

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.

Point 2 on page 12 of the consultation document discusses the lack of "unique identifiers" in use across Scotland. In practice, The CHI number, NHS registration number and National Insurance number (mainly over 16s) all cover the vast majority of the population and the opportunity for making greater use of these identifiers should be explored.

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.

In general the guiding principles are appropriate but there are two areas that might benefit from more clarity:

- Section 1 of the consultation document is very clear that the principles

do not cover the provision of co-ordinated services to individuals and it would be helpful to see this carried through to the principles in a more explicit way. As a service provider we have existing agreements for the exchange of personal information – eg with the NHS – which we expect to continue but there is always a potential grey area. The example of looked after children is relevant: linked personal information is held at an operational level under an agreement protecting privacy. Should this linked data be supplied through the data linkage centre, and at what point in the chain do the principles apply?

- Section 3a *Guiding Principles* mentions the Information Commissioners Data Sharing Code of Practice as a starting pointy for the principles. Many research organisations operate across the UK, and there will continue to be many benefits from this. The principles should be clear whether all research in Scotland must be handled through the proposed National Data Linkage Centre, or whether protocols developed elsewhere which are consistent with the UK Data Sharing Code of Practice are acceptable. (This is covered to some extent in 3b *Governance* and 3c *Privacy Advisory Service* but with no obvious conclusion).

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