



## Sharing Data and Resources for Functional Genomics Hotel Ponte Sisto Rome 20-22<sup>nd</sup> May 2009

### Meeting scope

The meeting will focus on issues directly relevant to mammalian functional genomics and will thus include consideration of various data types, ranging from those generated by high throughput technique data – “omics” technologies, to sequence, gene expression and phenotype data, which itself will range from measurements of metabolites to behaviour patterns. It will also look at sharing of bioresources such as mice, ES cells, antibodies and DNA, together with availability of technologies and know-how.

It will bring together experimental scientists and investigators with experience of data storage and management; funders of research; intellectual property and technology transfer experts; and representatives of the major journals and policy makers.

The main thrust of the meeting will be:

- *To explore the factors which prevent investigators submitting data to public databases and to make bioresources such as mice and ES cells freely available; to evaluate the imperatives for data sharing and to suggest incentives or means of compulsion for compliance on the part of recipients of public funding.*
- *To consider the impact of IP protection on the ready availability of resources and scientific progress*
- *To discuss the public availability of data underpinning publications; particularly data from high throughput technologies.*
- *To set the framework for discussions in the wider community taking mouse functional genomics as a microcosm. Nearly all the issues which apply to the wider life sciences apply to the mouse.*
- *To consider and make recommendations on the infrastructure required to manage data, facilitate data sharing and secure its funding.*

### Session 1

#### Towards a European Policy on Resource Sharing – Community Requirements

This session addresses what the key stakeholders want from access to data and bioresources and will consider what are perceived as the most important opportunities to exploit, and roadblocks to avoid, if we are to develop a useful policy. Questions to answer include: What guides the principles of a sharing policy; what should be shared; what should our priorities be?

What is inhibiting the key stakeholders – academic researchers, industry, the public - from benefiting optimally from the exploitation of technology, bioresources and data sets? Is there a need for a set of community standards for facilitating access, validation, collaboration and

exploitation? And if so, what should a policy look like from an end-user perspective? What is the balance between exploitation and scientific freedom and co-operation? Are there new technologies or research themes that will affect a sharing policy and how can the community respond to these changes?

## **Session 2**

### **BioResources - Examples and Experiences from Major International Resource Centres**

This session addresses the main bioresources for the Mouse community. What wider community/ies do they serve? What hinders them from fully achieving their aims? What problems are there, actual or perceived, with investigators submitting resources for open dissemination? Do Institutional IP policies inhibit scientific advancement? Is there sufficient compulsion/encouragement for investigators to make their resources available through them? Long term funding of the infrastructure? Is there a sustainable cost recovery model?

## **Session 3**

### **Data Resources**

This session addresses the sharing of different kinds of data and the impact on both the scientific community and on the economy. It will address models for data release and data management, experience of problems in obtaining data pre- and post-publication, and factors inhibiting investigators from putting primary data on public databases. What are the bottlenecks and challenges going forward as more and more databases emerge? Is primary data available to support publication? How are ongoing production databases funded and are there long-term plans in place for financial sustainability? What is the potential cost of NOT sharing data?

## **Session 4**

### **Policy Forum**

Presentations from three major funding agencies. What is the thinking behind their sharing policies, how are they implemented, do they work? Is there a need for internationally agreed principles to align policies? Is there asymmetry of benefit when agencies have unaligned policies? What are the next steps?

## **Outcomes**

The discussion will be used as the basis for a summary document to go to the European Commission, but we hope that there will be a published account of the meeting in the literature to stimulate debate and share the results of our discussions.

## Programme

**Wednesday May 20<sup>th</sup>**

### **14.00 Welcome and Introduction**

Paul Schofield, CASIMIR

### **Session 1: Towards a European Policy on Resource Sharing – Community Requirements Chair, Paul Schofield**

#### **Keynote**

14.15 Principles of open access and resource sharing

Jack Dixon, Vice-President and Chief Scientific Officer, Howard Hughes Medical Institute

#### **Stakeholders**

15.00 What do academic researchers want and how can this facilitate blue skies research?

John Quackenbush, Professor of Computational Biology and Bioinformatics, Dana Farber Cancer Institute, Editor Genomics

15.20 The University perspective; how can Universities facilitate access to research outputs?

Angus Livingstone, Managing Director, University-Industry Liaison Office, The University of British Columbia

#### **15.40 Coffee**

16.00 A Research Council perspective on sharing of data and bioresources.

Joanna Jenkinson, MRC

16.20 Transgenics: what does “Big Pharma” biopharmaceutical industry need and how can it participate?

Malcolm Skingle, Director, Worldwide Business Development, GlaxoSmithKline

16.40 How can Small to Medium Sized Enterprises (SMEs) participate?

Julie Barnes, Chief Scientific Officer BioWisdom Ltd

***17.00 – 18.00 Panel discussion – chair and speakers to facilitate discussion.***

**DINNER**

**Thursday 21<sup>st</sup> May**

**Session 2: BioResources - Examples and Experiences from Major International Resource Centres**

**Chair, Tom Weaver, MRC Harwell**

**Keynote**

9:00 Real Impediments to Academic Biomedical Research.

John Walsh, Professor of Public Policy, Georgia Institute of Technology, Atlanta, USA

**Stakeholders**

09.40 National Mouse Genetics Infrastructure in the UK

Tom Weaver, Director, Mary Lyon Centre, MRC Harwell, Oxford, UK

10.00 European Mouse Mutant Archive and German Mouse Clinic

Martin Hrabe de Angelis, Director, Institute of Experimental Genetics, Helmholtz Zentrum Muenchen, Germany

10.20 Mutant Mouse Regional Resource Center (MMRRC) and Knockout Mouse Project (KOMP) repository

Kent Lloyd, Associate Dean for Research and Graduate Education Programs and Associate Professor of Anatomy, Department of Anatomy, Physiology & Cell Biology, UC Davis, USA

**10.40 Coffee**

11.00 Experiences of data and bioresource sharing at the Toronto Centre for Phenogenomics

Colin McKerlie, CEO, Toronto Centre for Phenogenomics, Toronto, Canada

11:20 Experiences with intellectual property and licensing at the Jax

David Einhorn, House Counsel for The Jackson Laboratory, Bar Harbor, USA

***11.40 - 12.40 Panel discussion – chair and speakers to facilitate discussion.***

**LUNCH**

**Session 3: Data Resources**

**Chair, Tania Bubela, University of Alberta School of Business**

**Keynote**

14.00 Data sharing - challenges and desiderata

Thinh Nguyen, Creative Commons

14.40 Facilitating scientific activity; the economic impact of restricting sharing of data and resources

Benedicte Callan, Head of Biotechnology Division, Organisation of Economic Co-operation and Development.

15:00 Data sharing; lessons from genome sequencing.  
Bob Waterstone, Washington University in St. Louis

15.20 Europhenome and phenome data resources  
John Hancock, Head of Biocomputing, MRC Harwell

**15.40 Coffee**

16.00 Data sharing and infrastructures in the NSIDC  
Mark Parsons, Programme manager National Snow and Ice Data center

16.20 Challenges in data sourcing and integration in MGI  
Janan Eppig, Mouse Genome Informatics, The Jackson Laboratory

16.40 NHGRI experiences with data release for ENCODE and TCGA  
Peter Good, Program Director, NHGRI, Washington, USA

***17.00- 18.00 Panel lead discussion including consideration of making data available to support publications.***

**DINNER**

**Friday 22<sup>nd</sup> May**

**Session 4: Policy Forum**

**Chairs; Steve Brown/Nadia Rosenthal**

09.00 NIH Data Sharing and Resource Sharing policies

Lilli Portilla, Senior Advisor for Technology Transfer, National Center for Research Resources, NIH.

09.20 Resource sharing in European Commission funded research

Patrik Kolar, Head, Genomics and Systems Biology, Directorate-General for Research, European Commission

09.40 Sharing with the Trust

Alan Doyle, Science Portfolio Manager, Wellcome Trust.

**10.00 Coffee**

***10.30 Panel discussion***

**11.30 Summary discussion**

Steve Brown, Director MRC Harwell

Nadia Rosenthal, Director, EMBL Mouse Outstation, Monterotondo.