



# Improving Personalized Medicine Research. Patient Education.

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 patient education about personalized medicine. **Patient education** means giving patients the information and tools they need to make decisions about their health.

## 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 patient education about personalized medicine?

Future research can improve patient education by answering these questions:

- What kinds of **new and existing educational tools and resources** can help empower patients and caregivers with different levels of health knowledge to be able to discuss personalized medicine treatment options with their health care provider?
- How can **patient advocacy organizations and health care providers work together** to provide the educational resources patients and caregivers need?
- How can we **change educational materials** about personalized medicine to meet the needs of audiences with different cultural backgrounds, languages, and **health literacy levels**?
- What **kind of information about personalized medicine and treatment options** do patients and caregivers want to get before, during, and after diagnosis and treatment?



### Patient profile

#### Ella Balasa

Ella was born with cystic fibrosis, a genetic disease which has caused continuing lung infections all her life. When a targeted treatment became available for cystic fibrosis patients with certain genetic mutations (changes in their DNA), she had genetic testing to find out what her mutation is. Fortunately, Ella has been able to benefit from taking this new targeted therapy because it works for someone with her genetic mutation. She now shares information about how personalized medicine can develop new treatments to help others with cystic fibrosis.



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

A person's **health literacy level** refers to how well they're able to find, understand, and use information and services to make informed health decisions. **Organizational health literacy** is how well organizations help all people find, understand, and use information and services to make informed health decisions.

## 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>

### CONTACT 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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