Improving Personalized Medicine Research. Coverage and Reimbursement.

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 coverage and reimbursement for personalized medicine. **Coverage** refers to the health care services and treatments that a health insurance plan covers (pays for). This can be for some or all of their costs. **Reimbursement** refers to 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. Laws, the government, and private health insurers decide on which health care services are paid for and how much is paid, including for 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

Which research questions can help improve coverage and reimbursement of personalized medicine?

Future research can improve coverage and reimbursement by answering these questions:

☐ How can personalized medicine **help employers and payers design health insurance plans or programs** that are more stream-lined, right for the patient, and based on patients' specific traits?

☐ How can **billing codes and payment incentives** encourage patients, caregivers, and family members to learn about genetic testing, the meaning of the results, and how it impacts treatment options?

☐ How would **coverage and reimbursement for genetic consultations** improve the use of personalized medicine?

☐ What **types of studies** are needed to inform payers about the value of covering the cost of genetic testing? For example, studies on the usefulness (clinical utility), costs and benefits (cost-effectiveness), and financial effects (budget impact) of covering genetic testing.

☐ What data are needed to help payers **reimburse for genetic testing more often** and to help providers choose the right genetic test for a patient?

☐ What evidence is needed, and what already exists, to help payers **create value-based contracts for personalized treatments** that may have higher up-front costs?

☐ How can **patient and caregiver preferences and beliefs** factor into the "value" (benefit) defined in value-based contracts?

Patient profile

Carissa Miyano

Given her family history of cancer, Carissa's health insurance covered for her to meet with a genetic counselor and get tested for genetic mutations (changes) that may raise her chance of cancer.

The test results found she had a BRCA2 gene mutation, which raises the chance of certain types of cancer, such as breast cancer. Carissa discussed her results with her genetic counselor and doctor to create a plan to manage her risk for cancer. Better coverage and reimbursement for genetic counseling services would help others use personalized medicine to prevent health problems.

Payers include 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.

Billing codes are 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.

Payment incentives are extra payments to reward providers for giving and billing certain health care services to patients. For example, Medicare and Medicaid have payment incentives.

A **genetic consultation** is 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.

A **value-based contract** is 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

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.