

Response to the Health and Social Care Information Centre about its consultation on its Data Sharing Framework Contract and Data Sharing Agreement

We are writing on behalf of the Royal Statistical Society, the Statistics Users Forum, the Faculty of Public Health and the Society for Social Medicine and we are copying this response to the National Statistician. Although we have been alerted to this consultation¹ by some of our members, there is insufficient time to compile organisational responses.

This is a matter of great concern to us as we are aware of the adverse impact these documents and the way in which they have been used have had in delaying and blocking access to data for research purposes. Although we have encouraged individuals to respond to describe their own experiences, we would have liked the opportunity to draw these together into a more strategic higher level response.

Our inability to do this is a consequence of problems with the consultation process, which is well out of line with Cabinet Office guidelines on the subject.²

1. Although the Cabinet Office has relaxed its earlier requirement that consultation periods should last 12 weeks, it still states that 'Timeframes for consultation should be proportionate and realistic to allow stakeholders sufficient time to provide a considered response.' In this case, consultation period was only three weeks which is totally inadequate. Added to this, the third week coincided with the half term holiday when some key people have been on annual leave. The Cabinet Office states that where consultations span holiday periods, mitigating action should be taken. Although half term is not on its list of holidays, it is well known that some parents and grandparents take leave at this point to provide child care.
2. The Cabinet Office states that a 12 weeks consultation period may not be necessary for an issue where interested groups have already been engaged in the policy making process. This did not happen in this case, where the documents were simply introduced without any formal consultation process.
3. No account appears to have been taken of the capacity of the groups being consulted to respond in the three week period.
4. The guidelines state that 'Policy makers should be able to demonstrate that they have considered who needs to be consulted and ensures that the consultation captures the full range of stakeholders affected.' In that case, we have yet to hear from anyone who has been directly invited to participate by the team conducting the consultation. It appears that no approach has been made to researchers who have applied to HSCIC for data, organisations which had responded to earlier related HSCIC consultations, professional organisations or funding bodies. As a consequence, the first of the three weeks of the consultation period had passed before news of the consultation

emerged and was disseminated via professional and voluntary networks.

5. Many of the questions in the consultation document are legal in nature, making it difficult for respondents without legal knowledge to answer. This contrasts with Cabinet Office advice that 'Information provided to stakeholders should be easy to comprehend'.

There are other aspects of the consultation which fall short of Cabinet Office guidelines, such as the timing of the consultation within the policy process, the information provided to stakeholders and transparency and feedback. As stated above these have made it impossible for us to respond adequately to a consultation on matters which have had serious adverse effects on research using data compiled at public expense by HSCIC and funded from public and charitable sources.

It is time for an adequate consultation on the subject of access to HSCIC data for research purposes. We request HSCIC holds a full and adequately designed consultation on the subject.

Mike Hughes
Chair, National Statistics Advisory Group, Royal Statistical Society

Paul Allin
Chair Statistics Users Forum

Julian Flowers
Chair, Information and Intelligence Committee, Faculty of Public Health

Carol Brayne
Chair, Academic and Research Committee, Faculty of Public Health

Aileen Clarke
President Elect, Society for Social Medicine

Simon Capewell
President, Society for Social Medicine

References

1. Health and Social Care Information Centre. Review of the HSCIC's Data Sharing Framework Contract and Data Sharing Agreement. Updated 5 November 2013. <https://consultations.infostandards.org/information-governance/hscic-dsfc-dsa-review>
2. Cabinet Office. Consultation principles. <https://www.gov.uk/government/publications/consultation-principles-guidance>