

Genomic data movement throughout the health system: integrating data across academia, government and industry for research and patient access

Overview:

Innovations in genomic science, which will revolutionize clinical practice, are rapidly spurring discoveries in personalized medicine. Clinicians face enormous challenges in keeping pace with evolving best practices in data management and implementing these technologies into routine care. A major implementation barrier is data transfer, flow, and interconnectivity. Genomics data is rarely generated, analyzed, interpreted, and clinically implemented in the same system. This panel will share real world successes and challenges in the sharing and utilization of genomic data among all stakeholders.

Summary:

Existing genomics data on a patient needs to be continuously reinterpreted, as our understanding of the clinical implications of the data changes. Interpreting data can require linking to external resources and pushing or pulling data. Genomic diagnostics produce such large amounts of data that it is neither possible nor desirable to insert it all into an electronic health record (EHR) system. Other challenges include uncertainty regarding what should be stored, raw data that is susceptible to misinterpretation, and regulations that may prevent the reporting of anything but results.

The EHR is where most clinicians are most likely to interact with genomic data. This data must be presented in clinician friendly language and in an intuitive manner. Clinical decision support tools for this data are growing beyond interruptive alerts and into novel contextual alert mechanisms. As patients become more engaged in their healthcare, tools must present genomic data to them in a meaningful manner. This might include mobile applications which provide translations of the genomic data into patient friendly language.

Underpinning and informing these tools and applications will be data from large population genomics studies such as the US Precision Medicine Initiative. Moving from such data to clinically useful solutions faces many challenges in data harmonization and analysis which will require a united effort from academia, industry, and government to overcome. Ultimately, to successfully implement and realize the maximum potential of genomic data in healthcare, data must travel across many systems and be translated to meet the needs of each disparate end user.

Panelists:

- *Mary R. Grealy, President – Healthcare Leadership Council (Moderator)*
- *Keith Stewart, M.B., Ch.B., Professor of Medicine – Mayo Clinic*
- *Emma Huang, Associate Scientific Director – Janssen R&D*
- *Henry M. Dunnenberger, Program Director, Pharmacogenomics – NorthShore University HealthSystem*