

# Technical Consultation Paper on the Design of Data Sharing and Linking Service

This consultation paper is aimed at anyone who may wish to carry out or facilitate research using data linkage

In particular it is expected that the following groups are most likely to be interested in the technical nature of the paper and would wish to respond

- Any researchers or statisticians wishing to use data linkage
- Data controllers and staff involved in sharing or improving the quality of data used for statistics and research
- Anyone involved in or interested in data linkage, data security and privacy within an analytical environment

However, this is a publicly available document and responses are welcome from anyone.

<http://www.isdscotland.org/Products-and-Services/eDRIS/DSLS-consultation/>

We invite responses to this consultation paper by 29<sup>th</sup> May 2013.

Please send your completed response form to:

[DSLS@gro-scotland.gsi.gov.uk](mailto:DSLS@gro-scotland.gsi.gov.uk)

## RESPONDENT INFORMATION FORM

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

### i) Name/Organisation

Organisation Name: **Scottish Council on Human Bioethics**

Surname

Forename

### ii) Contact Details

Postal address

**15 Morningside Road**

**Edinburgh**

Postcode **EH10 4DP**

Phone **0131 447 6394**

Email **mail@schb.org.uk**

### iii) Permissions

Are you responding as an Individual?  Yes - please answer a), b) then d).  
OR as a Group or Organisation?  Yes - please answer c) then d).

#### *Individuals*

**a)** Do you agree to your response being made available to the public (via the survey 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   
Yes, make my response available, but not my name and address   
Yes, make my response and name available, but not my address

#### *Group or organisation*

**c)** The name and address of your organisation *will be* made available to the public (via the survey web site). Are you content for your response to be made available?

*Please tick as appropriate*  Yes  No

#### *All*

**d)** We will share your response internally with other 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 us 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)

### Question 1: The Data Sharing and Linkage Service is intended to add capacity and speed up the data linkage process

*1.1 To what extent do you think this proposal will achieve this?*

The Scottish Council on Human Bioethics believe that the data sharing and linkage service would add capacity and support the data linkage process.

*1.2 How could the proposal be improved to deliver this better?*

### Question 2: The proposal is intended to provide better technology and improve methodology and processes to improve the linkage experience for users

*2.1 To what extent do you think this proposal will achieve this?*

*2.2 How could the proposal be improved to deliver this better?*

**Question 3: The proposed approach to ‘Read Through’ using the linking population spine is intended to avoid a need to maintain actual linked datasets and to improve the efficiency of linking**

*3.1 To what extent do you think this proposal will achieve this?*

*3.2 Are you content that the proposals for the linking population spine are appropriate and secure?*

*3.3 How could the proposal be improved to deliver this better?*

**Question 4: The proposed approach intends to deliver both the benefits of efficient linking of data and the privacy of individuals by managing projects in a flexible manner that is proportionate to the risks associated with them**

*4.1 To what extent do you think this proposal will achieve this?*

The Scottish Council on Human Bioethics (SCHB) believes that the consultation paper relating to the design of the data sharing and linking service is not easy to understand. Because of this it was concerned that it would be difficult for many stakeholders to assess whether the procedures could be considered ethical.

The SCHB was also uneasy that many amongst the general public would be uncertain about what is actually being proposed and that the procedures appropriately satisfy their ethical expectations. In short, it is very difficult for organisations and lay individuals to ascertain whether the proposal is actually ethical and in the public interest.

A greater effort should be invested in better explaining the different steps in the procedure of (1) anonymising the different sets of data being held and (2) the manner in which these data sets are being linked to each other for research. The use of better diagrams could, for example, be used.

Based on what the SCHB has been able to interpret concerning the suggested procedure, it is of the opinion that:

- Indexing ensures that personal information such as names and addresses is kept separate from the rest of the process. Such personal information should be removed as soon as possible after it has been used for producing the keys which will be employed to replace the personal information in the rest of the process.

- The information held on the SPINE linking the personal information of individuals, including the name, date of birth, gender and postcode for everyone in Scotland associated to the linkage ID which permits each individual to be characterised should never be given to NHS National Services Scotland (NHS NSS) in any circumstances. If this ever did happen, the amount of information that could be obtained on a person would be extremely troubling.

The SCHB would like to question how this could be 'future proofed' to ensure that the general public can have complete confidence that such a breach in procedures would never happen in the future. This should take into account the possibility of:

- (1) a court order enforcing a link to be established between the SPINE and NHS National Services Scotland in order to investigate an individual. Precedent in the use of court orders happened, for example, when Stephen Kelly, who was a prisoner in Scotland, agreed to give a blood sample to a study of an HIV outbreak among drug addicts in his prison. All participants were assured that the findings would be kept confidential. However, police were able to override guarantees of confidentiality by the researchers and Kelly's sample later provided crucial evidence in a criminal trial. He was found guilty of knowingly infecting his girlfriend with HIV. It resulted in Kelly being sent to prison for another five years<sup>1</sup>.

- (2) the directives of an authoritarian (totalitarian) Scottish government.

- The SCHB believes that it should be made clear how persons can opt-out of their data being used in data sharing and linking services (unless this data was unlinked anonymised). It would prefer if individuals could actively opt in to the use of their data being used in this way through, for example, their consent being taken in GP surgeries.

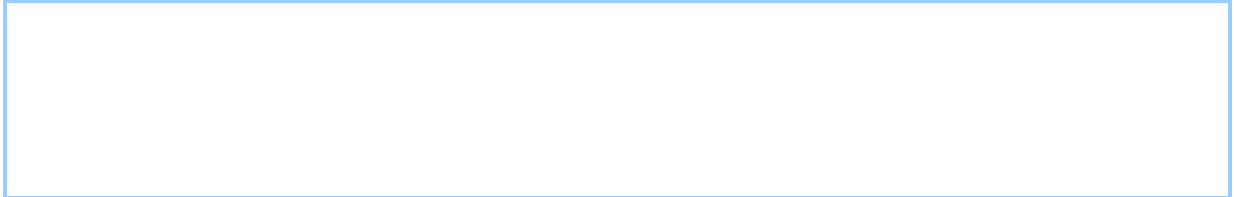
- The SCHB notes that the SPINE would be under the responsibility of a number of named and trusted individuals but would like clarifications about the manner in which these individuals are chosen and how they have been ascertained as trustworthy.

- The persons responsible for the SPINE together with the procedures being suggested under these proposals would need to be independently monitored and inspected to make sure that due process is being respected. They should be accountable to the proposed Privacy Advisory and Ethics Committee and ultimately to Government Ministers.

- The consultation document indicates that the information contained on the SPINE should only be accessed under very strict controls in order to mitigate privacy risks. But the SCHB would like clarifications about how this would be achieved.

- The consultation indicates that the service is not a data archive and will not hold research datasets beyond the lifetime of the project. The SCHB, however, would like clarifications about how and by whom this will be ensured. There is always a danger that data sets end up being stored for very long periods of time because nobody knows that the research has ended.

*4.2 How could the proposal be improved to deliver this better?*



(please extend the boxes or add additional pages if required)