

Brocher Workshop Agenda (as of November 6, 2013)
Returning Genetic Results in Biobanks: Opening an International Dialogue
November 19-21, 2013
Brocher Foundation, Hermance, Switzerland

Tuesday, November 19, 2013

- 12:00pm **Welcome lunch at Brocher Foundation**
- 13:00-13:30 **Welcome and Introduction**
Workshop objectives, format and introduction of participants
Workshop Chairs: Prof. Bernice Elger, Switzerland; Dr. Jane Kaye, UK;
Prof. Barbara Koenig, USA; Prof. Susan M. Wolf, USA
- 13:30-15:00 **Setting the Scene – What are the different approaches to return of results and incidental findings internationally?**
In this session we discuss current ethical approaches, legal contexts, and practices in different countries, regions, and settings, such as H3Africa.
Moderator: Dr. Jean McEwen, USA
- Prof. Susan M. Wolf, USA
 - Prof. Kazuto Kato, Japan
 - Dr. Morisola Adegbehingbe, Nigeria
 - Dr. Jantina de Vries, South Africa
 - Prof. Nikola Biller-Andorno, Switzerland
- Discussion*
- 15:00-15:30 **Refreshments**
- 15:30-17:00 **Does the context of biobanks raise special issues?**
This session focuses on specific issues pertaining to return of results and incidental finding in the context of biobank-facilitated research.
Moderator: Ms. Katherine Littler, UK
- Dr. Anne Cambon-Thomsen, France
 - Prof. Bartha Knoppers, Canada
 - Dr. Deborah Mascalzoni, Sweden
 - Prof. Michael Burgess, Canada
 - Dr. Michelle Lewis, USA
- Discussion*
- 17:30-18:30 **Synthetic Discussion** -- *What are the key issues that we have identified that can and should form the basis of cross-national and international policy? What are the challenges? What else do we need to consider?*
- 19:00 **Dinner & Informal Networking**

Wednesday, November 20, 2013

- 10:00-12:30 **What findings, if any, should be offered to research participants and individuals whose data and specimens are archived in biobanks?**
What are the current proposed criteria to distinguish what findings to offer back to participants and sources of specimens and data? What are the arguments against return of results? What progress has been made across the world in creating lists of returnable genetic results? Who

should control and update such lists? When should findings be offered versus returned without consent?

Moderator: Prof. Susan Wolf, USA

- Prof. Annelien Bredenoord, Netherlands
- Prof. Steven Joffe, USA
- Prof. Ellen Wright Clayton, USA
- Dr. Jane Kaye, UK
- Prof. Scott Roberts, USA

Discussion

12:30-13:30

Lunch

13:30-15:30

When should findings be offered to parents, guardians, research representatives for incompetent adults, and family or kin? Should findings be offered based only on their usefulness to the person tested, or should they also be offered based on their usefulness to others?

How does cultural context affect how individuals interpret genetic results? Do understandings of kin relationships and privacy differ across cultural groups or across international lines? Why does this matter? How should cultural variability be addressed within international borders and cross nationally? What is the range of results (if any) that should be considered for return to kin or family? How should reproductive results be addressed?

Moderator: Prof. Bernice Elger, Switzerland

- Prof. Ingrid Holm, USA
- Prof. Nils Hoppe, Germany
- Prof. Gloria Petersen, USA
- Prof. Barbara Koenig, USA
- Prof. Graeme Laurie, UK
- Prof. Pascal Borry, Belgium

Discussion

15:30

Refreshments

16:00-18:00

Implementation challenges

What are key consent issues in return of results? Should clinical consultation be sought before returning results? What issues arise in determining best methods of return? What results and incidental findings should be documented and in what record? What are the challenges in arranging clinical follow-up?

Moderator: Prof. Barbara Koenig, USA

- Dr. Jennifer Harris, Norway
- Prof. Paul Appelbaum, USA
- Prof. S. Malia Fullerton, USA
- Prof. Richard R. Sharp, USA
- Prof. Donald Chalmers, Australia
- Prof. Bernice Elger, Switzerland

Discussion

19:00-20:00

Dinner at Caveau des dix, Hermance

20:00-21:00 **Beginning to Brainstorm About Next Steps**
Have we covered all the issues? What are next steps toward building global policy? What should we be thinking about in terms of publications?

Thursday, November 21, 2013

9:00-10:30 **What is needed in terms of policy? Can ELSI 2.0 be useful for developing and implementing return of results policy in biobank research?**
What should be our strategy for advancing progress? What publications should we consider producing?
 Moderator: Dr. Jane Kaye, UK
Group discussion by all & debate

10:30-11:00 **Refreshments**

11:00-12:30 **Working on a Group Report: What are our conclusions from this Workshop? Next steps?**
 Moderators: Workshop chairs
Group discussion by all & debate

12:30-13:30 **Lunch**

13:30-15:30 **Continuing work on a Group Report & committing to writing individual and small-group papers for publication**
Group discussion by all & debate

15:30-16:00 **Final Wrap-up**
 Workshop chairs

16:00 **Adjourn**