



COMMENTARY

Health-literate care organizations for precision health

Jason L. Vassy^{1,*} , Maren T. Scheuner², Marla L. Clayman³



¹VA Boston Healthcare System and Harvard Medical School, Boston, MA; ²San Francisco VA Health Care System and University of California San Francisco School of Medicine, San Francisco, CA; ³Edith Nourse Rogers Memorial Veterans' Hospital, Bedford, MA, UMass Chan Medical School, Worcester, MA

ARTICLE INFO

Article history:

Received 31 March 2024

Received in revised form

10 June 2024

Accepted 12 June 2024

Available online 19 June 2024

Keywords

Genomic Medicine

Health-literate care organization

Health literacy

Precision health

Introduction

Personal health literacy is defined as an individual's "ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others." Health literacy is positively associated with numerous health outcomes and is considered a social determinant of health.^{1,2} Health literacy is increasingly important as health care and medical decision making become arguably more complex, with the advent of precision health approaches to prevent, diagnose, and treat disease. In this commentary, we illustrate how, in becoming

precision health-literate care organizations, health care systems can promote precision health literacy at scale for patients and clinicians, fostering the equitable translation of precision health innovations into improved outcomes.

The growing need for precision health literacy

Precision health technologies, including novel molecular tests and targeted therapies, have proliferated in recent years and are emerging as important components of health care across the lifespan. Examples include prenatal cell-free DNA screening, which can detect fetal genetic abnormalities in maternal blood samples, multi-cancer early detection and other liquid biopsy tests that can detect and monitor dozens of cancer types from circulating tumor DNA and other biomarkers in the blood, and precision therapeutics for diseases such as sickle cell anemia. These and other precision health technologies present challenges for patients with low health literacy, who may have difficulty understanding their benefits, limitations, and uncertainties and using that information in complex decision making. Rapid developments in precision health technologies, made possible by the increased availability of clinical data and advances in computational tools, such as artificial intelligence, may create unprecedented challenges for patients of all literacy levels, who may struggle to conceptualize changing diagnostic and treatment paradigms.

One-third of Americans have inadequate personal health literacy, but assessing literacy and tailoring care at the individual patient level are difficult to achieve at scale. Hence,

*Correspondence and requests for materials should be addressed to Jason L. Vassy, VA Boston Healthcare System, 150 South Huntington Avenue, 151B, Boston, Massachusetts 02130. Email address: jvassy@bwh.harvard.edu

there have been recent calls for increased organizational health literacy, defined as “the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.”¹ The Agency for Healthcare Research and Quality recommends health care providers adopt a universal precautions approach to health literacy, always using clear and comprehensible information with the assumption that every patient is at risk for low health literacy and its attendant poor outcomes. Becoming a health-literate care organization thus entails additional system-wide support and training so that health literacy barriers are addressed at all points and all levels within a health care system.

Attributes of a precision health-literate care organization

The National Academy of Medicine Roundtable on Health Literacy has identified 10 attributes of a health-literate care organization.³ We propose how this model can be applied to promoting precision health literacy specifically (Table 1). A precision health-literate care organization integrates precision health considerations in multiple and innovative ways throughout the system, including ongoing training for non-genetics clinical staff and health educators, introduction of precision health navigators, access to educational materials designed with input from a variety of populations, and inclusion of clinical genetics and other specialty providers in the planning and evaluation of these efforts at all levels of the organization. The goal is not to train every physician, medical assistant, and health care executive to be a genetic counselor; rather, it is to create systems that give patients and health care workers the information and tools they need to use precision health technologies appropriately in medical decision making. Here, we focus on how such a precision health-literate care organization can promote the quality and health equity of precision health.

Precision health quality

In the precision health context, quality of care refers to the extent to which health care organizations use precision health technologies to optimize patient outcomes in a manner that is effective, safe, and patient-centered. Key indicators of precision health care quality might include the accuracy and reliability of genetic testing processes, the appropriateness of how a precision treatment is used in the health system, rates of precision health adverse events, and patient understanding of and engagement in decisions to use precision health technologies in their care plans. A health-literate care organization can promote quality at several key steps in organizational processes and patient care paths. For example, a literacy-adapted, patient-facing family history collection tool can improve assessment of hereditary cancer risk, whereas plain-language guides for breast cancer genetic counseling can promote the understanding of testing options

for patients of all literacy levels.^{4,5} Such systems-level strategies promote high-quality shared decision making and decrease the likelihood that patients, including those with low health literacy, experience adverse outcomes or make health care decisions discordant with their preferences and values.

Precision health equity

Low health literacy is more prevalent among patient populations who already experience poorer health outcomes due to other social determinants of health, including lack of health insurance, lower educational attainment, and neighborhood deprivation. In adopting a universal precautions approach, precision health-literate care organizations promote the safe, effective, and equitable use of precision health technologies. Moreover, most genetic associations with human disease are best understood in populations of European descent, and the clinical trials supporting the use of certain precision therapeutics enrolled predominantly non-Hispanic White patients.^{6,7} Although the biomedical research community must address these inequities in the evidence base, precision health-literate care organizations must transparently communicate accurate information about how the risks, benefits, and uncertainties of precision health technologies might differ between populations. Given the high costs of most of these technologies, systems must also provide transparent coverage and out-of-pocket cost information to patients.

Toward a precision health-literate future

Several health care systems have taken steps toward becoming health-literate care organizations.⁸ In parallel, frameworks for integrating precision medicine into learning health systems and other health organizations have been proposed.^{9,10} Because precision health technologies will increasingly become integral parts of health care, both types of initiatives should implement and evaluate measures to promote organizational precision health literacy. Rapid advances in the field will pose challenges for the creation and maintenance of such programs, but the investment will help ensure that all patients benefit from precision health care.

Funding

This work was supported by grant I01HX003627 from the US Department of Veterans Affairs Office of Research and Development. This work does not represent the views of the US Government or the US Department of Veterans Affairs.

Author Contributions

Conceptualization: J.L.V., M.L.C.; Funding Acquisition: J.L.V., M.L.C.; Project Administration: J.L.V., M.L.C.;

Table 1 Application of the attributes of a health-literate care organization to precision health

Attributes of a Health-Literate Care Organization	Example Applications in a Precision Health-Literate Care Organization
1. Has leadership that makes health literacy integral to its mission, structure, and operations	<ul style="list-style-type: none"> • Leadership prioritizes the advancement of understanding and communication of precision health concepts across the organization. • Responsibility and authority for precision health literacy are assigned to a senior leader or high-level task force that includes genetics or other precision health experts. • Organizational goals for precision health literacy are set, monitored, and incentivized.
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement	<ul style="list-style-type: none"> • Metrics for precision health literacy are defined, tracked, and used to inform literacy improvement initiatives. • Precision health literacy disparities are monitored. • Safety concerns related to poor understanding or communication of precision health concepts are reported and inform root-cause analyses.
3. Prepares the workforce to be health literate and monitors progress	<ul style="list-style-type: none"> • Precision health literacy education is continually provided to clinicians and frontline staff. • Roles and responsibilities for explaining relevant precision medicine concepts to patients and families are clarified. • Resources are made readily available to staff that can help guide conversations about precision health technologies.
4. Includes populations served in the design, implementation, and evaluation of health information and services	<ul style="list-style-type: none"> • Patients from diverse backgrounds and different health literacy levels are consulted in the design of health information about precision medicine. • Genetic counseling and other services are designed with input from populations of diverse cultural and linguistic backgrounds.
5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatization	<ul style="list-style-type: none"> • Precision health literacy “universal precautions” are adopted to normalize clear communication and ensure comprehension among all patients. • Resources and personnel are available for additional support to patients with the greatest precision health literacy needs.
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact	<ul style="list-style-type: none"> • Patient understanding of relevant precision health information is verified at each interaction. • Decision making about precision health testing includes discussion of risks, benefits, and uncertainties. • Question-asking about precision health is encouraged throughout the organization. • Technology is used to facilitate effective communication about precision health where appropriate.
7. Provides easy access to health information and services and navigation assistance	<ul style="list-style-type: none"> • The organization provides patients access to electronic systems that facilitate the exchange of genetic and other molecular results among providers and coordinate care between primary, nongenetic specialty (eg, oncology), and genetic specialty care services. • Precision health navigators help patients problem solve and overcome challenges to accessing precision health information and services. • Novel service delivery models (eg, specialty integration or e-consult models) are used to expand access to precision health services.
8. Designs and distributes print, audiovisual, and social media content that is easy to understand and act on	<ul style="list-style-type: none"> • A collection of high-quality educational materials for patients of diverse precision health literacy levels is produced or curated (eg, brochures, videos, and photo-novellas) • Genetics professionals or other personnel with precision health communication expertise are consulted in the development of new materials.
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines	<ul style="list-style-type: none"> • Systems are created to ensure accurate exchange of genetic and other molecular test results between episodes of care. • Measures are implemented to ensure the accuracy and safety of precision management and treatment decisions (eg, gene therapy).

(continued)

Table 1 Continued

Attributes of a Health-Literate Care Organization	Example Applications in a Precision Health-Literate Care Organization
10. Communicates clearly what health plans cover and what individuals will have to pay for services	<ul style="list-style-type: none"> • Staff and resources are provided to help patients find out the coverage, out-of-pocket costs, and reimbursement process for a precision health test or treatment. • Staff have familiarity with different insurance plans and take coverage and cost into consideration when ordering precision health test or treatment.

Writing-original draft: J.L.V., M.L.C.; Writing-review and editing: J.L.V., M.T.S., M.L.C.

Conflict of Interest

The authors declare no conflicts of interest.

Declaration of AI and AI-Assisted Technologies in the Writing Process

During the preparation of this work, the authors used ChatGPT-4 from OpenAI to brainstorm preliminary ideas and examples of precision health-literate care organizations. After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

References

1. What is health literacy? Centers for Disease Control and Prevention. Accessed December 20, 2023. <https://www.cdc.gov/healthliteracy/learn/index.html>
2. Nutbeam D, Lloyd JE. Understanding and responding to health literacy as a social determinant of health. *Annu Rev Public Health*. 2021;42:159-173. <http://doi.org/10.1146/annurev-publhealth-090419-102529>
3. Brach C, Dreyer B, Schyve P, et al. Attributes of a health literate organization. *NAM Perspect*. 2012;2(1):1-3. <http://doi.org/10.31478/201201f>
4. Mittendorf KF, Lewis HS, Duenas DM, et al. Literacy-adapted, electronic family history assessment for genetics referral in primary care: patient user insights from qualitative interviews. *Hered Cancer Clin Pract*. 2022;20(1):22. <http://doi.org/10.1186/s13053-022-00231-3>
5. van der Giessen JAM, Ausems MGEM, van Riel E, de Jong A, Fransen MP, van Dulmen S. Development of a plain-language guide for discussing breast cancer genetic counseling and testing with patients with limited health literacy. *Support Care Cancer*. 2021;29(6):2895-2905. <http://doi.org/10.1007/s00520-020-05800-7>
6. Sirugo G, Williams SM, Tishkoff SA. The missing diversity in human genetic studies. *Cell*. 2019;177(1):26-31. <http://doi.org/10.1016/j.cell.2019.02.048>
7. Aldrighetti CM, Niemierko A, Van Allen E, Willers H, Kamran SC. Racial and ethnic disparities among participants in precision oncology clinical studies. *JAMA Netw Open*. 2021;4(11):e2133205. <http://doi.org/10.1001/jamanetworkopen.2021.33205>
8. Kaper MS, Sixsmith J, Reijneveld SA, de Winter AF. Outcomes and critical factors for successful implementation of organizational health literacy interventions: a scoping review. *Int J Environ Res Public Health*. 2021;18(22):11906. <http://doi.org/10.3390/ijerph182211906>
9. *Roundtable on Translating Genomic-Based Research for Health; Board on Health Sciences Policy; Institute of Medicine. Genomics-Enabled Learning Health Care Systems: Gathering and Using Genomic Information to Improve Patient Care and Research: Workshop Summary*. National Academies Press; 2015. <http://doi.org/10.17226/21707>
10. Agarwal A, Pritchard D, Gullett L, Amanti KG, Gustavsen G. A quantitative framework for measuring personalized medicine integration into US healthcare delivery organizations. *J Pers Med*. 2021;11(3):196. <http://doi.org/10.3390/jpm11030196>