



# **Moving Beyond Population Averages: Patient Principles for a Personalized Medicine Research Agenda**

## **Webinar #4**

**January 28, 2020**

**1:00 p.m. – 2:30 p.m. ET**



# Who We Are



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# Agenda

## I. Welcome and Overview

- Instructions
- PMC and PCORI Project Overview
- Feedback from Web Forum #3 Participant Survey
- Web Forum #3 Takeaways

## II. Web Forum #4 Objectives

- Finalize proposed principles for a patient-centered research agenda in personalized medicine
- Share next phases of project and outline opportunities for additional engagement

## III. Open Discussion of Proposed Principles with Polling

(continued)

# Agenda (cont'd)

- IV. Further Engagement Through CoDigital: An Online Collaboration Platform**
- V. Next Steps**
- VI. Additional Comments or Questions**
- VII. Conclusion**

# Web Forum Instructions

- The separate teleconference line you are all on will allow for active discussion. We will mute your lines until the discussion period. **To unmute your line, press 4\***
- When you speak, please announce yourself and be willing to share the mic with others.
- Your WebEx Q&A function is also enabled for you to ask questions. This can be found in the sidebar on your screen.
- If you need technical assistance, please contact us through the Q&A feature, or email [ddavenport@personalizedmedicinecoalition.org](mailto:ddavenport@personalizedmedicinecoalition.org)
- This web forum is being recorded. It will be archived for future viewing and dissemination.
- Note: The raise your hand feature is disabled.

# What is Personalized Medicine?

Personalized medicine, often referred to as precision medicine, is an evolving field in which physicians use molecular diagnostic tests to determine which medical treatments will work best for their patients. By combining the data from those tests with an individual's medical history, circumstances, and values, health care providers and patients can develop targeted treatment and prevention plans.

# Project Overview

- We will work with you to develop a set of patient-centered principles to advance personalized medicine during a series of web forums.
- Once the principles are finalized, we will invite you to participate in an online platform brainstorming potential research projects.
- Approximately 45 patients, caregivers, researchers and health care providers will convene for an in-person roundtable in Washington, D.C., at which participants will translate the principles and suggested topics into a research agenda.
- We will publish the complete research agenda in the form of a white paper in 2020.
- The research agenda will be publicly disseminated to inform future studies that will provide patients, caregivers and clinicians with the evidence they need to make more informed health care decisions.

## 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.



# Web Forum #3 Participant Survey Feedback

- Thank you for providing feedback on Web Forum #3, held May 2019.
- Participants found the discussion informative and said they learned something they did not know before the web forum.
- Participants thought it was useful for PMC to state the objectives and expectations for the web forum up front.
- Participants appreciated the opportunity to receive discussion questions in advance and to provide feedback afterward.
- Participants appreciated the ample time for open discussion and commented positively on the facilitation.

# PMC's Response to Participant Survey Feedback

- We included in the agenda specific objectives for the web forum and have organized the discussion to achieve these objectives.
- We kept the 90-minute web forum duration but decided not to have a guest speaker to allow more time for Q&A and live discussion.
- We scheduled the web forum after polling participants to identify a convenient time that would allow the greatest participation.
- We changed the way that participants join the web forum to allow all participants to speak by unmuting their own lines.
- We kept the discussion questions from the last web forum open for several months and, in advance of today's discussion, shared the proposed principles for feedback and review.

# Findings from Web Forum #3

- Participants reviewed proposed principles for the research agenda based on feedback from the previous two web forums and discussed additional principles.
- Participants expanded definitions for patient values and patient circumstances.
- Participants agreed the agenda should address the education of patients, the education of providers, and improving communication between patients and providers in the context of personalized medicine.
- Participants agreed access challenges, beyond those created by a lack of communication and education, should be considered. This includes research topics that PCORI may not be able to fund.

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# Findings from Web Forum #3 (cont'd)

- Participants agreed the research agenda should apply across disease areas and not limit its focus to a particular disease area, as well as be inclusive of patients of diverse backgrounds and experiences.
- Participants suggested the advisory committee consider which areas the agenda should include/exclude to have the greatest impact.
- Participants suggested expertise that should be represented on the advisory committee, including expertise in shared-decision making and patient education.

# Advisory Committee

- Thank you for submitting nominations!
- Based on feedback received, we used a formal nominations process to select members of the advisory committee.
- We wanted to create opportunities for volunteers to take a leadership role and to ensure diverse representation of diseases and perspectives.
- The committee is made up of more than half patients, caregivers, and patient advocates from diverse backgrounds, age groups, and disease areas, including expertise in rare disease, oncology, aging, and health disparities.
- The remaining advisory committee members are health care providers, researchers, one industry representative, and one payer.



# Background on Proposed Principles

- The purpose of these principles is to identify how a research agenda in personalized medicine can be most beneficial to patients by informing the scope, content, and impact of the final research agenda.
- These principles are based on discussions and feedback received during the previous three web forums and feedback received from the advisory committee.
- This process has resulted in 9 principles that cover the following themes:
  - a. Defining patient values and circumstances
  - b. Improving patient-provider communication
  - c. Improving the education of patients and providers
  - d. Access challenges
  - e. Representativeness
  - f. Impact and feasibility

# Review and Discussion of Proposed Principles

**Q: Which statement best describes your thoughts about the proposed principles?**

- A. I would approve the principles as is.
- B. I would approve the principles with some minor changes or additions.
- C. I have significant changes/concerns I would like to raise.
- D. I have not yet read the principles.

**\* Please press 4\* to unmute your line**

# Further Engagement: CoDigital

Demo: <https://codigital.com>

- Following feedback from previous web forums, we will use Co-Digital, an online collaboration platform, to help us brainstorm and refine potential topics for a research agenda in personalized medicine that are based on the principles developed through this web forum series.
- Through the platform, users can suggest ideas, propose edits to ideas, and vote to resolve edits or rank ideas.
- The platform is easy to use and will be open to all web forum participants and anyone else interested in participating.
- We will send email invitations to participate in February 2020.
- CoDigital will enable us to maximize engagement from the patient community and other stakeholders during the next phase of the project.



# Next Steps

- We will post the webinar recording, slides and final principles. These will be available on PMC's website: [www.personalizedmedicinecoalition.org](http://www.personalizedmedicinecoalition.org).
- In February 2020, we will invite you to participate in CoDigital, an online collaboration platform, to suggest and refine potential research topics that align with the patient-centered principles developed through this web forum series.
- This summer, we will share the final white paper with the patient-centered principles and a final list of proposed research topics for a research agenda in personalized medicine.
- You will receive an evaluation survey for this web forum. We encourage you to fill it out so that we can see how we did on our final web forum.

# Additional Comments & Questions

\* Please press 4\* to unmute your line

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

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