

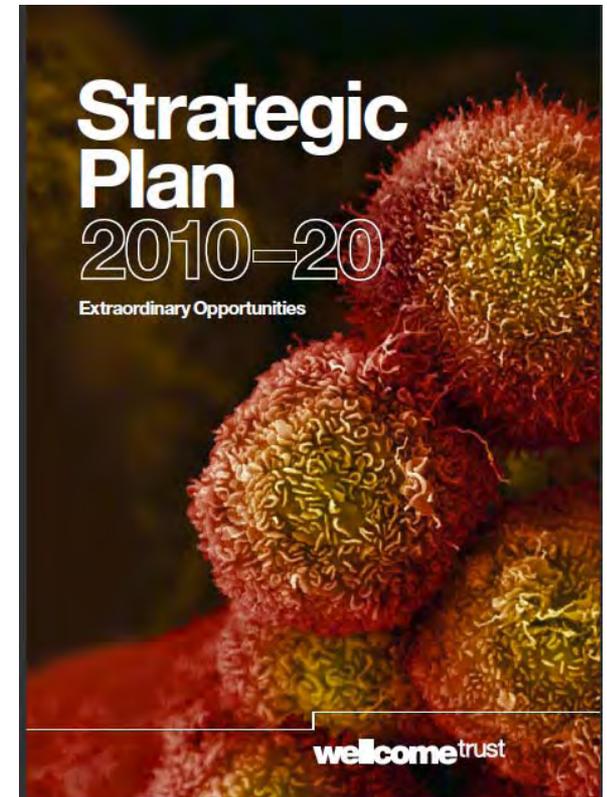
Funding Strategies: Creating Conditions for Sharing



**Thomas Sutherland, Frederick Hayden
Influenza Team, International Activities and
David Carr, SPPU**

A key strategic priority...

- The Strategic Plan notes our long-standing commitment to ensure the outputs of research are used in a way that maximises the resulting benefit
- Leading advocate of open access publishing
- Long track record in maximising access to research data
 - funding key data resources
 - brokering international policy consensus



Implementation of Policy: *Application stage (pre award)*

- Data-sharing question on application form → response subjected to full review process
- Guidelines to assist applicants with completing the data sharing section of their application

Implementation of Policy: *Grant Stage (post award)*

- No formal monitoring process to assess compliance, except self reporting at end of grant report form
- Maintaining a close relationship with our grant holders allows monitoring
- There may be more formal checks for some of our larger awards but currently this is largely an *ad hoc* process...

Support for Data Sharing

- Grant applicants can include costs for data sharing in their application
- Applicants encouraged to use existing repositories – web-based, institutional, etc
- Where no public repository exists, funds can be requested to develop a new system to make data public.
- Meetings for award holders to encourage cross-project sharing
- Open dissemination meetings for studies of high importance to scientific community + policy makers

CASE STUDY: COSI (Combating swine influenza initiative) 1

- Research response to the pandemic
- Funded jointly by BBSRC, Defra, MRC and Trust (£1.7m).
- Two interlinking grants:

1. **Epidemiological & evolutionary investigations of pandemic H1N1 in pigs and associated occupational risks.** *James Wood, University of Cambridge* - Real time monitoring of infection and spread in UK farms and workers and analysis of viral evolution.

2. **Transmission, infection dynamics and immunopathology of pandemic H1N1 in pigs and comparability to human infection.** *Ian Brown, Veterinary Laboratories Agency* - Experimental challenge studies and analysis of the effects of prior infection with 'European swine flu'

CASE STUDY: COSI (*Combating swine influenza initiative*) 2

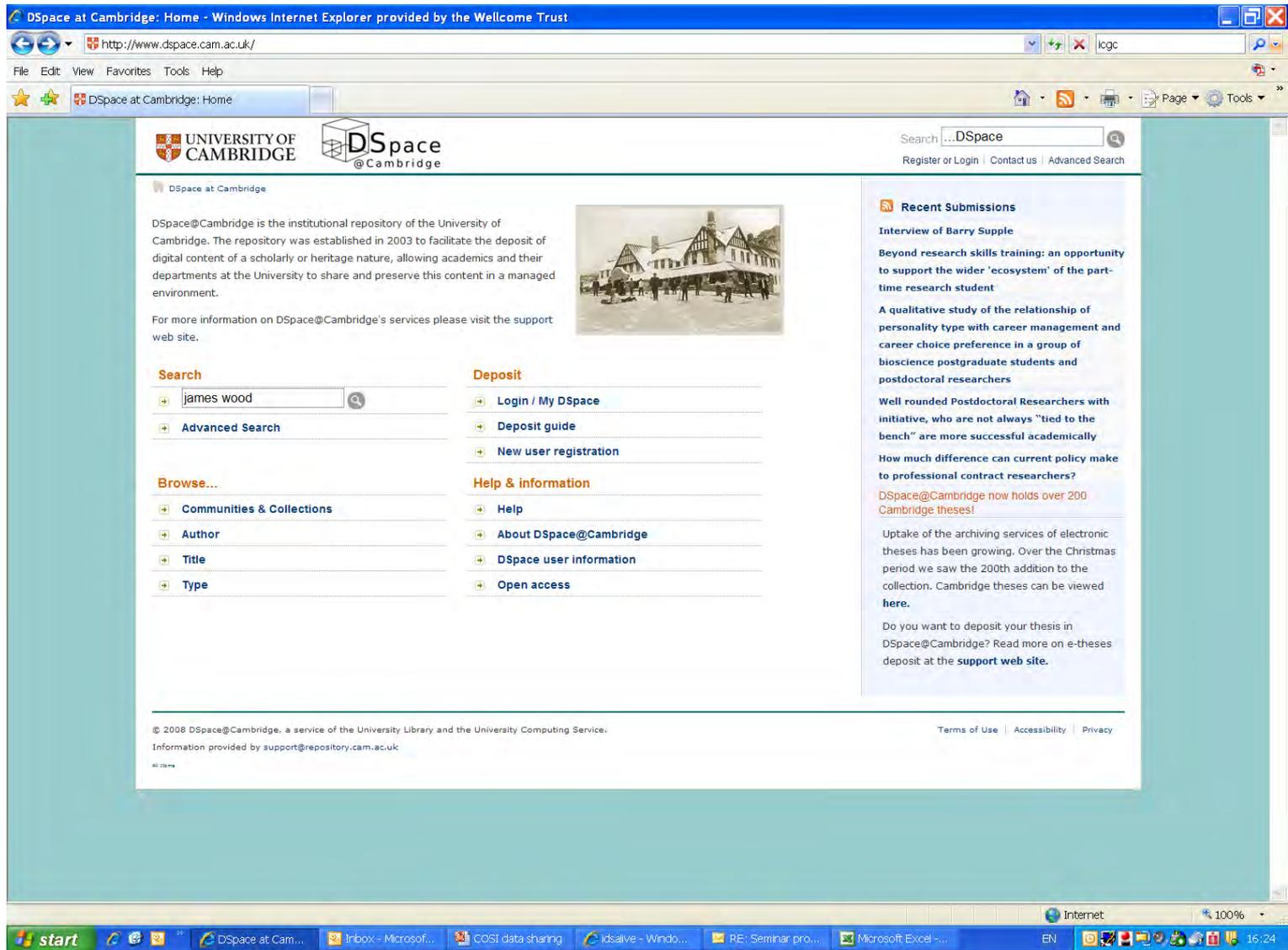
- Per award letters:

‘...making all samples and data available as soon as reasonably possible, to the influenza research community at large (both in the UK and globally) for the purposes of further research and to inform policy and practice of the NHS, Government bodies, medical research and health charities and other relevant policy makers and stakeholders in the influenza community. This should not be delayed for the purposes of publication or the protection of intellectual property rights.’

CASE STUDY: COSI (*Combating swine influenza initiative*) 3

- COSI data where possible will be placed on web based systems – e.g., FluDb and GISAID
- Much data generated cannot be held by these repositories at the moment
- These data will be placed on University of Cambridge D-space site, where it will be publically available for foreseeable future:

<http://www.dspace.cam.ac.uk/>



- Searchable, open data repository

Other Pandemic H1N1 Grants in UK

- COSI, MOSAIC, and FluWatch
- Trust hosted bimonthly meetings of all researchers from the 4 grants to allow them to discuss progress and share data during the pandemic.
- FluWatch has been able to feed data into the COSI awards... studies of community burden of disease in workers in the pig industry
- All 4 projects will present major results (much unpublished) and implications for policy at a meeting in May/June 2011
 - All funders supporting. Wellcome hosting.

Recent Publications on Data Sharing from Wellcome Trust

Time for fair trade in research data

**Elizabeth Pisani, James Whitworth, Basia Zaba,*

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Centre for Population Studies, London School of Hygiene and
Tropical Medicine, London, UK (BZ); and Department of Health
Statistics and Informatics, WHO, Geneva, Switzerland (CA-Z)
pisani@ternyata.org

www.thelancet.com Vol 375 February 27, 2010

Sharing research data to improve public health

**Mark Walport, Paul Brest*

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www.thelancet.com Published online January 7, 2011

Foggy Bottom Meeting, 25 May 2010

- Public + charitable funders of biomedical research
- Joint statement on revised Code of Conduct
- “Making research data sets available to investigators beyond the original research team in timely and responsible manner.”
 - Faster progress in improving health
 - Better value for money
 - Higher quality science
- Flexibility- variety of approaches that balance rights of individuals/communities that contribute data, investigators, and wider scientific community

Sharing research data to improve public health: joint statement of purpose (Jan 2011)

- Seventeen initial signatories - major public and charitable funders of health research
- Commitment to work together to expand availability of research data
- Recognises each funder will need to work within own legal & operational framework
- Statement sets out:
 - **one vision** – to increase availability of research data generated by our funding to accelerate improvements in public health
 - **three principles** – share data in ways that are **equitable**, **ethical** and **efficient**
 - **seven goals** – immediate goals and longer term aspirations

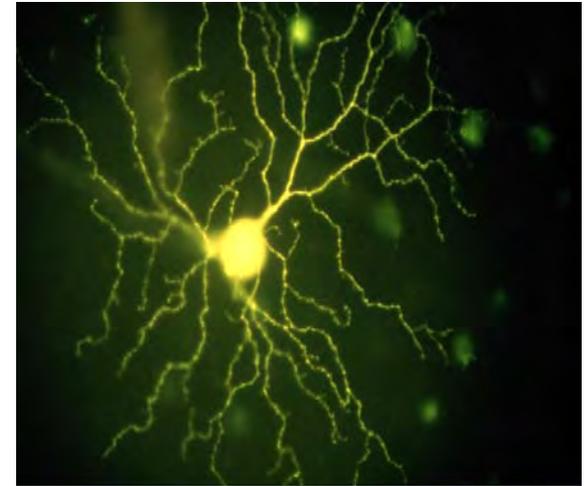


Immediate Goals

- Data management standards developed to support routine data sharing.
- Data sharing is recognized as professional achievement.
- Secondary data users respect rights of producers and add value.
- Secondary data users are expected to share their datasets, act with integrity, and to acknowledge the generators of the original data.

Next steps

- Final statement, published in January 2011, remains open for other funders to join as signatories
- Funders have formed a Forum and three working groups to develop joint activities in line with the statement
- Working groups will focus on:
 - capacity & skills
 - culture & incentives
 - infrastructure & tools

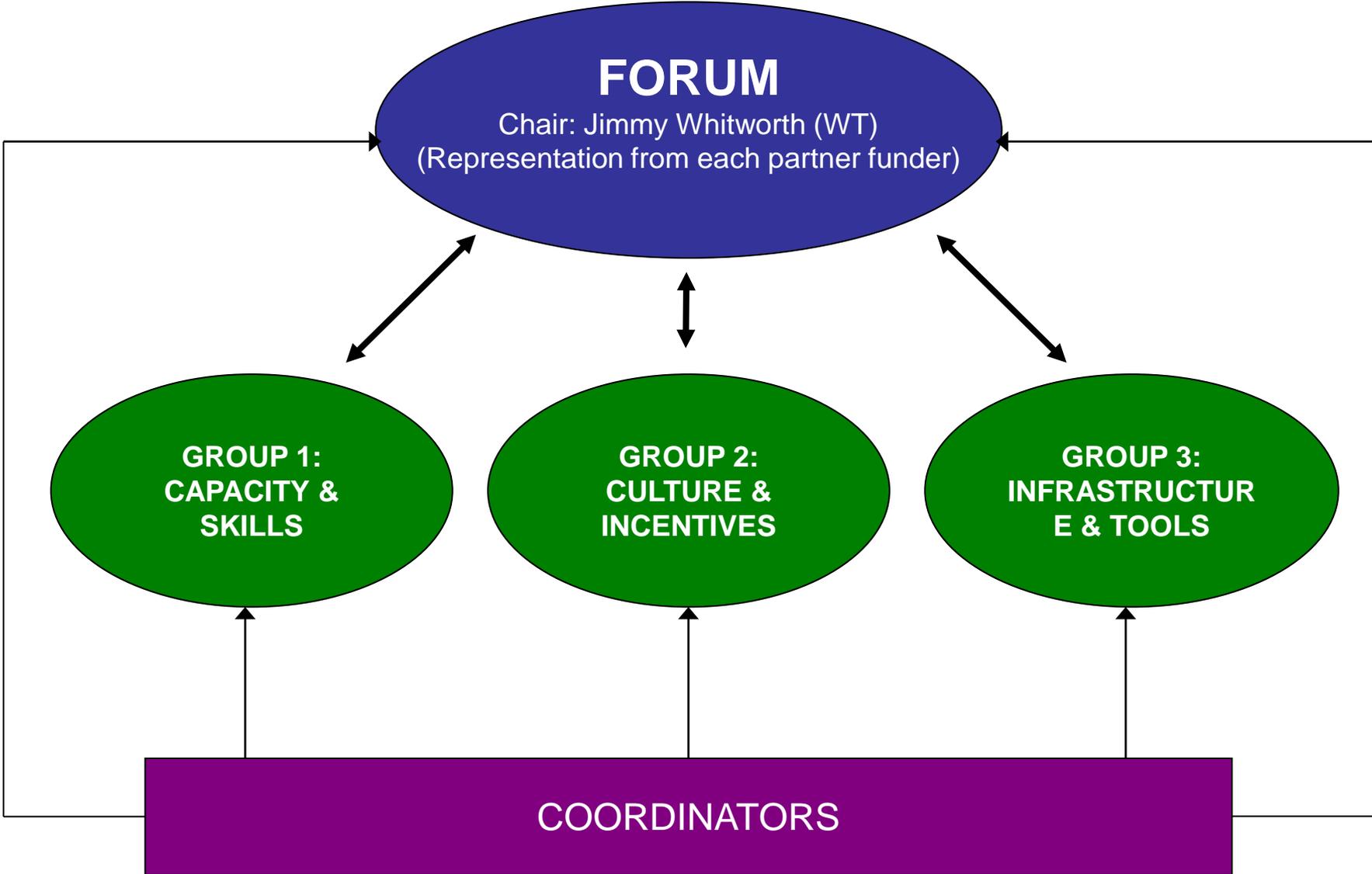


Wellcome Images



Wellcome Images

Public Health Research Data Forum



Further information

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

The screenshot shows the Wellcome Trust website's 'Data sharing' page. At the top, the Wellcome Trust logo is visible. Below it is a navigation menu with tabs for 'Our vision', 'Funding', 'Managing a grant', 'Education resources', 'News and features', 'Investments', and 'About us'. The 'About us' tab is selected. To the right of the navigation menu, there are links for 'eGrants', 'About', and 'Log in'. Below the navigation menu, there is a search bar with a 'Search' button. The main content area is titled 'Data sharing' and contains the following text: 'We aim to ensure that the data generated by the research we support is managed and shared in a way that maximises the benefit to the public.' Below this, it states: 'We work actively with the research community and other relevant stakeholders to shape and apply good practice with regard to the management of research data.' Further down, it says: 'In addition to implementing our policy, which applies across the full breadth of the research we support, we are taking forward targeted activities in partnership with others to promote data sharing in specific research fields.' The page also features a sidebar on the left with a 'Spotlight issues' section, which includes links to 'Counterfeit medicines', 'Health impacts of climate change', 'Influenza', 'Personal information', and 'Data sharing'. The 'Data sharing' section is expanded, showing links to 'Data management and sharing', 'Guidance for researchers', 'Public health and epidemiology', 'Large-scale genetics research', 'Open access', 'Harmful misuse of research', and 'Human Fertilisation and Embryology Act'. On the right side of the page, there is a 'REPORT' section titled 'Ethical, legal and social issues arising from the use of GWAS in medical research', with a 'Download PDF' button. Below the main text, there are four small images with captions: 'Data management and sharing policy', 'Guidance for researchers', 'Public health and epidemiology research', and 'Large-scale genetics research'.

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