

# **A Scotland-wide Data Linkage Framework for Statistics and Research**

## **Consultation Paper on the Aims and Guiding Principles**

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Our vision for the future is one where evidence of what works in delivering positive outcomes for all of Scotland is delivered quickly and efficiently with minimal burden on front-line services. Where the public recognises that their information is secure, and is used ethically, legally and efficiently to answer crucial research questions, providing answers on how to tackle the major issues facing Scottish people. Where Scotland is recognised the world over as a hub of innovative and powerful statistical research, attracting investment and job creation.

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## Summary Overview

Scottish Government is working with a wide range of partners to establish a collaborative framework that will facilitate data linkages for research and statistical purposes to be conducted safely, securely, legally, ethically and efficiently.

It is in the public interest both to safeguard individuals' right to privacy and to make efficient use of data for statistical and research purposes. The Data Linkage Framework aims to help every-one involved in data linkage to balance these values; to provide the public with assurance that personal data are being used safely and appropriately; and to provide a common framework of principles and standards that data custodians and users can work within.

Data linkage is already widely used in the health sector, and Scotland has an international reputation as a leader in linkage-based research. But there is scope to extend the use of data linkage within and between sectors and to develop the methods collaboratively. The framework is broad, and is intended to provide multiple benefits to a wide range of stakeholders. The aims of the data linkage framework are to:

- a. Speed up cycles of improvement through the delivery of a higher quality cross-sectoral evidence base to inform public policy and strategic spending decisions
- b. Enable better use of existing data to develop efficient and reliable methods of producing demographic and census-type statistics
- c. Increase the power of statistics available to all
- d. Allow relatively low cost longitudinal research to be conducted both retrospectively and prospectively, informing preventative spend
- e. Increase the capacity to robustly evaluate the costs, benefits and risks of new health, social, educational and associated programmes
- f. Provide exemplars of research excellence, enhancing Scotland's reputation and attracting investment and job creation to Scotland

The foundation of the Framework will be a set of principles which provide common standards for safe and effective data linkage and which will underpin a robust governance mechanism that reflects and promotes the core values in play.

**The main purpose of this consultation is to seek views on the aims of the Data Linkage Framework and a draft set of guiding principles.**

Once a set of principles has been agreed, the details of the other parts of the framework (a National Data Linkage Centre and an Analytical Privacy Advisory Service) will be developed. Comments to help develop plans for both of these are welcome at this stage, but there will be further opportunity to comment when more details have emerged.

This written consultation is just one part of a broader and on-going dialogue with a wide range of organisations and individuals. **Responses to this consultation paper are invited by Friday 15 June 2012.**

# 1. A brief explanation of data linkage for research and statistical purposes

In this framework, data linkage is the joining of two or more administrative or survey datasets to greatly increase the power of analysis then possible with the data.

**This framework is concerned exclusively with data linkage for research and statistical purposes.** It does not cover the sharing of personal information about an individual between organisations in order to deliver a co-ordinated service to that person. The following examples are all **beyond the scope of this framework**:

- A Child Protection Officer sharing a particular family's case file with a School and the Police, in order that all three can work together to protect a child at risk.
- A Local Authority sharing information about named individuals claiming Housing Benefit with any other organisation for the purpose of combating fraud.
- A GP sharing information about an individual patient's symptoms or diagnosis with a hospital in order that the patient receives a co-ordinated service from all parts of the NHS.

**This framework is concerned exclusively with the linkage of data for research and statistical purposes** where there is no direct impact on an individual because of information about that individual being linked. Many examples are given throughout section 2, and can be seen as falling into three categories:

1. Development and production of Official Statistics, including development of alternatives to the Census and the production of aggregate statistical information.
2. Production and dissemination of research resources, such as longitudinal statistical products like the Scottish Longitudinal Study.
3. Ad-hoc research projects, or linkages conducted to answer specific research questions using statistical analyses, such as the West of Scotland Coronary Outcomes Prevention Study.

## **Example of how Data Linkage for Research and Statistical Purposes can work: The Scottish Health Survey**

The Scottish Health Survey is a sample survey of approximately 6,000 adults and 2,000 children per year. It is conducted through face-to-face interviews, and respondents are asked about a wide range of health issues including smoking, alcohol intake, diet, levels of physical activity, self-assessed health and mental well-being; prescribed medicines; and symptoms of ill-health. Some biological measures are also taken, such as waist and hip circumference, height, weight and blood, urine and saliva samples.

All aspects of the Scottish Health Survey, including data linkage, are approved by The National Research Ethics Service before being conducted.

All respondents are asked to consent to their name, address and date of birth being sent to the Information Services Division of NHS Scotland (ISD) so that their responses to the Health Survey can be linked with records holding data on medical diagnoses, in-patient and out-patient visits to hospital, and other information about cancer registration, GP registration and mortality.

Where the respondent gives consent for linkage the following process then occurs:

- First, respondents name, address, date of birth and a unique serial number (which is different to that used on the publicly available survey dataset) are separated from the rest of the health survey dataset (all the responses to the health survey questions) and sent by the survey contractors to ISD.
- ISD then link respondents name, address, date of birth and a unique serial number, with the health records, and delete the respondents name, address, date of birth. This leaves a file of unique serial numbers and administrative health data. This file is then sent to a named analyst in Scottish Government.
- The Scottish Government analyst then merges that file with the data collected through the Health Survey, using the unique serial number. The unique serial number is then deleted and a new random one added.
- This dataset is then analysed, results are checked for risk of disclosure, and the aggregate results and conclusions are disseminated as widely as possible.

**All data is sent between the three organisations by secure FTP (File Transfer Protocol) servers and can be accessed only by a small number of named people in each organisation.**

**None of the three organisations – Scottish Government, the contractor, or ISD - has access to both survey and health records with personal identifiers attached at any time.**

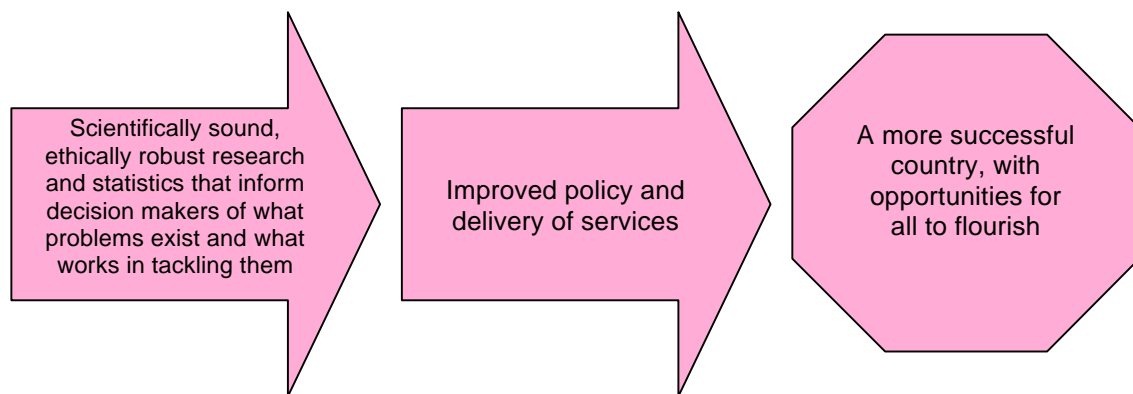
This is one example of how linkage projects for statistics and research purposes can be conducted in a way that protects privacy. Other projects and systems may use different procedures.

## 2. The benefits of data linkage and the need for a Scotland-wide framework

This section sets out the long-term benefits that can arise from data linkage, followed by a summary of the challenges that prevent more data linkage occurring. This demonstrates why a strategic framework is needed to help overcome the challenges and encourage data linkage, particularly across sectors (e.g. health, education, justice etc).

### **Benefit 1: Data linkage will help speed up cycles of improvement through the delivery of a higher quality cross-sectoral evidence base to inform public policy and strategic spending decisions**

High quality policies and delivery of services are heavily dependent on high quality information about what problems exist, how they come about and what works in tackling them.



By making better use of data that already exist the evidence base that forms the foundation of public services in Scotland will be improved. This will in turn allow for improved decision-making, and allow for funding to be better targeted at delivery mechanisms that have been shown to really work.

For example, it is known that:

- School attendance for Looked After Children is lower than for the population as a whole. Looked After Children are 8 times more likely to be excluded from school than other children.
- The average tariff score (a measure of attainment) for Looked After Children leaving school is 67 compared to 372 for all school leavers.
- 59% of looked after children leave school for a positive destination compared to 87% of the population as a whole.

These insights were achieved through linking data from Local Authority social work service departments, publicly funded schools, the Scottish Qualifications Authority and Skills Development Scotland. It is exactly this kind of evidence that is needed for improvement in policies and delivery to occur. If health data or income records were linked in to these analyses too, a more detailed picture of how outcomes for Looked After Children come about could be formed. Public services would then be able to more usefully direct resources and support where it is most needed.



## **Benefit 2: Enable better use of existing data to develop efficient methods of producing demographic and census-type statistics**

Linking administrative datasets offers the potential to provide more frequent and up-to-date counts of the population and basic information on its characteristics, such as gender and age profiles. This could remove the requirement for an expensive decennial census, or at least reduce the scale and complexity of it, as well as increasing the timeliness of key population statistics central to funding decisions and strategic decision making across Scotland.

National Records of Scotland is assessing the feasibility of replacing traditional census enumeration with alternative methods, and data linkage is part of this research. Stakeholders will be consulted on alternative census options in due course. A similar programme of work is being taken forward by the Office for National Statistics to establish and test models that will, in future, meet users' needs for census type statistics in England and Wales. National Records of Scotland will work with the ONS to maximise the potential for harmonious statistical outputs (i.e. population and socio-demographic statistics) where practicable and mutually beneficial.

## **Benefit 3: Data linkage will increase the power of official statistics available to all**

Scottish Government and others collate statistics from Local Authorities and other public bodies, quality assure that data, analyse and publish aggregate statistics. This provides all interested parties with a national picture, and comparable information for bench marking, which is a vital component of performance management and improvement. Where data provided to Scottish Government can be linked, safely and securely, at a record level, the value and power of the analysis can be greatly enhanced. This is already occurring in the education sector, through ScotXed - the Scottish Exchange of Education Data programme.

The development of ScotXed provided the impetus and platform for improving the data held by schools and Local Government, and sharing those data at an individual pupil level safely and securely. This has allowed for linkages to be made between different aspects of the educational experience as well as allowing data from different parts of local government (e.g. social work and education) that were previously disconnected to be linked. It has also allowed the outcomes for pupils after education to be linked with educational experiences.

The statistics that are produced are published as National Statistics as well as being used for additional analysis to support policy development and are securely shared with academics to assist their research. Their National Statistics status means they have been assessed by the UK Statistics Authority as being produced and explained to high standards and that they serve the public good. For example the "Summary statistics for attainment, leaver destinations and school meals" National Statistics publication draws on data on attainment shared with Scottish Government by Scottish

Qualifications Authority linked with data shared by Skills Development Scotland on pupil destinations post school and information shared by all 32 Local Authorities on their pupil populations. This is an excellent example of collaborative working to enable data sharing for the purposes of linking data to add significant value to that available from the separate data sets.

A central component of ScotXed was the investment in data quality. It was not just a question of linking the data that already existed – new collections had to be developed and existing collections had to be improved to make linking it worthwhile. A programme of investment to improve existing data quality and methods of securely and efficiently sharing information to allow for their future inclusion in linkage projects will be a necessary component of the Data Linkage Framework.

Experience tells us that advances in data quality held in administrative systems across different organisations only occurs with sufficiently high-level endorsement of the activity and resource investment. Experience also tells us that the benefits to the data custodians in terms of improving management information are well received. Strategic decisions about when and where to focus investment, based on consultation with data custodians, policy makers and analysts, will be necessary.

**Benefit 4: Data linkage will allow relatively low cost longitudinal research to be conducted both retrospectively and prospectively, informing preventative spend**

Longitudinal surveys, which interview the same individuals multiple times over many years, are expensive and difficult to implement in a robust way and are limited to the extent that they only provide information about the cohort under study. Where administrative data sets exist, data linkage offers a more efficient way to get much of this information, to a higher level of quality, and to constantly refresh the cohort being studied giving much richer, more broadly applicable results. This allows longitudinal surveys to focus on questions that cannot be answered from linked administrative data such as those relating to attitudes, thoughts and feelings.

One longitudinal linkage study that is already underway is the Scottish Longitudinal Study. This covers 5.3% of the Scottish population, and has been created using data available from the 1991 and 2001 Censuses, data from civil registration (births, deaths, marriages), GP registrations on migration in or out of Scotland, information on attendance and attainment from Scottish publicly funded schools and has the facility to incorporate information from NHS records on cancer registrations and hospital admissions.

The Scottish Longitudinal Study has been used to explore some key health and social issues for Scotland:

- Boyle, Feng and Raab<sup>1</sup>, for example, showed that there is an increased mortality risk due to widowhood. It was previously thought that this 'widowhood effect' could be due to selection, i.e. married

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<sup>1</sup> Boyle, P., Fend, Z. and Raab, G. (2009) [Does widowhood increase mortality risk? Comparing different causes of spousal death to test for selection effects.](#)

couples often share characteristics related to health risks. However, the study found that risk was the same regardless of the cause of death of the spouse, suggesting that this is a causal effect, rather than a result of selection. This study has therefore been able to highlight the importance of health interventions to support widows.

- Clemens, Boyle and Popham<sup>2</sup> showed that being unemployed is related to significantly higher odds of death within 7 years relative to being employed, that this is true regardless of other socioeconomic circumstances, and cannot be simply explained by people becoming unemployed because of illness.
- The SLS has also been used to look at sectarianism, testing views that sectarianism is a continual characteristic of Scottish society. Holligan and Raab's analysis<sup>3</sup> showed that over time there are an increasing number of inter-sectarian partnerships amongst younger people, and that this is true across all of Scotland but the higher proportion of Roman Catholics in the West of Scotland leads to a much higher proportion of inter-sectarian couples there. Furthermore, a high proportion of Roman Catholics continue their religious practice, even when part of a religiously mixed couple. Taken together these findings suggest a breakdown of sectarianism in Scotland between Roman Catholics and others.

Longitudinal data provide a better basis for understanding the process of causality and allow for a better understanding of how outcomes are achieved, as data from different points in the input → process → outcome chain could be linked. This will allow policy makers to understand how a situation has arisen and design more effective policies. For example, linking data about adults' employment status back to school attendance and educational attainment records, and any children's services (such as support to attend a childcare centre and any social work support given to the family), would help understand what long term impact children's services have on people's lives. That understanding could then be used to inform decisions about overall spending, in particular 'preventative spend' whereby investment early on saves money in the long run as it avoids problems, such as poor health, or people getting involved in criminality.

Currently, this kind of evaluation is possible only through relatively costly bespoke pieces of longitudinal research that take a number of years to produce results. Longitudinal studies, which make use of administrative data, also provide material to study the effect of policy interventions enacted in the past as natural experiments.

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<sup>2</sup> Clemens, T., Boyle, P. and Popham, F. (2008) [Unemployment, mortality and the problem of health-related selection: Evidence from the Scottish Longitudinal Study.](#)

<sup>3</sup> Holligan, C. and Raab, G. (2009) [Inter-sectarian couples in the 2001 census.](#)

**Benefit 5: Increase the capacity to robustly evaluate the costs, benefits and risks of new health, social, educational and associated programmes**

Linkage of clinical trial data with records of subsequent hospitalisations and mortality is a highly efficient way of assessing the long term benefits and risks associated with new medical treatments. Randomised control trials are acknowledged to be the most effective way of ascertaining whether medical treatments are effective, but extended follow-up of those involved in the trials to assess long term safety and effectiveness is difficult and expensive. Record linkage can markedly reduce the costs of long-term monitoring. It can also extend follow-up to determine whether benefits are sustained, and to explore risks of adverse events that occur too rarely within the initial study.

Important Scottish trials that are being extended through record linkage include the West of Scotland Coronary Outcomes Prevention Study<sup>4</sup> and PROSPER trials<sup>5</sup> which helped to establish the effectiveness of cholesterol-lowering drugs for primary prevention of heart disease.

The creation of large-scale biobanks containing biological samples along with demographic, social and economic data, is now one of the key ways in which researchers hope to extend understanding of the process of healthy ageing and the causes of chronic and life-threatening diseases. Scotland is a participant in the UK Biobank<sup>6</sup> and hosts other more specialised biobanks such as the Generation Scotland: Scottish Family Health Study.<sup>7</sup> Participants in these studies are asked to consent to follow-up of events such as the onset of disease or death. Record linkage allows such follow-up to be conducted more completely and economically than would otherwise be possible.

**Benefit 6: Data linkage will provide globally unique exemplars of research excellence, enhancing Scotland's reputation and attracting investment and job creation to Scotland**

The West of Scotland Coronary Outcomes Prevention Study, PROSPER, the Scottish Health Informatics Programme and the Scottish Longitudinal Study are all recognised across the UK and internationally as producers, enablers and products of high quality research. Academic interest in them brings research funding to Scotland, contributing to the Scottish economy and employment opportunities.

The capacity to link individual hospital records with other sources of data was developed relatively early in Scotland, and the many effective uses of such linkages has gained Scotland an enviable reputation as a centre for clinical, epidemiological and health services research. Expanding on these successes and enabling and facilitating cross-sectoral linkages will increase interest and improve the reputation of Scotland as the most attractive place for doing research in Europe.

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<sup>4</sup> Ford I et al. (2007). "Long-term follow-up of the West of Scotland Coronary Prevention Study". *N Engl J Med*. 357: 1477-86.

<sup>5</sup> Shepherd J et al on behalf of the PROSPER study group. (2002). "Pravastatin in elderly individuals at risk of vascular disease (PROSPER): a randomised controlled trial". *Lancet*. 360: 1623-30

<sup>6</sup> <http://www.ukbiobank.ac.uk/>

<sup>7</sup> <http://www.generationscotland.org/>

## International examples

In **Western Australia**, cross-sectoral data linkage is relatively advanced and all of the benefits outlined above are already being seen. A report in 2008 concluded that because of the Western Australia data linkage system:

“Longitudinal studies have become cheaper and more complete; deletion of duplicate records and correction of data artifacts have enhanced the quality of information assets; data linkage has conserved patient privacy; community machinery necessary for organised responses to health and social problems has been exercised; and the commercial return on research infrastructure investment has exceeded 1000%. Most importantly, there have been unbiased contributions to medical knowledge and identifiable advances in population health arising from the research.”<sup>8</sup>

The Western Australia Developmental Pathways Project is linking a range of routinely collected data to investigate the perinatal, familial and early childhood characteristics of young adults who develop mental illness, criminal behaviours or early worklessness. Data are being linked from:

- Health: Perinatal, Home Visitor/Public Health Nurse, Mental Health and Substance-Abuse Registers
- Child and family services: including Child Protection records
- Justice: including Juvenile and Adult Orders, Custodial Data, Police Incidents and Cautioning, Convictions
- Education: Absenteeism, Suspensions, Standardized Test Results
- Social welfare: Benefit recipient status through mid-adulthood.

Researchers are using these linked data to assess whether early characteristics can be used to help target sub-populations at risk, for parental and early-years interventions.

Data linkage is similarly advanced in **Manitoba (Canada)** where the Centre for Health Policy is conducting a Foetal Alcohol Spectrum Disorder (FASD) study using databases analogous to those listed above for the Western Australia Pathways Project plus a register of FASD cases which contains data on hospitalisation, psychological referral, and special education. Researchers are using these linked data to ask: What are the early-life familial and child markers of risk for diagnosed and suspected FASD? How do the burden of illness/disability, labour-market non-participation, and benefit receipt among those affected compare to non-affected children matched on appropriate factors? Can these risk-markers for FASD be used to target families and neighbourhoods at high risk, with preventative, remedial educational and care interventions?

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<sup>8</sup> D’Arcy, H. et al (2008) [“A decade of data linkage in Western Australia: strategic design, applications and benefits of the WA data linkage system”](#). Australian Health Review 32(4): 766–777

***Consultation question 1:***

*Are there any benefits of data linkage for statistical and research purposes that are not sufficiently described here?*

*If yes, please describe the further benefits.*

**Current challenges preventing more effective and efficient data linkages**

As is clear from the examples given above, benefits of data linkage are already being seen in Scotland. The benefits could be much greater though, if the capacity of analysts to conduct data linkages for research and statistical purposes safely, securely, legally, ethically and efficiently was increased.

Currently, it is difficult and time-consuming for data linkage projects to get off the ground. There are four main reasons for this:

1. Uncertainty about the legalities and public acceptability of data sharing and linkage.<sup>9</sup>

There is considerable variation in the interpretation of the legal and regulatory environment. Data custodians may often be unsure whether they can legally and appropriately make data available for linkages and so, to be on the safe side, turn down requests for access to data.

This is exacerbated by concern amongst data custodians that the public may not consider sharing of their data acceptable, and would be unlikely to consent to personal data being used for research and statistical purposes if asked.

Personal privacy might therefore be protected, but potentially valuable research findings, which could benefit large parts of the community including the data-subjects themselves, are lost. It is not clear, however, that such a cautious approach is either necessary or sufficient to protect privacy nor that it strikes an appropriate balance of the interests in play.

2. Incomplete data, or data that cannot be linked.

As mentioned above, not all data that exists is of good enough quality to be worth linking. Administrative systems may be out of date, incomplete or used so inconsistently that the data within them is not suitable for statistical or research purposes.

In addition, there are several different “unique identifiers” in use across Scotland, which means it is extremely complex to link datasets from different systems. This is particularly true for different sectors and partly explains why cross-sectoral linkages are so rare. For example, the Community Health Index (CHI) Number and the NHS Registration

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<sup>9</sup> G Laurie and N Sethi, “Information Governance of Use of Health-related Data in Medical Research in Scotland: Current Practices and Future Scenarios” (Working Paper No.1, 2011), available on the Social Science Research Network: <http://www.ssrn.com/>

Number are both used in parts of the health sector; Scottish Candidate Number in parts of the education sector; the Criminal Justice Reference Number and the Armed Forces Number. There are many more examples, and no example of a unique identifier that covers the whole population.

3. Limited capacity for secure exchange and access to data.

For data linkage to occur securely and safely, the technological infrastructure must exist, including the IT hardware and software to collect data securely, to conduct linkages, and to provide routes for analysts to access the linked data.

Routes to access linked data may vary from secure e-mail transfer through to 'safe havens'. Safe havens are stand-alone (not networked) computers within secure premises, which only authorised and trusted researchers can arrange to use to do their analysis.

4. Limited capacity of public sector organisations to analyse and make use of linked data.

The analytical expertise required includes the methodological know-how to conduct linkages, particularly when different unique identifiers are used; to understand the linked dataset, particularly when it has been created using incomplete data; and to effectively analyse linked datasets, particularly longitudinal datasets. None of this is simple and many public sector organisations do not have the resources to invest in analytical training and development of staff to create the capacity needed.

***Consultation question 2:***

*Are there challenges or barriers preventing more effective and efficient data linkages for statistical and research purposes taking place that are not sufficiently described here?*

*If yes, please describe the challenges or barriers.*

**Why a data linkage framework is needed**

The Data Linkage Framework aims to address these problems, and to widen the range of data linkages that can be carried out, without impinging inappropriately on personal privacy of data subjects.

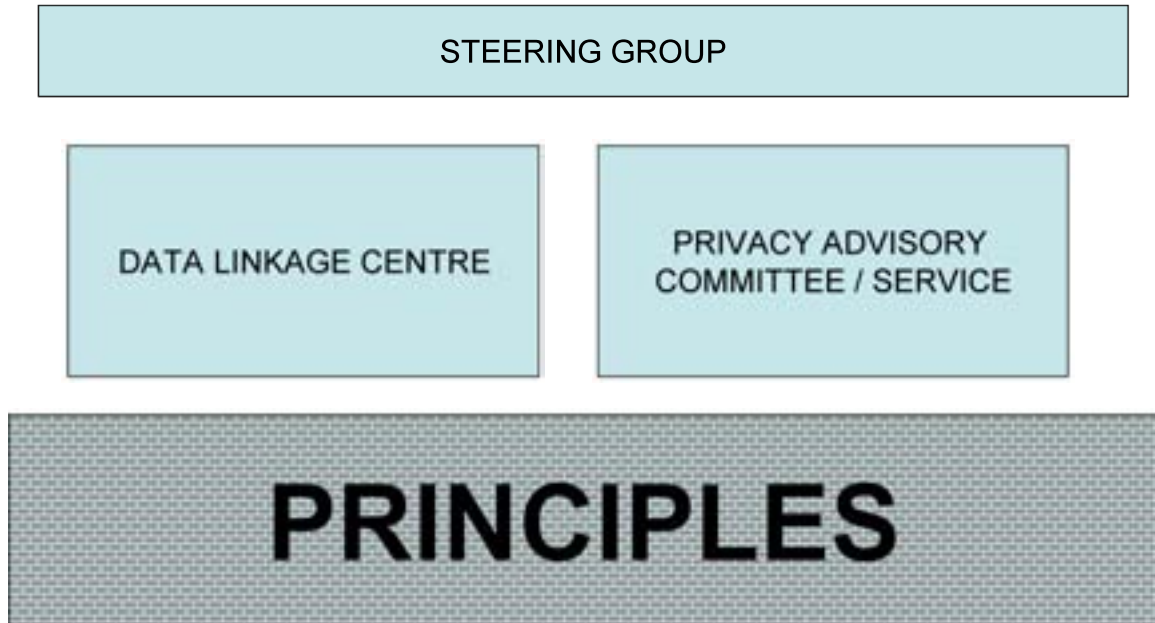
Delivering a strategic data linkage framework in collaboration with major stakeholders across Scotland will capitalise on the direct benefits outlined above more quickly and effectively than if progress continued piecemeal, sector by sector or dataset by dataset. By co-ordinating what is currently a fragmented landscape of activities under a strategic framework there would be immediate benefits in terms of efficiency through the sharing of ideas, solutions, best practice and methods across different data linking projects.

This framework will allow the statistical system in Scotland to be enhanced and in so doing, make advances on the evidence base - particularly in terms of a joined-up understanding of how outcomes are achieved – that will allow for more informed spending on public services and early interventions that save money in the long run.



### 3. Data Linkage Framework

The foundation of the framework will be a set of principles on which the other elements – The Analytical Privacy Advisory Service and The National Data Linkage Centre – can be built. The framework will be governed by a Steering Group.



#### 3a. Guiding Principles

Before the details of a National Data Linkage Centre and an Analytical Privacy Advisory Service can be established it is necessary to have a set of principles on which all subsequent plans and implementation will be based. These principles should protect individuals and their data and be underpinned by the requirement to act lawfully.

The principles should flow from Human Rights Legislation, the Data Protection Act, common law requirements, guidance issued by the Information Commissioner (specifically the [Data Sharing Code of Practice](#)), and the Scottish Government [Identity Management and Privacy Principles](#).

The draft set of principles below is an edited version of the [SHIP Guiding Principles](#)<sup>10</sup>. As to date SHIP has primarily been concerned with sharing and linking of health records for ad-hoc research projects the edits mainly reflect a broadening to other sectors and the production of official statistics.

As explained in the SHIP document, principles are not rules. Principles sometimes conflict. This is why they are starting points for deliberation or action. Because of their fundamental importance, however, it is expected that they are followed where they are relevant to a given data use, storage,

<sup>10</sup> Written by Professor Graeme Laurie and Nayha Sethi at the Edinburgh Law School, University of Edinburgh, available at [http://www.scot-ship.ac.uk/sites/default/files/Reports/Guiding\\_Principles\\_and\\_Best\\_Practices\\_221010.pdf](http://www.scot-ship.ac.uk/sites/default/files/Reports/Guiding_Principles_and_Best_Practices_221010.pdf)

sharing or linkage practice. The value is that such principles provide a common framework of reference so that all parties can agree what is at stake; moreover, they provide a statement of the standards against which all parties agree to be bound.

## **The Principles**

Resource allocated to the application of the principles should in proportion to the risk involved in the linkage proposed.

## **Public Interest**

1. Scientifically sound and ethically robust research and statistics are in the interest of the public. The objective of the Data Linkage Framework is to facilitate scientifically sound and ethically robust research and statistics through the appropriate and safe use of data.
2. The rights of individuals should be respected with adequate privacy protection, while at the same time the benefits for all in the appropriate use of data for research and statistical purposes should be recognised.
3. The production of scientifically sound and ethically robust research and statistics should be considered necessary grounds for data sharing, providing that ethical and legal standards are met.
4. The production and dissemination of statistics through data linkage should be in accordance with the Code of Practice for Official Statistics, [The Pre-release access to Official Statistics Order \(Scotland\) 2008](#) and National Statistician's [Guidance on Confidentiality of Official Statistics](#).
5. Where linkages resulting in commercial gain are envisaged, this should be clearly and publicly articulated and widely communicated.
6. Benefits arising from linkage of personal data are public goods and should be shared as widely as possible.

## **Governance and Public Transparency**

7. Data sharing and linkage should be carried out under transparent controls and security processes, and the purposes and protection mechanisms should be communicated publicly and to oversight bodies/individuals with responsibility for data processing.
8. Information about all approved linkages; all privacy impact risk assessments; and all data sharing agreements for linkage purposes, should be made publicly available.
9. All practices, including all data linkages, shall be appropriately monitored and regulated by a relevant individual, organisation or governance body as appropriate. It is possible that these activities will be monitored at an individual and organisational level simultaneously.
10. There should be a clear distinction in roles between those carrying out linkages, analyses and those policing governance and enforcing sanctions.

11. As far as possible, account should be taken of the full range of stakeholder positions in the development and implementation of governance arrangements.
12. The interests of one (or a few) stakeholder(s) should not dominate use/linkages or the conditions of the same, especially where this might be at the expense of other stakeholder interests.

### **Privacy**

13. Data controllers should demonstrate their commitment to privacy protection through the development and implementation of appropriate and transparent policies.
14. Every effort should be made to consider and minimise risks of identification (or re-identification) to data subjects and their families arising from all aspects of data handling.
15. Serious consideration should be given to carrying out privacy-impact risk assessments, following the most up to date ICO guidance. Where a PIA is not considered feasible or necessary that should be clearly and publicly articulated. PIAs should be made publicly available (excluding sections as necessary for reasons of security), before any cross-sectoral linkage occurs.
16. Linked datasets should be kept for the minimal time necessary for the original purpose of the linkage to be met. If a secondary purpose arises, a new Privacy Impact Risk Assessment should be conducted, and data sharing agreements revised.

### **Removal of names and direct identifiers**

17. The default position should be that data users have access only to data from which names and direct identifiers have been removed, and data users should be subject to an obligation not to attempt to re-identify individual data subjects. Any requirement for researchers to have access to data containing identifiers should be fully justified and risk assessed.
18. Data controllers should determine and agree upon the appropriate extent of anonymisation to be applied to any given dataset or linkage exercise.
19. The risk of re-identification of data subjects must be assessed by a body/individual with the relevant expertise to make such judgments.

### **Consent**

20. Where possible and practicable, explicit consent should be obtained from each data subject prior to the linkage of personal data for statistical and research purposes. Personal data are those from which an individual is identifiable or is likely to be identifiable.
21. Where possible and practicable, individuals collecting data should adequately inform data subjects of all material issues relating to the storage and use of their data. Material issues are those likely to affect a person in a non-trivial way.
22. Where personal data are used, the minimum amount of personal data should be used to achieve the stated objective; the reasons and justification for its use should be adequate and clearly explained; and

reasonable efforts should be made to inform data subjects of the purposes of the use.

23. Where obtaining explicit consent is not possible/practicable, and in all uses of data which are beyond those specified when consent was obtained then (a) removal of direct identifiers should occur as soon as is reasonably practicable and/or (b) authorisation from an appropriate oversight body should be obtained which can confirm that the public interest in data linkage is met and appropriate safeguards are in place.

### **Security**

24. Data linkage activity must be governed by an Information Security Policy appropriately implementing [HMG Information Security Policy Framework](#) .
25. Appropriate physical and technical security measures should be applied to ensure the confidentiality, integrity and availability of information and reflecting the assessed risk level of information assets.
26. All personnel involved in data linkage activities should be properly trained on the data security policies and procedures, and should undertake periodic refresher training.
27. The importance of data security should be reflected in the business objectives of all organisations involved in data linkage.
28. Information about data security policies and procedures should be highly visible within organisations conducting indexing or linking or sharing of personal data.

### **Access and Personnel**

29. Access policies should be developed in a transparent and open manner; these should also be subject to public scrutiny and review.
30. All data recipients should be appropriately vetted to ensure they have adequate training. Vetting procedures should be robust and transparent and proportionate to the requests made and the sensitivity of the data requested.
31. All personnel involved in data linkages should be fully aware of their roles and responsibilities, including these principles, and must abide by the relevant Data Sharing Agreement.
32. These roles and responsibilities should be subject to robust governance mechanisms designed to ensure that these roles are being carried out appropriately and to the standards legally and ethically required.
33. Whether a single data controller or otherwise, a clear distinction should be maintained between each of the functions of linker, indexer, recipient and data custodian. Linkers should be responsible only for linking data.

### **Clinical Trials**

34. Mechanisms for linkages involving clinical trials must permit re-identification by the principal data source, this is particularly important for pharmacovigilance purposes.

35. The specific circumstances and conditions governing whether or not patients involved in clinical trials can be contacted and by whom, should be clearly set in place in transparent policies.
36. Researchers should only seek to contact participants directly with respect to information arising from a clinical trial in which they took part where prior consent to be contacted for specific purposes has been obtained.

**Data sharing agreements and sanctions**

37. Roles and responsibilities of parties to data linkages should be identified from the outset, terms and conditions for data sharing should also be agreed upon in the form of a memorandum of understanding.
38. Where researchers wish to deviate from/modify the terms of the data use/sharing agreement at any time, new terms must be agreed upon by all parties concerned and such changes should be monitored by the relevant oversight body/mechanisms.
39. Sanctions for failure to respect terms and conditions should be clearly stipulated in all data use/sharing documentation.
40. Sanctions should be enforced by a body/individual independent of those granting permissions for access to data sets (i.e. data controllers)

***Consultation question 3:***

*Are the guiding principles sufficient and appropriate?*

*Please explain your answer fully and make suggestions for improvement.*

### **3b. Governance**

The Data Linkage Framework is a fully collaborative, cross-sectional, multi-agency approach to enabling and facilitating data linkage for statistical and research purposes in Scotland.

A Data Linkage Steering Group has been established to oversee and guide delivery of the framework, including the strategic direction of the National Data Linkage Centre and The Analytical Privacy Advisory Service.

Chaired by Director General: Governance and Communities (Scottish Government), the Steering Group comprises academic experts on medical research and jurisprudence, as well as representatives from:

- The Information Commissioner's Office
- National Records of Scotland
- NSS: Information Services Division
- Scottish Collaboration for Public Health Research and Policy
- Scottish Government (various directorates)
- Society of Local Authority Chief Executives
- Research Councils.

#### **The UK Context**

In government, law, education, health and many other spheres Scotland has distinct systems from those in England, Wales and Northern Ireland, as well as correspondingly different needs for statistical evidence. The Scottish Government is however keen to work collaboratively with other administrations across the UK to share best practice and to reap the benefits of co-ordinated approaches where sensible to do so.

Such partnership working is desirable where UK level statistical outputs are of mutual value, such as in making better use of existing data to develop and test more efficient methods of producing census type information and for producing summary statistics about the size and structure of the population; in understanding migration between parts of the UK; and on issues reserved to Westminster.

The Data Linkage Steering Group is working with partners across the UK through the Administrative Data Task Force. Established in October 2011, this Task Force will consider data sharing and linkage for research and statistical purposes across the UK. It is expected to report in September 2012 and to make recommendations to UK and Devolved Government Ministers.

### 3c. Privacy Advisory Service

One of the challenges that can cause difficulties in establishing efficient and effective data linkage projects is the considerable variation in the interpretation of the legal and regulatory environment. Data custodians may often be unsure whether they can legally and appropriately make data available for linkages and so, to be on the safe side, turn down requests for access to data.

To address this, a National Privacy Advisory Service is proposed, with the aims of helping all those involved in data linkage projects strike the right balance between safeguarding individuals' right to privacy and the efficient use of data for statistical and research purposes through careful application of the Guiding Principles.

This section provides a summary of early ideas about a Privacy Advisory Service. Firm proposals will be consulted on at a later stage, when this consultation on Principles has been completed and the UK wide Administrative Data Task Force has made its recommendations. An important consideration will be avoiding any increase in regulatory burden and complicating the landscape further.

Early ideas, on which views are welcome, are that the Service will provide a one-stop-shop for quality advice on linkages and associated ethical, legal and social issues applying advice on data linkage projects that is proportionate to the risks to privacy and potential for public benefits<sup>11</sup>. Objectives for the Service could include:

1. Helping data custodians consider the privacy implications of applications to link their data to other data
2. Helping researchers navigate through the ethical, regulatory and legal issues when planning and conducting data linkage projects, in particular by making recommendations to mitigate risks to the privacy of individuals and maximising the public good.
3. Making recommendations as to whether or not data linkages are conducted, giving advice that is proportionate to the risks involved, such as privacy and reputational risks, and in light of the public benefits that would accrue if the linkage took place.
4. Making technical suggestions for improving security, methodology and analysis of any linkage.
5. Publicly demonstrate high standards of decision making about the use of personal data for cross-sectoral linkage projects.

A Service that can advise on data linkages across sectors as well as within them would need to have all sectors within its scope, and would need to incorporate people with experience and expertise of legal, technical and public acceptability issues from different organisations. Whether any or all appointments to the Privacy Advisory Service should be appointed through

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<sup>11</sup> These suggestions follow recommendations made as part of the SHIP initiative, mentioned previously.

the Public Appointments Scheme and according to the Nolan Principles is under consideration, as is the potential for the service to have some statutory footing to approve data linkages at some point in the future.

***Consultation question 4a:***

*Are the objectives for a Privacy Advisory Service set out in section 3c the right ones? Please explain your answer fully and make suggestions.*

***Consultation question 4b:***

*Do you wish to be consulted on firmer proposals for a Privacy Advisory Service as and when they are developed?*



### 3d. National Data Linkage Centre

A National Data Linkage Centre will be established to provide a clear focus of activity and development. It will function according to the Guiding Principles under consultation.

The centre will build on the experience and expertise of organisations already involved in data linkage, and will be a collaboration between NSS:ISD and National Records of Scotland in the first instance. A collaborative approach to further developing data linkage infrastructure, methods and expertise in Scotland will realise efficiency savings.

The Centre will provide those functions that are best hosted centrally and/or are integral to developing alternatives to the decennial census. This includes:

1. Leading development of data linkage IT and expertise
2. Development and maintenance of methods for read-through between different individual referencing systems
3. A linkage service: conducting approved within and cross-sector data linkages where necessary and efficient
4. A trusted data-exchange service
5. Development and maintenance of a 'population spine'
6. Co-ordination and support for any 'satellite' data linkage units/safe havens that continued to function in other bodies (for example ScotXed)

Data security will be a high priority for the Data Linkage Centre and there will be provision to fund information security management activities with visible support and commitment from all levels of management. Accreditation of IT systems to formally assess them against their information assurance requirements, resulting in the acceptance of residual risks in the context of business requirements will be properly considered.

***Consultation question 5a:***

*Are the functions that will be led by the National Data Linkage Centre set out in section 3d the right ones? Please explain your answer fully and make suggestions.*

***Consultation question 5b:***

*Do you wish to be consulted on firmer proposals for a National Data Linkage Centre as and when they are developed?*

## 4. Summary and Next Steps

It is in the public interest both to safeguard individual's right to privacy and to make efficient use of data for statistical and research purposes.

The Data Linkage Framework aims to help everyone involved in data linkage to balance these values; to provide the public with assurance that personal data is being used safely and appropriately; and to provide data owners with assurance that data can be shared when the appropriate safeguards are in place.

The framework does not at this stage require any changes to legislation, and the requirement for all data linkage to be conducted within the law will continue to be emphasised at every stage. It does not remove, or seek to remove, the responsibility of data custodians or the need for Privacy Impact Assessments of any intended data linkage project.

The purpose of this consultation paper is to gather views on the aims and the guiding principles of a data linkage framework. Written responses will be considered alongside:

- Results from first phase research into public acceptability of cross-sectoral data linkages
- Issues raised at meetings, workshops and seminars that are underway
- Recommendations from the UK wide Administrative Data Task Force.

Responses to this consultation paper are invited by Friday 15 June 2012. A report will be published in August 2012, and, providing there is broad agreement, work will continue to develop the details of the National Data Linkage Centre and Privacy Advisory Service. This will be done collaboratively with key stakeholders and there will be further opportunity to provide comments before final decisions are made.

## 5. How to respond

We invite responses to this consultation paper by **15 June 2012**. Responses to this consultation are welcome from any individual or organisation with an interest. The following have been invited to respond:

Various individuals  
Association of Chief Police Officers Scotland  
Association of Directors of Social Work  
BCS: The Chartered Institute for IT  
Big Brother Watch  
British Medical Association  
British Security Industry Association  
Caldicott Guardians  
Care Inspectorate  
Chi Advisory Committee  
Community Planning Partnerships  
Consumer Focus Scotland  
Convention of Scottish Local Authorities  
Department for Work and Pensions  
Economic and Social Research Council  
Equalities and Human Rights Commission  
Equality Network  
Experian  
HM Revenues and Customs  
Improvement Service  
Information Commissioner's Office  
Liberty  
Local Authority Chief Executives  
Local Authority Research and Information Association  
Medical Research Council  
MRC|CSO Social & Public Health Sciences Unit  
National Institute for Social Care and Health Research  
NHS Chief Executives  
No2ID  
Northern Ireland Statistics and Research Agency  
Office for National Statistics  
Pan-Lothian Data Sharing Partnership  
Privacy International  
Public Health Directors  
Records of Scotland  
Royal College of GPs  
Royal College of Nursing  
Royal Statistical Society  
Scottish Centre for Social Research  
Scottish Children's Reporters Administration  
Scottish Collaboration for Public Health Research and Policy  
Scottish Council of Voluntary Organisations  
Scottish Human Rights Commission  
Scottish Longitudinal Studies Centre  
Scottish Members of European Parliament

Scottish Privacy Forum  
SHIP Management Board and International Advisory Board  
Wellcome Trust  
Welsh Assembly Government

Please send your completed response form (in annex E) to

[datalinkageconsultation@scotland.gsi.gov.uk](mailto:datalinkageconsultation@scotland.gsi.gov.uk)

Or

Office of the Chief Statistician and Performance  
4N-06 St Andrews House  
Regent Road  
Edinburgh EH1 3DG

If you have any queries about how to reply, or require a copy of this paper in an alternative format, please contact Andrew Paterson on 0131 244 3341 or e-mail [datalinkageconsultation@scotland.gsi.gov.uk](mailto:datalinkageconsultation@scotland.gsi.gov.uk)

### **Handling your response**

We need to know how you wish your response to be handled and, in particular, whether you are happy for your response to be made public. Please complete and return the Respondent Information Form, which can be found at Annex E, as this will ensure that we treat your response appropriately. If you ask for your response not to be published, we will regard it as confidential and treat it accordingly. All respondents should be aware that the Scottish Government are subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act, for information relating to responses made to this consultation exercise.

Copies of all the written responses received to a consultation exercise (except those where the individual or organisation requested confidentiality) are placed in the Scottish Government library at Saughton House, Edinburgh (K Spur, Saughton House, Broomhouse Drive, Edinburgh, EH11 3XD, telephone 0131 244 4565).

All Scottish Government consultation papers and related publications (e.g. analysis of response reports) can be accessed at: Scottish Government consultations (<http://www.scotland.gov.uk/consultations>).

The views and suggestions detailed in consultation responses are analysed and used as part of the decision making process, along with a range of other available information and evidence. Final decisions on the issues under consideration will also take account of a range of other factors, including other available information and research evidence. While details of particular circumstances described in a response to a consultation exercise may usefully inform the policy process, consultation exercises cannot address individual concerns and comments, which should be directed to the relevant public body.

# Annexes

## **A: Glossary**

### **Administrative Data**

Data derived from information collected and maintained as part of an administration system, such as health records, vehicle licensing and tax systems.

### **Aggregate Statistics**

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

### **Consent**

Explicit agreement by the data subject for his or her personal data being processed for a specific purpose.

### **Data Controller**

The organisation (or individual) legally responsible for a dataset and who determines the purposes for which and the manner in which personal data are to be processed. This may be carried out jointly or with other persons.

### **Data custodian / Data Guardian**

A person, normally appointed from within an organisation, tasked with the responsibility of ensuring compliance with safe, secure and appropriate processing of personal data in connection with the legitimate functions/activities of the organisation.

### **Data subject**

Person to whom data relates: an identifiable person is one who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, social or cultural identity.

### **Data recipient**

Researcher who initiates a data linkage to answer a research question.

### **Linker**

Individual (or body) who receives datasets from data controllers and links them together using a key created by the indexer.

### **Longitudinal Survey**

A survey in which information is collected about the same group of individuals on more than one occasion over a period of time.

### **Index**

A dataset of individual references that can be used for cross-referencing between sources.

### **Indexer**

Individual (or body) who receives personal data from one or more data controllers and determines which records in each dataset relate to the same individual (or entity). The indexer then creates a unique

reference for each individual (or entity) and a corresponding key to allow the data from the different sources to be joined.

**Data Linkage / Record Linkage**

Data linkage is the joining of two or more administrative or survey datasets using individual reference numbers / identifiers or statistical methods such as probabilistic matching. See also "Indexer".

**Personal Data / Identifiable Data**

Information about a living individual who can be identified from that information and other information which is in the data controller's possession.

**Individual Reference / Identifier**

Frequently a sequence of characters and/or numbers that is used and / or assigned by an organisation to a person to identify uniquely the person for the purposes of the organisation's systems and operations.

**Information Asset Owner**

Person appointed by the Senior Information Risk Owner to ensure specific information assets are handled and managed appropriately. This includes ensuring information is protected appropriately but also that it is used within the law for public good.

**Population Spine**

A dataset created by cross-referencing indices that allows for an accurate count of the population.

**Safe Haven**

A physically secure area, containing a computer, with no external devices e.g. disc, CD, USB drives or printer access, in which trusted and authorised researchers can analyse personal data.

***B: Questions & Answers for data subjects and custodians***

- Q Doesn't Scottish Government link all the data it holds about citizens already?
- A No. Data linkage is not new and it does happen already to some extent, (mostly within the health sector, where different records from different systems are sometimes linked to provide a better understanding of diseases and so on) but Scottish Government does not link all data held about citizens. The aim of this framework is to enable data linkages to occur within and across sectors when there is a strong argument that the public good would be served by the statistical information that would result.
- Q Will Scottish Ministers or other politicians be given access to identifiable personal data?
- A No. Access to identifiable personal data is strictly controlled and will continue to be strictly controlled. The objective of the Data Linkage Framework is to facilitate scientifically sound and ethically robust research and statistics through the appropriate and safe use of data. That means only trusted researchers will be given access to personal data with names and other direct identifiers removed.
- Q If I don't want my personal data used in any data linkage will I be able to opt out?
- A When data are collected, it is best practice for data subjects to be made fully aware of the uses and potential uses of that data. For example, when data are collected through the Scottish Health Survey participants are asked whether they are willing for the data to be linked to health administrative data for research purposes, and if the participant says no then their Health Survey data is excluded from any linkage. It is not always a practical or sensible option though to put in place a system whereby a person can request that their data is identified and removed from every dataset used in a linkage project. Self-selection can bias the results and therefore prevent getting the full benefit from research. In other cases it may not be possible to contact data subjects when data collected in the past are being reused for new purposes.
- Q Will this give my GP, or any other service access to my personal information held in systems across the country?
- A No. The Data Linkage Framework aims to enable secure data linkages for statistical and research purposes only. It does not address data linkage for operational purposes, such as identifying individual people requiring a service, and it does not change the requirement for data custodians to protect and limit access to the data they hold.
- Q Will linked data be sold to commercial organisations?
- A No. The purpose of this framework is NOT to allow the public sector to profit from data it holds about citizens, and the framework makes no allowances for this to occur.

### **C: Questions & Answers for researchers and data users**

- Q Will this framework make it quicker and easier to access linked data for my research?
- A Yes and No. The framework should help researchers gain access to data and to link it when there is a good argument to do so. It will in time make the permissions process easier to navigate, help researchers and others make sound decisions about whether to link data and if so how, and through improvements to data, analytical methods and technical expertise it will ease the technical difficulties of linkage and analysis. But every part of the process should be given due care and attention and should never be rushed.
- Q Does this mean I don't have to go through my own organisations ethics committee anymore?
- A No, individual organisation's ethics committees still have a very important role to play. The intention is that in time the Analytical Privacy Advisory Service will provide consistent and well-considered advice on data linkage, but not remove the need for organisations to carefully consider the ethics of data linkage themselves.
- Q Scientific standards require that results be replicable, and it is often the case that following peer-review of academic work, re-analysis of data is required. This suggests that linked datasets may need to be held indefinitely. How long will the data linkage centre keep linked datasets for, and will other researchers be given access to them?
- A Linked datasets will NOT be held indefinitely. The period for which they will be held will be considered on a case by case basis and will never be longer than is necessary. In line with the principle of transparency, information on how long each linked dataset will be held will be publicly available information. Other researchers may apply to access to the linked datasets, and their applications will be subject to the same scrutiny as the original investigator, and the same levels of security will be applied.



## **D: Relevant publications and links**

Special Issue of Healthcare Policy (Longwoods, 2011)

<http://www.longwoods.com/publications/healthcare-policy/22111>

Identity Management and Privacy Principles (Scottish Government, 2011)

<http://www.scotland.gov.uk/Topics/Government/PublicServiceReform/efficientgovernment/privacyprinciples>

Data Sharing: Legal Guidance for the Public Sector (Scottish Government, 2004)

<http://www.scotland.gov.uk/Publications/2004/10/20158/45784>

Data sharing code of practice (ICO, 2011)

[http://www.ico.gov.uk/for\\_organisations/data\\_protection/topic\\_guides/~media/documents/library/Data\\_Protection/Detailed\\_specialist\\_guides/data\\_sharing\\_code\\_of\\_practice.ashx](http://www.ico.gov.uk/for_organisations/data_protection/topic_guides/~media/documents/library/Data_Protection/Detailed_specialist_guides/data_sharing_code_of_practice.ashx)

Government Security Policy Framework (Cabinet Office, 2011)

[http://www.cabinetoffice.gov.uk/sites/default/files/resources/hmg-security-policy\\_0\\_0.pdf](http://www.cabinetoffice.gov.uk/sites/default/files/resources/hmg-security-policy_0_0.pdf)

National Statistician's Guidance: Confidentiality of Official Statistics (Government Statistical Service, 2009)

<http://www.statisticsauthority.gov.uk/national-statistician/ns-reports--reviews-and-guidance/national-statistician-s-guidance/confidentiality-of-official-statistics.pdf>

SHIP Guiding Principles and Best Practices (Scottish Health Informatics Programme, 2010)

[http://www.scot-ship.ac.uk/sites/default/files/Reports/Guiding\\_Principles\\_and\\_Best\\_Practices\\_221010.pdf](http://www.scot-ship.ac.uk/sites/default/files/Reports/Guiding_Principles_and_Best_Practices_221010.pdf)

Transparent Government, Not Transparent Citizens: A Report on Privacy and Transparency for the Cabinet Office. (Cabinet Office 2011)

<http://www.cabinetoffice.gov.uk/sites/default/files/resources/transparency-and-privacy-review-annex-b.pdf>

### **Links to data linkage projects and centres worldwide**

Scottish Health Informatics Programme <http://www.scot-ship.ac.uk/>

Scottish Longitudinal Survey <http://www.lscs.ac.uk/sls/>

ScotXed <https://www.scotxed.net/default.aspx>

South Australia and Northern Territory DataLink <https://www.santdatalink.org.au/>

Data Linkage Western Australia <http://www.datalinkage-wa.org/>

Australian Government: Statistical Data Integration Involving Commonwealth Data

<http://www.nss.gov.au/nss/home.nsf/pages/Data+Integration+Landing+Page?OpenDocument>

Manitoba Centre for Health Policy: Population Health Research Data Repository

[http://umanitoba.ca/faculties/medicine/units/community\\_health\\_sciences/departamental\\_units/mchp/resources/repository/health\\_admin.html](http://umanitoba.ca/faculties/medicine/units/community_health_sciences/departamental_units/mchp/resources/repository/health_admin.html)



## E: RESPONDENT INFORMATION FORM

Please Note this form **must** be returned with your response to ensure that we handle your response appropriately

### 1. Name/Organisation

Organisation Name

Title Mr  Ms  Mrs  Miss  Dr  other

Surname

Forename

### 2. Postal Address

Postcode	Phone	Email

### 3. Permissions - I am responding as...

**Individual** / **Group/Organisation**   
 Please tick as appropriate

**(a)** Do you agree to your response being made available to the public (in Scottish Government library and/or on the Scottish Government web site)?

Please tick as appropriate  Yes  No

**(b)** Where confidentiality is not requested, we will make your responses available to the public on the following basis

Please tick **ONE** of the following boxes

Yes, make my response, name and address all available

OR

Yes, make my response available, but not my name and address

OR

Yes, make my response and name available, but not my address

**(c)** The name and address of your organisation **will be** made available to the public (in the Scottish Government library and/or on the Scottish Government web site).

Are you content for your **response** to be made available?

Please tick as appropriate  Yes  No

**(d)** We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Please tick as appropriate  Yes  No

## CONSULTATION QUESTIONS

**Are you responding *primarily* as a data custodian, data user or data subject? (We recognise all people are data subjects and many organisations act as data guardians and data users, but please tick only one box)**

Data Custodian

Data User (e.g. researcher)

Data Subject (e.g. member of the public or group representing citizens)

**1. Are there any benefits of data linkage for statistical and research purposes that are not sufficiently described here?**

Yes, there are further benefits  No, the benefits are described fully

If you ticked 'yes', please describe the further benefits of data linkage for statistical and research purposes.

Comments

**2. Are there challenges or barriers preventing more effective and efficient data linkages for statistical and research purposes taking place that are not sufficiently described here?**

Yes, there are further challenges  No, the challenges have been identified

If you ticked 'yes', please describe the challenges or barriers.

Comments

**3. Are the guiding principles sufficient and appropriate? Please explain your answer fully and make suggestions for improvement.**

Yes, they are sufficient and appropriate  No, they are not

Please explain your answer fully and make suggestions for improvement.

Comments

**4a. Are the objectives set out for a Privacy Advisory Service in Section 3c the right ones?**

Yes, the objectives are right  No, they are not

Please explain your answer fully and make suggestions for improvement.

Comments

**4b. Do you wish to be consulted on firmer proposals for a Privacy Advisory service as and when they are developed?**

Yes  No

**5a. Are the functions that will be led by the National Data Linkage Centre set out in section 3d the right ones?**

Yes, they are the right functions  No, they are not

Please explain your answer fully and make suggestions for improvement.

Comments

**5b. Do you wish to be consulted on firmer proposals for a National Data Linkage Centre as and when they are developed?**

Yes  No



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**w w w . s c o t l a n d . g o v . u k**