

FUNDERS' RESPONSE TO THE EAGDA REPORT ON DATA ACCESS

The Economic and Social Research Council, the Medical Research Council, Cancer Research UK and the Wellcome Trust would like to thank the Expert Advisory Group on Data Access (EAGDA) for this insightful report and its recommendations.

As research funders, we are committed to improvements that maximise the value from the datasets generated by research, and to supporting the communication of good practice in data management and accessibility. Ultimately such improvement will enhance the value and accessibility of human cohort and longitudinal studies data.

We accept these recommendations from EAGDA and we will work together to respond to the challenges presented. We recognise that there are variable approaches and traditions across our disciplines that have led to the current divergence in practice, however we will use this variability and breadth in experience to tackle the challenges and, where possible, to develop joint approaches. The recommendations from EAGDA and the actions we will take will seek to promote good communication and understanding between the disciplines which in turn will help promote interdisciplinary research on these rich and valuable datasets.

Our research data policies set out our expectations on how data access for our studies should be governed. However we acknowledge that there are differences in how these policies are presented, made visible and implemented. Funders are actively working together to harmonise their research data policies. We will seek to identify and draw on good practice to agree appropriate requirements for data access that are proportionate and in keeping with the scale of the study. We expect all cohort and longitudinal studies to have in place a process of independent oversight for access decisions.

At the heart of the recommendations is the central role of data sharing and management plans within the grant application process. As funders we already have in place an obligation for applicants to develop these plans at the earliest stage. We recognise the need to work together with our peer reviewers to harmonise our requirements and our approach to reviewing these plans, and where appropriate to ensure they are properly weighted and factored into funding decisions. As a priority, we are developing further practical guidance to support decision-making for researchers as they develop their data sharing and management plans.

In accepting EAGDA's recommendations, we commit to act on the following issues:

- Respect for participant consent underpins the good governance of data sharing, ensuring maximised value from data whilst protecting the rights of research participants. We will work with the studies that we fund to ensure that consent processes adhere to best practice.
- Making decisions about access to depletable resources can be complex and we commit to work together and with EAGDA to develop clear policies and guidance on their management.
- We will seek to bring together leaders across our disciplines to exchange knowledge and ideas on discoverability and the interoperability of data. This is with the expectation that our communities will commit to the on-going development of standards and formats, and also to improve transparency and discoverability of data and access arrangements.
- We will encourage and support the sharing of good practice in governance arrangements, including data access committees, to maximise data access and minimise the administrative burden on studies. In line with EAGDA's recommendations, the ESRC, the MRC and Wellcome Trust have recently approved the creation of a consolidated Data Access Committee that will operate across several studies, funded independently of the scientific grant cycles.
- We will take action to address instances in which usage of data is only permitted in collaboration with a study team, in order to ensure data is shared responsibly and fairly.

- We recognise our responsibility to support good research practice and to address lack of research integrity. Where researchers abuse their responsibilities to funders, studies and ultimately to participants by breaching data sharing rules, we will explore mechanisms for imposing penalties and sharing information about such breaches.
- We will undertake to work together and gather the evidence to understand the short term and longer term costs of making the metadata both visible and available to other researchers, as well as considering the appropriateness of cost recovery models.
- We will work together to explore sustainable funding models for key data repositories and other research infrastructures.

We convened EAGDA in 2012 in order to co-ordinate across precisely the issues EAGDA has highlighted for us in their report. These issues are relevant across studies, and across funders, both in the UK and abroad. We support the findings of this report and will set out together to take action, and to engage other funders and institutions in the UK and internationally to address the significant challenges and opportunities for the data community that are being highlighted.

Cancer Research UK, Economic and Social Research Council, Medical Research Council, Wellcome Trust
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