Working in partnership to maximise the value of research data

Research Data Management Forum 15
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David Carr
Wellcome Trust
d.carr@wellcome.ac.uk
Sharing research outputs: our position as a research funder

• we are a global foundation dedicated to supporting research with the goal of improving health
  – annual spend of over £700m
  – expect to spend £5bn over next five years

• committed to ensuring research outputs (inc. papers & data) can be accessed and used in ways that will maximise health & societal benefit

• a passionate long-term advocate of open access & data sharing
Making data more ready available holds the potential to...

• enable data to be accessed, combined and used in ways that accelerate discovery and application

• help ensure research findings can be validated and reproduced

• increase efficiency in research - reducing duplication and waste

• make research outputs more readily accessible to full range of users – including public, policymakers, healthcare professionals, etc.
The broader context: openness as core element of good practice

• Growing policy and political consensus:
  – Royal Society – Science as an Open Enterprise report (2012)
  – G8 Science Ministers’ statement (2013)
  – EU focus on open science

• Increasing spotlight on research reproducibility and waste

• UK concordat on research data – clear commitment on path to openness

Wellcome Trust policy on data management and sharing

• Policy published 2007 (updated in 2010):
  - expects all researchers we fund to maximise access to research data with as few restrictions as possible
  - requires data management & sharing plan, where the research is likely to generate data of value as a resource for the community
  - commits to review and support costs of plans as integral part of the grant

• associated guidance sets out key elements for inclusion in data management and sharing plans (DMPs)
Implementing the policy: our experience

• periodic reviews have suggested:
  - quality of DMPs is variable, but indications they have improved over time
  - assessment of DMPs during grant review is also variable (as is the level of understanding/buy-in from reviewers)
  - resource implications of plans not adequately considered

• post-award tracking of plans is patchy
  – a pragmatic, targeted approach is needed

• punitive sanctions for non-compliance so far felt to be premature
Maximising the value of research data - key challenges to overcome

• There are significant barriers to data sharing:
  – **Infrastructural** – data resources
  – **Cultural** – incentives & recognition
  – **Technical** – standards and metadata
  – **Professional** – supply of data skills
  – **Ethical** - protecting research participants

• Disciplines at varying points, different data types raise different issues

• Committed to working with other funders, researchers and institutions to address these challenges.
Working in partnership – current cross-funder initiatives

- **Expert Advisory Group on Data Access** advises ESRC, MRC, CRUK & Wellcome on data access issues for cohort studies in genetics, epidemiology & social sciences.

- **Clinical Trial Data** – working with others to enhance access to clinical trial data.

- **Public health emergencies** – supporting rapid sharing of findings and data relevant to Zika and future emergencies.

- **Public Health Research Data Forum** – global initiative to increase access to public health & epidemiology research data.
Key priorities 1: Resources and platforms for data access

- working with others to develop data platforms:
  - independent access mechanism for clinicalstudydatarequest.com
  - platforms for access to ebola trial data (and other infectious diseases)
- investigating solutions to enable discoverability for public health & epidemiology research data
- Participating in key consortia – e.g. ELIXIR, Global Alliance for Genomics and Health

http://www.wellcome.ac.uk/About-us/Policy/Spotlight-issues/Data-sharing/Public-health-and-epidemiology/WTP054675.htm
Key priorities 2: Incentives & culture change

- Report by Expert Advisory Group on Data Access (May 2014)
- Research culture and environment not perceived to provide sufficient support or rewards for data sharing
- Key recommendations focused on:
  - strengthening processes for review and tracking of data management plans;
  - providing more explicit recognition for high quality data outputs in key assessment processes (especially REF)
  - recognising and building career paths for data managers
  - enhancing key data resources

http://www.wellcome.ac.uk/About-us/Policy/Spotlight-issues/Data-sharing/EAGDA/WTP056496.htm
Future opportunities for open research – key questions for Wellcome

• How can we build & sustain infrastructure needed to ensure data are findable, accessible, interoperable and re-useable?
• How can we embed a culture that incentivises openness and work towards best practices in different fields?
• How can we equip our communities with the skills for data-driven science?
• How can we spark disruptive innovation in the way research outputs are communicated, shared and re-used?
Promoting re-use of content and data

http://openscienceprize.org
Closing thoughts...

• We are committed to working with our communities to maximise the value of research data
• We want to work in partnership with institutions to support researchers and enhance research enterprise:
  – data sharing planned as an integral part of planning research
  – costs met as shared responsibility
  – establish and adopt good practice in ensuring datasets of value are discoverable, useable and accessible
  – data outputs recognised in a meaningful way
  – data infrastructure is developed and sustained
Any Questions?

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