

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.

I do not believe that enough is made of the ability of data linkage to evaluate long term or rare outcomes or side effects.[1] Related to this, data linkage over a long period can also be used to study the accumulation of small exposures (such as being exposed to particular social environments) that may accumulate over a long period of time.[2] The instant transformation from cross-sectional study to longitudinal study can be exemplified by the linkage of the Scottish Health Survey to routine data.[3] Finally, and not covered anywhere in this document, is the ability to use linked data to assess the extent to which surveys are representative of the populations from which they are drawn in terms of subsequent outcomes.[4]

References

1. Lewsey JD, Leyland AH, Murray GD, Boddy FA. Using routine data to complement and enhance the results of randomised controlled trials. *Health Technology Assessment* 2000; 4(22).
2. Leyland AH, Næss Ø. The effect of area of residence over the life course on subsequent mortality. *Journal of the Royal Statistical Society Series A* 2009; 172:555-578.
3. Gray L, Batty GD, Craig P, Stewart C, Whyte B, Finlayson A, Leyland AH. The Scottish Health Surveys cohort: linkage of study participants to routinely collected records for mortality, hospital discharge, cancer and offspring birth characteristics in three nationwide studies. *International Journal of Epidemiology* 2010; 39:345-350.
4. Non-participation and mortality in different socioeconomic groups: the FINRISK population surveys in 1972–92. Harald K, Salomaa V, Jousilahti P, Koskinen S, Vartiainen E. *Journal of Epidemiology and Community Health* 2007; 61:449-454.

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.

It is in the public interest that steps be taken to improve the completeness, comprehensiveness and quality of the data collected and the accuracy of subsequent linkage since this would clearly improve the value of all data including those data that have already been collected.

More detail is required in point 20 concerning the determination of whether it is possible and practicable to obtain consent from individuals. How will it be judged whether this is possible and practicable? Who will make this judgement?

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.

The aim of the PAS is stated as “helping all those involved in data linkage projects strike the right balance between safeguarding individuals’ right to privacy and the efficient use of data for statistical and research purposes through careful application of the guiding Principles”. Objective 5 calls for this body to “demonstrate high standards of decision making about the use of personal data”. It does not seem appropriate that the PAS should be a decision making body; this should be kept separate from the role of helping others. Objective 3, “making recommendations as to whether or not data linkages are conducted”, is probably also beyond the role of an advisory service.

The PAS could usefully take a role in the advocacy of the extension of existing linkages to be more comprehensive – for example, through linkage to tax returns and welfare benefits in an attempt to move towards a Nordic model of data linkage – and to be more complete, such as through the inclusion of data covering private health care and education.

The PAS should also consider a role extolling the benefits of data linkage to the wider public (e.g. through the publication of the importance of existing data linkage projects and their results) and allaying fears regarding the safety of the use of linked data for research. The widespread publication of instances of security breaches resulting in the loss or disclosure of personal information not used for research purposes may have led to an overestimation of the risk of breaches of confidentiality in data used for research purposes.

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