



Improving Personalized Medicine Research. Clinical Trials.

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 clinical trials about personalized medicine.

Clinical trials are research studies that learn about the effects and safety of new medical approaches in people. Medical approaches include tests to screen for and diagnose disease, vaccines to prevent disease, and treatments for disease.

People with certain traits may respond differently to a new test or treatment. Because of this, it's important for clinical trial participants to reflect the diversity of patients who may get personalized medicine in the real world. To do this, researchers must take steps to ensure people from **underserved and underrepresented groups** take part in clinical trials.

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.



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.

Underrepresented groups are groups in which 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.

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 clinical trials about personalized medicine?

Future research can improve clinical trials by answering these questions:

- What changes are needed to how researchers design and carry out clinical trials to **ensure the trial participants represent all of the groups** who have a disease in the real world, including certain races, ethnic groups, and genders?
- How can health care providers **build trust with patients, caregivers, and patient groups from diverse backgrounds** to openly discuss their concerns and fears of mistreatment when deciding on personalized medicine treatments and whether or not to join a clinical trial?



Patient profile

Candace Henley

As a black woman with no guidance on how to manage her diagnosis with colorectal cancer, Candace felt like she was falling through the cracks of the health care system. She now advocates to bring both clinical trials and cancer resources to underserved communities.

For health care to be truly personalized, clinical trials must ensure all groups affected by a disease are included. Researchers must also learn how to build trust with underserved and underrepresented communities to address their concerns and fears about taking part in clinical trials.

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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