



Call For Webinar Participants

To Inform a Patient-Centered
Outcomes Research Agenda
for Personalized Medicine

The Personalized Medicine Coalition (PMC) is seeking patients, patient advocates, caregivers, health care professionals and academic researchers to participate in a series of discussions to inform a patient-centered research agenda for personalized medicine. These discussions will be held via webinar, and participants will join online and/or by phone. The final research agenda, which will be based on these discussions and an in-person meeting, will address gaps in patient-centered outcomes research (PCOR). PCOR “helps people and their caregivers communicate and make informed health care decisions, allowing their voices to be heard in assessing the value of health care options.”ⁱ

WHAT IS PERSONALIZED MEDICINE?

Personalized medicine is an evolving approach to health care based on the latest science where physicians use diagnostic tests to determine which medical treatments will work best for each patient. By combining the information from those tests with an individual’s medical history, circumstances and values, health care providers can develop tailored treatment and prevention plans.

Personalized medicine can benefit patients in a number of ways, including by (1) shifting the emphasis in medicine from reaction to prevention, (2) reducing trial-and-error prescribing, (3) reducing adverse drug reactions, (4) revealing additional uses for medicines, (5) increasing patient adherence to treatment, (6) reducing high-risk invasive testing procedures, and (7) helping control the overall cost of health care.ⁱⁱ

WHY PARTICIPATE?

For many diseases, outcomes that are a priority for patients are not well understood and considered at the time of treatment decision-making. During these webinars, patients will provide input to shape principles for patient-centered personalized medicine. The principles will help define a research agenda to identify evidence gaps that must be filled to ensure that personalized medicine treatment strategies better align with priority patient outcomes.

WHO CAN PARTICIPATE?

1. **Any patient, patient advocate and caregiver** is invited to participate, regardless your disease, illness, diagnosis, diagnosis status, age, gender, race/ethnicity or location. You are also welcome to participate whether or not you have received a personalized medicine treatment or are familiar with personalized medicine.

2. **Academic researchers and health care professionals** with experience in personalized medicine, patient-centered outcomes research and/or comparative effectiveness research are also invited.

NOTE: To participate, you will need access to a computer with internet and/or a phone, and you will need an email address to register for the webinar and to receive instructions for joining the discussion.

WHAT DOES MY PARTICIPATION INVOLVE?

Over the next year, you will be asked to participate in a series of four webinars lasting one to two hours each. These webinars will feature open discussions among participants to develop guiding principles for the research agenda mentioned above. To join these webinars, participants will need to have access to a computer connected to the internet and/or a phone at the time of the webinar. Participants will also need an email address to register for the webinar and to receive instructions for joining the discussion. At a later date, you may also be invited to participate in an advisory committee and in-person meeting for the project.

HOW CAN I SIGN-UP?

If you are interested in participating or have any questions, please contact:

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ADDITIONAL INFORMATION

This project is led by the Personalized Medicine Coalition (PMC) and funded by the Patient-Centered Outcomes Research Institute (PCORI) through a Eugene Washington Engagement Award.

PMC is a nonprofit coalition representing innovators, scientists, patients, providers and payers that promotes the understanding and adoption of personalized medicine concepts, services and products to benefit patients and the health system. For more information about PMC, please visit www.personalizedmedicinecoalition.org.

PCORI is an independent, nonprofit organization authorized by Congress in 2010 to fund comparative effectiveness research that will provide patients, their caregivers, and clinicians with the evidence needed to make better-informed health and health care decisions. PCORI is committed to seeking input from a broad range of stakeholders to guide its work. For more information about PCORI, visit www.pcori.org.

ⁱ <https://www.pcori.org/research-results/patient-centered-outcomes-research>

ⁱⁱ http://www.personalizedmedicinecoalition.org/Resources/The_Personalized_Medicine_Report_An_Annual_Overview_of_the_Field