



Relevance of Health Literacy to Precision Medicine: Workshop in Brief

DETAILS

4 pages | 8.5 x 11 |
ISBN 978-0-309-44405-7 | DOI: 10.17226/23538

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Relevance of Health Literacy to Precision Medicine— Workshop in Brief

On March 2, 2016, the Roundtable on Health Literacy of the National Academies of Sciences, Engineering, and Medicine convened a workshop to examine the relevance of health literacy to precision medicine, a growing field that takes into account individuals' differences in genes, environments, and lifestyles. The workshop explored the intersection of health literacy and precision medicine through a number of topics, but its impetus was the Precision Medicine Initiative (PMI). The PMI is a multiyear effort announced in 2015 and launched in 2016, led by the White House and including agencies across the federal government, to advance the practice of precision medicine. As Bernard Rosof (Quality in Healthcare Advisory Group) noted in his introductory remarks, a central goal of the PMI is to recruit more than 1 million volunteer participants to contribute health and genomic data as part of the PMI research cohort. Rosof further noted that historically vulnerable populations, such as minorities and low-income populations, may have much to gain from this research, as they are also the most likely to have low health literacy and be underrepresented in research. Rosof said that was the reason the roundtable chose to convene a workshop on this issue; to highlight the importance of health literacy to the practice of precision medicine.

The workshop was organized into four sessions. The first session set the stage for the rest of the day by offering presentations on precision medicine, health literacy, and the ways in which they overlap. The second session was devoted to health literacy in precision medicine research and the third session explored the communication of risk and uncertainty in the clinical setting. The final session focused on communicating with the public about precision medicine. This Workshop in Brief follows that structure and is organized by panel. The information and viewpoints summarized in this Workshop in Brief reflect the knowledge and opinions of the workshop participants and should not be construed as consensus.

INTRODUCTION AND BACKGROUND

The workshop began with a stand-alone presentation from Joseph D. McInerney (American Society of Human Genetics) on the history of communication and teaching about genetics and the overall importance of genetic literacy, which he defined as an understanding of genetics as the study of inherited biological variation. This presentation was followed by the first moderated panel of speakers.

McInerney said that he believed there were two reasons to promote genetic literacy. The first is to help people understand the history and nature of life on Earth, and the second is to better understand the future of health care. He stated that he believes that medicine is moving toward “a prevention-based health care system increasingly informed by genetic perspectives.” This focus on prevention will require a partnership between health care providers and the public, said McInerney. The key questions challenging educators of health professionals, McInerney said, are (1) What content is appropriate, and for whom is it appropriate?, (2) Which clinical behaviors and attitudes do we want to change, and can we?, and (3) How do we define and measure success?

McInerney believes that providers and educators should communicate to the public that genes play varying roles in illness depending on the disease and other factors, such as age. He also stated that genetic literacy is part of a broader concept of science literacy, which is an understanding that science is a way of learning about and explaining the natural world.

Ruth Parker (Emory University) moderated the first panel and introduced the speakers: Sara Van Driest (Vanderbilt University), William Elwood (National Institutes of Health), and Michael Wolf (Northwestern University).

Van Driest discussed the definition and evolution of precision medicine. She defined precision medicine as “an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person.” She noted that “genes,” “environment,” and “lifestyle” are the words most often emphasized but said that for her the “key words in this definition are ‘individual variability’” because as a physician that is the crucial component. Van Driest said that all doctors treat individuals but that precision medicine is a different way of thinking about disease and treatment. According to Van Driest, precision medicine is already being practiced for a number of diseases, and the goal is to increase the number of physicians and patients who benefit from the precision medicine approach to treatment. Van Driest closed by saying that the key point physicians, patients, and the public should understand about precision medicine is that it requires a probabilistic approach to health care instead of a deterministic one.

Elwood discussed health literacy and how the field has grown and changed. He explained that health literacy is not just about medical decisions but also about health and fitness, prevention, and other behaviors and decisions that influence overall health and well-being. He presented an overview of past and current research in the field of health literacy and noted that effective communication is a big part of health literacy. According to Elwood, health literacy is a dynamic state that depends on context. The field of health literacy research studies the processes by which people obtain, maintain, and manage their health and well-being, he said.

In his presentation, Wolf examined the PMI and why health literacy matters in this effort. According to Wolf, paying attention to health literacy in recruiting and communicating with the PMI’s 1-million-plus cohort will avoid generating data that are not useful. Wolf explained that the first two health literacy challenges for the PMI will be building trust with the public and gaining truly informed consent from participants. The final challenge, said Wolf, will be communicating to the public what is being learned from the PMI and the value of that knowledge. To be successful, asserted Wolf, the PMI will have to use health survey instruments that have been validated across all levels of health literacy and a multifaceted approach to retention.

HEALTH LITERACY IN PRECISION MEDICINE RESEARCH

Laurie Myers (Merck & Co., Inc.) moderated the second panel and introduced the speakers: Suzanne Bakken (Columbia University), Consuelo Wilkins (Meharry-Vanderbilt Alliance), and Paul S. Appelbaum (Columbia University).

Bakken gave an overview of the Washington Heights/Inwood Informatics Infrastructure for Comparative Effectiveness Research (WICER),¹ an informatics study conducted in an immigrant community at high risk for health disparities. Bakken’s presentation focused on the elements of the study that concentrated on obtaining truly informed consent and the best way to communicate study results and health information to a population with low health literacy. She observed that it was possible to recruit low health literacy populations into research cohorts but that it required time and resources to do so. In this project, the researchers developed and tested numerous documents and infographics, said Bakken, and found that giving data without context was meaningless to study participants who would “create the story that went with the data.” Bakken said that they created graphics that were tailored to the community through an iterative process that relied on participant input. As a result of this process, researchers were able to communicate complex information in a way that was very accessible to study participants. She also noted that rigorous testing and validation of methods of communication were critical to finding a way of conveying information that was meaningful to the people receiving it.

Wilkins began her presentation on engagement and retention in research studies by noting that engagement is not the same as outreach. Outreach only goes one direction, said Wilkins, whereas in engagement both sides are learning about the other. Both approaches have merit in certain contexts, explained Wilkins, but for a long-term study such as the PMI engagement is required. There are different strategies for effective engagement, said Wilkins, but for a study as large as the PMI it is necessary to involve a greater number of people very early in the process. Wilkins noted that since her organization’s award to be a part of the PMI was announced the previous week, researchers had identified 17 different

¹ The Washington Heights/Inwood Informatics Infrastructure for Comparative Effectiveness Research study was funded by the Agency for Healthcare Research and Quality from 2010 to 2013. More information on WICER can be found at http://repository.edm-forum.org/ahrq_arra_cer-grants/6 (accessed May 6, 2016).

populations as priorities for engagement. She said that for some of those populations, building trust toward the research community would be a critical first step that requires time and effort on the part of researchers.

Appelbaum addressed the issue of reporting the results of genetic testing and sequencing to research participants. He began by explaining that genetic tests can reveal a lot of information that is secondary to the principal aims of the research and that some of this information may have health implications for the individual. Appelbaum presented the results of a survey of genetics researchers that showed that most thought that participants should be warned of the possibility of secondary findings before they engage in the study. He also presented further research showing that there was little consensus among researchers regarding the best way to obtain informed consent related to secondary findings or how to counsel participants about those results.

COMMUNICATING RISK AND UNCERTAINTY IN THE CLINICAL SETTING

Laurie Francis (Oregon Primary Care Association) moderated the third panel and introduced Lori Erby (Johns Hopkins University) and Jessica Ancker (Weill Cornell Medical College).

Verbal communication can be just as challenging as written communication for those with lower health literacy, asserted Erby in her discussion of the challenges of effective communication in the clinical setting. Studies have shown that even those with high levels of literacy can struggle to retain information that has been presented verbally, said Erby. In the context of genetic counseling, Erby's work has found that people understand better when the use of jargon is limited, when language is less complex, and when the counselor is more interactive. Erby said that providers are uncomfortable with communicating genetic information for two reasons: (1) they do not feel knowledgeable about genetics, and (2) they are uncomfortable with communicating about risk over time. She also noted that, for patients, decision making is rooted not just in knowledge but in values, which will influence how they act on the information they receive.

Ancker gave her presentation on the challenges of communicating risk to low health literacy populations within the context of precision medicine. Ancker began by noting that low literacy and low numeracy are significant issues that can affect both the research and the practice of precision medicine. Addressing these issues, Ancker explained, is not just about the patient and provider but also about the documents and materials used in the encounter. Ancker noted that if medicine is not one size fits all, it is not a surprise that information is not either. Ancker provided a number of ways to present information that have been found to be effective. She commented that the intent of the information can also determine how it is displayed; for example, information that is intended to spur behavior change can be presented differently from information intended as a decision-making tool. Ancker also highlighted that it is important to test communication tools and information displays because there is always a risk that the message intended will not be the message received by the audience.

COMMUNICATING WITH THE PUBLIC

Catina O'Leary (Health Literacy Missouri) moderated the fourth panel and introduced Kathleen Hickey (Columbia University Medical Center) and Chris Gunter (Marcus Autism Center).

Hickey's perspective as a nurse informed her overview of the role of health professional and health advocacy organizations in educating providers and the public. She said that improving her communication skills with patients and families over many years had taught her that these types of organizations can play an important role in promoting genetic literacy among providers. The field is continually evolving, said Hickey, and a number of professional and health care organizations are very active in providing continuing education opportunities for health care professionals to learn more about genetics, precision medicine, and effective communication about these topics with their patients.

The dynamic role of social media in promoting health literacy in precision medicine was the focus of Gunter's presentation. She noted that research shows that although social media platforms reach millions of people, within any topic there tend to be key opinion leaders who filter and explain complex information. Gunter encouraged other scientists to work to become key social media opinion leaders for health literacy, precision medicine, and genetics. According to Gunter, the public needs well-informed communicators to counter misinformation and misconceptions that are present on social media. She also noted that interacting on social media is one way for researchers and practitioners to hear from the communities they are studying or serving and to learn their values and concerns.◆◆

DISCLAIMER: This Workshop in Brief was prepared by **Melissa G. French** as a factual summary of what occurred at the meeting. The statements made are those of the author or individual meeting participants and do not necessarily represent the views of all meeting participants; the planning committee; or the National Academies of Sciences, Engineering, and Medicine.

REVIEWERS: To ensure that it meets institutional standards for quality and objectivity, this Workshop in Brief was reviewed by **Laurie Myers**, Merck & Co., Inc., and **Kim Parson**, Humana, Inc. **Lauren Shern**, National Academies of Sciences, Engineering, and Medicine, served as the review coordinator.

SPONSORS: This workshop was partially supported by the Agency for Healthcare Research and Quality, Health Resources and Services Administration, National Institutes of Health, National Library of Medicine, and Office of Disease Prevention and Health Promotion at the Department of Health and Human Services. Nonfederal sponsorship was provided by the Aetna Foundation; AbbVie Inc.; American Dental Association; Bristol-Myers Squibb; Eli Lilly and Company; Health Literacy Missouri; Health Literacy Partners; Humana; Institute for Healthcare Advancement; Kaiser Permanente; Merck & Co., Inc.; Northwell Health; and UnitedHealth Group.

For additional information regarding the meeting, visit
www.nationalacademies.org/hmd/Activities/PublicHealth/HealthLiteracy/2016-MAR-2.aspx.

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