Data Matters: a view from a research funder

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The world today:
knowledge sharing
The world today: communications
The Wellcome Trust

• a global charitable foundation dedicated to achieving extraordinary improvements in human and animal health

• support the brightest minds in biomedical research and the medical humanities

• Sir Henry Wellcome, was a businessman, philanthropist and collector, dedicated to enhancing global health and preserving and sharing his diverse collections

• in our work today, we have retained a long-standing commitment to maximising the long-term value of research outputs (including research papers and datasets)
Sharing research data: a long track record...

• building key data resources for research community:
  – lead role in major international projects – including Human Genome Project
  – funding key databases (e.g. EBI resources)
• brokering policy consensus on data sharing issues:
  – Bermuda principles (1996),
  – Fort Lauderdale principles (2003)
• leading advocate of open access publishing – requirement for all grants since 2006
Rising volume and complexity of research data

• according to the EBI, the volume of new biological data is **doubling every 5 months**

• the growth is particularly rapid in genomics:
  - we can now analyse the equivalent of a human genome every 14 minutes at a cost of $5,000 - **400 times quicker** than when the draft human genome was first published in 2000.
  - expected that sequencers will become **1000 to 1,000,000 times more productive** over the next decade
Data management and sharing policy

• Our data management and sharing policy was published in Jan 2007:
  – requires all funded researchers to maximise access to research data with as few restrictions as possible
  – requires data management & sharing plans for proposals generating data that could be shared for added value
  – commits to meet costs for data sharing activities outlined in the plans

• The policy was reviewed in 2010:
  – we produced new guidance to clarify what should be covered in data sharing plans
  – we will track adoption of plans through ongoing liaison with researchers
An example – the Wellcome Trust Case Control Consortium (WTCCC)

- researchers recognised the massive potential of genome-wide association studies to characterise the genetic factors underlying diseases
- in order to achieve required power, research groups needed to join forces to study effects in large numbers of patients and healthy volunteers
- WTCCC (launched in 2005) – bought together over 20 leading UK groups to look at 500,000 points of genetic variation in 17,000 samples
- initiative has had two further phases – now involves over 50 groups, and has identified over 90 new variants in diseases analysed
- Trust has worked with WTCCC to establish its data access mechanisms – data rapidly available via application to data access committee
Data sharing – the key challenges

**Infrastructural:**
sustaining the infrastructure required for long-term data storage and curation

**Cultural:**
incentives and recognition for researchers who share their data

**Technical:**
developing data standards, metadata, platforms needed for inter-operability

**Professional:**
training and career development of data specialists and bioinformaticians

**Ethical:**
protecting the confidentiality of research participants
Working together to address the challenges

We are working in partnership in the UK, Europe and internationally:

- working with other global health funders to promote sharing of research data to improve public health (joint statement in Jan 2011)
- partnering in the ELIXIR initiative to build sustainable funding model for life science data infrastructure in Europe
- strengthening data access & governance procedures for genetics & cohort studies with MRC, ESRC and Cancer Research UK
- contributing to key policy discussions (e.g. Royal Society project on Science and Public Enterprise; National Science Board)
Promoting research access to public data - opportunities

- increasing research access to **administrative data** offers immense potential for health research and other fields

- we believe that use of **electronic patient records** will deliver major benefits for patient care, planning and service delivery – experience in Scotland demonstrates this

- there are also tremendous opportunities to utilise data from patient records in research in order to enhance:
  - pharmacovigilance
  - recruitment to clinical trials
  - epidemiology and cohort studies
Realising the opportunities

• we are engaging actively in discussions on open data:
  – discussions with Cabinet Office and Treasury on the open data strategy and Plan for Growth
  – member of the new administrative data task force

• we are taking forward a broad range of activities to develop e-health
  – funding major research e-health initiatives in partnership with UK research councils
  – convening pilot programmes to inform the roll out of e-health systems in the NHS
  – engaging key stakeholders – patients and GPs
  – working with Government on implementation of the Clinical Practice Research Data Link
Building an enabling environment

• the regulatory framework governing research access to data must achieve an appropriate balance:
  – ensuring proportionate safeguards to protect the privacy of data subjects…
  – …whilst enabling legitimate research uses to maximise public benefit

• to achieve this, there is a need to:
  – reduce regulatory complexity and ensure consistent interpretation
  – ensure revisions to data protection legislation at EU level, and its UK implementation, recognise and support research use
  – build the systems (‘safe havens’) needed to enable data to be used safely and securely
Encouraging developments

We welcome Government’s recent commitments to:

— establish a new ‘Open Data Institute’ to innovate and exploit opportunities provided by the open data strategy

— link primary and secondary healthcare datasets, including a complementary secure service for research

— provide on-line access to health records for all patients in the NHS
Conclusion – our role as a funder

• As a research funder we are dedicated to ensuring that:
  – research data are managed, preserved and shared in a way that maximises public benefit
  – researchers can access data of value in a safe and secure manner

• We achieve this through:
  – **funding** major data resources and data sharing as an integral component of research
  – **policy leadership** to develop and implement policies to maximise value of data
  – **working in partnership** to build the resources and culture needed for data sharing
  – **advocacy** – influencing Government and contributing to key policy discussions
Further information

http://www.wellcome.ac.uk/About-us/Policy/Spotlight-issues/Data-sharing/index.htm

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