

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

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.

While the challenges identified are quite true, to a large extent data linkage is a political problem (with a small "p"). We would benefit from a clearer articulation of these problems and what the solutions might be. For example linkage can fail because neither data controller feels able to hand his or her data to the other or to a third entity. Systems that afford data controllers more equal relationships while sharing should be explored. The solution to the political problems is to create mechanisms that will protect participants so that linkage is not solely dependent on trust in particular people or bodies. We need to think not just about the protections but also the motivations for the various actors to take their part in linkages and this will have bearing on the problems of metadata as well as the data quality issues that have been identified.

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.

Number 33 is ineffectual because “a clear distinction” is open to any convenient interpretation. It needs to specifically express that where data from more than one data controller is linked these functions must be physically, technically, financially and organisationally separate.

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.

There may well be a problem of some data controllers not having the confidence to sanction use and linkage of data under their purview. Consequently many may be making overly conservative decisions. However the law gives them the right to make these decisions. It's necessary and desirable for two or more data controllers to meet to discuss the implications of a particular linkage that concerns them all but that's not what this is. The solution is to educate, support and empower data controllers – not create a body that will make their decisions for them.

Plans to give a privacy advisory service (PAS) a statutory basis would make it very hard for a DC to gainsay their decision. In other words it will give PAS "teeth". It's a strange advisor that needs to have "teeth". If as a data controller you agree with PAS you can act with confidence but if you disagree what then? PAS will effectively be able stop a linkage even if the data controllers want it. I question whether they should have that power. It would not only erode the legal basis of the system but will erode the position of data subjects who can currently entrust their data to the controller expecting to be able to call that person or body to account.

The body that needs more "teeth" is the regulatory body. To strengthen powers of the Information Commissioner's Office would be much more apposite.

It's true that there may be increased pressure on data controllers in the future and that some may not be as prepared as we would hope. So support them to create their own privacy advisory committees within their own organisations which could be in the model of the excellent one convened by the NHS Information Services Division. Perhaps create "if not why not" systems where they must justify any decision to deny data access or linkage. Rather than usurp their authority - educate them. Give them the tools. Campaign to them if appropriate. The aim should be to have strong confident data controllers who are fitted to take the responsibilities given them by law.

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.

I see this as being more about setting standards eg security standards and making sure they're met. It's about facilitating linkage and making sure data controllers have a choice about where they put their data for linkage. It's about creating a healthy system. So for example licencing should be one function.

If you children want to play football do you tell them it's your ball so they have to make you captain of both teams? No - you provide the pitch and the ball and the rules and the referee and you stand and watch them and see fair play. And if in time more teams come to use the facilities so much the better.

So leading development of data linkage IT and expertise is good.

But conducting cross-sector data linkages should not be done by a single entity – see question 3.

A trusted data exchange service needs clearer definition.

Co-ordination and support for satellite linkage units is good – in the sense of harmonisation i.e. the concept of setting standards.

Development and maintenance of a population spine would be good provided it holds no other data except the identifying information. It should give out encrypted identifiers to data controllers but should not allocate project specific identifiers.

Beware of the “efficiency” argument. It would be much more efficient if the police and legal system were one body but there are good reasons to keep them separate and these reasons apply equally to data linkage systems. Indeed a better situation would be for other entities to provide the various linkage services at no cost to the government and for the government to regulate them.

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

Yes No