



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

Web Forum #3

May 16, 2019

12:00 p.m. – 1:30 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 #2 Participant Survey
- Web Forum #2 Takeaways

II. Web Forum #3 Objectives & Expectations

- Identify principles and parameters for our patient-centered agenda by:
 - (1) reviewing takeaways from web forums #1 and #2
 - (2) gathering your feedback on what else the agenda should include and how it can be most useful to you

III. Conclusion and Next Steps

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
- This web forum is being recorded. It will be archived for future viewing and dissemination.

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.
- We will invite approximately 45 patients, caregivers, researchers and health care providers to an in-person roundtable in Washington, D.C., at which participants will translate the principles 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 #2 Participant Survey Feedback

- PMC heard from about 1/3 of the web forum participants about web forum #2. Thank you!
- Participants found the guest speaker presentations informative and said they learned something they did not know before the web forum.
- Participants thought that it would be useful for PMC to clearly state the objectives and expectations for the web forum up front.
- Participants said that the virtual discussion mechanism used in previous web forums #1 and #2 limited feedback that could be provided.
- Participants would like more time for Q&A and live discussion.

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.

Findings from Web Forum #2

- Participants heard presentations from Food Allergy Research and Education (FARE) and the Cerebral Palsy Research Network (CPRN) on their models for successfully setting research priorities as part of PCORI-funded projects.
- When asked to identify process elements of the FARE and CPRN projects that would enhance PMC's project, participants responded that PMC should:
 1. Use a structured application process to solicit and select members for the advisory committee;
 2. Include multiple, diverse stakeholder groups on the advisory committee;
 3. Consider incorporating an online platform to further vet the principles we are developing together through these web forums; and
 4. Develop a dissemination plan with the project advisory committee.

For Review and Discussion

Part I. Definitions

- **Patient/caregiver values** includes personal priorities, religious/spiritual values, societal and cultural values (including family involvement in care decisions), views around quality of life, and beliefs about health and personal responsibility.
 1. What other factors should be considered?
- **Patient/caregiver circumstances** include emotional state, socio-economic situation, race/ethnicity, language, ability to work, access to care, social support, cognitive abilities, attitude toward illness, personality, symptom burden, health-related quality of life, ability to consent and choose, relationship with the healthcare provider, the role of patient as a caretaker, and other expressed needs or barriers.
 2. What other factors should be considered?

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For Review and Discussion

Part II. Scope and Content

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.

1. How can providers improve communication to help patients make decisions about their health and health care?
2. To what extent should this research agenda address education of patients directly? And how?
3. Should access challenges beyond those created by a lack of communication and education be considered? What about timely access to novel therapies (i.e. affordability, insurance coverage, provider availability)?

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For Review and Discussion

Part II. Scope and Content (continued)

- *Disease Areas*

4. Should the research agenda apply across disease areas?
5. Or should it identify research priorities for particular disease areas? Which disease areas?
6. How can the research agenda apply to additional disease areas as new personalized medicine treatments come to market?

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For Review and Discussion

Part III. Impact

The research agenda should be holistic by identifying research topics inclusive of diverse patient needs, disease, backgrounds, and experiences, including patients under-represented in medical research.

1. What else would a successful patient-centered research agenda accomplish? What other parameters should we set to ensure its impact and success?
2. How can the agenda best provide novel ideas?
3. What should NOT be a focus on the agenda?
4. Should the agenda identify research priorities that only PCORI can fund? Or should it identify priorities that other institutions and organizations may want to fund?

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Next Steps

- We will post the webinar recording and slides. These will be available on PMC's website: www.personalizedmedicinecoalition.org.
- We will take feedback from this program and use it to inform our final webinar. This is where we will finalize the patient-centered principles and receive suggestions for the in-person meeting. Target timeframe for the final webinar is January 2020.
- You will receive an evaluation survey for this web forum. We would encourage you to fill it out so that we can see how we did and how we can improve our final webinar.
- Please apply to be a member of the project advisory committee by filling out this nomination form by June 21, 2019
<https://www.surveymonkey.com/r/BVF7YN7>

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

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