

Funders and Promotion of Public Access to Public Health Data

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Doris Duke Charitable Foundation
COHRED Fair Research Contracting Meeting
Bellagio Center
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Funder's Initiative



Mark Walport begins crusade for more access to public health data:

Nov 2008- Global Ministerial Forum on Research For Health in Bamako, Mali

May 2010- Foggy Bottom (Washington)

Jan 2011- Lancet commentary with Paul

Brest and 15 other funders

Sharing research data to improve public health



The purpose of medical research is to analyse and understand health and disease. A key and expensive element is the study of populations to explore how interactions between behaviour and environment, in the context of genetic diversity, determine causation and variation in health and disease. As funders of public health research, we need to ensure that research outputs are used to

ingrained in how researchers work. In genetics and genomics, the pooling of studies of different populations has led to an explosion of knowledge on the genetic determinants of human variation in health and disease.¹ Well-established repositories and tools enable researchers to access and interrogate shared data resources, and build on one another's work.²

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Joint Statement of Purpose by Funders*

- Make research data sets available beyond the original research team
 - Faster progress in improving health
 - Better value for money
 - Higher quality science
- “every last ounce of knowledge will be wrung from research”

*published with Lancet Commentary online in January 2010
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February 2011: The Lancet, [Volume 377, Issue 9765](#), Pages 537 - 539,
12 February 2011



Called for “Equitable Data Sharing”

- Those who collected the data have a right to “first use” of the data.
- This right is **time limited and balanced with rights of “the field” and the communities that stand to benefit from research.**
- Those who conducted research should not have their private needs (publications, recognition) outweigh in perpetuity the potential public benefit of their data.

Signatories to Joint Statement

Foundations:

- Wellcome Trust
- Hewlett Foundation
- Gates Foundation
- Doris Duke

Government Research Agencies:

- Australia, Canada, France,
Germany, NZ, USA, UK,

Government Agencies

- USA

Multilaterals

- World Bank
- (WHO not a signatory)

Response to Walport & Brest in Lancet

- Joint letter to Lancet by COHRED and INDEPTH
 - “Sharing research data to improve public health: a perspective from the global south”
 - www.thelancet.com Vol 378 July 30, 2011
- Nairobi data management training program 28-29th July 2011
 - Held at African Population Health Center (APHRC)
 - Convened by COHRED and INDEPTH
 - 3 themes identified as key to data sharing :
 - Ethics
 - Sustainability
 - Operational/technical

COHRED/INDEPTH Input

- Stressed importance and complexity of data sharing
- Ethical, sustainability and operational/technical issues
 - Dangers of misunderstanding/misusing
 - Need to support entire cycle of knowledge generation
 - Many technical issues in creating useful repositories

Funders Forum

- Established after 2010 Foggy Bottom Meeting
 - Currently 20 funding organizations
- 3 workgroups
 - Capacity & Skills Building
 - Culture & Incentives
 - Infrastructure & Tools
- 2011 Meeting in Geneva
 - Work Plan established
 - WG disbanded – replaced by individual projects

Landscaping Funders' Policies

- 11 funders have dedicated policies on data sharing & management
- 9 funders have varying guidance in place
 - explicit policy, or have endorsed an external agreement, or have plans to develop a dedicated policy

Funder Guidance Typically Covers to Five Broad Areas

1. Data Management Plans
2. Time Frames
3. Use of Public Databases and Central Repositories
4. Ethics and Confidentiality Requirements
5. Compliance

Organization	Data Management Plans	Time Frames	Databases/ Repositories	Ethics & Confidentiality	Compliance
Bill & Melinda Gates Foundation	Yes (for grants over \$500k)	No – submit data access plan in proposal	Yes	Yes	Yes
Canadian Institutes of Health Research	No	Yes – papers should be accessible within 6 months of publication	Yes	No	No
Centers for Disease Control & Prevention	Yes	Yes – data released one year after data preparation	Yes	Yes	Yes
DFG, German Research Foundation	Yes	No – submit data access plan in proposal	No	No	Yes
Doris Duke Charitable Foundation	Yes	Yes – data released 2.5 years after data collection	Yes	Yes	Yes
Economic & Social Research Council, UK	Yes	Yes – data released within 3 months of the end of the award	Yes	Yes	Yes
Medical Research Council, UK	Yes	No - submit data access plan in proposal	No	Yes	No
NHMRC, Australia	No	Yes – publications deposited to open access institutional repository w/in 12 months of publication	Yes	No	No
National Institutes of Health	Yes (for grants over \$500k)	Yes – no later than the acceptance for publication of main findings	No	Yes	Yes
Wellcome Trust	Yes	Yes – 6 months of final publication	Yes	Yes	Yes
World Bank	No	Yes – paper should be deposited upon acceptance of manuscript for publication	Yes	No	No

Time Frames

- Some funders expect that time frames for data sharing be built into data sharing plans
- 4 funders have explicit expectations for time frames for public data release
 - CDC, NIH, ESRC, DDCf
- For specific timelines, “when the clock starts” varies and even these may be hard to define
 - Clock starts variously with data cleaning, data collection, publication of “main results” or grant end date

Economic and Social Research Council

- Requires that the data must be made available for preparation for re-use and/or archiving with the ESRC data service providers within three months of the end of the award otherwise ESRC will withhold the final payment.

Organizations without specific data sharing and management policies, but may be developing policies and guidance

- Chief Scientist's Office, Scotland
- FAPESP, Brazil
- Health Research Council of New Zealand
- Hewlett Foundation
- INSERM, France
- MRC South Africa
- UNICEF
- USAID

Half a Funders Lack a Specific Policy for Grantees

- Most have no “one size fits all” policy on time to public release
 - 4/20 have a timeline specified
 - Clock starting may be subject to interpretation
 - Ex: publication of “main results”
- How will the policy be implemented?
 - Tailored grant by grant
 - Formulated in grant agreement
 - Hard to say what really happens

Doris Duke Approach

- Applies to a portfolio of 5 projects
- Timeline specified- 2.5 years
- Main target for data sharing is national institutions
 - Schools of Public Health
 - Ministry of Health
- Support writing workshops
 - Modeled on INDEPTH SAGE experience

List of Signatories

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