POWERFUL PATIENT DATA:
GENOMICS AND FAMILY HEALTH HISTORY IN HEALTH IT
SALT LAKE CITY, UTAH | MAY 30-31, 2013

DAY 1: THURSDAY, MAY 30, 2013

8:30 AM – 9:00 AM Welcome
9:00 AM – 9:30 AM Keynote: The Value Proposition
9:30 AM – 10:00 AM Overview of Use Case
10:00 AM – 10:30 AM Break
10:30 AM – 11:30 AM Panel: Putting the Patient at the Center
11:30 AM – 12:30 PM Panel: From the Patient to the EHR
12:30 PM – 1:30 PM Lunch and Exhibits
1:30 PM – 2:30 PM Panel: Living, Breathing Data
2:30 PM – 3:30 PM Panel: Getting to Outcomes
3:30 PM – 4:00 PM Breaking the Mold and Building the Future
4:00 PM – 4:30 PM Break
4:30 PM – 5:30 PM Breakout 1
   Data Collection
   Data Connection
   Data Activation
5:30 PM – 6:30 PM Reception, Tech Demos, and Exhibits
6:30 PM Dinner on Your Own

DAY 2: FRIDAY, MAY 31, 2013

8:30 AM – 9:15 AM Keynote: Real World for Patients
9:15 AM – 11:00 AM Breakout 2
   Data Collection
   Data Connection
   Data Activation
11:00 AM – 12:30 PM Refining the Use Case/Recommendations
12:30 PM – 12:45 PM Closing
1:00 PM Intermountain Healthcare Tour (Optional)

HOSTED BY:
Intermountain Healthcare
Clinical Genetics Institute

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The Family History Campaign
Individualizing Medicine One Family at a Time
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DAY 1: THURSDAY, MAY 30, 2013

8:30 AM - Welcome
Welcome and charge for the day from organizers and premier meeting sponsor.

Speakers
Charles Sorenson, Intermountain Healthcare
James O’Leary, Genetic Alliance
Fred Lee, Oracle

9:00 AM - The Value Proposition
What potential value do family health history and genetic and genomic data in the electronic medical record provide the patient, their family, and society as a whole? This keynote will discuss patient and clinical value, cost benefit, and — with the development of advanced health IT tools — the future impact of genomics-based medicine.

Speaker
Kevin Hughes, Massachusetts General Hospital

9:30 AM - Overview of the Use Case
A model use case will be presented as a framework for the meeting, highlighting the workflow from patient to EHR and back to patient. Particular focus will be given to existing solutions and standards that need to be implemented and gaps that will be further discussed in the panels and breakouts.

Speakers
James O’Leary, Genetic Alliance
Grant Wood, Intermountain Healthcare

10:00 AM - Break

10:30 AM - Putting the Patient at the Center
What does it mean for the patient to be put at the center of the health IT ecosystem? Many of the barriers that keep individuals and families from contributing and accessing data in the medical system are only magnified for family health history and genomic information. Issues of data ownership, return of results, and utility to the patient will be discussed.

Moderator
Sharon Terry, Genetic Alliance

Speakers
Ken Chahine, Ancestry.com
Leslie Kelly Hall, Healthwise
Sally Okun, PatientsLikeMe

11:30 AM - From the Patient to the EHR
In order for patients to benefit from health IT, their information must be transferred from the physical to the electronic record accurately and efficiently. In addition, there are a myriad of other sources of useful data that can feed into a learning healthcare system. This session will discuss data collection mechanisms and tools in multiple settings using different forms of technology.

Moderator
Kevin Hughes, Massachusetts General Hospital

Speakers
Roger Downey, GlobalMed
Bruce Lin, March of Dimes
Lori Orlando, Duke University

12:30 PM - Lunch and Exhibits

1:30 PM - Living, Breathing Data
What does it mean to empower data? This session will discuss how to connect data and allow it to grow and develop over time. What will it take to allow family health history and genomic data enrichment and integration to occur in most healthcare settings? And what do we do when those rich data sets yield incidental or uncertain findings?

Moderator
Grant Wood, Intermountain Healthcare

Speakers
Josh Denny, Vanderbilt University
Stan Huff, Intermountain Healthcare
Fred Lee, Oracle
Elaine Lyon, ARUP Laboratories

#powerfuldata
DAY 1: THURSDAY, MAY 30, 2013

2:30 PM - Getting to Outcomes
How do we advance the use of data to create benefit for the patient and healthcare provider? This session will explore 1) the use of data in clinical decision support and the development of risk algorithms and assessment tools, and 2) how the healthcare provider will use those tools to improve patient care. How do we ensure that solutions reach as many people as possible, including the underserved?

Moderator
Greg Downing, Immediate Office of the Secretary, United States Department of Health and Human Services

Speakers
Mark Hoffman, Cerner
Ken Kawamoto, University of Utah School of Medicine
Philip Strong, Palo Alto Medical Foundation
Marc Williams, Geisinger Health System

3:30 PM - Breaking the Mold and Building the Future
While many valuable resources exist within our current healthcare system, overall use of family health history and genomic data is incomplete. How do we use the innovative tools presented today to create a patient-centered, coherent system for the use of family health history, genetic, and genomic data?

Speaker
Gil Alterovitz, Harvard Medical School

4:00 PM - Break

4:30 PM - Breakout 1
During this first breakout, participants will discuss desired outcomes and what steps are needed to meet that reality. This discussion will attempt to build a complete list of steps that can be discussed further on the second day.

5:30 PM - Reception, Tech Demo, and Exhibits
Attendees can apply to give a short, 5-minute demo of a relevant health information technology solution during the cocktail reception. Eight products will be selected. Please apply as part of the event registration if you are interested.

DAY 2: FRIDAY, MAY 31, 2013

8:30 AM - The Real World for Patients
What does this world of health information technology currently look like for patients? What could it look like? We will start the day with inspiration from an individual who has her feet in the present, but her mind on the future.

Speakers
Regina Holliday, The Walking Gallery

9:15 AM - Breakout 2
This breakout will build off of the first and focus on how to make the use case a reality. Participants are expected to plan next steps for technology, standards, and policy development, as well as outline necessary follow-up activities.

11:00 AM - Refining the Use Case/Recommendations
Participants will gather together to report on the progress of the breakout groups and participate in a town hall-style meeting to outline next steps.

12:30 PM - Closing

Breakout | Data Collection | Data Connection | Data Activation
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Facilitator | James O’Leary | Grant Wood | Marc Williams
Outcomes | Consumer data collection tools | Data transmission standards adoption | Risk algorithm development and sharing
| Core data set | EHR implementation strategy | CDS development and sharing via web services
| Consumer promotion and education | New solutions | New solutions
| New solutions | Collaboration goals | Collaboration goals
| Collaboration goals |
TECHNOLOGY DEMONSTRATIONS AND EXHIBITS

GeneInsight Suite
GeneInsight Suite®, an IT platform developed at Partners HealthCare, streamlines interpretation and management of vast amounts of data, offering a key step towards the promise of personalized medicine and better patient care.

HRA (HughesRiskApps)
HRA is a tool used to calculate the genetic risk of breast cancer in different patients. This tool has multiple purposes focusing on genetic risk of diseases among patients.

MeTree
A family health history and risk stratification program for improving uptake of risk-stratified evidence based guidelines in primary care practices.

MyFamily
MyFamily, built by Cleveland Clinic, enables the collection of patient-entered personal and family health history information. MyFamily integrates a Disease Risk Reference document into the EMR at the point-of-care, which presents stratified disease risks along with evidence-based, clinically actionable recommendations.

ORACLE Health Sciences Translational Research Center
Oracle provides a complete solution that enables the use of open source, proprietary and acquired algorithms as well as data. For organizations driving research, Oracle offers a platform that enables management through the entire lifecycle of biomarker discovery and scales to millions of patient records and petabytes of data.

Our Family Health
Intermountain Healthcare’s Clinical Genetics Institute and Homer Warner Center for Informatics Research created this online, easy-to-use tool that allows patients to compile, store, and share information about their children, parents, grandparents and more. The application features infobuttons that give the user reliable information on diseases.

Pregnancy and Health Profile: A Screening and Risk Assessment Tool
Pregnancy and Health Profile is a freeware with clinical decision support. It allows prenatal providers and patients to identify and discuss risk based on family history and make shared, informed decisions about prenatal testing and screening options.

Progeny Online Family History Questionnaire (FHQ)
The Progeny FHQ is a patient questionnaire designed to gather a patient’s health history before they visit the clinic. An embedded triage algorithm called GENTRI - based on the most current NCCN guidelines for referral criteria - identifies patients as High, Medium, or Low risk for several diseases including breast, ovarian, and colon cancer.

RunsInMyFamily.com
ItRunsInMyFamily.com is an easy to use, patient-centric family health history (FHx) collection tool. Built on the AHIC FHx core data set standards, ItRunsInMyFamily.com can be used by any individual or organization to collect a FHx pedigree in a standardized way.