

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

**10:30 – 16:00 THURSDAY 16 OCTOBER 2014, WELLCOME TRUST**

**Present:**

James Banks (until 13:00)

Martin Bobrow (chair)

Paul Burton

Paul Flicek

Mark Guyer

Tim Hubbard

John Hobcraft

Bartha Maria Knoppers

Onora O'Neill (until 13:00)

**Funders:**

Geraldine Clement-Stoneham (MRC)

Vanessa Cuthill (ESRC)

Suzanne Mills (ESRC)

Holly Baines (Wellcome Trust)

David Carr (Wellcome Trust)

Nicola Perrin (from 12:00, Wellcome Trust)

Natalie Banner (Wellcome Trust)

**Apologies for absence:**

Ros Eeles

Mark Elliot

Mark McCarthy

Melanie Wright

Fiona Reddington (CRUK)

## **1. Welcome**

John Hobcraft (University of York) was welcomed as a new full member of the group, along with Mark Elliot (Manchester University) *in absentia*.

The funders have agreed to fund EAGDA for a further three years, with costs split equally between the four. Additionally, there will be £40,000 per year available for funding commissioned research on EAGDA's behalf, subject to approval by the funders.

The minutes of the fifth meeting of EAGDA, dated 10 March 2014, were ratified.

## **2. Data Access Report**

NB provided an overview of the draft data access report and guidance to studies. Several key themes were considered by the group and it was agreed that EAGDA funders could be more prescriptive in their requirements and guidance for researchers, clearly describing best practice for data access procedures.

**ACTION:** Secretariat to redraft paper into a report format by end of the year in light of the above issues as well as: data protection and re-identification; proportionality and governance within legal frameworks; quality data governance and trade-offs between data use and protection.. Consideration to be given to possibility of commissioning research into establishing the costs of setting up and maintaining data access for different studies.

## **3. Priorities for current and future work plan**

Topics for work in the short and medium term were discussed among the group:

**Risks** (following the jointly commissioned Nuffield Council on Bioethics/EAGDA report by the Farr Institute on evidence of harms relating to uses of biomedical and health data).

### **International links and reciprocity**

### **Commercial access**

**Public trust:** NB briefed the group on the Wellcome Trust's thinking on possible activities to explore the issue of public trust in data sharing. The Trust is considering:

- More focused research to examine public attitudes towards commercial uses of health and biomedical data..
- Engaging with the Farr Institute's public engagement work stream, considering options for joining up initiatives to articulate the benefits of data sharing to medical research and to understand how best address public concerns.

**ACTION:** Secretariat to report back to EAGDA on progress of Wellcome Trust work on public trust at next meeting.

**Sample sharing:** It was agreed that data and sample sharing/ access mechanisms face the same issues, with the exception of depleteness.

**ACTION:** The Data Access report will include an additional section on depleteness of samples, the implications and the need to formulate management strategies.

Other topics mooted for inclusion were:

- Metrics for monitoring data sharing and compliance.
- Sustainability: what does it mean and the cost implications?

#### **4. Updates on changes to EAGDA**

- Minor changes to EAGDA will include: rotation of the membership to ensure a good balance of expertise and representation.
  - Minor amendment to ToRs to reflect a slightly broader scope to support studies
  - Raising the profile of EAGDA: Amy Cox (Comms Team, Wellcome Trust) attended to discuss communication strategies and it was agreed that:
    - The website should be updated and made more user-friendly.
    - Brief text to be agreed by the funders to be displayed on individual websites.
- Establish a mailing list to disseminate reports from EAGDA.

#### **5. Funders' report back on EAGDA recommendations**

**Incentives:** DC reported on the steps the funders have agreed to take in response to the EAGDA report on *Establishing Incentives*, including:

- Strengthening approaches to assess compliance Working with HEFCE to ensure data outputs are recognised in the post-2014 Research Excellence Framework.
- Recognising data outputs as part of a researcher's track record.
- Establishing career paths for data managers and data scientists.
- Developing and supporting key data repositories.

EAGDA welcomed the steps funders were taking, and emphasised the importance of education and training.

**ACTION:** Funders to update EAGDA on progress towards implementing these recommendations at next meeting.

**Identifiability:** NB reported on funder progress towards implementing recommendations of the identifiability statement.

Key topics discussed included:

Handling of “white hat” hacking i.e., situations in which non-malicious researchers identify security flaws Such activities should not lead to sanctions. The group would prefer to recognise and reward good practice rather than blacklist researchers. Alternative models for accrediting or authenticating researchers were discussed. Policies that include reference to sanctions will differ between funders. Sanctions should apply to any breach of data sharing, not just re-identification.

Institutions are usually responsible for sanctions and authentication of research lies with DACs, which can make the position of responsibility less clear.

**ACTION:** Secretariat to outline potential sanctions and how these might work in practice, along with developing a template to be used by funders. An outline for authentication criteria will also be drawn up using the P3G model.

## **6. Roundtable funder updates – for information**

### **Wellcome Trust:**

- Public Health Research Data Forum:
  - A report on data discoverability focused on public health and epidemiology datasets was published in July 2014..
  - A further report is being commissioned on data linkage, with a specific focus on low- and middle-income settings.
- Clinical Trials:
  - The Trust has commissioned research into the demand for and benefits of increasing access to clinical trial data, and models for providing support for bringing academic and commercial clinical trial data together. The Trust are talking with GSK and several partners on moves to allow access to clinical trial study data, and the Trust is exploring the possibility of running of the independent review panel for assessing applications for data.

The European Medicines Agency will begin making available data on approvals for requests for drug development data from January 2015, which will provide a sense of the demand for clinical trial data.

**ACTION:** NB to recirculate Data Discoverability report to EAGDA members.

### **Cancer Research UK**

- CRUK is undertaking a review of its data sharing policy.

Two recent instances of complaints against CRUK researchers using international data sharing repositories were outlined. A push towards ensuring researchers comply with data sharing policies was seen as reassuring. Statistics on compliance and the number of sanctions imposed could prove useful.

### **MRC**

- MRC is taking forward the recommendations from the Academy of Medical Sciences' report on safe havens, examining different models for "trustworthy environments" for data.

PB mentioned a relevant paper he has co-authored on data havens that is currently under review that will be of interest to EAGDA.

**ACTION:** Once accepted for publication, PB to send paper to the Secretariat for circulation among the group.

## **ESRC**

- Update on the Administrative Data Research Network
- ESRC Business Data Research Centres have recently been launched, focusing on the use of local government data. Work is also being undertaken on public trust in commercial data usage.
- The Cabinet Office is currently working with Involve to develop a series of policy papers around the creation of better legislation for data-sharing across government departments (excluding health) and for research.

## **7. Roundtable EAGDA member updates**

The NIH Genomic Data Sharing policy is now live. All genomics projects generating large amounts of genomic data will now need to deposit in a public database. A data management plan is required for all projects and there are sanctions for misuse. Broad consent is assumed to be obtained for these projects.

The NIH Big Data to Knowledge (BD2K) initiative has recently announced awards of \$32m for 12 large centres to undertake work to help maximise the use and useability of large datasets, including the development of a data discoverability index and training and career development awards for data scientists.

## **8. AOB**

The meeting dates for 2015 were confirmed as:

Monday 20 April 2015

Wednesday 30 September 2015

**CLOSE**