

**MINUTES OF THE FIRST MEETING OF THE EXPERT ADVISORY GROUP ON
DATA ACCESS (EAGDA)**

10.00-16:30, THURSDAY 21 JUNE 2012, WELLCOME TRUST

Present:

Chairman- Martin Bobrow
James Banks
Paul Burton
Tim Hubbard
Bartha Knoppers
Onora O'Neill
Melanie Wright

John Hobcraft- ESRC
Katherine Littler – Wellcome Trust
Geraldine Clement-Stoneham- MRC
Priya Umachandran- Wellcome Trust

Apologies for absence:

Rosalind Eeles, Mark Guyer, Mark McCarthy, Andrew Morris, Nigel Shadbolt, Chris Skinner, George Davey Smith, Fiona Reddington - CRUK

1. Terms of Reference (ToR) and Operations of EAGDA

- Chairman welcomed the group and explained EAGDA's initial two year life span (the Group will then be reviewed by the funders) and asked the group to locate gaps where EAGDA could add value in this relatively short time frame. With this in mind, it is likely that EAGDA will pick 3-5 key areas to focus on.
- The funders reiterated that they saw EAGDA as a high level group of influence which would be both forward thinking and international in focus, and that EAGDA would look to influence best practice to promote positive behaviour.
- The group agreed that issues such as researcher recognition and incentives for data sharing fell within the group's remit.
- In response to the Stakeholder workshop held in April to discuss EAGDA, the group felt that it was not in a position to roll out best practice. But proposing best practice was within its remit.
- The idea of responding to consultations (e.g. Information Commissioner) and reports (e.g. Royal Society – *Science as an open Enterprise*) was also discussed by the group.
- EAGDA must be visible and operate in a transparent manner. With this in mind, the group will explore how best to interact with the respective research communities, the wider public and funders.

- EAGDA must be aware of the breadth of its field of operations, and that a single mode of best practice covering all data and studies may not exist.
- Finally, the group were reminded of the issue of how data access affects the wider public, both in terms of the risks associated with sharing and the risks and consequences of not sharing data.

2. Mapping the Landscape

- The group spent the rest of the morning session discussing the current landscape. This discussion was informed by a background paper on current activities and policies produced by Jane Kaye and other literature and papers supplied by the funders and members of EAGDA.

Reports and activities

- The group noted that there is a plethora of activities in this area, including the:
 - Administrative Data Taskforce
 - Finch group report on open access publishing
 - Government White Paper on open access
 - OECD Global Science report
 - Royal Society Report 'Science as an open enterprise'
 - Information Commissioner consultation

Legislation

- In terms of legislation, the EU Data Protection Directive was thought to be something that EAGDA should consider, especially in terms of:
 - Ramifications for consent practises
 - Classification of data - why is genetic data exempted from medical data?
Personal data is personal, be it social, medical, financial

The Wellcome Trust offered to provide additional information on this Directive to the group.
- The potential impact of the UK Freedom of Information Act, and its recent amendment in the Protection of Freedoms Act 2012, in this area was also noted.

Data Collection, Access, and storage

- There was a long discussion around these areas. Some of the issues highlighted included:
 - How to ensure data is collected in a harmonized way?
 - The plurality of current access mechanisms can be a barrier to data access
 - Who controls the data, who 'owns' the data and how does this affect research practice?
 - Lack of consistency in policies relating to governance and oversight mechanisms
 - Unclear frontier on combining data –how best to link to different infrastructures and ensure they are appropriately governed
 - It is important to distinguish between what current studies (can) do and what expectations are for future studies.
 - Costs of data storage and curation, and the need for infrastructural support.

- What happens to data when studies finish?
- How to decide the value of data, especially as its value can change over time
 - who has the right to decide what data is kept?

Intellectual property

- The group agreed that IP is an important topic. However, given the scale of the issue and EAGDA's core remit, the group doubted this could be a focal point of EAGDA's activities. It would be minded to consider it in relation to its work plan.
- EAGDA could present any relevant information it discovered on IP in its deliberations to the funders for further consideration.

Data Sharing

- The group considered that there are some key questions to focus on in regard to data sharing, including:
 - Barriers and time delays
 - European data sharing barriers, as well as international data sharing barriers
 - Discoverability & knowledge of datasets (for example in the social science field ESRC has an online list of studies with their respective data release policies)
 - Why are some datasets not used?
 - Is there a role for promoting demand? Whose role would that be?
 - Not using data affects the quality of the science, results need to be replicable
 - What are the risks associated with sharing? Any policy on sharing should be proportionate to the risk.
 - What are the risks associated with not sharing the data?

3. Developing a work plan

- In the afternoon, there was a round table discussion on priorities for EAGDA's work plan. The main themes that emerged are:
 1. The need to map and clarify the usage of custodianship, ownership and control of data and understand how the usage of these terms affects research (consent procedures, data access policies and material transfer agreements) and practice. What do we mean by 'data sharing'? What are the desirable levels of control over data? Does linking different datasets affect who controls access to each dataset?
 2. Incentives: What are the current incentives for sharing data? What kind of recognition currently exists for those who share data or make it available in forms that can be shared, what do they need to be? How do we further develop the career path for those who curate, manage and share data? Can we look to standardize credentials? How does/could this tie into researcher ID initiatives?
 3. Plurality of Gateways to Access Data – is there a way to reduce the number of gateways that researchers have to negotiate in order to access and link

data? Can we harmonize mechanisms for data access and develop international norms for data access? How does/could this tie into researcher ID initiatives and safe harbour schemes?

4. Risk stratification – the group felt it was important to understand the actual risks associated with data sharing, as opposed to the perceived risks, to data subject, researchers, the wider public and the commercial sector. It would also be important to try and quantify the risks associated with not sharing data.
 5. Changing the culture – The group is keen to understand what is actually happening in terms of data access and sharing in the field currently. Is there a high degree of compliance with funder policies? If not, why not? Are there restrictions of access to particular datasets? What are the reasons for delays in data sharing? Are there ways to make compliance easier so that researchers can see the value of making data available? Are embargo periods currently working?
- The impact of the EU Data Protection Directive cuts across some of these topics and will need to be considered in any development of a work plan
 - Rethinking consent – no work plan will be able to avoid the complex issue of how to frame consent and this will need to be taken into consideration in any projects EAGDA undertakes.
 - The group are aware that returning research results to individuals is an important and topical issue. The Wellcome Trust and the MRC are currently undertaking work in this area and will feed this back to EAGDA in the near future.
 - When EAGDA meets again in October to agree which projects to take forward, it will also need to agree on the best way to take forward the work plan (i.e. working as one group or as several sub-groups).

Next steps

- It was agreed that the Secretariat together with the Chair would draw up discussion briefs on the key areas (as stated in section 3 above) that emerged from this initial discussion on the work plan. Members of EAGDA would be consulted as and when necessary. These papers would be circulated before the next EAGDA meeting for discussion. Decisions on which to take forward as EAGDA's work plan will be made at the next meeting.
- The Chair together with the Secretariat will also contact all members of EAGDA who were unable to attend the first meeting to ensure there are no critical issues missing from the initial list of proposed discussion briefs.

Date of next meeting: Friday 19 October 2012