



Request For Proposals – *Research into determining the best model for strategic cross-funder advice on data access, use and management*

Who we are

Wellcome exists to improve health for everyone by helping great ideas to thrive. We're a global charitable foundation, both politically and financially independent. We support scientists and researchers, take on big problems, fuel imaginations and spark debate. Based in London, Wellcome employs over 600 staff. Further information about Wellcome can be found at www.wellcome.ac.uk.

Wellcome is acting on behalf of the Expert Advisory Group on Data Access (EAGDA) for this procurement. EAGDA was convened in 2012-2017 by a group of UK research funders (Economic and Social Research Council, Medical Research Council, Cancer Research UK and the Wellcome Trust) to provide strategic advice on the emerging scientific, legal and ethical issues associated with data access for human genetics research and cohort studies: <http://www.wellcome.ac.uk/EAGDA>

Summary

The research and data environment has changed substantially since EAGDA was formed. EAGDA's term of funding ended in June 2017 and its funders are keen to explore how to take forward the model of strategic, cross-disciplinary advice on issues relating to data access and use. They would like to commission an expert/expert group with good knowledge of the UK data sharing environment to undertake a mapping exercise to identify existing initiatives in this space and to propose a new model for wider cross-funder advice mechanisms, if appropriate. This will include:

- Identifying the current structures, groups and initiatives in place to enable research funders to identify emerging issues for data use, access and management, and to formulate strategic policy decisions in response to these;
- Understanding the features of the existing EAGDA model that have worked well to break down disciplinary siloes for funders, including the input of the research community into funders' strategic thinking. This should cover views on both the demand side (what funders want) and the supply side (the research community);
- If appropriate, recommending a model that could provide broader cross-funder, cross-disciplinary advice and guidance to better coordinate funder approaches to data access, use and management in human research.

The output of the research will inform the funders' discussions on how best to work together and with the research community to ensure the best policy and operational approaches to access, governance and management of data generated by research they fund.

Further details of the specification can be found in **Appendix 1**.

Responding to this RfP

Structure of the Response

Interested parties who wish to respond to this Request for Proposals should submit an expression of interest as well as:

- Short (max. 4 pages) proposal outlining how you would approach this piece of work, including plans for data collection and methods of analysis, and why you are best placed to fulfil the requirements of the RfP
- Proposed team and CVs, including what their respective roles are on this project
- Samples or examples of past, relevant work of the lead application
- Budget of the proposed activities
- Proposal validity dates
- Contact name, location, telephone and email details
- Details of two references

Draft Terms and Conditions

The terms and conditions for this procurement are set out in Appendix 3 (available on request). Prospective applicants are required to submit a marked-up copy of this document with any proposed wording changes via the track changes functionality within Microsoft Word. For the avoidance of doubt, the marked-up copy should propose wording changes and represent your organisation's position in terms of what represents an acceptable contract. It must not contain any "should our bid be of interest to you, we wish to discuss the following points with you" or "for discussion" comments.

Proposed Costs

Proposals must include a detailed breakdown of proposed costs and state if the proposed costs do or do not include VAT or any other levies or discounts, for example, prompt payment discounts. Applicants are asked to complete financial input template CT2 (Appendix 2) which is available on request.

Prospective applicants should note that the Wellcome's standard payment terms are 30 days in arrears from receipt of a valid invoice.

Timetable

30 January 2018

7 March 2018

14 March

Issue of Request for Proposals (RFP)

Deadline for return of Proposals to Wellcome

Initial Response from Wellcome

Response Return

One email copy of your response should be submitted to n.banner@wellcome.ac.uk no later than **5pm** on the **7 March 2018**:

Any queries regarding this document should be directed to Natalie Banner who can be contacted by email (above) or telephone on 020 7611 8235.

Non Disclosure and Confidentiality

The information contained within this document or subsequently made available to prospective applicants is deemed confidential and must not be disclosed without the prior written consent of Wellcome unless required by law.

Independent Proposal

By submission of a proposal, prospective applicants warrant that the prices in the proposal have been arrived at independently, without consultation, communication, agreement or understanding for the purpose of restricting competition, as to any matter relating to such prices, with any other potential applicant or with any competitor.

Costs Incurred by Prospective Suppliers

It should be noted that this document relates to a Request for Proposal only and not a firm commitment from Wellcome to enter into a contractual agreement. In addition Wellcome will not be held responsible for any costs associated with the production of a response to this Request for Proposal.

Innovation

Wellcome is committed to considering new and innovative ideas and approaches to research questions. To that end, proposals suggesting ideas on how Wellcome can reduce costs through innovative suggestions and/or working closer together will be awarded additional credit in the decision making process.

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Appendix 1 – Specification;

Additional

Please contact Natalie Banner for copies of:

Appendix 2 – Financial input template CT2;

Appendix 3 – Standard Wellcome Trust Terms and Conditions

Appendix 1

Specification for research commissioned by EAGDA funders (CRUK, ESRC and Wellcome): Research into determining the best model for strategic cross-funder advice on data access, use and management

Purpose

1. To provide an overview of the current landscape of groups and activities that provide channels for UK research funders to receive strategic advice and feedback from the research community about issues relating to human research data and metadata access, use and management¹.
2. To identify what features of the existing model of EAGDA should be preserved, desirable and feasible in a new advisory model.²
3. If appropriate, to propose a new model for the provision of strategic advice to a wider range of funders on ethical, social, legal and practical issues relating to human research data access, use and management,³ including where and how such a group would best be located and resourced.

Background

Since EAGDA was established in 2012, the policy, governance and conversations around research data access and use have changed significantly. The field of data science has rapidly advanced, enabling greater potential for innovative linkages but also increasing the possibility of individual re-identification. Increasing concerns about patient data use and data privacy have demanded deeper scrutiny of data sharing and governance practices. The implications of the EU GDPR and Data Protection Bill on research data access and use are far from clear.

Several bodies and academic-led centres, networks and committees have also been set up that deal specifically with large scale data sharing, notably the ADRN; NHS Digital; Genomics England; the Global Alliance for Genomics and Health; CLOSER; METADAC; the Farr Institute and Health Data Research UK. The UK Statistics Authority, which has oversight of the ONS now has more powers in relation to data sharing following the Digital Economy Act. Additionally, the Nuffield Foundation is in discussions to set up a 'Convention' on Data Ethics, following recommendations from the Royal Society/British Academy report on Data Governance⁴.

There is a strong need for research funders to: have oversight of how all of these groups, initiatives and activities fit together; identify where there are gaps and inconsistencies in

¹ This should focus on data that is not 'open', i.e., that requires some degree of control or governance for access and use. It should not cover issues relating to data infrastructures, data discoverability or 'open' data, although these may be included incidentally in any relevant mapping.

² The Secretariat undertook a review of EAGDA's role and function in early 2017, which can serve as a background document for this research.

³ This should not include addressing technical issues about data standards and formatting, or intellectual property rights over data.

⁴ <https://royalsociety.org/~media/policy/projects/data-governance/data-management-governance.pdf>

terms of their competence and spheres of influence; work across traditional disciplinary siloes; and understand where they are best placed to act jointly, if they are to maximise the value of the data generated by their investments.

The EAGDA model has served a useful function over the past five years; however the funders would now like to take stock of the existing landscape and identify whether a different model for providing advice on strategic and operational issues in relation to data access for studies involving people is now needed. Unpacking this question will require a creative approach to:

- identifying what sorts of issues funders might **jointly** need to engage with in future;
 - what audiences or constituencies they should interact with and seek to influence;
- in order to respond to emerging ethical, scientific, practical challenges in relation to data access, use and management.

It may be feasible to propose the model is integrated into a national-level body, such as UKRI, via the Data for Discovery Group, SCHOPR (Strategic Coordinating Body for the Health of the Public)⁵, or in some way linked to the Nuffield Foundation data ethics initiative. Alternatively, it may be the case that there is not a clear role for such an advisory group in the evolving landscape.⁶

Scope

This research needs to address key questions about the scope, feasibility and resourcing of an advisory model to make it fit for purpose as issues relating to data use become more important for UK and international research funders. The funders would also be open to further creative suggestions about what might help address the main objectives of this call.

The first two phases of research should specifically cover:

- An overview of the key groups, activities and initiatives with any relevant remit, that UK funders can or could jointly draw on for:
 - strategic or operational advice; and
 - awareness of current issues for their research communities, relating to data access, use and management for human participant studies.
- A gap analysis and horizons scanning to identify where funders may not be getting or have access to evidence, advice and guidance on topics of strategic importance relating to data access, use and management. This should include where technologies are producing new forms of data and new ways of dealing with increasing volumes of data, and may require different strategies for the analysis and governance of data in the future. These topics should not be disease or discipline specific, but address cross-cutting issues that would benefit from cross-funder activity, consensus or strategic direction.

⁵ <https://acmedsci.ac.uk/policy/policy-projects/health-of-the-public-in-2040>

⁶ Bodies primarily concerned with fulfilling statutory functions with regard to access to data, such as the HRA Confidentiality Advisory Group and the Scottish Privacy and Public Benefit Panel, are probably beyond the scope of this research. This is because funders do not typically have established roles or relationships with respect to these bodies.

- What features of the EAGDA model (2012-2017) have been effective and less effective, and have added a unique perspective to funders' strategic thinking and policy. This is both in terms of providing advice to the funders and for helping build networks and relationships across disciplinary siloes.

The third phase of research should specifically cover:

- Whether there is a need for a group to provide strategic advice about human research data access, use and management issues to UK funders, where there are cross-cutting issues where there would be a strategic benefit to funders thinking and acting collectively.
- What might be the form and function of any advisory model that could effectively address such a need (if identified).
- What the most appropriate mechanism for funders would be, to maintain cross-disciplinary conversations about issues of strategic importance, informed by a broad range of expertise.

Approach

It is envisaged that this research would involve:

- Desk research on existing initiatives and channels of communication across UK research funders and between funders and the research community.
- Stakeholder interviews with funders, EAGDA members and other key stakeholders in the field.
- The use of appropriate evaluation methods with respect to current, and potential future, models of advice, communication and input to strategic and operational matters concerning data for health-related research.

Budget

As this is an output specification, we are unable to place a strict value on the cost of the research to be undertaken. However, to help gauge the scale of research, as a ballpark guide we expect it to cost in the region of £30,000 inc. VAT.

Format of results and timeframe for delivery

The data and analysis should be presented as a report to funders delivered no more than four months after the project commences. The successful supplier will be invited to provide regular light-touch updates update on their progress to the funders, with delivery milestones to be determined and agreed between the funders and the supplier.

The report should contain recommendations to the funders or, if further research is needed, indicate what additional work would need to be done and in what areas in order for an appropriate advisory model to be developed.