ANALYTICS, DATA-SHARING, AND REAL-WORLD EVIDENCE FOR EVALUATING OUTCOMES IN PRECISION MEDICINE

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Speaker Introductions

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Conflicts of Interest

Abdul Shaikh, PhD, MHSc
- No real or apparent conflicts of interest to report

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Session Overview

In addition to health systems, payers, patients, and public agencies have a stake in understanding the value of precision medicine from both quality and cost perspectives. This session presents additional perspectives on how demonstrating the utility of precision medicine requires a systems approach and appropriate IT solutions for improved outcomes.

I. Broad Trends in Precision Medicine
II. A Patient-Provider Perspective
III. Discussion
Learning Objectives

• Describe the value of precision medicine using a multi-stakeholder perspective (e.g., patients, providers, payers, and government stakeholders)

• Assess challenges in evidence collection and translation of science-to-practice for precision medicine

• Summarize ongoing efforts to use IT solutions to demonstrate the value of precision medicine to patients, providers, and payers
STEPS - How Benefits Were Realized for the Value of Health IT

Satisfaction: Technology-enabled precision medicine approaches can be used to enhance provider systems at POC, facilitate patient-centered communication and drive new engagement with a broad ecosystem of stakeholders including patient advocates.

Treatment/Clinical: Using emerging digital technology and mobile platforms can reduce re-admissions and medical errors, and enhance patient-provider communication for treatment outcomes.

Patient Engagement/Population Management: A systems approach to precision medicine will incorporate disparate data (i.e., clinical, biomedical/genomic, epidemiological, and patient-generated data), advanced analytics, and multi-disciplinary applications to translate science-to-practice for individual and population health.
## Broad Trends in Precision Medicine

<table>
<thead>
<tr>
<th>Trend</th>
<th>Implications</th>
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<tr>
<td>I A Complex Ecosystem consisting of academic enterprise, providers, pharma, Dx, payers, technology enablers, and regulators / policy makers</td>
<td>Knowledge across industry participants and successful partnering are critical to success</td>
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<td>II The Federal Landscape in precision medicine driven by a shared vision of a true learning health systems approach to achieving the Triple Aim</td>
<td>Improving the patient experience (including quality and satisfaction) and the health of populations at reduced cost</td>
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<td>III Large Consortia / Collaborations including public-private partnerships driving innovative large scale studies and the development of standards</td>
<td>Collaboration with entities entrenched in the precision medicine ecosystem has been the chosen path to market entry for new entrants</td>
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Precision Medicine – A complex ecosystem

- National
- Public
- Regional

- Clinics
- Integrated Delivery Networks
- Managed Care Organizations
- Community Hospitals
- Academic Medical Centers

- Healthcare Providers
  - Patient Outcomes
  - ACO Model
  - Molecular Testing
  - Genomic Data Analysis
  - Clinically Annotated Patient Samples

- Healthcare Payers
  - Clinical Input / Training
  - Therapy / Dx Uptake

- New Entrants
  - Dx / Drug Performance
  - Likelihood of Reimbursement

- Manufacturers
  - Disease Pathway / MOA
  - Discovery / Research Innovation
  - Enabling Tools / Treatments
  - Clinical Trials

- Research Institutes and Labs
  - Translational Medicine
  - Translational Research
  - Personalized Therapies

- Research Institutes
- Federal Research Institutions
- Niche CLIA Labs
- Commercial / Reference Labs

- IT Infrastructure
- Drugs / Biologics
- Diagnostics
- Research Tools & Technologies
The Federal Landscape

Big Data to Knowledge (BD2K)

National Institutes of Health

National Cancer Institute
Genomic Data Commons

PopSciGrid

All of Us

HealthData.gov

pcori

Health Indicators Warehouse

TOPMed

Sentinel Initiative

pcornet

FDA

openFDA
Large Consortia and Collaborations

The scope and scale of initiatives / studies required to fuel discovery often requires a consortium of multi-disciplinary partners to accomplish.

- In June 2016, Providence Health, Intermountain Healthcare, Stanford Cancer Institute, and Syapse announced the launch of the Oncology Precision Medicine Network (OPeN).
- Aimed at improving cancer care through data sharing and increased access to clinical trials, the consortium expects to begin with 100K patient datasets and continue building with access to 50K new cancer patients each year.

- Global Alliance for Genomics & Health is an international coalition aimed at maximizing the potential of genomic medicine through data sharing.
- Comprised of hundreds of organizations, collaborative projects to share real-world data include BRCA Challenge and Beacon Project.

- The Oncology Research Information Network (ORIEN) was founded in 2014 through a collaboration between Moffitt Cancer Center (‘Moffitt’) and The Ohio State University Comprehensive Cancer Center.
- Grounded in the Total Cancer Care protocol – A research protocol which enables the tracking of cancer patients, along with their clinical data, throughout their lifetime.

- First project to sequence genomes of a large cohort with the goal of providing a comprehensive resource on human genetic variation.
- Results have been the source of hundreds of publications, discovery and development initiatives.
A Patient-Provider Perspective on Precision Medicine

1. Evolving consumer demands
   - In a digital age of patient engagement and awareness, the health system will become more patient-centric. Consumers will demand **greater choice of treatment options, convenience of delivery location, and greater price transparency**.

2. Innovative business models disrupt the market
   - **New entrants** from industries such as retail, telco, and technology will disrupt the market. These companies will meet gaps in stakeholder needs, delivering new products, services, and delivery systems. Patient expectations and technology advancements will drive greater personalization of care delivery.

3. Shift towards diagnosis and tx delivery at the PoC
   - As technology advances, the **number and quality of PoC tests** used in all therapy areas will increase. Key drivers will include patient convenience and lower costs involved.

4. Increased collaboration
   - Increased **collaboration between traditional and non-traditional players** to meet consumers’ needs, for example, collaborations between big pharma and tech players to provide digital solutions, e.g., mobile health apps. Increased public-private sector partnerships as a means to finance healthcare delivery.

5. Usage of digital technologies and data to drive value and outcomes
   - New collaborations between payers, hospitals, and pharma and medtech companies to **collect, analyse and share patient data** as a means to improving healthcare delivery and make it more personalized will emerge. Further, uptake of wearable devices and personalized digital tools will increase.
Digital trends are making connectivity and data collection a priority for patients, payers and providers in the precision medicine ecosystem.

### Providers
- **Shifting care locations**, e.g. growth in POC testing, outpatient procedures are require technologies that are increasingly portable and interoperable.

### Payers
- **Utilization of big data / analytics**. Opportunity to identify patients at risk for diseases or conditions, and target through care management programs or more effective marketing to employers.

### Patients
- **Increasing mobility**. Increased adoption of mobile technologies, increasing use of wearables / implantables with connectivity. Facilitates collection of patient data.

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**HealthKit**: New cloud-based information platform expected to help Apple become a "hub of health data".

**Simband** (prototype wearable tracker), and **SAMI**, a "data broker" enabling devices to upload info to the cloud.

**Converged Health Management** platform collects and stores biometric data from devices patients use at home.

**Verizon** and **Alere**.

**Patient data** used in conjunction with behavioral change-coaching and clinical decision support.
Both new and mature healthcare systems are open to considering disruptive models of precision medicine.

- Samsung’s LABGEOPT is a portable PoC clinical chemistry analyzer that improves efficiency by saving time for clinicians and patients through fast, easy and accurate analysis.
- Blood results available to patients in 7 minutes.
- Evolution in this area of PoC diagnostics is expected to continue towards a convenient, non-invasive customer experience.

- The Qualcomm Tricorder XPRIZE is for innovation and integration of precision diagnostic technologies, helping consumers make their own reliable health diagnoses anywhere, anytime.
- It is a real life competition – the winning device has to be able to diagnose 5 basic vital signs and has to be able to record the presence and absence of 13 other conditions.
- This is what we see as the future state... a consumer device not a clinical device.
Precision-Medicine in Action

The Multiple Myeloma Research Foundation’s (MMRF) Precision Medicine Model focused on accelerating rare disease research

- Based on three pillars
- Advancing data sharing, collaboration, and technology-mediated research
- A systems-approach, and
- A central focus on improving patient outcomes
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Discussion

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