

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)

Also, other- privacy practitioner.

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 Although the principles appear to be sufficient and appropriate, the plans for implementing them in practice will be more telling. For example, making information publicly available after linkages have occurred will have less impact than beforehand (principles 7 and 8, yet cf principle 15).

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 Yes, with the caution that the PAS would need to be appropriately resourced to manage what could be significant demand for its services. If it is not, it risks being unable to meet the proposed objectives. Also, how best to avoid organisations abdicating accountability and responsibility for thinking through the issues and standing behind decisions they make as a result of receiving advice and support from the Service merits careful attention, as does the question of liability.

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 It would be worthwhile considering whether the Centre needs a statutory footing for conducting its activities and whether additional legal requirements are needed to protect privacy, and which clearly authorise sharing personal information with the Centre. For example, Ontario's Personal Health Information Protection Act establishes requirements and authorities relating to the use of personal health information for research and for 'the purpose of analysis or compiling statistical information with respect to the management of, evaluation or monitoring of, the allocation of resources to or planning for all or part of the health system, including the delivery of services' (PHIPA, s45 http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_04p03_e.htm#BK58).

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

Yes No