

Take charge of your health today. Be informed. Be involved.



ESTHER BUSH

Precision Medicine

This month, the “Take Charge of Your Health Today” page focuses on a new area of research—precision medicine. Jennifer R. Jones, MPH, CTSI community engagement senior coordinator, and Esther L. Bush, president and CEO of the Urban League of Greater Pittsburgh, discussed this topic.

JJ: Good morning, Ms. Bush. Today we’re discussing an exciting new concept of health care called “precision medicine.” You and I have already had many conversations about this. I’m looking forward to sharing information with our Courier readers. I’m sure many people are wondering what we mean by “precision medicine.”

EB: You’re probably right, Jennifer. I know that at first, I didn’t quite understand precision medicine and its long-term goals. After many enlightening conversations and presentations, I boil it down to this—the medical community providing the best possible care for each person. Care that is based on all the things that make us unique. Our genetics. Our family health history. Our daily behaviors. Our lifestyles. The medicine we take. What we put into our body. How we treat our body as we age.

JJ: Yes, Esther. Our bodies are complex. There’s still so much to learn. Our health is an overall expression of all the internal and external factors you have just outlined. Some of the factors that influence our health we can change; unfortunately, some of them we cannot. Dr. Massart really does a great job detailing the main points of precision medicine in the overview section below. Precision medicine is care that is tailored to you as an individual. It aims to have your care provider understand and treat you based on your genetics and your environment.

EB: This topic ties in with our topic last month—research and health equity. We all want to know that when we go to the doctor, we’re getting the best care, no matter what we look like or what health conditions we have. I want to reiterate something. Health care is based on research. Health care and research are moving forward, whether we are a part of them or not. I choose to participate in research because I want to know that people like me are represented in the data when those health and treatment decisions are made.

JJ: I always appreciate your openness and honesty, Esther. You’re right. In the past, research has not always been inclusive, whether it is because of a lack of diversity based on age, race, gender, sexual orientation, or even where you live. But things are changing. Former President Obama had a big vision when he announced the Precision Medicine Initiative in 2015. All across our country, the best physicians and researchers are focusing on learning more about all of us to improve health care. The research network is growing in our region, and it’s really exciting.

EB: I’m so glad that the Urban League of Greater Pittsburgh can be a part of this through our partnership with CTSI. History is truly being made through this national initiative. I encourage everyone to learn more about precision medicine using the resource links provided on this page. We need to have informative and meaningful conversations in our families and communities about research. This is what the future of health care looks like for our children and grandchildren.

JJ: As always, thank you for your time and input, Esther. If anyone has questions or would like more information about precision medicine, e-mail partners@hs.pitt.edu. Our team is more than willing to come to your organizations, schools and churches to answer questions and engage in meaningful conversations.

This year is winding down quickly! Our December topic will examine cyberbullying. Unfortunately, this seems to be a growing problem, especially among our school-aged children and adolescents. We have experts here at Pitt who care deeply about this and are going to share research and current interventions.



VISIONARY MESSAGE—President Barack Obama delivers the State of the Union address in the House Chamber at the U.S. Capitol in Washington, D.C., Jan. 20, 2015. (Official White House Photo by Pete Souza)

Precision Medicine a new concept of individual healthcare

Doctors have always recognized that every patient is unique, and doctors have always tried to tailor their treatments as best they can to individuals. You can match a blood transfusion to a blood type—that was an important discovery. What if matching a cancer cure to our genetic code was just as easy, just as standard? What if figuring out the right dose of medicine was as simple as taking our temperature?—Former President Obama, January 30, 2015, State of the Union Address

What former President Barack Obama is describing is precision medicine. With the launch of the Precision Medicine Initiative in 2015, he helped bring to people of the United States a new concept of health care that is tailored to the individual.

Precision medicine means that doctors will use patients’ medical histories, genetic information and relevant research to create a treatment plan designed for them. It will give doctors the tools they need to best care for and treat their patients, says Mylynda B. Massart, MD, PhD, assistant professor of family medicine at the University of Pittsburgh. She is also medical director at UPMC Matilda H. Theiss Health Center.

“If doctors know what diseases patients are at risk for through genetic testing, we might be able to treat them in a way that would help prevent those diseases,” says Dr. Massart. “For example, people are at risk for cancer because they’re smokers. From research, I know that smokers have a certain chance of getting lung cancer. But with precision medicine, I might be able to tell patients that, based on their genetic information and family history, whether they will get a disease like cancer. Having that data will allow health care providers to talk specifically about their patients’ health.”

Health care is based on research. Medications are developed through research, under rigorous review and with people agreeing to participate in research studies. But, in the past, research did not always include people from all racial and ethnic backgrounds. Also, historically, people from certain racial and ethnic backgrounds have been

reluctant to participate in research. Therefore, research has been done on limited patient populations.

“For example, a lot of research on cholesterol medication has been done on middle-aged white men,” says Dr. Massart. “We wouldn’t know if that medication would have the same effect on, say, African American women or Latino men. So, we can’t always base health care practices on the research that has been done.”

Precision medicine involves getting as much data as possible, from a patient population as possible. It allows doctors to put research in context with a patient’s personal information and create a treatment specific to that person. Health care providers like Dr. Massart consider this a step forward in the practice of medicine.

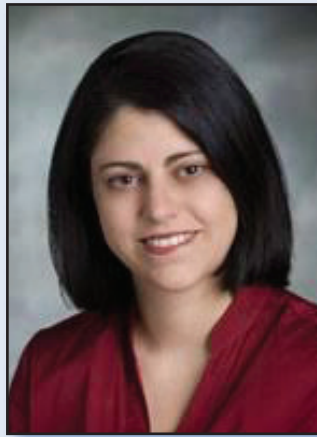
Precision medicine also has the potential to positively affect the use of medications. Research is revealing more about how people’s genetic makeup affects their response to certain medications (the field of pharmacogenomics). With this information and all the data about personal history, doctors can know right away which medicine will work best for an individual instead of going through the

sometimes-long process of trying a medication, waiting to see if it works, moving on to the next medication, waiting to see if it works and so on.

Because precision medicine involves the use of personal information, people sometimes have privacy concerns. Dr. Massart notes the Genetic Information Nondiscrimination Act (GINA) of 2008. It prohibits the use of genetic information in health insurance and employment. GINA provides some protection.

People from Southwestern Pennsylvania have an opportunity to contribute to the precision medicine momentum. Former president Obama, recognizing that we needed a much broader and diverse research database, created the All of Us research program through the National Institutes of Health. PA Cares for Us is the local arm of the national program. The University of Pittsburgh was awarded a grant to recruit participants over the next five years. The goal is to recruit a truly diverse population—diverse in terms of geography, age, ethnicity, race, sexual orientation, gender identification, etc.—from Western Pennsylvania. Participants will join a research network where they will provide access to their electronic health records, personal history, and bio samples (urine and blood for genetic testing, weight, height, blood pressure, etc.). Participants will have opportunities over many years to provide data about themselves that will help researchers learn more about how individual differences in lifestyle, environment and biological make-up (such as genetic background) influence health and disease. This is expected to lead to new treatments tailored to individual patients.

Precision medicine is starting to be a part of people’s health care. Dr. Massart says, “We’re using genetic information to know patients’ risk for having certain diseases and how to treat them (like testing a patient for a BRCA gene mutation, which can indicate a higher risk for cancer, if that patient has a consistent family history of breast or ovarian cancers). We don’t have global genomic information being integrated into many health systems yet, but some are starting that process.”



Mylynda B. Massart, MD, PhD

Learn More about Precision Medicine

Are you interested in precision medicine and want to learn more? Check out the following websites:

PA Cares for Us Research Program explains the local precision medicine initiative and how participants can help create a healthier future: <https://pacareshforusresearch.org/>.

Precision medicine experts have partnered with WebMD to provide an overview of the topic at

www.webmd.com/cancer/precision-medicine#1.

Precision Medicine Initiative page in the White House archives, which includes testimonials and stories about how this new area of research has helped individuals as they battle serious diseases and cancer:

obamawhitehouse.archives.gov/node/333101.

Questions about precision medicine can be e-mailed to partners@hs.pitt.edu.

Understanding the Ethics of Research

Did you know that there are many ethical principles that researchers must follow? This is to ensure that research is done in a way that minimizes risk and provides benefit to research participants. “Research” is a broad term for an organized way to gather information. The information is collected through the use of surveys, interviews, medical record reviews, tests or medical procedures. Research needs to provide valuable knowledge to benefit people. It also has the potential to improve the care or well-being of future generations.

The University of Pittsburgh takes research ethics seriously. Its Human Research Protection Office (HRPO) oversees all studies. The mission of this Institutional Review Board is “to protect and serve.” Each study is reviewed by multiple trained staff members to ensure that the study meets research ethics principles.

Recently, there have been national efforts to increase community engagement in research and demonstrate respect for cultural differ-

ences. When communities are involved in research and working with researchers, people can benefit from the shared knowledge. Community involvement also gives people a voice in the direction of the research.

Judith Navratil, MA, CIP, is a faculty research liaison for the University of Pittsburgh Human Research Protection Office. Ms.

Navratil works with academic researchers to ensure that their research meets regulatory and ethical standards. She also gives presentations to community members, people working in academics and students on the importance of conducting ethical research. She trains researchers and communities on how important it is for research to be equi-

table. This means that the risks and benefits of scientific research are equally distributed among all communities.

Ms. Navratil says, “Before joining the staff of HRPO, I worked for nearly 20 years as a research coordinator. I ran studies of children and teens with mental health issues. From this experience, I learned that research participants are the most important members of the research team. Without their willingness to share their experiences, advances in scientific knowledge would not be possible.”

If you would like to learn more about Pitt’s HRPO, visit www.irb.pitt.edu.

APPLYING GUIDELINES

Principle	Applications
Respect for Persons	•Informed consent •Privacy (Confidentiality and Anonymity)
Beneficence	•Protecting participants from harm •Assessment of risks and benefits
Justice	•Choosing participants

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