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

10.30-16:00 MONDAY 10 MARCH 2014, WELLCOME TRUST

Present:
James Banks
Martin Bobrow (Chair)
Paul Burton
Ros Eeles
Mark Guyer
Tim Hubbard
Andrew Morris
Chris Skinner
Melanie Wright
Jon Fistein – MRC
Vanessa Cuthill- ESRC
Helen Dewberry – ESRC
Fiona Reddington – CRUK
David Carr – Wellcome Trust
Katherine Littler – Wellcome Trust
Natalie Banner – Wellcome Trust
Jane Simmonds – Wellcome Trust

Apologies for absence:
George Davey Smith
Paul Flicek
Bartha Knoppers
Onora O’Neill
Nigel Shadbolt
Peter Knight (new member)
John Hobcraft – ESRC
Peter Elias
Mark McCarthy
1. Welcome

Jon Fistein and Jane Simmonds were welcomed.

Minutes from the previous meeting of 10 October 2013 were ratified.

2. Update on care.data and HSCIC (Nicola Perrin, Head of Policy, Wellcome Trust)

NP provided a verbal update on the background for the Government postponing the launch of care.data, in light of negative publicity, a lack of clear processes for data access conditions, and concerns over the opt-out system. Also, several amendments to the Care Bill, have been tabled to: restrict permitted access; improve the governance and oversight of the Health and Social Care Information Centre (HSCIC); and propose criminal sanctions for misuse and re-identification.

The group discussed whether EAGDA could occupy a role in providing scientific advice that is oriented towards policy.

ACTION: The Secretariat to continue discussion with the Chair over whether a statement or guidance from EAGDA, oriented towards policy makers, could serve a useful purpose.

3. Identifiability paper

KL provided a brief update on the identifiability statement and joint response from funders. The statement draws on the possibility of using criminal sanctions, and the proactive movement of the research community to address concerns around the use and linking of genomic and other biomedical research data.

ACTION: The funders to continue with plans to launch the joint response to the identifiability statement, and the Secretariat to publish the statement on the EAGDA website for 26 March.

4. DACs paper

NB introduced the working paper on Data Access Committees (DACs), together with the guidance on data access processes and an overview of options for the consolidation of data access mechanisms across studies.

ACTIONS: Melanie Wright to contact Secretariat to correct inaccuracies in terminology in the paper. Secretariat to discuss possible ways to address the question of thresholds for data sharing and the categorisation of data with Paul Burton and James Banks. Paper to be redrafted by next anticipated meeting (October 2014).

5. Incentives report

DC outlined progress made including a further focus group with early career researchers, which revealed competing pressures between collaborating in sharing data and the need for first-authored publications to benefit career prospects.

ACTION: The report will be polished and comments made taken into account before circulating to EAGDA. It will be published as an EAGDA report before the next meeting.
6. Report for funders/ role and remit of EAGDA
EAGDA’s funding period runs until June 2014, and it will need to produce a report to its funders outlining the value it has added and the potential further areas where EAGDA could make a valuable contribution.

**ACTION:** The funders to meet on 17 April to discuss what they would like to see covered in the EAGDA report, and funding and resource arrangements going forward.

7. Future workplan
Possible topics included:
   i) Risks/harms of data breaches
   ii) Enabling linkage including guidelines, governance and advice on best practice.
   iii) Considerations for commercial access.
   iv) Sample access strategies.
   v) International links and reciprocity
   vi) Clinical trial data and transparency
   vii) Public trust in data sharing.

**ACTION:** Funders to discuss topics for workplan at funders’ meeting on 17 April, and how the relation between EAGDA and the funders should be configured.

8. Updates
   a) Farr Institute (Andrew Morris)
The Institute is a collaborative funding initiative investing in health informatics research, focusing on cross-sector data linkage. Key recent developments include:
   - £20m Government funding for capital resources
   - £50m funding for medical bioinformatics across several centres
   - The UK Health Informatics Research Network, is examining data governance, public engagement, developing methodologies, communications, capacity building and ways of increasing the value of the 33 existing MRC cohorts.

   b) Administrative Data Research Network (Melanie Wright)
The ADRN undertakes activities around improving access to administrative data. Key recent developments include:
   - Four centres in the UK have been announced, which are collaborating with their respective national statistics organisations.
   - The Network is being co-ordinated by the Administrative Data service in Essex and working groups have been established across the centres.

It was noted that the Farr Institute and ADRN operate on different business models: ADRN is free at the point of delivery; Farr operates on a cost recovery model.

   c) Global Alliance for Genomes and Health (Martin Bobrow)
The first meeting of the Alliance was held at the Wellcome Trust last week, which > 150 people attended. Its ethos is to establish international tools and standards for the sharing of genomic and clinical data to facilitate advances in medical research and healthcare.
It was noted that the activities are being led by researchers, not government or funders’ initiatives, but that governance structures and funding models will need to be established soon.

d) Genomics England (Tim Hubbard)
Genomics England (GeL) is constructing a ‘pipeline’ for data, with procurement for sequencing capacity and high quality annotations of data proceeding at present. Key recent developments include:

- Phase 2 – currently running as a pilot, with 10,000 whole genomes going to sequencing this year. Phase 3 will aim for 30,000 whole genomes being sequenced per year from 2015-17.
- Consent models used in the different phases were discussed along with the mechanisms being used for storage, distribution and access to the data.
- The project will be evaluated by whether or not it produces sequence data of good enough quality for research and a direct effect on patients care and management.

e) EU Data Protection Regulation (Beth Thompson, Wellcome Trust)
Attention was given to the upcoming vote in the EU Parliament on the LIBE committee amendments that are potentially extremely damaging for research. Key points addressed:

- Specific and explicit consent for all uses of personal data, with only very narrow exemptions for research.
- Parliament will vote this week and they are highly likely to be passed.
- The Council of Ministers have yet to develop a position on the EU Commission’s original draft of the Regulation.
- There has been a recent groundswell of support (>70 signatories) from research communities against the restrictive amendments tabled in Parliament, led by the WT.

**ACTION:** A copy of the statement to be circulated to EAGDA for information and further dissemination if appropriate.

f) ESRC (Vanessa Cuthill)
ESRC are using a portion of capital investment to fund four big data centres in to examine commercial data (not necessarily health data).

The ESRC Biosocial Research Strategy, to support infrastructure and capacity, is currently being drafted, and should be ready to circulate to EAGDA before the next meeting.

g) MRC (Jon Fistein)
Three areas of current work were highlighted:

- A strategy for maximising the value of MRC cohorts is due to be published.
- MRC is working closely with WT on clinical trials data transparency initiative with the US Institute of Medicine, which involves close work with industry.
- MRC has recently announced a joint call with other UK funders on tissue and biobank sample discoverability.

h) CRUK (Fiona Reddington)
CRUK are considering how to discuss partnership funding models with other funders for possible studies in relation to the Global Alliance for Genomes and Health.
CRUK is committed to ensuring its data sharing policies are implemented fully and carefully. CRUK may be able to provide some staff resources for assisting on progressing the DACs paper into a report and formalised guidance.

i) Wellcome Trust (Katherine Littler)
The Wellcome Trust recently co-organised a meeting in Paris on health data sharing with Aviesan (the French National Alliance for Life Sciences and Health). Key messages from the meeting were:

• Issues concerning data access, information governance and public engagement are very similar in France and the UK.
• France has some very rich and valuable longitudinal data assets.
• There is a strong appetite to share best practice between countries.

The Trust is also helping run the Public Health Data Sharing Forum, which is a group of 17 international funders in public health. It has commissioned a piece of research on the discoverability of data that is due to report in May.

It was noted that the NIH is conducting a three year pilot project compiling a data discoverability index across NIH studies, as part of its' Big Data to Knowledge (BD2K) initiative.

**ACTION:** The Aviesan meeting report will be circulated to EAGDA once completed.

9. AOB

Next meeting date: October/November 2014 (date tbc)

CLOSE