Health Literacy.

JOIN THE CONVERSATION.

A Report from THE SISTERS of CHARITY FOUNDATION of Cleveland
HEALTH LITERACY IS AN INDIVIDUAL AND FAMILY ISSUE, A COMMUNITY RESPONSIBILITY, AND A NATIONAL CHALLENGE.

The Sisters of Charity Foundation of Cleveland, a ministry of the Sisters of Charity Health System, is committed to improving health outcomes and access to care for people living in poverty. The Foundation views health as vital to supporting families, building stable neighborhoods and reducing poverty. In our strategic vision, the Foundation focuses on improving our community’s capacity to eliminate health disparities, exemplified by health outcomes that are significantly worse for vulnerable populations.

In our view, Health literacy lies at the intersection of many socioeconomic conditions, from gaps in education to the complexity of the health care system. It encompasses an individual’s ability to find, understand, evaluate, and use health information, to engage the services needed to make appropriate health decisions and navigate the health care system.

Since 2007, we have led a collaboration that has invested significant funds in planning and demonstration grants, convening’s and evaluation to advance health literacy in Cuyahoga County by enhancing the capacity of providers and organizations to implement or adapt health literacy practices into effective programs and strategies. I wish to thank the Cleveland Foundation for their collaboration and generous support to this important initiative.

The 5-year investment in health literacy has led to many discoveries for the Foundation and contributions to the field. Grantee partners across clinical and community-based practices have executed an assortment of strategies to increase health literacy and impact patient outcomes — cutting across disease states, socioeconomic and racial backgrounds. The assortment of new findings has occurred amid the constant evolution of the healthcare system. With the implementation of the Affordable Health Care Act, greater emphasis is placed on prevention, access, readmissions, health equity and quality of care — particularly among a population of new users of the healthcare system.

So while our learning has been valuable, we find ourselves asking new questions and re-evaluating the complexities that a patient faces within a healthcare delivery system, as the scope and scale of health literacy becomes greater with the rollout of current healthcare system changes.

We are pleased to share our perspective on health literacy — the issue, the impact on patients and health outcomes, the cost and our personal experience with addressing health literacy locally. We hope our lessons learned, experiences and success will encourage others to join in the conversation, seek innovative partnerships, collaborations and stimulate further action within communities, organizations and the healthcare sector to continue to understand the role of health literacy in positive health outcomes.

Susanna H. Krey
President
Sisters of Charity Foundation of Cleveland
where should we begin?
We know that health literacy involves an individual's ability to find, understand, evaluate and use health information; to engage services needed to make appropriate decisions; and to navigate the system. More than reading, health literacy is the capacity to comprehend prescriptions, appointment notices, hospital admission policies, insurance coverage, and financial eligibility information. It also concerns issues of personal empowerment, and active participation in decision-making. A misstep in anyone of these areas can greatly change the course of one’s health.

The Implications of Health Literacy

Did you know that low health literacy crosses all socioeconomic strata, and is a result of factors ranging from gaps in education to the complexity of the healthcare system? Like many urban communities, Cleveland, Ohio, the largest city in Cuyahoga County, faces many health challenges, impacting individuals from all walks of life — which is illustrated substantially in the report, “County Health Rankings and Roadmaps.” Five years ago, the Sisters of Charity Foundation of Cleveland led an integrated approach to health literacy, coordinating patients, healthcare providers and insurers, schools, libraries, media, the business community, government agencies and other community organizations to increase health literacy and improve health outcomes in Cuyahoga County.

The Sisters of Charity Foundation of Cleveland recognizes the complexity of Health literacy. Is it simply an issue of “functional literacy” and a person's cognitive capacity, or is it a determinant of health, which poses larger systemic challenges? Is health literacy a concern only for those seeking medical care, or are healthcare providers also responsible for addressing the issue? Does the community at large have a responsibility to ensure that its members are health literate?

Health literacy transfers knowledge into practice. It draws upon a wide range of skills and competencies that people develop in order to seek, understand, assess and act on health information.

Health literacy is the connecting point between health promotion, education and health delivery. Therefore it is a critical factor in improving patient knowledge, quality of care and patient outcomes. In contrast, health promotion or health education narrowly focuses on increasing patient’s control over their health and the gap between what people know about health and what they practice.

The field of health literacy continues to evolve, the questions continue to be debated, and models continue to be tested and implemented to decrease health disparities and increase positive health outcomes.

LOW HEALTH LITERACY = A DECREASED ABILITY TO PREVENT ILLNESS OR MANAGE CHRONIC CONDITIONS

Here are three situations demonstrating low health literacy:

1) A man confused by a questionnaire in his doctor’s office reflexively answers “no” to every question because he doesn’t understand what is being asked.

2) An elderly woman sent home from the hospital develops a life-threatening infection because she doesn’t understand the warning signs listed in the discharge instructions.

3) A two-year old is diagnosed with an inner ear infection and prescribed an antibiotic. Her mother understands that her daughter should take the prescribed medication twice a day. After carefully studying the label on the bottle and deciding that it doesn’t tell how to take the medicine, she fills a teaspoon and pours the antibiotic into her daughter’s painful ear.

Low health literacy is most prevalent among:

- Older adults
- Minority populations
- Recent immigrants (non-native speakers of English)
- People of low socioeconomic status
- Medically underserved people
- People with chronic physical and/or mental health conditions

Those with low health literacy are more likely to have difficulties:

- Locating providers and services
- Completing medical history forms
- Seeking preventative health care
- Connecting risky behaviors and health consequences
- Managing chronic health conditions
WHY IS HEALTH LITERACY IMPORTANT?

It’s a big deal because nearly half of all American adults, 90 million people—have difficulty understanding and using health information, according to a report by the Institute of Medicine. That’s 1 out of every 2 adults—just imagine, the person sitting next to you on the bus, in a meeting, standing behind you in line at the grocery store, or you—struggle with understanding health information. Other consequences include:

- Reduced use of preventative health services
- Mismangement of chronic medical conditions
- Medication errors
- Misunderstanding due to poor communication between patients and doctors and nurses
- Low rates of patients’ following doctors recommended course of treatment
- Billions of dollars in avoidable healthcare costs
- Unnecessary emergency dept. visits and hospitalizations

Health literacy is firmly linked to successfully implementing the federal Affordable Health Care Act and controlling medical costs, which is discussed widely in the report, “Health Literacy Implications of the Affordable Care Act,” produced by the Center for Health Strategies Inc, and commissioned by the Institute of Medicine. The new law requires that information about medications and providers be made accessible to those with limited literacy skills. This requirement is in concert with the Plain Writing Act of 2010, which requires federal agencies to use “clear government communication that the public can understand and use.”

What does health literacy mean to patients? To healthcare professionals? What are the current challenges in addressing low health literacy?

Health literacy means that individuals can manage their own care with confidence. They do not hesitate to ask questions for fear of appearing naïve or unsophisticated, and they have no sense of inadequacy or intimidation when interacting with their physicians. They have effective patient/provider experiences, are included as a partner in their healthcare, and are empowered to advocate for quality care. They are capable of making informed decisions and practicing preventive behaviors. Health literacy also means that family members or other non-professional caregivers can effectively assist in supportive care because they understand and can follow instructions.

For healthcare professionals, health literacy means delivering vital information clearly and simply. It means not using medical jargon and overly-complicated terms when plain language is called for. It means using a “teach back” method in which patients are asked to repeat what they have been told. This method’s efficacy is supported by experts in the field, and is highlighted in the book, Advancing Health Literacy. Communication is not simply speaking and listening. Effective communication requires assurance that what has been said has also been understood. The challenges we face to ensure the general public is health literate are real:

- Basic literacy, the ability to read and write. It is estimated that nearly 36% of American adults are functionally illiterate, though they hide the problem and/or have learned to compensate for it. For example, a patient may say that he is unable to complete paperwork because he has forgotten his eyeglasses.
- Over-scheduled doctors who claim they do not have time to add literacy concerns to their list of responsibilities.
- System navigation. Where should an individual go for medical care of back ache? To the emergency room, the primary care physician, a specialist, a neighborhood clinic? For those faced with too many choices and not enough practical guidance, simply identifying the most sensible route to healthcare is a challenge.
- The emotional component. Even for the 12% of the population deemed “proficient” in dealing with health-related material, illness-induced stress and anxiety compromise a patient’s ability to grasp a diagnosis, follow instructions for self-care and next steps, and/or learn how to operate in home equipment.

Health literacy means that the communication, whether written or spoken, has been delivered well enough so that the patient understands their condition and what to expect as a result of that condition. The patient knows how to care for himself or herself because questions that have troubled them have been asked, answered and understood.

Outcomes in healthcare are very dependent upon the patient understanding what is wrong, and how to get better and stay better. With chronic diseases like diabetes and heart problems, well understood communication is critical to decreasing medical errors and cost, as well as improving overall health outcomes.

Gisele Robinson Greene, MD, CMCCE, FACP
Chief Medical Officer
Sisters of Charity Health System

What are the costs of low health literacy, what is the prescription for change and the national impact?

The cost is estimated to range from $106 billion to $238 billion annually according to the National Institutes of Health. This staggering estimate represents between 7% and 17% of all personal healthcare expenditures. The savings, by improving health literacy, is estimated to be enough to insure all 47 million + people in the U.S. who lacked coverage in 2006.

Federal agencies and private organizations have recognized the consequences of low health literacy. The Agency for Healthcare Research and Quality; the Centers for Disease Control and Prevention; the Food and Drug Administration; the American Medical Association; America’s Health Insurance Plans, and the National Institutes of Health are among those paying attention to this issue.

Partnership for Clear Health Communication’s mission is to build awareness and advance solutions to improve health literacy, and positively impact health outcomes. Among its accomplishments are “Ask Me 3,” a quick, effective tool designed to improve health communication between patients and providers; and “Medicare Rx,” a collaboration with the Centers for Medicare & Medicaid Services that aims to increase awareness and understanding of the new Medicare Part D Prescription Drug Benefit.

Health literacy is the level of understanding and ability to manage the health system and one’s own (or one’s children’s) health. An adequate level of health literacy is required for preventive care, care of chronic or recurrent illnesses as well as appropriate use of emergency facilities. Low health literacy is not limited to low socioeconomic demographics. Emotional stress (such as hearing bad news…) can lower a person’s health literacy level by causing cognitive regression. The health care system needs to address health literacy at all levels of care in order to lower health care costs by improving adherence to care.

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TWO DOCTOR’S PERSPECTIVES

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The action.

A LOCAL RESPONSE: THE SISTERS OF CHARITY FOUNDATION OF CLEVELAND

One of the Sisters of Charity Foundation of Cleveland’s five focus areas is Health Disparities. Even with steady advances in medical sciences, higher rates of chronic disease, premature death, and other poor health outcomes continue to affect racial and ethnic minorities in disproportionate numbers compared to non-minorities (see appendix A). The differences start at birth, with higher rates of low-birth weight and infant mortality for African Americans, Hispanic/Latinos and other minority groups. The gap continues, with minorities experiencing higher rates of diabetes, cancer, heart disease, obesity and asthma. The causes of health disparity are varied and complex, however experts agree that inadequate access to care, substandard quality of care and health literacy are all contributing factors.

The Sisters of Charity Foundation of Cleveland seeks to improve health outcomes for those most in need in order to enhance health literacy skills, particularly among high-risk, low-literacy, underserved populations. The Foundation built support for a community-wide effort to advance health literacy and connection with similar efforts developing throughout the Midwest and nationally.

The goal of the health literacy initiative is:— Improve health literacy and connection with similar efforts developing throughout the Midwest and nationally.
— Increase integration of health literacy principles, policies and practices to improve patient outcomes; as well as prepare hospitals capacity to implement health literacy principles, policies and practices to improve patient outcomes. As the Foundation’s investment in health literacy continued, funding supported ongoing implementation of health literacy strategies, including effective models with measurable impact on target populations and synergistic collaborations that broaden the reach of health literacy.
— As the grant-making arm of the initiative was set to conclude at the end of five-years of investment, the Foundation emphasized to grantees the importance to plan for continuation and sustainability, less foundation support, of health literacy models, strategies and practices over the long term.

Since 2007, the Sisters of Charity Foundation, in partnership with The Cleveland Foundation, has awarded substantial dollars in planning, demonstration, implementation, continuation and sustainability grants to advance health literacy in Cuyahoga County by enhancing the capacity of providers and organizations to implement and adapt health literacy practices effectively.

The efforts of the Foundation and grantees partners has increased visibility and understanding of health literacy across Greater Cleveland. Their contributions to the field of health literacy and locally, include:— Providing health literacy education and training, including plain language writing to local healthcare providers, public health professionals and community organizers.
— Increasing competence in negotiating work-related and child-rearing responsibilities among parents and providing health literacy education to pediatric health professionals.

The Foundation held a day-long forum entitled Getting from A–Z in Health Literacy in June 2007 that attracted more than 75 clinical and community-based providers and agencies. We have, throughout the initiative, also held a dozen Health Literacy Learning Circles to build knowledge and support. These educational forums have welcomed prominent speakers as well as grantees and others interested in forming collaborations to advance health literacy through local ideas and solutions, training in effective communication, and sharing resources.

The Foundation’s grant-making portfolio was eclectic, we followed the hospitals capacity to implement health literacy principles, policies and practices to improve patient outcomes. As the Foundation’s investment in health literacy continued, funding supported ongoing implementation of health literacy strategies, including effective models with measurable impact on target populations and synergistic collaborations that broaden the reach of health literacy.

Specific objectives identified to reach this goal:— Improve health literacy skills, particularly among high-risk, low-literacy, underserved populations.
— Empower and engage the community of consumers.
— Increase integration of health literacy principles, policies and practice among community-based and clinical providers.

The Foundation used several strategies to implement the Health Literacy Initiative: a) convening, b) capacity building c) technical assistance, d) grant-making and e) evaluation.

The goal of the health literacy initiative is: to focus on building successful programs to improve the health outcomes for those most in need in order to enhance the health status of Cuyahoga County residents.

St. Vincent Charity Medical Center nurse and director of education Karen Komodor has long recognized that a patient may forget 80 percent of what they’ve been told and what they do remember may be incorrect. Funding through the Health Literacy Initiative supported the development of a strategic approach to building the hospitals capacity to implement health literacy principles, policies and practices to improve patient outcomes. A rewrite of over 100 health brochures and pamphlets, for easy readability (an 8th grade level) and the development of the five STEPS approach, are two examples of how the hospital staff communicates more effectively with patients.

St. Vincent Charity Medical Center STEPS model for health literacy:

S — Speak slowly. Take time to understand a patient’s concerns. Studies show that a patient speaks for no more than 22 seconds before being interrupted by a health care provider.
T — Teach back. Ask patients to describe in their own words what they’ve just heard, or what their condition is and how it should be treated.
E — Encourage patients to ask questions, including writing down questions beforehand.
P — Plain language is the best way to communicate with a patient.
S — Show examples of what you’re talking about, including drawing a picture. Many people are visual learners.
What advances in health literacy have been realized through the Foundation’s initiative?

When the Sisters of Charity Foundation of Cleveland launched the Health Literacy Initiative, no major health system in the region had incorporated health literacy awareness and/or training in its operations in a widespread manner. Project: LEARN was the only agency with staff trained to work with area organizations to systematically infuse health literacy elements into daily operations, and to evaluate and revise consumer materials. Systemic changes began to emerge in large hospitals, and funding to a variety of health literacy projects across community-based providers began to demonstrate findings at the program and individual level. These findings discuss efficacy, empowerment, integration of health literacy tools such as the “teach back” method into provider-consumer interventions, and changes in organizational communications such as the use of plain language printed materials.

By the third year, the Initiative’s efforts created significant local interest in health literacy and plain language tools specifically. This generated collaboration among the Foundation’s grantees and other agencies to improve health literacy practices and policies. Positive movement was taking place as the community began to turn to the Foundation and its health literacy grantees to provide materials and training for others.

The Foundation engaged Case Western Reserve University’s Prevention Research Center for Healthy Neighborhoods (PRCHN) to establish an evaluation framework and common measures for the Health Literacy Initiative. The work was led by Dr. Erica Trapl, co-director of the PRCHN and assistant professor of epidemiology & biostatistics at CWRU. The PRCHN issued a report in July 2010, on grantees project performance—reviewing each agency’s project goal, evaluation plan and utilization of common metrics. It reviewed each agency’s articulated project goal, evaluation plan, and utilization of common measures. Just as important, the evaluators provided general observations regarding the Foundation’s Health Literacy Initiative. These observations have helped guide the Foundation’s activities going forward.

Making an impact

In addition to the individual grantees’ project successes, the investments made by the Foundation and its partners have had a positive impact in our community and beyond. Among the accomplishments:

— **Building health literacy awareness among providers, and developing health literacy expertise and capacity locally:** Paraprofessionals and clinical staff across the health care community, including safety net providers and community-based organizations received training in techniques for improving health literacy, and several organizations have established programs to train new staff. Individuals within these organizations have become experts in revising consumer materials in plain language and infusing health literacy principles and practices into the organization’s policies and procedures, and into employee orientation and ongoing training programs.

— **Launching a Health Literacy Center of Excellence at the St. Vincent Charity Medical Center:** From its collaboration with Project: LEARN, St. Vincent Charity Medical Center (SVCMC) has succeeded in instilling health literacy awareness into hospital-wide practices. Together with Project: LEARN, St. Vincent has created a new Health Literacy Center of Excellence to more broadly share expertise in enlightened policies, procedures and materials and other hospitals and community-based organizations. The Center offers guidance on how to successfully institutionalize health literacy practices from staff training to evaluating and improving hospital navigation signage and consumer materials.

— **Replicating models and scaling up:** The Foundation supported Project: LEARN/SVCMC partnership to instill health literacy principles and programming. It is being expanded to other area healthcare organizations ranging from Rainbow Babies & Children’s Hospital to the Visiting Nurses Association. Reading Health, Project: LEARN’s model which provides technical assistance to health care providers to effectively communicate with patients who have low education levels is also being adopted by area healthcare organizations, to train staff and rewrite policies, procedures, and patient materials to incorporate best practices.

— **Creating a local burgeoning health literacy movement:** A cadre of individuals and groups passionate about the critical elements of health literacy for improving health, managing chronic disease, and delivering health service efficiently and effectively lead this movement. Local health literacy leaders are engaged with others in Ohio, outside the state, and in federal agencies.

Call to action

Health literacy is an individual and family issue, a community responsibility, and a national challenge. While not in a position to pursue each of the following items, the Sisters of Charity Foundation of Cleveland believes that these are areas of opportunity for focused collective action:

— Raise awareness of the shared definition of health literacy among healthcare providers from receptionists to physicians to administrators

— Raise consumer health literacy through provider and public health collaborations to create best practice strategies in skill building for self-care, health maintenance, chronic disease management, finding a medical home, the appropriate use of emergency care and other areas vital to health and well being.

— Expand efforts to reduce health disparities by implementing health literacy interventions and documenting and evaluating those outcomes

— Communicate to consumers the critical importance of health literacy to their overall wellness

— Arm consumers with tools to improve health literacy, including awareness of their right to understand basic health information critical to managing their health and how to access care through the Affordable Care Act

— Invest in informing healthcare organizations about the financial benefits of health literacy, and provide structures to support health literacy — supportive elements would include clear navigation signage, effective discharge instructions to reduce readmissions, and continuing education for all staff — and to reduce readmissions

— Instill health literacy best practices in collaborative quality improvement teams, preparing teams to deliver the best care from hospitals to home to physician offices and safety net clinics — the care continuum

For more information on the Sisters of Charity Foundation of Cleveland’s Health Literacy Initiative, please contact Toleangé Thomas — Program Officer, Health at 216.241.9300 or email tthomas@socfcleveland.org
The Impact of Health, Education and Wealth on Health Literacy

Health literacy lies at the intersection of many socioeconomic conditions. There is a direct correlation between a person’s level of health literacy and their overall health status. In an urban area like Cuyahoga County, trends demonstrate a linkage between poor health such as heart disease, limited education and low-income populations, which in Cuyahoga County’s case disproportionately impacts African Americans and other ethnic minorities.

(Health Literacy & Health Disparities, Center for Health Policy, Missouri 2009)

SPECIAL THANKS

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The Cleveland Foundation   clevelandfoundation.org
CASE Prevention Research Center for Healthy Neighborhoods   www.prchn.org
Cleveland Department of Public Health   clevelandhealth.org
Diabetes Partnership of Cleveland   diabetespartnership.org
Environmental Health Watch   ehw.org
MomsFirst   clevelandhealth.org/Health/MaternalChildHealth/MomsFirst
Project: LEARN   projectlearn.org
Rainbow Babies & Children's Hospital   uhospitals.org/rainbow
St. Vincent Charity Medical Center   stvincentcharity.com/programs-services/centers-excellence/health-literacy
The Free Medical Clinic of Greater Cleveland   thefreeclinic.org
Urban Community School   urbancommunityschool.org

RESOURCES

For additional information and resources on health literacy, we recommend:
Agency for Healthcare Quality & Research   www.ahrq.gov
The Center for Disease Control and Prevention   www.cdc.gov
The Health Resources & Services Administration   www.hrsa.gov
The Institute of Medicine   www.iom.edu
The National Institutes of Health   www.nih.gov