



Glossary of Terms

Found throughout Briefs 1–10 on Improving Personalized Medicine Research

Access and use: whether a patient is able to get personalized medicine when they need it, including being able to visit a doctor, insurance coverage, and cost

Affordability: whether a patient has the income to pay the costs of personalized medicine

Billing codes: numbers and letters assigned to each health care service a health care provider may give to a patient. All providers in the U.S. use the same, standard set of codes to submit to payers for reimbursement.

Caregiver (also called family caregiver): someone who tends to the needs of a family member, friend, or neighbor who needs help due to an illness, injury, or disability

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

Coverage: the health care services and treatments that a health insurance plan covers (pays for). This can be for some or all of the cost.

Data management: how doctors, researchers, and organizations, such as hospitals, store and share information they get about patients, their health, and health care

Data transparency: doctors and researchers clearly and openly communicate to patients about:

- What data is collected
- Who can see and use it
- How it will be used

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

Genetic consultation: a meeting with a health care provider trained in genetics to talk about genetic testing and its results. This could be a meeting with a genetic counselor or certain pharmacists.

Genetic driver: 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.

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

Health care provider: a medical professional, hospital, or other medical facility that provides health care services

Health literacy: there are 2 definitions of health literacy:

- **Personal health literacy:** how well a person is able to find, understand, and use information and services to make informed health decisions
- **Organizational health literacy:** how well organizations help all people find, understand, and use information and services to make informed health decisions

Informed consent: a process researchers follow to give people important information about taking part in a study, including what will happen during the study and possible risks and benefits of taking part

New technologies: digital devices or programs, such as computers, mobile devices, and health apps, that doctors and patients use to connect, record, and share information about their health and health care

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

Off-label treatment: 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.

Outcomes research: 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.

Patient advocacy organizations: nonprofits, usually with a mission to support patients who have a certain disease or condition

Patient-centered, patient-focused: focuses on the patient's preferences, needs, and values

Patient education: giving patients the information and the tools they need to make decisions about their health

Patient-provider communication: exchange of information between a patient and their health care provider, including spoken, written, and non-verbal communication

Payers: private health insurance companies and government programs that pay providers for health care services they give to patients, such as Medicare, Medicaid, and Veterans Affairs

Payment incentives: extra payments to reward providers for giving and billing certain health care services to patients

Pediatric: areas of medicine that focus on children

Peer navigators and community health workers: people who are trained to help patients get health care information and resources. Peer navigators are often patients themselves and are trained to assist other patients diagnosed with the same health condition.

Personalized medicine (also called precision or individualized medicine): an approach to tailor health care to each patient's unique traits. It aims to prevent or treat disease in the best way for each patient using their specific information. This information can include a patient's health history, genetic test results, values, and life situation.

Real-world data: information about patients, their health, and health care that is gathered by sources such as a doctor's or hospital's electronic health records (EHRs), insurance claims and billing, and mobile phone apps

Reimbursement: the payment private health insurance companies or government programs make to health care providers, hospitals, and facilities for health care services they give to patients

Research agenda: a plan that names the top issues and related research questions in a certain field. A research agenda guides future research to advance that field.

Risk: 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

Shared decision-making: a process in which a patient and provider work together to make decisions based on research and patient preferences

Targeted treatment: a type of treatment that works best for a specific type of disease. For example, in cancer, a targeted treatment works to attack cancer cells with a certain change (mutation) in a gene and not harm healthy cells.

Telemedicine: a type of health care visit where the patient and doctor talk using an electronic device such as a phone, tablet, or computer

Underrepresented in medical research: the percent of certain study participants with a health condition is too low compared to the percent of those people with the health condition in the real world. This can include people of a certain race, ethnicity, gender, or age.

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

Value-based contract: a written agreement that states how much to pay for a health care service based on the value (benefit) the service offers a patient

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 10 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/uppyxa4>

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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