

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)

The Scottish Consortium for Learning Disability (SCLD) is a Centre for Excellence that is made up of 12 partner organisations that have joined together, with funding from The Scottish Government, to help people make the changes set out in 'The same as you?' 'The same as you?' provides a national policy framework for supporting and transforming services for people with learning disabilities and their families in order that people are enabled to lead full lives in their communities. 2010 marked its tenth anniversary. SCLD's partner organisations are ARC, BILD, Badaguish Outdoor Centre, Capability Scotland, Central Advocacy Partners, Down's Syndrome Scotland, ENABLE Scotland, KEY Community Supports, PAMIS, University of Dundee, University of Glasgow and the University of St Andrews.

SCLD manages a national data collection on behalf of the Scottish Government called the eSAY return. An eSAY statistical release is published on an annual basis and details the number of people with learning disabilities known to each local authority social work service. The data is collected by local authorities and Partnerships, which then submit anonymised individual records to the eSAY team for analysis and publication. The data is used to monitor implementation of 'The same as you?' policy.

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.

The benefits of data linkage for statistical and research purposes are well defined within the consultation document. SCLD believes that data linkage can help to build a well-rounded and robust evidence base about people's lives which can be used to monitor the outcomes of public policy.

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.

SCLD recognises the challenges which have been identified in the consultation paper. The eSAY team, in their work to collect and develop data items on people with learning disabilities, have also identified further challenges which prevent more effective and efficient data linkages:

- Lack of joint working between different departments in the same public authority. For example, lack of joint working within local authorities means that accurate data recording, data collection and data linkage **within** local authorities does not take place, thus frustrating efforts to provide accurate data for either internal or external purposes. Anecdotal evidence suggests that there may be some resistance to data sharing within local authorities, for example between education and social work departments.
- As the consultation paper itself reflects, it is SCLD's experience that the lack of national data sharing agreements between different public authorities has serious implications for the amount and quality of data there is available about the lives of people with learning disabilities. Furthermore, being unable to link data means that there can be duplications of data to the potential detriment of datasets. Both of the above points may need to be addressed, as is suggested on page 7, through 'sufficiently high-level endorsement of the activity.'
- Agreement on data items and coding will be critical for any meaningful high level data linkage to take place; furthermore consistency of data items will be critical for the validity of longitudinal studies.

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.

SCLD welcomes the principles which have been set out to guide the process of establishing the Data Linkage Framework, The Analytical Privacy Advisory Service and The National Data Linkage Centre.

We believe that for the most part, the principles are sufficient and appropriate. However, we would propose that there could be some strengthening of the principles to ensure that accessibility is given a greater weight. For example, Principle 6 should be strengthened to include the

requirement that the findings from the use of statistics and research in questions should be widely publicly disseminated in a way which is accessible to the widest audience possible. People with learning disabilities, other disabled people and other equality groups can be excluded from finding out about research which is of interest to them because findings are not available in a format which is accessible to them. This kind of exclusion is not in the public interest. Furthermore, the accessibility of information to people with learning disabilities, and some people belonging to other equality groups, is critical both to enabling consent to data linkage processes at an individual level, but also to facilitating a wider public debate on such issues.

With regard to the principles on Consent, we would hope to see some recognition of processes under the Adults with Incapacity Act which could enable people who may not be able to give consent themselves to be included in research studies through their guardians.

We would also suggest that there should be a principle around inclusivity. Research populations often have a valuable contribution to make to the design, delivery, analysis and reporting of research, as well as to the routine collection of statistics. Even where research is being undertaken at a remove from the population, it may still be desirable to consult representatives of the groups concerned to ensure an inclusive and democratic research process. This can offer significant insights to the research team as well as opening channels for more effective dissemination of findings.

As the principles have been developed from a health perspective, it may be desirable to consult on these more widely with researchers and ethicists from non-health fields.

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.

While SCLD would welcome the support that a Privacy Advisory Service could potentially offer, we would like to see greater clarity on some points of the proposed Privacy Advisory Service and National Data Linkage Centre. These include:

- the relationship between the two proposed bodies and the potential overlap in roles; is there a risk that by separating the technical and ethical functions that there could be a loss of skills and knowledge on either side?
- the interaction between the two proposed bodies and other bodies, for example NHS or University Ethics Committees
- ensuring that both bodies have the necessary expertise across a wide range of fields, given that the intention behind the data linkages

project is to link datasets which span across subjects, for example, there should be expertise across the fields of health and social care

- what the proposals on the statutory footing to approve data linkages would be and whether these will strike the right balance between protecting privacy and facilitating research; will the Privacy Advisory Service risk creating a duplication in research approval practices?
- the interaction between reserved and devolved responsibilities in this area.

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.

As in 4a, while SCLD would welcome the support that a National Data Linkage Centre could potentially offer, we would like to see greater clarity on some points of the proposed Privacy Advisory Service and National Data Linkage Centre. These include:

- the relationship between the two proposed bodies and the potential overlap in roles; is there a risk that by separating the technical and ethical functions that there could be a loss of skills and knowledge on either side?
- the interaction between the two proposed bodies and other bodies, for example NHS or University Ethics Committees, as well as the GROS
- ensuring that both bodies have the necessary expertise across a wide range of fields, given that the intention behind the data linkages project is to link datasets which span across subjects, for example, there should be expertise across the fields of health and social care

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

Yes No