

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.

Further benefits include:

Tools to help the management of long term conditions

e.g. <http://www.cso.scot.nhs.uk/Publications/ExecSumms/JanFeb08/Donnan.pdf>

This generation of primary care based risk prediction tools has the potential to benefit patients as well as reduce costs to the NHS in Scotland. In particular, tools derived from linked primary care data can help general practices identify patients (in real time) at high risk of emergency hospitalisation and tailor appropriate cost-effective prevention strategies.

Prognosis and prediction of major

Illness e.g. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2722695/>

Many conditions are seen at an early stage in primary care when the probabilities are very different from those encountered in specialist settings, and decisions are taken in situations of uncertainty. For instance, primary care linkage databases have been used to describe the clinical course of patients in general practices with a diagnosis of angina as their first manifestation of ischaemic heart disease. Such patients differ from patients with angina who are seen in hospital clinics and who are more likely to be entered into clinical trials, with respect to complication rates and outcomes of surgical interventions

[Professor Graham Watt: <http://www.sapc.ac.uk/images/documents/blue.pdf>]

Evaluation of health-care interventions

e.g. <http://www.hta.ac.uk/2224>; <http://bmjopen.bmj.com/content/2/2/e001019.full>

Observational studies can be used to evaluate health-care interventions in situations in which it is not ethical or feasible to mount more rigorous experimental studies. Primary care linkages to ISD's Scottish Morbidity Record and Health Protection Scotland Virology databases are being used to evaluate influenza vaccination programmes.

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 X

If you ticked 'yes', please describe the challenges or barriers.

For similar projects using primary care linkage to continue in Scotland (highlighted in answer to question 1), a coordinated effort, potentially using the National Data Linkage Centre as a conduit, is required to consolidate extraction and linkage of primary care data in Scotland.

3. Are the guiding principles sufficient and appropriate? Please explain your answer fully and make suggestions for improvement.

Yes, they are sufficient and appropriate X ? No, they are not

Please explain your answer fully and make suggestions for improvement.

Comments

4a. Are the objectives set out for a Privacy Advisory Service in Section 3c the right ones?

Yes, the objectives are right x 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 x 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 x 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 x No