

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

We warmly welcome the proposed data linkage framework to enable exploitation of valuable data within a robust governance framework of data sharing and linkage.

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

Whilst the benefits of better data linkage are clear, it must be made explicit that data users and custodians must abide first and foremost with the principles of the Data Protection Act to ensure that any research is undertaken ethically and robustly. Any data that is produced must be in the public interest and unlikely to cause substantial damage or distress to the data subject or any other person.

Clarity with regard to the ethical justifications of secondary use of data for research would be helpful particularly in situations where re-consent is impractical. What types/levels of measures with regard to minimising risks of identification would be acceptable?

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

Setting out some worked examples perhaps from SHIP may help the process of clarifying how these principles already operate in practice and where ambiguities arise.

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.

A Privacy Advisory Service is a good idea although it will have to be appropriately resourced to enable a timely response to help researchers and data custodians identify the ethical implications and navigate the various regulatory and legal requirements when linking datasets.

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.

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

Yes No