

## 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 document makes a compelling case, with impressive exemplars of the pioneering work already being undertaken in Scotland

### 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 challenge section provides an excellent summary of key challenges and covers the main points – but there are some issues that could be elaborated slightly further. In addition to variation in interpretation of the legal framework, it is important to acknowledge some government departments have distinct legal constraints, which limit what is permissible. The issue of consent is mentioned briefly – but it should be acknowledged that this is a highly complex area, around which much uncertainty exists. There is also a need to develop skills in data management and analysis, and further develop appropriate data standards, in the research sector as well as in the public sector. The existing lack of coordination and leadership across government is not explicitly highlighted – but is clearly an area the framework is seeking to address.

**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

In our view this is an excellent series of principles and achieves the right balance.

**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

We strongly support the concept of a 'privacy advisory service' that would provide a recognised source of expert advice to researchers, and offer assistance to them in managing associated risks. The key unanswered question, as acknowledged in the text, is whether there would be any formal requirement for researchers to gain the approval of this body – and, if so, what impact this would have on the regulatory burden.

**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

Again we strongly support the case for a designated coordinating body to take a strong leadership role in realising the potential of data linkage. Clearly this should build on existing structures and best practice as far as feasible, and engage all relevant stakeholder groups.

Overall, we are extremely supportive of the proposed framework set out in the consultation document. Scotland has led the way in developing the systems needed to realise the immense potential of data to advance

research and enhance public services, and this framework represents an extension of its pioneering work. We are pleased that the consultation document recognises the wider UK context – and the need to ensure that there is a coordinated approach which ensures that data can be shared and used across the devolved nations.

We sincerely hope that this innovative framework will provide a template for other parts of UK.

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

Yes  No