Brief 9

Improving Personalized Medicine Research. New Technologies and Data Management.

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 new technologies and data management for personalized medicine. **New technologies** in health include 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. **Data management** is how doctors, researchers, and organizations – such as hospitals – store and share the information they get about patients, their health, and health care. Improving how we use new technologies and manage data will make it easier 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

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Which research questions can help improve new technologies and data management in personalized medicine?

Future research can improve new technologies and data management by answering these questions:

- ☐ How can the **informed consent process for research participation be improved to:**
  - Make use of advances in new health technologies and data management?
  - Create trust with patients and caregivers over sharing their data for health research?
- ☐ How can the **sources of real-world data improve:**
  - **Data sharing** so doctors and researchers can more easily learn and share information about using personalized medicine and its outcomes for patients?
  - **Data transparency** for patients about how their data is shared and used?
- ☐ How can **doctors use real-world data to help choose the best personalized treatment option** for each patient?
- ☐ How can **doctors use telemedicine** to help patients and caregivers continue to learn about their genetic information, personalized medicine, and treatment options?

Patient profile

Bradford Power

After being diagnosed with a type of blood cancer called lymphoma, Brad was able to get cancer sequencing, which is a new technology to understand the genes causing his cancer. Luckily, chemotherapy worked well to treat his cancer. If his cancer returns, he hopes personalized medicine will be able to help by using this information. New technologies and data management will make it easier to develop future personalized treatments that have fewer side effects than chemotherapy and match Brad to better treatments.

Informed consent is 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.

Real-world data are the 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.

Data transparency means that 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

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

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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