

Digital Economy Act, part 5: data sharing codes and regulations

Response from the CLOSER consortium

Q10. Overall, do you find this Code of Practice and accreditation criteria clear and easy to understand?

- yes
- no
- not applicable

Overall we think they are clear and easy to understand and welcome the explicit mention of the unique nature of longitudinal studies and research in respect of retention periods. Our use and interpretation of previous Code of Practice documents (e.g. ICO anonymization code of practice) has been aided by the inclusion of 'case study' illustrations. We recommend the inclusion of case studies in this Code of Practice and would be happy to help contribute to a case study based on longitudinal studies.

Q11. Do the Code and accreditation criteria explain clearly the principles by which information may be shared under these powers?

- yes
- no
- not applicable

The greatest value of longitudinal research resources will only be realised when participants data – drawn from multiple sources – can be linked reliably and analysed together within a secure single research environment. Given the unique nature of longitudinal studies we think that the principles would benefit from an illustrative exemplar involving cohorts using linked records to help ensure clarity. CLOSER would welcome the opportunity to help develop this exemplar.

Q12. Is there anything which you think is missing from the Code or accreditation criteria or which requires greater detail?

- yes
- no
- not applicable

We would like to see more detail and clarity on a number of points in the Code and accreditation criteria. These are as follows:

- We recognise that the Act does not provide a legal gateway to access health data. However, our understanding is that it does not preclude the possibility that health data accessed using a suitable legal gateway cannot be brought into the same secure research environment as administrative records accessed via the Act. To jointly analyse linked health and administrative data has tremendous research and policy potential. It was neither the intention of this Act to preclude this potential, nor to enable it. We would value this possibility being made clear within the code of practice.
- Clarity around the potential complication that arises in longitudinal/cohort studies in that staff can be both a processor and researcher and how this should be managed in practice.
- More detail on the levels of and routes to accreditation (illustrative examples and/or case studies, flow charts and tick boxes would be useful to help guide through the process).

CLOSER would be happy to help construct a case study or series of case studies to illustrate the process.

- Clarity over whether ISO27001 accreditation can be considered acceptable security accreditation.
- A clearer definition of what 'significant proportion' (25.1) means in practice, for example does someone with a sociological degree with a module on statistics qualify?
- A section promoting the benefits of data sharing and the requirement that researchers publish their work into the public domain.

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