
From: Taylor Rae (NHS TAYSIDE) [mailto:rae.taylor@nhs.net]
Sent: 24 May 2012 10:53
To: Data Linkage Consultation 2012
Subject: A SCOTLAND-WIDE DATA LINKAGE FRAMEWORK FOR STATISTICS AND RESEARCH: CONSULTATION

I attach the response to the consultation on behalf of NHS Tayside. As explained in my telephone call, Mr Gerry Marr, Chief Executive; Dr Drew Walker, Director of Public Health (Caldicott Guardian) and Dr Andrew Russell, Medical Director (Caldicott Guardian), were each specifically invited to respond and the attached represents a common response on behalf of them all.

I will of course be happy to provide more information or explanation if required

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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

The above limits comments to where there are further benefits not sufficiently described. This does not give any opportunity to comment where benefits are described inaccurately or without appropriate clarity. Where this is the case, such comments have been included as though there were additional benefits not described.

- Some benefits are described too specifically. Whilst they correctly reflect the focus of the aim, there may be related benefits which could be excluded through such specificity. Examples are provided below:
 - o The first aim (a)/benefit 1 limits the aims of “delivering a higher quality cross-sectoral evidence base” to “speeding up cycles of improvement.” would exclude improving the robustness of the evidence or extending the scope of coverage of the evidence base. It also restricts the aim to inform public policy and strategic spending decisions which would exclude informing management decisions on the operational or strategic deployment of resources, which may be workforce or technology. These issues are explored in more detail within the response to each individual section.
 - o The fourth aim (d)/benefit 4 limits the aim to informing preventative spend. Whilst this is a very important element, low cost longitudinal research can be used for more than just such a limited purpose
 - o The fifth aim (e)/benefit 5 limits evaluation to new programmes. The evaluation can also be applied to existing programmes or modifications to existing programmes
- Some benefits not clearly described
 - o The third aim (c)/benefit 3 refers to the “value and power” of the analysis with no clarity as to what this means. Some examples

appear to link events in a similar way as described under benefit 1 (a) without a clear description of the distinction. However the assertion that data linking in itself improves data quality which in turn improves the usefulness of the consequent analysis is well made.

- Note also that the terminology of “aim” and “benefit” appear to be used interchangeably. It would be preferable to use consistent terminology.

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

The above limits comments to where there are further challenges. This does not give any opportunity to comment where challenges are described inaccurately or without appropriate clarity. Where this is the case, such comments have been included as though there were further challenges.

- Challenges relating to the acceptability of data sharing
 - o The concerns regarding the lost opportunities through a cautious approach to privacy are described clearly. However, the challenges posed through problems resulting from an inconsistent approach across data custodians is not raised
 - o A common concern of the public relates to the purposes to which their data will be used. This can be difficult to describe simply and accurately to the public. Furthermore, there may be a belief that the data will be used for other purposes than agreed which can lead to a very cautious approach from the public as well as data custodians which also raises challenges.
- Challenges relating to cross-sector expertise
 - o The capacity and capability of organisations to analyse and make use of linked data begins with the understanding of the differences in the nomenclature and the associated definitions and standards across sectors. Whilst the availability of resources with the information management expertise within sectors is limited, very few can extend that expertise across sectors
- Challenges of secure exchange and access
 - o Safe havens are not limited to stand-alone computers. Closed systems of networked resources where access is restricted to secure access points with no capacity for the extraction of data can provide an option. Such a safe haven arrangement has been piloted and now adopted by the Health Informatics centre (HIC) in Dundee.

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

- The principles derived from the SHIP model are very helpful but need in some cases to be widened from the health-focussed model
 - o Sections 34 to 36 relate to clinical trials which are clearly related to health data. This should be generic to reflect similar issues relating to other data sets
- Some of the terms used are not adequately defined:
 - o There is a statement that data security should be reflected in the “business objectives“ of all organisations but is not clear specifically what is meant by the “business objectives” or how this should be achieved.
 - o There is a reference to a “Data Sharing Agreement” under section 31 which is not explained or included in the glossary. A clear definition would be helpful.
 - o There is a reference to a “data use/sharing agreement” under section 38 which is not explained or included in the glossary. A clear definition would be helpful.
 - o There is a reference to a “memorandum of understanding” under section 37 which is not explained or included in the glossary. A clear definition would be helpful.
 - o It is also unclear how the “Data Sharing Agreement”, “data use/sharing agreement” and “memorandum of understanding” interrelate, or even whether they are all the same thing, and what they should consist of.
- In section 20 it suggests that explicit consent should be obtained prior to linkage of personal data. It is unclear whether this relates to the linkage itself or the release of the linked data to the researcher. Many systems which provide linked data provide the linkages within the infrastructure rather than perform the linking exercise for each research project.

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

- Whilst we would support the objectives outlined. specific issues which would need to be considered would include.
 - o The capacity of the Service to manage the likely workload
 - o The timeframes which the service would need to work to be effective
 - o The implications for individual data guardians who would retain the legal responsibility for the data releases irrespective of the views of the Advisory service.

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

- We would agree that the functions outlined are appropriate for such a Centre. However, the function of the Centre is described as including the listed functions. This needs to be a comprehensive list and also more completely described. This clearly requires further work.

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

Yes No