

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

GHA believe that data linkages have immense benefits for both researchers and the delivery of services. The renewed focus from the Christie Commission on partnership working has meant that public sector bodies will be more likely to be working together on strategic direction and policy decisions. Data linkages are necessary to ensure that all parties have access to all of the relevant information to make the most informed decision.

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

One of the main challenges will be the role of the data custodians of balancing the privacy of the individual citizen with the wider public interest. There will be a need to demonstrate that there will be sufficient public transparency (commercial benefits) and robust information governance (access, security, information sharing agreements and sanctions) and thereby give comfort to the data custodians and the individual service user of the custodian.

Integral to demonstrating tangible benefits will be awareness raising campaigns and who will fund such campaigns, which will have a significant impact on resources in an already difficult financial environment. Therefore buy-in of the data custodians may prove difficult with the need to enter into individual information sharing agreements, invest in compatible technology for the secure transfer of personal data and ensuring legislative and regulatory compliance. Are resources/financial costs to the data custodians a barrier to the framework progressing?

Data custodians may require support in considering the privacy implications of applications (to share data) whilst considering whether the risks of sharing are proportionate. Who will support the data custodian?

The paper suggests that “data custodians” are primarily local authorities but is not clear what other public bodies may be asked to participate in the framework. Will it follow that housing associations will be asked to participate?

If only a limited number of data custodians agree to participate in the framework what impact, if any, would this have upon the operation of and the cost/benefit ratio of the framework i.e. does the framework require a minimum number of data custodians to participate to safeguard efficiency of costs and production of meaningful results?

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

Appropriateness and sufficiency of the guiding principles – they encapsulate the core principles for sharing information. However it is lacking in detail and we have identified below where believe further work needs to be considered:

Principle 9 – who should meet the costs of the governance body that will monitor data linkages?

Principle 11 – there must be adequate consultation with a full range of stakeholders.

Principle 13 – in accordance with ICO Anonymisation code of practice (currently draft).

Principle 15 – the limited availability of resources of relevant parties will impact upon the consideration. There is a risk that it may become common practice not to carry out a PIA where there is no sanction for not doing so.

Principle 16 and 17 – the operation of these principles is based upon a PIA being carried out but how does this sit alongside Principle 15 where a PIA may not be carried out if not considered feasible?

Principle 19 – who should assess the risks of re-identification?

Principle 20 – the data controller may not have the means/resources to obtain explicit consent particularly where the agreement to share current data-sets will be a secondary purpose.

Principle 22 – how will a data controller balance this principle with principle 20? It is contradictory to expect the data controller to obtain ‘explicit consent’ for use and to ‘inform’ data subjects of purposes of use of their personal data. The principles on consent need to be clearer.

Principle 23 – suggest what is an appropriate oversight body?

Principle 40 – who is appropriately independent and knowledgeable?

Improvement to the principles will be achieved through effective consultation with key stakeholders.

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

We believe an Advisory Service will help ensure that a culture of data-sharing is treated as the norm unless there are real grounds to dispute this.

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

An important point to recognise is that privacy advisory service must be wholly independent and publicly recognised as such, from the data linkage centre and the steering group. However, overall we feel that the functions suggested are the right ones.

Nevertheless it must be noted that until real proposals have been issued for the replacement to the census, the assumption must be that this will continue to be used as a source of data gathering. The information from the census provides planners with a unique opportunity to survey the whole country at once gaining a snapshot of society. Armed with this and other information, the data collated is paramount to future planning decisions. Many datasets already in use rely on census information and so the National Data Linkage centre must ensure that provision is made to continue holding this data in a secure and accessible manner until any decision on the census is agreed.

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

Yes No