

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.

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.

- Requiring 'explicit consent' and 'adequately' informing people about data usage requires identification of individuals to the research team or, more likely, the data custodians, in order to contact them to ask for this consent/give this information. Broad NHS consent to share data should be enough to cover this 'explicit' consent and adequate information about storage and use of data. 'Opt-in' processes on a study by study basis would result in very low uptake. This usually invalidates and removes the reason for the linkage. Thus explicit opt-in consent should only be sought when there is an overwhelming

reason to seek this in the interests of privacy. Clause 23 could be amended by adding the words “or reasonable” after the words “Where obtaining explicit consent is not possible/practicable”

- Linkers do not need to be separated from data custodians. We have found ISD and education services can provide excellent linkage services for us and this should be allowed to continue.
- The guiding principles should include a commitment to encourage the use of a single identifier on all databases. In Glasgow, talks are already taking place about making CHI available on the SEEMIS education information system in order both to make linkage quicker and easier and to facilitate transfer of information about children between professionals working with those children.

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.

But... the costs of the bureaucratic processes and associated costs to researchers need to be monitored. There needs to be an emphasis on making things easier and quicker for researchers and evaluators.

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.

Where data linkage is difficult at present, this centre with these functions may help to facilitate future linkage.

Where linkage is already being performed effectively, it is important that any involvement of the Centre does not result in unnecessary delays.

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

Yes No