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 <u>please tick only one box</u>)*

Data Custodian ☐

Data User (e.g. researcher) X

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 x   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 document would benefit from further information on the envisaged <u>mechanisms</u> through which investment in a common framework & national data linkage service would be expected to produce economic returns. For example, through attracting *external investment* in R&D (the 'Test Bed Scotland' concept) or reducing the costs of *research* (trials, correlational studies or policy evaluations) and *government analytics* (e.g. census). These are implied but could be made more concrete.
Similarly, more could be made about the advantages of record linkage for accelerating the translational lifecycle between medical knowledge and clinical treatments.

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 x

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

Comments
- More consideration of the role of private enterprises and global corporations in the use of the Scottish population's data would be worthwhile, as would greater transparency about the business models underpinning this emerging information economy. This has implications for the public interest mandate and is relevant to decision making about appropriate use, governance and benefit sharing.
- There are considerable human resource challenges associated with the application of high level expertise in data analytics and IT security,

which need to be addressed. (See also section 4a).

- An important set of challenges relates to cultural issues for different data holders and data users. For example, service sectors may vary in terms of the perceived sensitivity of their data or in their history of data sharing. Critically, we need to bear in mind the vested interests of different bodies that are currently engaged in record linkage initiatives. Some of these have already invested considerable resources and intellectual property in developing their own approaches and may feel a sense of territoriality which could, to some extent, be threatened by the more open national initiatives which are envisaged in this document. Achieving a common set of principles, standards and methods may therefore be difficult without considerable additional attention to and investment in mutual incentives.

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
As high level concepts these are sufficiently comprehensive and well-principled. However, at the more detailed level, further elaboration would be useful, particularly around:
- monitoring arrangements, criminal law and sanctions
- determining, articulating and balancing stakeholder interests
- determining the appropriate lifespan of linked datasets (bearing in mind that some will effectively become everlasting public resources).
- the circumstances under which consent will, or will not, be required for research and will, or will, not be requested from the data subject. In this regard there is a need to more clearly differentiate the issues pertaining to identifiable personal information, anonymised personal information and aggregated population-based datasets. In its present form the guidance is likely to confuse both the public and data custodians.
- ensuring public representation on the relevant oversight committees
- separating physical from technical security measures (taking account of data security, system security, location security, user security etc.)

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
While the objectives are laudable, achieving them will be challenging for a number of reasons. One is the capacity of the PAS to cope with the sheer volume of traffic that is likely to come from its multi-sectoral scope and overarching remit for supporting all types of data linkage research.   It will also be important to ensure the right balance of expertise and stakeholder representation if the service is to be successful.
For example, informatics expertise will be necessary for assessing the risks of subject re-identification due to association, and for suggesting algorithmic alternatives to data linkage where specific legal restrictions make this difficult. Consideration should be given to locating the PAS within a university in order to make best use of Scotland's academic knowledge base.

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
Greater articulation of the vision for integrating the strategies and activities of different data linkage entities would be useful. It remains unclear to what extent it will be possible to harmonise their activities or what implications this will have for intellectual property and control.
Developing the technological infrastructure and support required for safe data sharing will be a major task and it will be important to ensure that this is sufficiently resourced to draw on the best available Scottish talent in this area, some of which is currently located in private data mining companies.

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 ☐