

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.

We believe that there are significant benefits for local planning partners in linking public service data in the short term. These include the ability to map cross-agency resource-use by linking routine data across all public services. Although this could be considered as research, in practice it is more of a tool around measuring demand and use which can inform the integration agenda across agencies. This kind of linkage must be safe, with appropriate controls, but must crucially take account of local contexts and data sources.

A specific comment received was the need to emphasise the potential benefits of including CHI in ISD datasets relating to primary care data in order to improve intelligence across the primary and secondary care journey of patients. Another comment around primary care data included a desire to extend the linkage achieved between the Scottish Health Surveys and SMR01 datasets to provide a similar link with primary care data, in order to inform the anticipatory care discourse.

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.

There is a widespread belief that all linkage must be centrally controlled via the ISD and Scottish Government's Privacy Advisory Group. Our experience

is that this centralised process may act as a significant barrier to the development of local linkage work, particularly the development of multi-agency linked data on demand and use for planning which is often required within relatively short timescales (of less than 3 months).

A further barrier is the lack of clarity around the role of research ethics committees in relation to data linkage.

We would reiterate our comments about ensuring that national datasets from primary care contain CHI to ensure deterministic linkage with other health datasets.

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.

Overall the principles are helpful in general and we would welcome them being refined and then disseminated across the public sector in order to stimulate greater linkage activity, taking account of all relevant legal issues and the views of the public and individuals.

Specific comments received included:

- There is an element of overlap and repetition. For example, the risks of identification, or of reidentification, of subjects from linked datasets are described in principles fourteen (in the Privacy section) and nineteen (in the Removal of names and direct identifiers section).
- It may be helpful to generate different categories of principles. Some of the principles appear to comprise broad aspirations rather than considerations that could be operationally useful. For example, it is difficult to see how a statement as broad as the first item, the statement that “Scientifically sound and ethically robust research and statistics are in the interest of the public” could be useful. In contrast, the statement (principle ten) that there should be a clear distinction between personnel responsible for linkage and those responsible for governance represents an important operational principle.
- There is a reference to linkage carried out for commercial gain in item (5). This could be a reference to linkage carried out primarily for the private sector or linkage in the public sector with the aim of income generation, although there is an assumption in most of the document that linkage will be carried out in public sector datasets owned by different public departments. The principles might be different for private sector than for public sector linkage. The commercialisation issue requires greater clarification and debate.

- Item eight is a statement to the effect that information about linkages should be available to the public but it is not clear how this is to be achieved.
- The list of principles could perhaps be distilled into a small number of items with more operational relevance.

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.

Whilst we accept that there is a need to support better understanding of the benefits, practices and implications of data-linkage, we would prefer to see a short-life workstream which developed products such as guidance and training which would address these issues via existing data-protection arrangements using local information services staff across community planning partnerships.

We believe that a centralised decision-making process might represent a new barrier to effective local linkage. Furthermore, at a time of limited public sector spending, we would suggest that a new centralised service may not represent the best use of public funding. We accept the need for the public to be reassured that their personal data is secure, and we believe that local information governance within the health service is generally robust and trusted by the public. We believe that privacy advisory groups should be local, building upon capacity across planning partners. In this regard, we would see the role of the Caldicott Guardian as providing leadership and co-ordination for such activity across CPPs. This approach would have the benefit of enhancing local accountability and skills across the wider remit of data governance.

Additional specific comments received included:

- Concerns about the status of existing privacy advisory services operating within Boards. An example was the Safe Havens project within 4 geographic boards. These projects have local privacy advisory committees and devolved ethical approval, being integrated with local information governance and with the leadership of the Caldicott Guardians. A Central Privacy Advisory Service would seem to threaten these units and the robust, devolved, short-loop governance processes created for local contexts.
- Concerns about the distance between a centralised PAS and local contexts for decision-making.
- Concerns about creating another bureaucracy around planning, research and development activity.

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.

In the main, the functions suggested are acceptable, and further to our concerns about the Privacy Advisory Service, it would be possible to enhance the National Data Linkage Service to provide the guidance and support elements suggested in response to question 4a in place of a central PAS. We believe that the provision of a linkage service and a data-exchange service are welcome, but that the Centre's main remit should be to build local capacity so that these functions could be carried out within community planning partnerships.

Some additional specific comments made related to uncertainty around the future role of local linkage services: within ISD; and within geographic Boards. There was a feeling that a centralised service might draw talent away from an already small specialist workforce and that this might undermine existing information services.

Another concern was that centralising the linkage service whilst leaving analysis and commentary to be produced locally might make the process clumsy. The individual commenting suggested that good linkage required a close working relationship between the local user and the information/linkage specialist. A central linkage service was felt to undermine this relationship, making useful products more difficult to create.

Finally, the term 'satellite units' was unclear. A number of local respondents wondered if this referred to board linkage staff, or Safe Havens. There was a feeling that a centralised service might threaten the operation and viability of local linkage arrangements.

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

Yes

No