



Improving Personalized Medicine Research.

Introduction.

Personalized medicine is an approach to tailor health care to each patient's unique traits. This brief will help you learn about personalized medicine and a project that identified research topics to improve patients' experiences with personalized medicine. We encourage you to share this with your family and friends and get involved – you can help improve personalized medicine for everyone!

What is the goal of this project?

This project aimed to create a **patient-centered research agenda** for personalized medicine that:

- Is based on feedback from patients, caregivers, and health care professionals
- Will help researchers ask the right questions to improve personalized medicine for patients

Why is this project needed?

We need more research to improve the ways doctors and patients use personalized medicine. A research agenda can help funders choose research projects that answer the right questions to ensure the results help patients in a meaningful way.



A **research agenda** is a plan that names the top issues and related research questions in a certain field.

Patient-centered means that it focuses on the patient's preferences, needs, and values.

Who carried out this project?

The Personalized Medicine Coalition (PMC) carried out this project with an award from the Patient-Centered Outcomes Research Institute (PCORI).

What happened during this project?

Over this 2-year project, PMC worked with over 120 patients, caregivers, and health care professionals to:

- 1 **Create** a list of guiding principles that should be included in the research agenda to be most helpful for patients. The guiding principles included:
 - Values and situations that patients and caregivers think are important
 - How patients think a research agenda could be most helpful to diverse patient needs, diseases, backgrounds, and experiences
- 2 **Name** their number 1 research question to improve patient care and treatment through personalized medicine
- 3 **Hear** their experiences with personalized medicine, how doctors and patients use personalized medicine, and needed changes to the health care system to improve personalized medicine

The patients, caregivers, and health care professionals played a key role in each step to create the research agenda. An advisory committee of mostly patients and other advocates oversaw the process and helped to refine the research questions.



What were the project results?

We identified 45 research questions that could improve the future of personalized medicine for patients. They grouped the research questions by 9 topics:



Patient-provider communication



Patient education



Caregiver, pediatric, and family considerations



Provider education, resources, and collaboration



Access, use, and affordability



Coverage and reimbursement



Clinical trials



New technologies and data management



Outcomes research



About Personalized Medicine

What is personalized medicine?

Personalized medicine aims to prevent or treat disease in the best way for each patient using their specific information.

Personalized medicine is based on a patient's:

- Health history, such as other health conditions they have
- Values and preferences
- Work, family, and life situation
- Results from tests, such as genetic tests, which learn if a patient does or does not have a specific gene or change (mutation) in a gene (genes are parts of DNA that tell your cells what to do)

Personalized medicine is also called precision or individualized medicine.

Who does personalized medicine help?

Personalized medicine can help patients with many different diseases or conditions, such as cancers, rare diseases, infections like COVID-19, and common chronic (long-lasting) diseases like diabetes or arthritis.

How does personalized medicine help patients?

Personalized medicine helps patients at different points in their health journey, such as to:

- **Prevent a future disease** — For example, screening tests can help find a disease before a patient has symptoms. If a patient has a certain gene or family history that raises their chance of a disease, patients and doctors can decide on the best steps to lower their chance of getting that disease.
- **Diagnose and understand a disease** — If a patient is diagnosed with a disease, doctors can do tests to learn more about what may have caused the disease, such as genes that may have helped cancer grow.
- **Treat a disease** — If a patient has a change (mutation) in a gene that caused a disease like cancer, patients and doctors can decide on the best treatment and doses of treatment for their unique disease, which is called a targeted treatment. Targeted treatments can have fewer unwanted side effects and work better to treat the disease.



Read the 9 briefs to learn about the topic areas, the research questions on the topic, and how it may apply to your own health care. To download the other briefs, visit <https://www.personalizedmedicinecoalition.org/Research/Agenda>.



Researchers are studying new tests and treatments every day, which means personalized medicine can help more patients. Read the 9 other briefs for examples of how personalized medicine can help patients with different diseases. Download the other 9 briefs and the complete report at <https://www.personalizedmedicinecoalition.org/Research/Agenda>.

How has this project helped patients?

This project created a research agenda that will help researchers ask the right questions to improve patients' experiences with personalized medicine.

How can I learn more?

Learn more about personalized medicine and how to access it

- Visit More Than A Number at [MTAN.org](https://www.MTAN.org)

Learn more about this project

- Read the 9 other briefs that describe the research questions to improve personalized medicine at <https://www.personalizedmedicinecoalition.org/Research/Agenda>
- Visit Personalized Medicine Coalition at [personalizedmedicinecoalition.org](https://www.personalizedmedicinecoalition.org)
- Download the complete report and research agenda at <http://tinyurl.com/uppyxa4>

How can I get involved?



Join an advocacy or support group related to your or your loved one's disease



Share this research agenda with your doctors, an advocacy or support group for your disease, and your friends and family



Take part in related research activities led by the Patient-Centered Outcomes Research Institute (PCORI). To learn more visit <https://www.pcori.org/engagement/engage-us>

CONTACT US

PMC@PersonalizedMedicineCoalition.org

About the Personalized Medicine Coalition (PMC)

The Personalized Medicine Coalition convenes over 230 organizations representing innovators, scientists, patients, providers, and payers to promote the understanding and adoption of personalized medicine concepts, services, and products to benefit patients and the health system.

THIS PROJECT WAS FUNDED THROUGH a Patient Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award (10438-PMC). The views, statements, and opinions presented from this work are solely the responsibility of the authors and do not necessarily represent the views of PCORI, its Board of Governors, or its Methodology Committee.