

## **Media release from the Wellcome Trust and the Hewlett Foundation**

**Embargoed until 00.01 GMT Monday 10 January 2011**

### **Global funding agencies commit to enhancing access to research data to improve public health**

Health research data must be made more widely available within the scientific community if we are to unlock the full potential of research and achieve significant advances in public health, according to leading funding agencies.

Seventeen major health research funders have signed up to a joint statement in which they commit to work together to support timely and responsible sharing of data that are collected from populations for the purpose of health research, in ways that are equitable, ethical and efficient.

In a comment article in *The Lancet* published today to coincide with the launch of the statement, Sir Mark Walport, Director of the Wellcome Trust, UK, and Paul Brest, President of the Hewlett Foundation, USA, outline the challenges and opportunities that face the research community.

The authors highlight how, in contrast to some other research disciplines, data sharing is not yet the norm within the public health research community, a situation that threatens to limit both the progress of this vital research and its application for health benefit. They recognise that increasing access to public health research data raises some key concerns, which centre on the rights and responsibilities of researchers and the potential risks to research participants.

To address these issues, the funders set out three core principles in the statement that underlie their commitment to data sharing. They agree to increase access to and use of data in ways that are:

- **Equitable:** recognising and balancing the needs of researchers who generate and use data, other analysts who might want to reuse those data, and communities and funders who expect health benefits to arise from research.
- **Ethical:** protecting the privacy of individuals and the dignity of communities, while simultaneously respecting the imperative to improve public health through the most productive use of data.
- **Efficient:** always sharing data in a way that improves the quality and value of research and increases its contribution to improving public health – adopting approaches that are proportionate, build on existing practice and reduce unnecessary duplication and competition.

The funders recognise that there are significant challenges that will need to be overcome to build the culture and resources necessary to support data sharing. The statement identifies immediate and longer term goals to address these issues. These include building capacity and skills in the research community to manage and analyse data, particularly in low- and middle-income countries; creating incentives for researchers to share data; and developing the data infrastructure and technical tools needed to store, preserve, and analyse research datasets safely and securely.

The signatories hope to encourage other research funders to join as partners in this important initiative; the statement will remain open for other funders to join as signatories over time.

"Today's announcement marks an important step towards improving access to important data which has the potential to improve the lives of many millions of people worldwide," says Sir Mark Walport. "Whilst it is imperative that appropriate safeguards are in place to protect individuals and communities, we already have the tools to ensure research data can be shared safely and securely. Moreover, we have a duty to those populations who participate in research to ensure maximum benefit is derived. Funders and researchers can and must do more."

"The commitment of so many leading funding agencies sends a strong signal that we are committed to maximising the full potential of public health research data to generate better health," says Paul Brest. "This is an urgent problem which needs the support of all researchers and funders and we call on them to join us in making this commitment."

## **Ends**

## **Contact**

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## **Notes for editors**

The full text of the joint statement of purpose can be found at  
[www.wellcome.ac.uk/publichealthdata](http://www.wellcome.ac.uk/publichealthdata).

The complete list of signatories to the joint statement of purpose is:

- Mark Walport, The Wellcome Trust, UK
- Paul Brest, The Hewlett Foundation, USA
- Warwick Anderson, National Health and Medical Research Council, Canberra, Australia
- Alain Beaudet, Canadian Institutes of Health Research, Ottawa, Canada
- Paul Boyle, Economic and Social Research Council, Swindon, UK
- Carolyn M. Clancy, Agency for Healthcare Research and Quality, Rockville, USA
- Francis S. Collins, National Institutes of Health, Bethesda, USA
- Thomas R. Frieden, Centers for Disease Control and Prevention, Atlanta, USA
- Ed Henry, Doris Duke Charitable Foundation, New York, USA
- Pamela S. Hyde, Substance Abuse and Mental Health Services Administration, Rockville, USA
- Matthias Kleiner, Deutsche Forschungsgemeinschaft (DFG), Bonn, Germany
- Tamar Manuelyan Atinc, The World Bank, Washington D.C., USA
- Robin Olds, Health Research Council of New Zealand, Auckland, New Zealand
- John Savill, Medical Research Council, London, UK
- André Syrota, INSERM, Paris, France
- Mary K. Wakefield, Health Resources and Services Administration, Rockville, USA
- Tachi Yamada, Bill and Melinda Gates Foundation, Seattle, USA