2013 data.

The detailed data linkage process for social care, housing support & health project (Stages 1-4)

50. ISD offers separate (CHI – Community Health Index number) indexing and data linkage services which is critical in maintaining client/patient confidentiality. The process outlined below ensure that personal identifiers and attribute data are never transferred and stored together at ISD Scotland. Furthermore, the personal identifiers and attribute data are accessed by entirely separate teams.

Social care & housing support data (annual process from 2014)

51. From 2014, local authorities will be asked to submit personal identifiers to ISD (part of National Services Scotland) at the start of the Social Care Survey (which includes housing support) data collection process (once data sharing agreements are in place). This will enable ISD to create a 'Linkage ID' which the local authorities will use as part of their Social Care Survey return to the Scottish Government. Once the first release of analysis from the Social Care Survey has been published⁴² (usually around November), the Social Care Survey data can then be linked to other datasets. Full details about this process can be found under the 'Data Collection Process' section in the Social Care Survey Privacy Impact Assessment:

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

Social care & housing support data (historic data 2010-2013)

52. For the historic social care & housing support data, **EITHER Option 1 OR Option 2** will be followed:

Option 1 - For those local authorities who haven't submitted personal details (forename, surname, date of birth, gender and full address) to the Scottish Government previously then:

Stage 1

⁴² <http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Publications>

53. Data controllers (local authorities) will be asked to provide to ISD Scotland's Indexing Team, 'Unique IDs' along with personal identifiers for each applicable dataset involved in the project, **once all approvals and data sharing agreements are in place**. This data will be transferred from the local authority to ISD Scotland's Indexing Team via the secure transfer method. *(Further details about this transfer method can be found from pages 26 and 35.)*

Stage 2

54. ISD Scotland's Indexing Team uses only client/patient demographics (for example, date of birth, gender, forename, surname, postcode) to create a 'Linkage ID' in a newly created 'Index File'. The 'Linkage IDs' are then encrypted. A 'Project Code' is created for each specific project.

55. The 'Index File' (containing the Unique IDs, encrypted 'Linkage IDs' and 'Project Code') is returned to the data controller (the local authority) from ISD Scotland's Indexing Team via the secure transfer method. The data controller (the local authority) matches the encrypted 'Linkage IDs' and the 'Project Code' to the original dataset using 'unique IDs' for each individual.

Stage 3

56. Using the **same unique IDs which have been previously supplied** to the Scottish Government for the Home Care, Self-Directed Support (Direct Payments) and Mental Health Benchmarking data, these Unique IDs along with the 'Linkage ID' and 'Project Code' are sent to the ScotXed Unit within the Scottish Government via Proxcd.Net. The ScotXed Unit will then match the 'Linkage IDs' and 'Project Code' using the client 'Unique IDs' to the social care data (Home Care, Self-Directed Support (Direct Payments) and Mental Health Benchmarking data). This ensures that the data being used in the project is consistent with what is supplied to the Scottish Government and is used in national statistical publications already.

57. The ScotXed Unit will then transfer the following information to ISD Scotland's 'Data Linking Team'; encrypted 'Linkage ID', 'Project Code' and attribute data (e.g. hours of home care, if the client has a community alarm etc.).

Option 2 - For those local authorities who have submitted personal details (forename, surname, date of birth, gender and full address) to the Scottish Government previously then:

Stage 1

58. The ScotXed Unit within the Scottish Government will be asked to provide to ISD Scotland's Indexing Team, 'Unique IDs' along with personal identifiers for each applicable dataset involved in the project, **once all approvals and data sharing agreements are in place**. (To note, *part of the approval process will be to seek written approval from the local authorities who originally supplied the personal identifiers to the Scottish Government.*) This data will be transferred from the Scottish Government's ScotXed Unit to ISD Scotland's Indexing Team via the secure file transfer method. (*Further details about this transfer method can be found from pages 26 and 35.*)

Stage 2

59. ISD Scotland's Indexing Team uses only client/patient demographics (for example, date of birth, gender, forename, surname, postcode) to create a 'Linkage ID' in a newly created 'Index File'. The 'Linkage IDs' are then encrypted. A 'Project Code' is created for each specific project.

60. The 'Index File' (containing the Unique IDs, encrypted 'Linkage IDs' and 'Project Code') is returned to the data controller (the Scottish Government under this option) from ISD Scotland Indexing Team via the secure file transfer method. The data controller (the Scottish Government) matches the encrypted 'Linkage IDs' and the 'Project Code' to the original dataset using 'unique IDs' for each individual.

Stage 3

61. The ScotXed Unit will then match the 'Linkage IDs' and 'Project Code' using the client 'Unique IDs' to the social care data (Home Care, Self-Directed Support (Direct Payments) and Mental Health Benchmarking data).
62. The ScotXed Unit will then transfer the following information to ISD Scotland's 'Data Linking Team'; encrypted 'Linkage ID', 'Project Code' and the **relevant** attribute data (e.g. hours of home care, if the client has a community alarm etc.) as specified under the '*Research questions to be answered through data linkage*' section (from page 8).

Health data

Stage 1-3

63. The health data being used in this project is already held at ISD Scotland. The health data will already have Linkage IDs created for the each of the datasets used in this project as they have been used in existing health data linking work. Therefore, in terms of what happens to the health data to be used in this particular project, **once all approvals are in place**, ISD Scotland's Indexing Team creates a 'Linkage ID' in a newly created 'Index File'. The 'Linkage IDs' are then encrypted. A 'Project Code' is created for each specific project.
64. The 'Index File' (containing only the encrypted 'Linkage IDs' and 'Project Code') is sent to ISD Scotland's Data Linking Team. The Data Linking Team already have access to the health attribute⁴³ data (date of admission, date of discharge etc.). Only **relevant** health attribute data (as

⁴³ Sometimes referred to as 'payload data' in health.

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specified under the '*Research questions to be answered through data linkage*' section (from page 8)) is used in the project.

Social care, housing support & health data

Stage 4

65. The Indexing Team send to the Data Linking Team a 'Linkage Key'. This 'Linkage Key' decrypts the 'Linkage IDs' from the datasets which are being used in the project. This is an automated process.

66. The Data Linking Team at ISD Scotland stores the datasets which contain 'Project Code', (decrypted) 'Linkage ID' and the attribute data (e.g home care hours). within a secure NHS safe haven. Clients/patients can be joined together from the separate datasets using the Linkage ID.

67. ISD Scotland are the data controller for these linked datasets.

68. Approved researchers (see page 42 for definition of 'approved researchers') will only be able to access data relating to their specific project which is identified by the 'Project Code'. Researchers will not be able to cross reference any data held in the safe haven with information which is contained in other datasets or Management Information Systems. This is achieved firstly by the encryption of the 'Linkage ID' and secondly by not allowing any downloading of data. In addition, no removable media is allowed in the safe haven. Further details are available in Annex 4.

69. All outputs are subject to statistical disclosure control (see paragraph 96 for further details) before being released to the researcher.

70. A Glossary of Terms can be found on page 53.

Transmission & storage of data

LAs exchanging data with ISD Scotland

71. 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.

72. 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.

73. Further details are available in Annex 4.

SG Receiving Data from LAs

74. This will be done using a simple ProcXed.NET data collection. This is an established secure service for collecting data for statistical analysis with which colleagues in local authorities are already familiar. 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. In addition, data held on the ProcXed.NET servers is encrypted using AES (American Encryption Standard) encryption. Further details about ProcXed.net can be found on page 61.

SG Exchanging Data with ISD

75. Transfer of attribute/payload data (i.e. social care data) from the Scottish Government to ISD Scotland uses Globalscape Secure File Transfer. This

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is certified as part of the eDRIS solution. Temporary account credentials are machine generated by the Globalscape platform for the upload/download of data.

76. 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.

77. Further details are available in Annex 4.

Retention

78. “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”*.

79. The use of the specified datasets⁴⁴ in this data linkage project will be retained, with agreement from the data controller, by ISD Scotland to enable longitudinal analysis (tracking individuals over time). The retention of data will be reviewed annually by the project Governance Group and the data controllers.

80. Data no longer required for the project will be destroyed, in line with ISD Scotland’s IT security protocols.

44

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

Consent

81. In accordance with the Code of Practice for Official Statistics⁴⁵ the Scottish Government and ISD Scotland have a duty to abide by Principle 5, which covers data confidentiality (see page 19). In addition to the governance processes which will be in place surrounding data transmission, storage and access, local authorities will be asked to update their privacy (fair processing) notices for clients and to inform them (for example at reviews) of how their data will be used. Clients (or their carers) *“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, 2008⁴⁶). Suggested text to be incorporated by local authorities into their privacy (fair processing) notices can be found in Box 1.

⁴⁵ <http://www.statisticsauthority.gov.uk/assessment/code-of-practice/code-of-practice-for-official-statistics.pdf>

⁴⁶ <http://www.justice.gov.uk/reviews/datasharing-intro.htm>

Box 1: Privacy notices – suggested text for local authorities (see Annex 6 for easier to read version)

Your personal details and support package may be shared with the Scottish Government and the National Health Service for statistical and research purposes.

- This information will help the Scottish Government, your local authority and your Health Board plan future care services. This will help improve services for you and others.
- Your data may be joined to other health and housing support data by the Scottish Government and the National Health Service Scotland. This is to produce statistics only. Statisticians/researchers will not be able to identify you from the data that they will use.
- Every effort will be made to ensure that your information is kept safe at all times.
- Only people in the Scottish Government and the National Health Service who need to see your personal information will be able to access it.
- All pieces of information which could identify you, such as names and dates of birth will be removed before the data is used by statisticians/researchers.

Example of the kind of publication which we use your data for:

The latest 'social care survey' 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

Note: Privacy notice has been tested through social care/health service user consumer panels.

82. A copy of ISD Scotland's privacy leaflet for patients explaining how their data may be used can be accessed here:

http://www.isdscotland.org/About-ISD/Confidentiality/Safe_and_secure_use_of_personal_health_info_De c2012.pdf

83. It is proposed that explicit consent will not be asked of the people who use social care, housing and health services. There are three main reasons for this decision. Firstly, the scale of the data collection (based on *existing* Management Information) makes this an incredibly large exercise to audit, and the pursuit of explicit consent may result in incomplete datasets and bias – which is of particular importance in statistical analysis. Secondly, although sensitive personal data is being collected for linking to other datasets, the end result is an anonymised dataset which will only be used for statistical/research purposes by ISD Scotland, the Scottish Government and other approved researchers (such as local authority, health board and academic researchers). Further information about accessing the anonymised data for statistical/research purposes can be found in the ‘Dissemination’ section. 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 ISD Scotland would not be in a position to verify that the client has fully understood the request for consent and the implications.

84. The ‘Data Sharing Review’ by Thomas and Walport (2008) discusses the need for consent in various contexts; an extract of particular relevance to this project is shown below:

85. *“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.”*

86. *“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.”

87. “.....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).

Consent & confidentiality - Mental Health (Care and Treatment) (Scotland) Act 2003, Section 279(4) and (5)

88. Section 279(5) of the Mental Health (Care and Treatment) (Scotland) Act 2003 requires consent to be obtained where the provision of information relating to the 2003 Act would breach any duty of confidentiality which applies in respect of that information. As the project proposal relates to sensitive personal data about individuals given in a healthcare context, a duty of confidentiality is likely to apply to that information. Accordingly, to comply with section 279(5), it is necessary to ensure that an individual’s right to privacy and confidentiality is not breached by disclosing personal (& social care) information to ISD Scotland without the consent of individual clients. This will be achieved by a number of means. Firstly (as outlined under the ‘Data linking process section (from page 30)’, the personal identifiers (names, date of birth, address, gender) will be supplied to ISD Scotland separate to the social care (attribute) data (which includes the indicator if a person has dementia, a mental health problem or a learning disability). The personal identifiers are stored and accessed by one team in ISD Scotland, and the social care (attribute) data is accessed and stored by a separate team in ISD Scotland. The personal identifiers and social care data are never joined or stored together at ISD Scotland.

89. Secondly, the aim of the project is to produce anonymised (i.e. without names, full date of birth and full address) datasets for the purpose of

producing statistical analyses. The data would never be published in a form which would identify individuals and thus, would not breach any duty of confidentiality because the disclosure of the data to ISD Scotland would have no effect on the individual's right to privacy. Ultimately, it will be up to the data controllers to decide whether they can pass the information requested to ISD Scotland without breaching section 279(5) of the 2003 Act (breach of that provision would also amount to a breach of the requirement of the first data protection principle in the DPA to process data lawfully). Data controllers will also have to comply with the terms of section 279(4) of the 2003 Act which requires them to consider whether information requested can reasonably be provided in a form which does not identify, or allow the identification of, individuals.

90. In summary, the social care and health 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 using person identifiable information is purely to link datasets to create an anonymised dataset for statistical and research purposes only.

Consumer panels

91. As part of this data linking project's full Privacy Impact Assessment (PIA), consumer panels (focus groups) have taken place to discuss the impact of linking data. These panels were chaired by an independent researcher from the University of Edinburgh, and participants were social care, housing support and health service users. The following topics were covered during the discussion:

- Assessing social care/housing support clients and patients' awareness and understanding of the data collected on their use of services
- Exploring social care/housing support clients and patients' perceptions of data linking
- Identifying concerns around data linking and sharing of data between organisations;

- Exploring how any privacy concerns could be addressed;
- Exploring what information would reassure social care/housing support clients and patients about how their data will be used;
- Examining the level of understanding and perceived appropriateness of explanations provided to social care/housing support clients/patients as to how their personal information may be used is and;
- Exploring the perceived impact of linking social care, housing support and health data on social care/housing support clients and patients', and the public more widely.

92. Analyses of the views from the panels can be found here:

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

The Scottish Health Informatics Programme⁴⁷ (SHIP) has also held a series of focus groups discussing some of the issues surrounding linking data, including ethics. Reports and publications from the SHIP public engagement can be found here:

<http://www.scot-ship.ac.uk/publications>.

Furthermore, as part of the Data Linkage Framework, a report on public attitudes towards data sharing can be accessed here:

<http://www.scotland.gov.uk/Topics/Statistics/datalinkageframework/PublicAcceptabilityResearch>.

Access to the linked data for analysis

93. Linked data will be held in a safe haven within NHS National Services Scotland and on ISD Scotland secure servers. Access will be provided to approved researchers, for example they have completed a training course in data protection, security and disclosure control if they are an academic⁴⁸, and/or they are employed by the Scottish Government, local authority or NHS Scotland.

⁴⁷ <http://www.scot-ship.ac.uk/c4.html>

⁴⁸ <http://www.isdscotland.org/Products-and-Services/eDRIS/Becoming-an-eDRIS-User/>

94. Researchers who access the data via the national safe haven (e.g. academics) will be bound by a contract and subject to sanctions if they breach the conditions of access. The data and analytical tools will be made available in the safe haven. The researcher will not be able to download any data, analyses or copy any information from the screen. Statistical Disclosure Control will be applied to outputs before release to the researcher.

95. Scottish Government, local authority or NHS Scotland analysts who access the data via ISD Scotland will be bound by a contract and subject to sanctions if they breach the conditions of access.

Statistical Disclosure Control

96. Even though personal identifiers will have been removed from the final linked dataset, the dataset could still potentially be disclosive. For example, if analytical outputs referring to a small population are used in conjunction with local knowledge then a client *may* be identified and new information may then be learned about them. To reduce the risk of this occurring, statistical disclosure control will be applied to all analyses based on the linked 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, either directly or by deduction. ISD Scotland and the Scottish Government have comprehensive disclosure control policy based on the Confidentiality Guidance released by the Office of National Statistics (ONS). Further information about statistical disclosure control can be found here:

<http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/Glossary>

and here: <http://www.isdscotland.org/About-ISD/confidentiality/>.

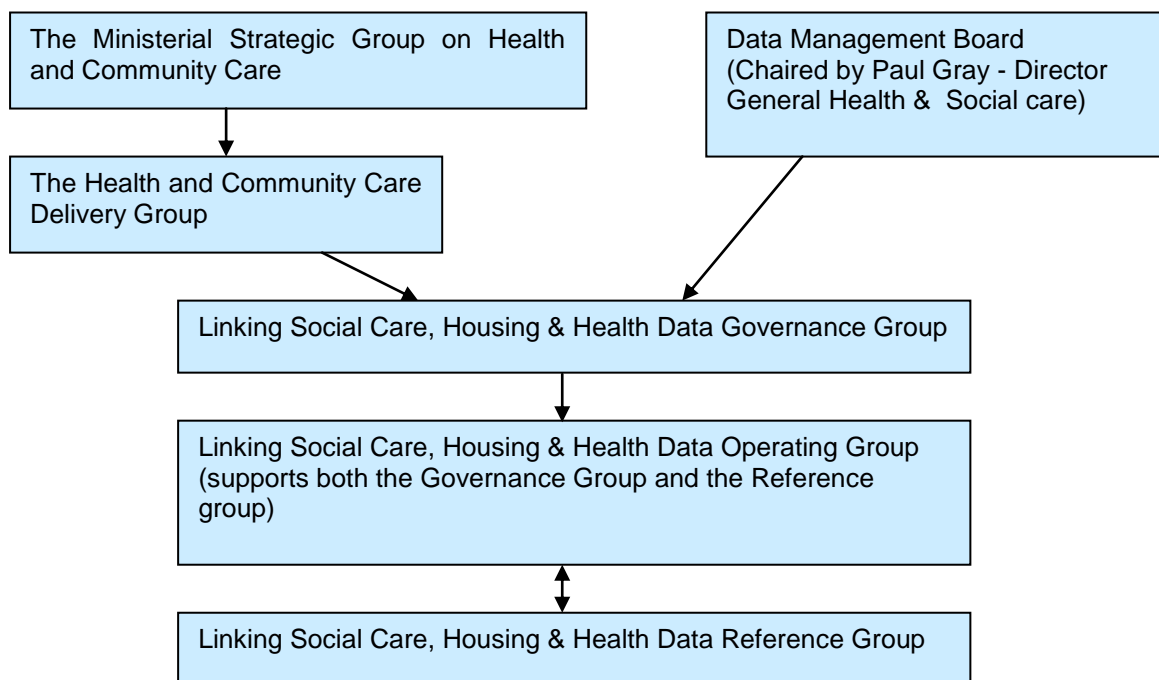
97. The linked social care (including housing support) and health dataset will be used firstly, to produce analytical papers (which will be published) secondly, to provide analysis for ad hoc requests⁴⁹ for a wide range of

⁴⁹ <http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Data>

organisations. These include; the Scottish Government, NHS Scotland, local authorities, GP practices, Social Care & Social Work Improvement Scotland (known as the Care Inspectorate), Association of Directors of Social Work, care providers, voluntary organisations, private sector and other Government Departments. Thirdly, the linked dataset may be accessed by other researchers, for example academics, under the same safe haven set up. Researchers who wish to access the linked social care (including housing support) and health dataset will have to obtain permission from the Privacy Advisory Committee (and possibly the CHI Advisory Group and Health Research Ethics depending on the nature of their research).

Governance - Social Care, Housing & Health Data Linking Project

98. A '*Linking Social Care, Housing & Health Data Governance Group*' has been established for this specific project. The '*Governance Group*' has representation from Scottish Government, ISD Scotland, local authorities and health boards. The '*Governance Group*' will report to '*The Health and Community Care Delivery Group*⁵⁰' and align priorities to the '*Scottish Government Data Management Board*⁵¹'.



⁵⁰ <http://www.scotland.gov.uk/Topics/Health/care/JointFuture/jfia>

⁵¹ <http://www.scotland.gov.uk/Topics/Economy/digital/digitalservices/datamanagement>

99. The '*Governance Group*' has responsibility for:

- Considering for approval⁵² all new data linkage proposals for statistical analysis/research using national social care, health and housing support data from Scottish Government, ISD Scotland, local authorities or health boards.
- Ensure projects meet current priorities and have a clear focus.
- Assisting with the arrangement for obtaining (including permission from data controllers), linking and holding data so that confidentiality is observed and identifiable data is held only where necessary to aid future linkage;
- The scope of the linked data to be held in NSS safe haven;
- Agree Statistical Disclosure Control methodology to be applied to datasets;
- Arrangements for analysing linked data and ensuring that any analysis released does not infringe legal or privacy constraints;
- Ensuring that the project complies with any changes to National Statistics Code of Practice on data sharing or data linkage;
- Keep all documentation relating to decisions, actions and minutes of Governance Group meetings.
- Publishing approved projects and subsequent analytical papers on the web.

100. The '*Social care, housing & health data linking operating group*' will support the '*Governance Group*' in carrying out its functions. The '*Operating Group*' will also report to the '*Reference Group*' to ensure that the relevant research questions are being put forward.

Other governance arrangements (also applicable for local data linking projects using the Farr Institute)

⁵² All projects would still require permission from data controllers, Privacy Advisory Committee, CHI Advisory Committee (if applicable) and Research Ethics (if applicable).

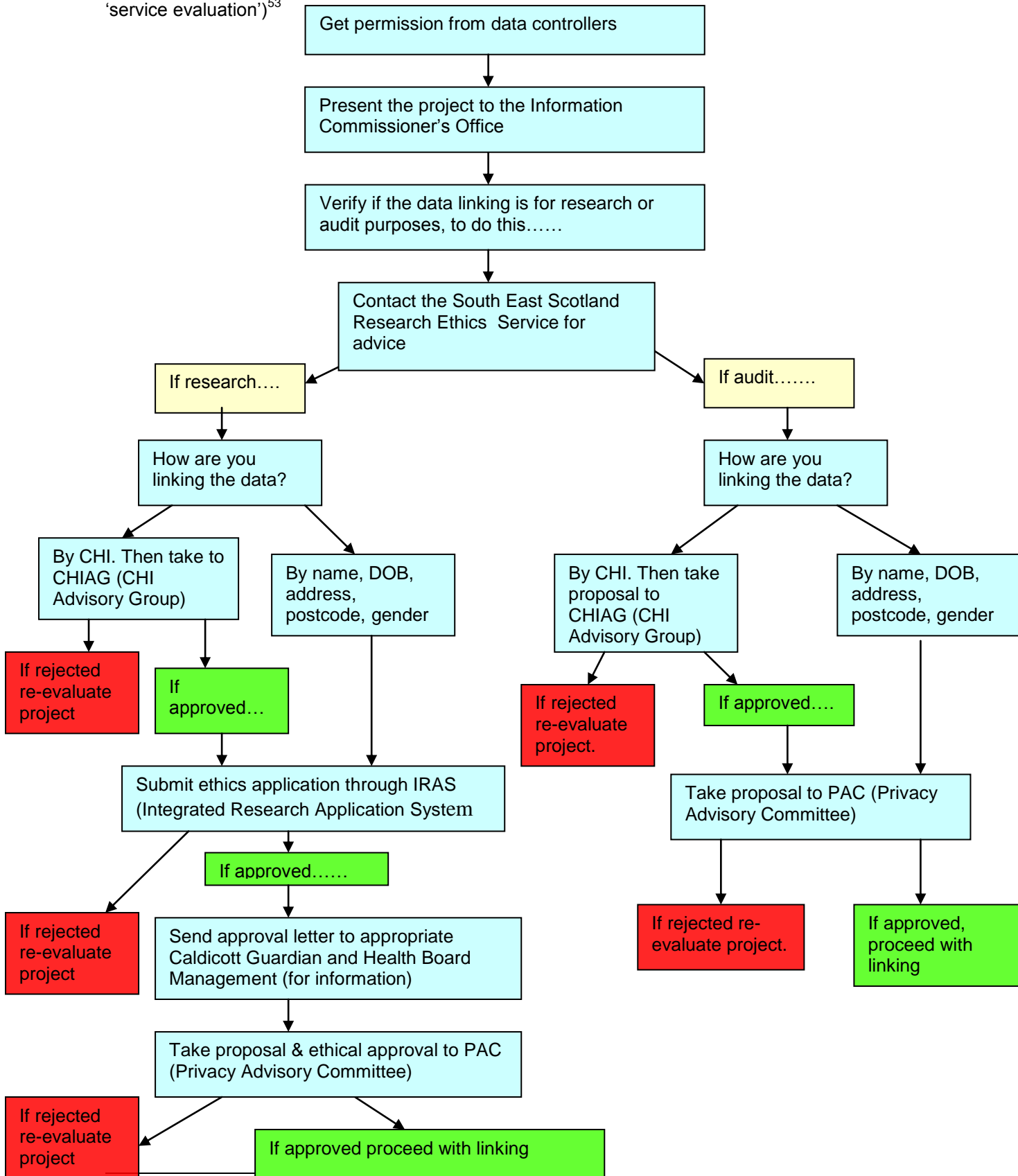
- **Data controllers** – Permission will be sought from all data controllers (local authorities, ISD Scotland, Scottish Government) before any data is linked. This will be in the form of a written data sharing agreement setting out what data will be linked, how it will be transmitted by the local authority, Scottish Government, ISD Scotland. How it will be stored, accessed, retained for, and how local authority clients will be informed of how their data is being used.
- **Support from Information Commissioner’s Office (ICO)** – the ICO have been involved in the development of the project and are supportive of how the project is balancing the use of personal (sensitive) data whilst maintaining data subject’s privacy.
- **Ethical approval (if deemed ‘research’ as opposed to ‘audit’ or ‘service evaluation’)** – The pilot project was presented to the ‘South East Scotland Research Ethics Service’ for advice as to whether it was ‘research’, ‘audit’ or ‘service evaluation’. The pilot project was classified as ‘service evaluation’ and as such did not need to go through full medical research ethical approval. This will be reviewed as the project develops and ethical approval will be sought if the project is classified as ‘research’ in the future.
- **Approval from the CHI Advisory Group** – An application was made by ISD Scotland on behalf of the ‘*Governance Group*’ to the CHI Advisory Group in order to use the care home flag as part of the project. Permission to use CHI as part of the data indexing process had previously been granted to ISD Scotland. A further application will be made to CHIAG to request the use of the GP practice flag in the project.
- **Approval from the Privacy Advisory Committee (PAC)** - An application was made by ISD Scotland on behalf of the ‘*Governance Group*’ to the Privacy Advisory Committee for approval to link the social care & housing data to the health data. Further approvals will be sought if significant changes are

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made to the project for example, the inclusion of further
datasets.

101. Further information about the Information Commissioner’s Office, ethical approval service, CHI Advisory Group and the Privacy Advisory Committee can be found in the ‘useful sources’ section (page 51).

102. The following diagram outlines the approval process for linking social care, housing and health data for research and audit (or service evaluation) purposes in Scotland:

Diagram 4: Approval process for linking social care, housing and health data for research or audit purposes in Scotland (note: sometimes statistics will fall under ‘audit’ or ‘service evaluation’)⁵³



⁵³ Note: If your proposal gets rejected, you can resubmit it after making amendments. Further information about what is defined as research and audit can be found at: www.nres.npsa.nhs.uk/applications/apply/is-your-project-research/

Audit

103. National statistics (which include the datasets: Social Care Survey, Home Care, Self-directed Support (Direct Payments), SMR01, SMR04) are assessed by the Statistics Authority⁵⁴ against the 'Code of Practice for Official Statistics (this includes against the principle concerning confidentiality). Furthermore, ISD Scotland have data security and confidentiality procedures in place which all staff have to abide by (further information is available on request).

Timescales

104. The sharing and linking of data for the pilot project occurred between late 2012-early 2014. 12 local authorities participated in the pilot project which was conducted in 3 phases. Further information about the pilot is available here:

<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Datalinking/HealthSocialCareandHousing> {*still to publish review and pilot analysis*}. All local authorities will be invited to take part in the project from 2014.

Conclusion

105. There is strong support within the Scottish Government, NHS Scotland and local authorities to improve the analytical evidence of how social care, housing and health interact and contribute to enabling people live at home for as long as possible. The linking of social care, housing and health data will provide analysis on the outcomes for clients who are receiving different combinations of services at different points in their care paths. For example, it will be possible for the first time to assess the impact of different service interventions on unplanned hospital admissions through the linkage of social care, housing and health data, without such data linkage, this would not be possible. Furthermore, the analytical evidence from using linked social care, housing and health data will be

⁵⁴ <http://www.statisticsauthority.gov.uk/assessment/index.html>

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pivotal for central government, local authorities, NHS Scotland, private and
the voluntary sector in the planning and evaluating of services/policies.

106. As a consequence of handling and linking sensitive personal information, appropriate security procedures will be put in place to ensure that the Farr Institute, ISD Scotland, the Scottish Government, and local authorities comply with legislation and the recommended procedures in the Information Commissioner’s Office’s ‘Data sharing code of practice⁵⁵’.

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Scotland**

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With thanks to the many other contributors.

⁵⁵ http://www.ico.gov.uk/tools_and_resources/document_library/data_protection.aspx

Annex 1 - Useful sources

CHI Advisory Group

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

Data Protection Act 1998

www.opsi.gov.uk/acts/acts1998/ukpga_19980029_en_9

Data Sharing & Linking Service

<http://www.gro-scotland.gov.uk/data-sharing-linkage-service/index.html>

Data Sharing Code of Practice

http://www.ico.gov.uk/tools_and_resources/document_library/data_protection.aspx

Data Sharing Review, by Richard Thomas & Dr Mark Walport, 2008

<http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/links/data-sharingreview.pdf>

Farr Institute

http://www.farrinstitute.org/centre/Scotland/3_About.html

Identity Management and Privacy Principles

<http://www.scotland.gov.uk/Publications/2010/12/PrivacyPrinciples>

Information Commissioner's Office

<http://www.ico.gov.uk>

Mental Health (Care and Treatment) (Scotland) Act 2003

<http://www.legislation.gov.uk/asp/2003/13/contents>

National Health Service (Scotland) Act 1978

<http://www.legislation.gov.uk/ukpga/1978/29>

National Research Ethics Service

www.nres.npsa.nhs.uk

Privacy Advisory Committee

http://www.nhs.uk/nhs.uk/pages/corporate/privacy_advisory_committee.php

Scottish Health Informatics Programme

<http://www.scot-ship.ac.uk/>

SHIP Guiding Principles and Best Practices

[www.scot-ship.ac.uk/.../Guiding Principles and Best Practices 221010.pdf](http://www.scot-ship.ac.uk/.../Guiding_Principles_and_Best_Practices_221010.pdf)

Social care, housing & health data linking project website

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

Health & Social care Data Integration

<http://www.isdscotland.org/Products-and-Services/Health-and-Social-Care-Integration/>

Social Work (Scotland) Act 1968

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

Statistics & Registration Service Act 2007

<http://www.statisticsauthority.gov.uk/uk-statistical-system/legislative-background/key-legislative-documents/index.html>

Statutory Instrument 2000 No.417 – The Data Protection (processing of Sensitive Personal Data) Order 2000

www.opsi.gov.uk/si/si2000/20000417.htm

The Confidentiality & Security Advisory Group for Scotland: Protecting Patient Confidentiality

<http://www.sehd.scot.nhs.uk/publications/ppcr/ppcr-00.htm>

The Guide to Data Protection, Information Commissioner's Office

http://www.ico.gov.uk/for_organisations/data_protection/the_guide.aspx

Annex 2 - 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>)

Annex 3: Summary of home care statistics progress

In 2010, the home care statistical data collection moved from an aggregate to an individual level return. This shift, firstly enables analysts to gain an improved understanding of social care services that an ‘individual’ receives and secondly, is the first stage in preparation of being able to link to other datasets. The data collection and process was developed in consultation with:

- Scottish Government policy
- Scottish Government IT/data management specialists (ScotXed)
- Scottish Government solicitor
- Scottish Government Head of Information Management
- Local authority service managers and analysts,
- Association of the Directors of Social Work,
- Information Commissioner’s Office,
- Scottish Privacy Forum,
- Local Authority Information Security Group,
- Other organisations that utilise this data (including from other sectors).

In order for the Scottish Government to collect and store personal information, a full Privacy Impact Assessment⁵⁶ was undertaken, as recommended by the Information Commissioner’s Office. As part of this process, new secure procedures were put in place to transmit and store the data from local authorities. Moreover, fair processing notices were developed – in conjunction with the Scottish Consortium for Learning Disabilities - to assist local authorities in informing their clients of how their data might be used.

The data referred to a snap shot (typical) sample week at the end of March 2010 and was submitted to the Scottish Government during

⁵⁶ See ‘Home care data confidentiality paper’
<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/HomeCareCensus>

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Spring/Summer 2010. The statistics were published on the 30th November
2010 and can be accessed at the following link:

<http://www.scotland.gov.uk/Publications/2010/11/30092349/0>

Annex 4 – Globalscape and eDRIS

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 5 – ProcXed.Net

Introduction

The purpose of this annex is to provide users of ProcXed.NET with information on the hosting and management arrangements for the application. The note covers the following:

1. Data Transmission & Storage
2. Physical Hosting
3. Application Management
4. Backup and Business Continuity

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 Government survey administrators and statisticians have no access to the data until the submitter explicitly submits it to the Scottish Government.

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). At this point, the Scottish Government become the data controllers.

Physical Hosting

ProcXed.NET servers are hosted at Scolocate. Scolocate provide physical server hosting including physical security, power and climate control. Scolocate staff have only limited⁵⁷ physical access to the ProcXed.NET servers and have no access to the systems.

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, CESA CLAS consultants and other authorities who advise the UK government on security matters.

⁵⁷ Only key staff have access under certain circumstances and all access is recorded.

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

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 Scottish Government staff only when the user submits the data to the Scottish Government.

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 is backed up in order that it can be restored in the event of a catastrophic failure.

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.

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.

Annex 6 – Privacy notice – easier to read version



Scottish Government and the National Health Service might want to know some information about you and the support you get. They will use this information to collect lots of numbers. These numbers are called “statistics” and they help Scottish Government to see what people’s lives are like.

You do not have to do anything. The Scottish Government and the National Health Service will ask for information they want from your Local Authority.

No one will know the information is about you. Personal information like your name, date of birth and postcode will not be used in the report.



The Scottish Government and the National Health Service will try to make sure that the information they get about you is always kept safe.

Only people who really need to see your information will be able to look at it and they will not share it with anyone else.

Scottish Government and the National Health Service might use other health and housing information that is about you to help write their report. The people who link the information up will not know the information is about you.





The information they collect will help the Scottish Government, your Local Authority and Health Board to plan for care services in the future. This will help to make services better for you and others.



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:



Scottish Government contact:



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



0131 244 3777



SWStat@scotland.gsi.gov.uk

