



Improving Personalized Medicine Research. Provider Education, Resources, and Collaboration.

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 health care provider education, resources, and collaboration about personalized medicine. Examples of **provider education, resources, and collaboration** include tools to help providers discuss personalized medicine with patients and ways to make it easier for providers to use 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 provider education, resources, and collaboration about personalized medicine?

Future research can improve provider education, resources, and collaboration by answering these questions:

- ❑ What kinds of **tools, technologies, and resources can help providers** from different health fields and with different levels of knowledge discuss personalized medicine with patients and caregivers?
- ❑ How can we **make it easier for providers to discuss and share information** with their patients about testing options, test results, treatment options, and enrollment in clinical trials?
- ❑ How can **all members of a patient's health care team**, such as nurses, **genetic counselors**, pharmacists, or social workers, help improve the delivery of personalized medicine?
- ❑ How can we **educate health care providers in non-research settings** about personalized medicine and how to start using it with their patients?
- ❑ How can health care professionals, including genetic counselors, **choose the right genetic test for a patient out of similar tests** available from different laboratories or companies?
- ❑ How can health care professionals **help patients and caregivers understand the limitations of genetic tests**, including how their condition could still have a **genetic driver** even if they get a negative test result?



Patient profile

Terri Booker, Esq.

Terri lives with sickle cell disease, a genetic blood disorder passed down from parents that causes red blood cells to be misshaped. When she was hospitalized in 2012 with a sickle cell crisis, most of the doctors and nurses caring for Terri were not familiar with how to treat the problems caused by sickle cell disease. These problems can include severe pain, stroke, heart attack, lung failure, kidney failure, blood clots, nerve damage, blindness, anxiety, depression, and even death. Better provider education, resources, and collaboration would have improved her experience in the hospital. When a treatment becomes available for sickle cell disease, provider education to use personalized medicine will be equally important.



A **genetic counselor** is a health care provider who is trained in genetics and can give information about how genetic conditions may affect you or your family.

A **genetic driver** is an error or change (mutation) in a gene's DNA that can cause problems, such as cancer. A gene has the code or instructions that tell the cell what to do.

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

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
- 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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