



# **Moving Beyond Population Averages: A Roundtable to Develop a Patient-Centered Research Agenda Advancing Personalized Medicine**

**Session 2: Practical Considerations to Improve the Delivery of Personalized Medicine within the Current Health Care System**

**June 22, 2020**

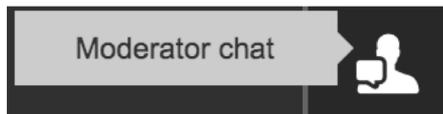
**1:00 – 3:00 p.m. ET**



# Welcome!

**We will start today's session momentarily.**

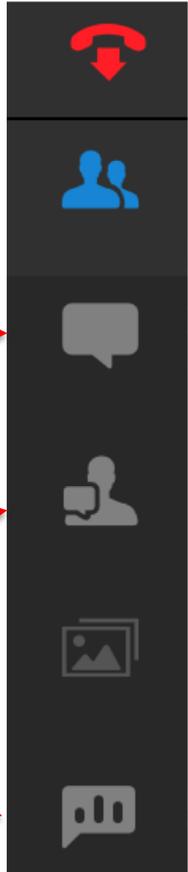
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# Who We Are

## **Cynthia A. Bens**

Senior Vice President,  
Public Policy

Personalized Medicine Coalition  
Engagement Award Project Lead

## **David Davenport**

Manager, Public Policy

Personalized Medicine Coalition  
Engagement Award Project  
Manager

## **Daryl Pritchard, Ph.D.**

Senior Vice President,  
Science Policy

Personalized Medicine Coalition  
Engagement Award Scientific  
Content Officer

## **Faswilla Sampson, M.S.**

Vice President, Operations  
Personalized Medicine Coalition  
Engagement Award Project  
Administrator



# Session #2 Agenda

## I. Welcome and Introduction

- What is Personalized Medicine?
- PCORI Engagement Award Project Overview
- Roundtable Objectives & Participants
- Ground Rules for Discussion

## II. Recap of Previous Session

## III. Panel Discussion: Practical Considerations to Improve the Delivery of Personalized Medicine within the Current Health Care System

## Session #2 Agenda (cont'd)

### IV. Group Discussion: Identifying Practical Research Topics to Improve the Delivery of Personalized Medicine

### V. Wrap-Up and Next Steps

- Summary of Key Takeaways
- Sharing Additional Feedback
- Evaluation Survey

### VI. Conclusion

# Why a Patient-Centered Research Agenda for Personalized Medicine?

- There are fundamental gaps in awareness and evidence that impact the speed at which personalized medicine products and services are integrated into health care.
- Personalized medicine and patient-centered outcomes research (PCOR) share the same goal of shifting healthcare from a one-size-fits-all, trial-and-error approach toward a targeted approach that utilizes patients' characteristics and preferences to inform healthcare decisions.
- PMC is engaging stakeholders across the healthcare spectrum to develop a research agenda that is informed by early successes in personalized medicine adoption and builds on principles defined by patients.

## Project Funding

This project was selected by the Patient-Centered Outcomes Research Institute (PCORI) to receive a Eugene Washington Engagement Award because it will establish partnerships and build a community equipped to participate as partners in advancing patient-centered clinical effectiveness research.

# Roundtable Objectives

1. To refine language in the proposed research questions to be most impactful and relevant to the patient priorities identified in the patient-centered principles.
2. To discuss suggestions for additional research questions that you think would improve patients' outcomes and experiences with personalized medicine.

# Roundtable Participants

## Disease Areas

- Alzheimer's
- Cancer (breast, lung, multiple myeloma, colorectal, lymphoma, rare blood, genetic risk)
- Caregiving
- COPD
- Cystic fibrosis
- Food allergy
- Health disparities
- HIV
- Kidney disease
- Rare diseases

## Areas of Expertise

- Community health
- Diagnostics
- Family medicine
- Genetic counseling
- Genomics education
- Health insurance
- Health IT
- Hospital and program administration
- Nursing and nurse education
- Outcomes research
- Pharmacogenomics
- Practicing physicians/researchers

# Moderator

**Susan McClure**

Founder, CEO, Genome Creative

# Recap of Previous Session

# Proposed Research Questions (Session 1)

1. How can education, communication and healthcare delivery strategies close the existing gap between a **patient/caregiver's expectations** about personalized medicine and the **reality** of how and when test results and treatment options are currently delivered?
2. What kinds of new and existing **educational tools and resources**, including those using digital platforms, would empower patients and providers, with varying levels of understanding about personalized medicine and its benefits, to discuss personalized medicine treatment options during visits?
3. How can patients and caregivers be encouraged to more **actively participate** in their personalized treatment when they prefer not to think about it, want to rely on their trusted medical team, or feel inadequate to participate?

# Proposed Research Questions (cont'd)

4. How can conversations between a patient and health care professional about personalized medicine treatment options best address issues related to **access and affordability** of care?
5. How can healthcare professionals and patients navigate **language and cultural differences** when discussing personalized medicine treatment options or delivering/receiving care?
6. How do a patient's needs and access barriers, including those related to cost and affordability, change depending on the **purpose of a genetic test** (e.g., to identify risk of developing a disease vs. to identify an appropriate treatment)?
7. How can outcomes research in personalized medicine consider the impact of treatment on a **patient's financial health, psychosocial well-being, and experience receiving care**?

# Panel Discussion: Practical Considerations to Improve the Delivery of Personalized Medicine within the Current Health Care System

**Moderator | Susan McClure**, Founder, CEO, Genome Creative

**Jennifer J. Bute, Ph.D.**, Associate Professor, Communication Studies, Indiana University-Purdue University Indianapolis

**Nadine Channaoui, M.S., L.C.G.C.**, Licensed Genetic Counselor, Cardiovascular Genetics Program, Brigham and Women's Hospital

**Lee S. Schwartzberg, M.D., F.A.C.P.**, Medical Director, West Cancer Center; Chief Medical Officer, OneOncology

*Please submit questions for speakers through the event chat.*



# Patient-Centered Principles

1. **Patient/caregiver values** include personal priorities, religious/spiritual values, societal and cultural values (including family involvement in care decisions), views around quality of life, privacy concerns, desired level of access to and understanding of personal genetic information, beliefs about health and personal responsibility, and attitudes and preferences toward end of life.
2. **Patient/caregiver circumstances** include emotional state, socioeconomic situation, race/ethnicity, sex/gender, language, health literacy, ability to work, access to care, access or lack thereof to a caregiver, social support, cognitive abilities, attitude toward illness (e.g., acceptance of diagnosis, willingness to accept help), personality, symptom burden, health-related quality of life, ability to consent and choose, relationship with the health care provider, the role of patient as a caretaker, preferences of family members, treatment setting (e.g., community, academic, other), familiarity with personalized medicine and its benefits, other social determinants of health, and other expressed needs or barriers.

# Patient-Centered Principles (cont'd) <sup>18</sup>

3. The research agenda would be most helpful if it focused on priorities that help providers in (a) **identifying and communicating treatment options** based on biological differences in the context of patient/caregiver values and (b) **understanding patient/caregiver circumstances** and presenting treatment options in ways that highlight how a treatment aligns/does not align with those circumstances.
  - The potential for shared decision-making tools and resources to facilitate these conversations should be explored.

(continued)

# Patient-Centered Principles (cont'd) <sup>19</sup>

4. The research agenda should address the **education of patients** directly by considering (a) the education of patients/caregivers as a continuing process over time and not just at diagnosis, including basic education defining personalized medicine and its benefits; (b) how both patients/caregivers and their providers can improve communication with each other; and (c) how to close the gap between patient/caregiver expectations and the reality of how/when test results and treatment options are delivered.
  - Educational tools and resources, including those available online, should address different learning styles and levels of health literacy.

# Patient-Centered Principles (cont'd) <sup>20</sup>

5. Opportunities to **educate providers** in genomics should be considered, along with providers' varying levels of understanding of genomics and varying levels of access to new and existing resources, such as translational tools, depending on their health setting (e.g., community, academic, other), health specialization, and health discipline (e.g., pharmacists, physician assistants, genetic counselors, nurses).
  - This includes opportunities to educate providers and other health care professionals in training.
6. The agenda should consider how to use **oncology as a prototype** for patient and provider education in disease areas beyond oncology.

# Patient-Centered Principles (cont'd) <sup>21</sup>

7. **Access challenges** beyond those created by a lack of communication and education should also be considered.
  - This includes timely access to novel and/or off-label therapies as a result of affordability, insurance coverage and provider availability.
  
8. The research agenda should be **representative** of diverse patient needs, diseases, backgrounds, and experiences (e.g., stage of life, disease trajectory, socioeconomic status and health literacy level), including patients underrepresented in medical research.
  - Specifically, the research agenda should apply across disease areas.
  - This includes considering how the research agenda can apply to additional disease areas as new personalized medicine treatments come to market.
  - This includes potential research topics related to the management of comorbidities.

# Patient-Centered Principles (cont'd) <sup>22</sup>

9. The advisory committee should consider areas the agenda must include and exclude to have the greatest **impact**, including the **feasibility** of proposed research topics.
  - This includes potential research topics related to artificial intelligence, data collection, data integration and interoperability, informed consent, and patient concerns related to data privacy and access.

# Proposed Research Questions

## Session 2

# Proposed Research Questions

8. How can the roles of other **health care professionals** beyond a patient's physician, such as nurses, nurse navigators, genetic counselors, and pharmacists, be maximized to improve the delivery of personalized medicine?
9. How can **barriers for physicians** and their medical teams in discussing and sharing with patients and caregivers information on personalized medicine, including testing, patients' results, treatment options, and enrollment in clinical trials, be addressed?
10. What strategies should be used to improve the knowledge and expertise of **primary care providers** in the integration of personalized medicine into clinical practice?

# Proposed Research Questions (cont'd)

11. What kinds of **tools and technologies** (e.g., clinical decision support tools) could be made better available to providers in varying health settings, health disciplines, and health specialties to improve the delivery of personalized medicine?
12. How can conversations between a patient and health care professional about personalized medicine treatment options best account for **shared-decision making**?
13. How can shared decision-making tools and resources better facilitate conversations between patients and providers about how personalized medicine treatment options align/do not align with a **patient/caregivers' values and circumstances**?

# Proposed Research Questions (cont'd)

14. How does a patient's and a health care provider's **understanding of genomics**, including the patient's understanding of his/her own genetic information, impact the integration of personalized medicine into clinical care?
  
15. What **mitigating strategies** are needed to address inequity in the proportion of variants of uncertain significance reported out for individuals of non-Western European ancestry/ethnicity compared with those of Western European ancestry/ethnicity?

# Group Discussion: Framing Research Questions in the Context of the Patient-Centered Principles to Improve Delivery of Personalized Medicine

Moderated by  
**Susan McClure**  
Founder, CEO, Genome Creative

*Please remember to mute your line when you are not speaking.*

# Summary of Key Takeaways

# Next Steps

- If you have additional comments or questions, please email them to David Davenport at [ddavenport@personalizedmedicinecoalition.org](mailto:ddavenport@personalizedmedicinecoalition.org).
- We will take your feedback and incorporate it into the final research agenda, which will be published in the form of a white paper in August 2020.
- We will share the session recording and slides and post them on PMC's website: <http://www.personalizedmedicinecoalition.org>.
- You will receive an evaluation survey for this session. We encourage you to fill it out so that we can see how we did and how we can improve future sessions.
- Please join us for our last session on Thursday, June 25, which will focus on “Disrupting the Health Care System for Personalized Medicine.”

Thank you for your attention.  
Questions or comments, please contact us.

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