



Improving Personalized Medicine Research. Access, Use, and Affordability.

Personalized medicine is an approach to tailor health care to each patient's unique traits. We need more research to improve the ways doctors and patients use personalized medicine. This brief explains which research questions can improve access, use, and affordability of personalized medicine. **Access and use** of personalized medicine refers to whether a patient is able to get personalized medicine when they need it. It includes being able to visit a doctor and insurance coverage (whether insurance covers, or pays for, some or all of the costs). **Affordability** refers to whether a patient has the income to pay the costs of 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



Values and preferences



Work, family, and life situation



Test results

Personalized medicine can help patients at different points in their health journey, such as to prevent a future disease, diagnose a disease, and treat a disease.

Where did the research questions come from?

The Personalized Medicine Coalition (PMC) worked with patients and other stakeholders to carry out a project to create a patient-centered research agenda for personalized medicine that:

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

Which research questions can help improve access, use, and affordability of personalized medicine?

Future research can improve access, use, and affordability by answering these questions:

- ❑ How do **barriers to access and affordability of a genetic test change** based on its purpose, such as to find a patient's chance of getting a disease vs. to find the right treatment?
- ❑ How does **affordability and insurance coverage** impact a patient's access to new and **off-label** personalized treatments when they need it?
- ❑ What factors cause doctors and patients to **not fully use personalized treatments** when they may be appropriate?
- ❑ How must the health care and health insurance systems change to address these factors and raise **use in underserved groups**?
- ❑ How can **greater support for patients' and caregivers' basic needs**, such as transportation and childcare costs, raise the use of personalized medicine in underserved groups?
- ❑ What tactics are needed to **give personalized medicine treatments to non-white people** where **underrepresentation in research** has made it harder to understand their genetic information?



Patient profile

Richard Knight

As a treatment for kidney disease, Richard received a kidney transplant 14 years ago. But he worried that his body would reject (attack) his kidney transplant. Now, diagnostic tests can help watch for signs that his body is rejecting the transplant. And, other tests can find genes that raise a patient's chance of getting kidney disease.

Kidney disease happens more often in African, Caribbean, and Latin Americans than white Americans. And these groups may have more barriers to health care, which may make it hard for them to access these tests for kidney disease. As President of the American Association of Kidney Patients, Richard now advocates for patients to get the care they need and for patient choice through new treatments for kidney disease. Richard believes that personalized medicine for kidney patients means the right treatment for the right patient at the right time.



Off-label treatment means that a doctor prescribes a treatment in a way that differs from the FDA (Food and Drug Administration) approved use. For example, a doctor prescribes for a different disease, dose, or age group than what the FDA approved it for.

Underserved groups are groups who have more barriers to health care, such as elderly, people who live in rural areas, and people with low incomes.

Underrepresentation in research means the percent of certain study participants with a condition is too low compared to the percent of people who have the condition in the real world. This can include people of a certain race, ethnicity, gender, or age.

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.mtana.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/uppyrxa4>

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.