



Improving Personalized Medicine Research. Outcomes Research.

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 outcomes research about personalized medicine. **Outcomes research** is a type of research that measures the outcomes (effects) of a treatment or health care service. Health outcomes include biological, clinical, and patient-centered indicators of health care intervention. Patient-centered outcomes can include health, well-being, and functioning – like the ability to work. Some outcomes research relies on report from patients themselves. Outcomes research can help us understand how personalized medicine does or doesn't work for patients.

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 outcomes research about personalized medicine?

Future research can improve outcomes research by answering these questions:

- How can outcomes research **measure the effect of personalized medicine** on a patient's financial health, well-being, and experience getting care?
- How does a **patient's, caregiver's, and doctor's understanding of genomics** (including the patient's understanding of their own genetic information) affect their decisions about personalized medicine as a possible treatment?
- How can outcomes research on genetic testing (testing **genes**) improve a **patient's and caregiver's understanding of the risk and severity** of their diagnosis and when it may or may not be better to get a more aggressive treatment?
- How does **having people other than doctors helping patients in their health journeys** (such as **peer navigators, nurse navigators, and community health workers**) affect patient outcomes with personalized medicine? How can these helpers be trained and supported, especially in **underserved groups**, to improve the delivery of personalized medicine?
- How does **family and friend caregiver involvement in decision-making and long-term**

care affect patients' outcomes with personalized medicine? Which activities should caregivers be involved in to improve care, and how can caregivers be prepared to take part in these activities?

- How can long-term outcomes research track **how much personalized medicine helps** to prevent patients from getting a disease or condition or to improve patient outcomes later in life?



Patient profile

Margie Sherlock

Type 1 diabetes runs in Margie's family. Over the years, Margie has cared for children in her family with Type 1 diabetes and other family members with long-term genetic diseases. Personalized medicine offers new ways to treat and manage different types of diabetes. Outcomes research on people with diabetes can help Margie and her family members understand how to get the best care possible for their unique situation. This includes how getting treatments and other resources can help them manage their disease and improve their quality of life and well-being.



Genomics is the study of a person's complete set of DNA (the genome). DNA contains the information needed to build the human body.

Genes are the part of DNA that carries instructions that tell a cell what to do. Testing genes can reveal problems in the body.

In genetics, **risk** is the chance that a person will get a certain disease based on their genes or environment, such as what was passed down from their parents, or where they live or work.

Peer navigators and community health workers are people who are trained to help patients get health care information and resources.

Nurse navigators are nurses who get special training to help patients get through a treatment process.

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

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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