



# Improving Personalized Medicine Research. Caregiver, Pediatric, and Family Considerations.

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 caregiver, pediatric, and family considerations about personalized medicine. Examples of **caregiver, pediatric, and family considerations** include how to involve caregivers in a patient's treatment and how a patient's genetic test results may affect other family members, including children.

## 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 caregiver, pediatric, and family considerations about personalized medicine?

Future research can improve **caregiver**, **pediatric**, and family considerations by answering these questions:

- How can health care providers **talk to patients about health transitions** as a patient gets older or their disease gets worse, such as moving from pediatric to adult care or becoming eligible for new personalized medicine treatments?
- How can **family caregivers be better integrated into the care team** as partners in delivering personalized medicine, and what information do they need to help a patient make decisions about their treatment?
- How can health care providers and patient education programs **help patients, caregivers, and their families understand the chance (risk) of getting a disease** based on a genetic test result, and help them understand what that result means for children or other family members?
- How can health care providers, **peer navigators**, and patient advocacy organizations **help families share their health history** and address concerns, reservations, or taboos?



## Caregiver profile

### Mike Graglia

Mike's son, Tony, was diagnosed with SYNGAP1 at 4 years old. SYNGAP1 is a rare genetic disease that causes brain problems and many lifelong challenges, like intellectual disability, seizures, and autism. Even though researchers have not yet found a cure, Mike is grateful he knows the exact cause of Tony's challenges. Genetic testing helped him find and confirm Tony's diagnosis. Now, he can stop looking for the cause of Tony's challenges, and he can access the community of SYNGAP1 families and experts treating SYNGAP1 patients. These experts know which treatments may or may not help, and they have improved Tony's medical care.

photo credit: Barb Kinney (barbarakinney.com)



A **caregiver** (also called family caregiver) is someone who tends to a family member, friend, or neighbor who needs help due to an illness, injury, or disability.

**Pediatric** refers to areas of medicine that focus on children. For example, a pediatric cancer patient is a child who has cancer.

**Peer navigators** are people living with a disease or health condition who are trained to help others with the same condition, for example by connecting them to services.

## 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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