



Improving Personalized Medicine Research. Patient-Provider Communication.

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 patient-provider communication about personalized medicine. **Patient-provider communication** is the exchange of information between a patient and a health care provider, including spoken, written, and non-verbal communication.

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 patient-provider communication about personalized medicine?

Future research can improve patient-provider communication by answering these questions:


- How can communication help patients and caregivers **know what to expect with personalized medicine**, including the process and timing of test results and decisions about treatments?
- How can patients and caregivers be **encouraged to take a more active role** in their personalized treatment and in clinical research, especially if they don't feel confident?
- How can we improve conversations about **access and cost** of personalized medicine treatments?
- How can providers, patients, and caregivers understand and work through **language and cultural differences** while discussing personalized medicine?
- How can providers understand and talk about the unique concerns of patients and caregivers from diverse racial and ethnic backgrounds, especially **concerns related to past mistreatment or underrepresentation in medical research**?
- What tools and processes can **help shared decision-making** between a patient or caregiver and a provider, such as checklists, decision aids, or conversation scripts?
- How can shared decision-making help patients and providers talk about how personalized medicine treatments **do or do not align with a patient's values and situations**?



Patient profile

Laura Holmes Haddad

After chemotherapy didn't work to treat Laura's stage 4 breast cancer, her doctor ordered a biomarker test, which is a test to find errors or changes in a gene's DNA that cause cancer. Laura and her doctor discussed her biomarker test results and decided together on a targeted treatment, which saved her life. Laura's discussion with her doctor also led to her family members getting genetic tests to learn if they have a gene that raises their chance of getting cancer.

 **Underrepresentation in medical research** means that the percent of study participants of certain races and ethnicities with a health condition is lower than the percent of people in the real world of those races and ethnicities with the health condition.

Shared decision-making is a process in which a patient and provider work together to make decisions based on research and patient preferences. For example, decisions about tests, treatments, and care plans.

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>

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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.

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