Workshop Agenda

Guidelines for Returning Individual Results from Genome Research Using Population-Based Banked Specimens

National Academy of Sciences
2101 Constitution Ave, NW
Washington, DC
Lecture Room

February 10-11, 2014

DAY ONE - FEBRUARY 10

8:15–8:45am – REGISTRATION (EAST COURT)
Continental breakfast available from 8:15am

8:45–9:00 am
Welcome and opening remarks
- Wylie Burke, *University of Washington*, Workshop Chair
- Connie Citro, *NRC Committee on National Statistics*
- Virginia Cain, *National Center for Health Statistics*

9:00–10:00 am
       Session chair: Wylie Burke, *University of Washington*
Genomics in population-based data collection: The example of the National Health and Nutrition Examination Survey (NHANES)
- Overview of NHANES (30 min) – Kathryn Porter, *National Center for Health Statistics*
- Discussion (30 min)

10:00–11:00 am
       Session chair: Jeffrey Botkin, *University of Utah*
Perspectives on returning genome-based research results
- Role-based obligations (15 min) – Henry Richardson, *Georgetown University*
- The case for a stringent approach to returning results (15 min) – Steven Joffe, *University of Pennsylvania*
- The case for broad return (15 min) – Susan Wolf, *University of Minnesota*
- Discussion (15 min)

11:00–11:15 am – **BREAK**

11:15–12:30 pm
      Session chair: Ellen Clayton, *Vanderbilt University*
Framing the discussion
- The evolution of genomic technology and clinical utility (20 min) – Gail Jarvik, *University of Washington*
- Ethical frameworks (20 min) – Benjamin Berkman, *National Human Genome Research Institute*
- Discussion (35 min)

12:30–1:15 pm – **LUNCH**

1:15–3:15 pm
      Session chair: Eileen Crimmins, *University of Southern California*
How is NHANES similar to/different from other population-based studies?
- National Longitudinal Study of Adolescent Health (Add Health) (15 min) – Carolyn Halpern, *University of North Carolina*
- Health and Retirement Study (HRS) (15 min) – David Weir, *University of Michigan*
- National Social Life, Health, and Aging Project (NSHAP) (15 min) – Martha McClintock, *University of Chicago*
- Wisconsin Longitudinal Study (15 min) – Robert Hauser, *National Research Council*
- National Children's Study (NCS) (15 min) – John Moye, *National Institute of Child Health & Human Development*
- Illumina (15 min) – Tina Hambuch, *Illumina*
- Discussion (30 min)

3:15–3:30 pm – **BREAK**

3:30–5:00 p.m.
      Session chair: Adam Berger, *Institute of Medicine*
Issues for the NHANES
- The scientific value of incorporating genomic data collection into NHANES – (20 min) – Sharon Kardia, *University of Michigan*
- Panel on "Determining what data are returnable" (30 min)
    1. Marc Williams, *Geisinger Genomic Medicine Institute*
    2. Muin Khoury, *Centers for Disease Control and Prevention*
- Survey participants' attitudes and preferences (20 min) – Laura Beskow, *Duke University*
- Discussion

6:30 pm – **DINNER** (Steering Committee and Invited Speakers) Rasika West End

8:30–9:00 – REGISTRATION (EAST COURT)
Continental breakfast available from 8:30am

9:00–10:45 am
> Session chair: Wylie Burke, *University of Washington*

The logistics of returning genomic results from NHANES
- Kathryn Porter, *National Center for Health Statistics* (20 min)
- Retrospective versus prospective samples (20 min) – Kelly Edwards, *University of Washington*
- Practical issues/aspects of returning results (20 min) – Barbara Biesecker, *National Human Genome Research Institute*
- Discussion (45 min)

10:45–11:00 am – BREAK

11:00–12:00 am
> Session chair: Les Biesecker, *National Human Genome Research Institute*

Special considerations for reporting of results in NHANES and similar surveys
- Statistical agency considerations in releasing DNA results (15 min) – Jennifer Madans, *National Center for Health Statistics*
- Genetic exceptionalism in NHANES? (15 min) – Jeffrey Botkin, *University of Utah*
- Discussion (30 min)

12:00–1:00 pm – LUNCH

1:00–3:00 pm
> Session chair: Wylie Burke, *University of Washington*

Summary of presentations and discussion
- Reports from Steering Committee members and selected speakers (10 min each)
- Group Discussion
- Wrap-up and Next Steps

3:00pm – ADJOURN