

How Well Do Your Patients Understand?

Improving the Health Literacy Environment of Hospitals

PROJECT REPORT OCTOBER 2010

PREPARED BY

*Sue Gaard, RN, MS, Confident
Conversations, LLC*

*Paul Smith, MD, Wisconsin Research and
Education Network*

*Michele Erikson, Wisconsin Literacy, Inc.
and Health Literacy Wisconsin*



Content

<i>Executive Summary</i>	<i>p. 3</i>
<i>The business case</i>	<i>4-5</i>
<i>The concept of collaboration</i>	<i>6</i>
<i>Resources and support required for success</i>	<i>7</i>
<i>How to begin</i>	<i>8-9</i>
<i>Lessons learned</i>	<i>10-11</i>
<i>Resources</i>	<i>11</i>
<i>References</i>	<i>12</i>
<i>Acknowledgements</i>	<i>13</i>

Executive Summary

Only 12% of U.S. adults are proficient in their capability to obtain, process, and understand basic health information and services needed to make appropriate health decisions. Common use of dense, sophisticated and complex language by health care systems creates significant demands on patients that they are often unable to meet. While attempts have been made to evaluate the readability of written health-related materials for patients, little attention has been given to the myriad of signs and documents used in health care settings and to the overall literacy environment of hospitals. The aim of this study was to test a collaborative model between hospitals and adult literacy students that would identify health literacy barriers. **What processes are necessary to cultivate a successful collaboration between hospitals and literacy organizations in order to improve the health literacy environment for all patients?**

BY THE NUMBERS

12%

The percentage of adults in the U.S. who are proficient in their capability to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

This project, conducted in Madison, Wisconsin, prepared 15 adult students enrolled in the General Equivalency Diploma (high school graduation equivalency) program at Omega School to be consultants to St. Mary's Hospital to improve the hospital's health literacy environment. A student and hospital team independently evaluated patient admission agreement, pain management and advanced directive patient information documents, and conducted a way-finding navigation exercise in the hospital. Students provided specific feedback about documents and hospital signage to improve understandability.

The Business Case

The impact of low health literacy in Wisconsin

Only 12% of US adults are proficient in health literacy.¹ **Health literacy is defined as:**

The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.²

BY THE NUMBERS

\$3.4-7.6
billion

The estimated annual cost of low health literacy in Wisconsin

The cost of low health literacy in Wisconsin is estimated in the range of \$3.4 billion to \$7.6 billion annually.³ While some may challenge Vernon's methodology, the order of magnitude compels us to action.

A recent study measuring patient comprehension of emergency department care showed that many patients do not understand their emergency department care or their discharge instructions. Furthermore, most patients were unaware of their lack of understanding and reported inappropriate confidence in their comprehension and recall.⁴

A Wisconsin research project comprised of 51 adults with low reading or limited English skills identified significant barriers in their experience of the U.S. health care system: difficulty understanding verbal and written health information, medication instructions and consent forms, and confusion while navigating through hospitals. Participants described feelings of shame and frustration as they attempted to understand complex health information, and the resulting withdrawal from further interaction.⁵

This research formed the foundation for a feasibility study designed to test a model of collaboration between hospitals and literacy providers. Through independent assessments and roundtable dialogue, hospital staff and literacy student teams identified health literacy barriers they experienced with hospital navigation and written patient communication. Together, they provided recommendations for improving document readability and hospital way-finding for patients and families. Focus group results confirmed the value of successful partnerships between health care systems and literacy organizations.⁶ Based on the outcomes of this study, this Project Report was developed as a reference for other literacy programs and health care systems that desire to improve the health literacy of their environments.

The opportunity for hospitals

The demands placed on patients by complex health care systems exceed the health literacy skills of most adults in the United States.⁷ While attempts have been made to assess health-related materials in sentence and paragraph form, little attention has been given to the myriad of signs and documents used in health care settings and to the overall literacy environment of hospitals.⁸ A review of the literature by Rima Rudd suggests that improving readability alone is insufficient to address the needs of patients with low health literacy and instead tends to most benefit those with higher skill levels. Moving beyond readability, hospitals can provide innovative opportunities for patients with low health literacy skills to communicate concerns about their health and health care. Concurrently, the literacy demands of patients must be modified; professional jargon in directives, forms, signs, patient education materials, and conversations need close examination and elimination where possible.⁹

In analyzing the economic cost of low health literacy, Vernon cites numerous studies demonstrating the influence of low health literacy on health care outcomes and resource use. Individuals with limited health literacy:

- reported poorer health status;
- were less likely to use preventive care;
- were more likely to be hospitalized and experience poor disease outcomes;
- experienced higher mortality rates;
- were less likely to comply with treatment and self-care;
- made more medication or treatment errors;
- lacked the skills needed to navigate the health care system; and
- were responsible for higher inpatient costs and overall health care spending by Medicare and Medicaid.¹⁰

From the perspective of social justice and rights, patients experience unreasonable barriers and challenges. Consents for research, due to their complexity, may not be “informed.”¹¹ By not reducing the literacy demands of patients, hospitals may be at increased legal risk.

On the national front, the Joint Commission has released its Roadmap for Hospitals to advance effective patient communication, cultural competence, and family/patient-centered care and the U.S. Department of Health and Human Services has recently published the National Action Plan to Improve Health Literacy.

The Concept of Collaboration

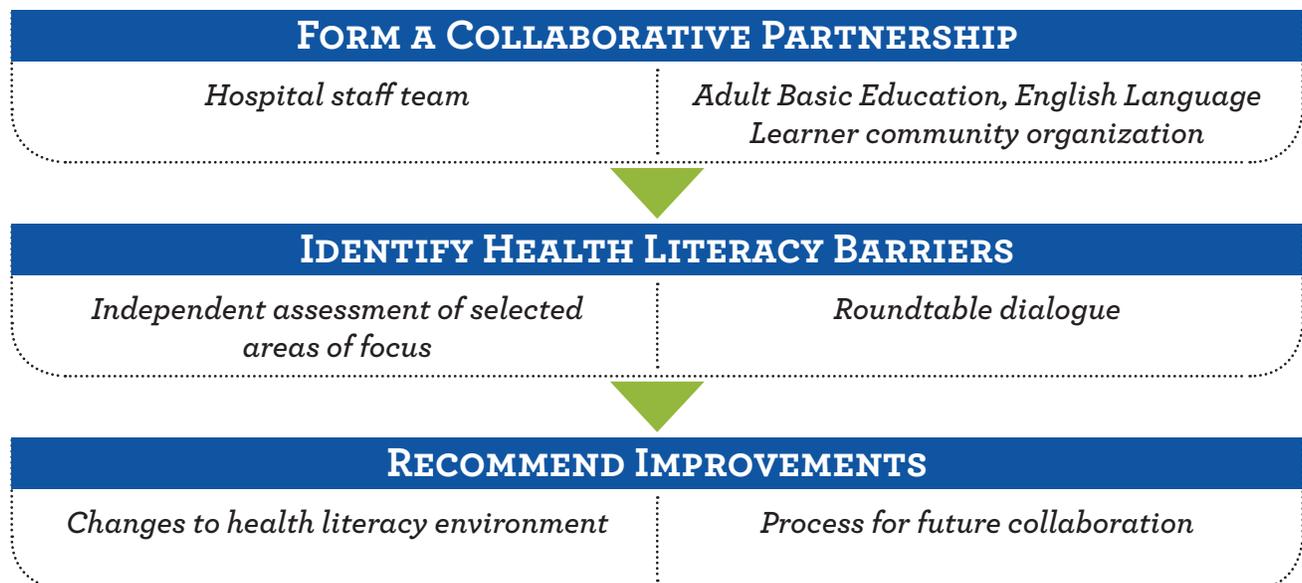
Health Systems and Literacy Organizations

This collaborative model is premised on the belief that adult literacy students are the eyes and ears of the communities they represent. To the extent that health information is understandable to them, it is understandable for all—a health literacy application of an engineering concept called universal design. Benefiting people of all ages and abilities, universal design simplifies life by making products, communications, and the built environment more usable by as many people as possible at little or no extra cost.¹²

The health literacy needs assessment of the hospital will best be accomplished through the input of those with known literacy limitations. Adult Basic Education and English Language Learners are uniquely motivated to identify barriers to their understanding of information, given their choice to address and improve their literacy skills. They are more likely than those with low literacy not enrolled in an educational program to express their ability or inability to understand complex health care information.

The foundation to this work is the formation of a successful partnership and ongoing relationship between a health care system and an adult literacy program. In the end, both literacy organizations and health care systems benefit from improved understanding of health care information.

The following flow chart describes the major steps toward a sustainable, collaborative working relationship.



Resources and Support

Required for Success

- ***Executive Support***
 - High-level executive support is needed to facilitate allocation of human and fiscal resources for the project.
- ***Project Leader***
- ***Facilitator***
 - A project facilitator is recommended to lead the training and working sessions of the student advisors. Required skills include: in-depth understanding of health systems and medical jargon; experience in working with diverse populations and adults facing many learning and life challenges; understanding of literacy deficiencies and the impact on life skills; facilitation expertise that fosters a sense of trust within the student community and ability to serve as a liaison to the hospital staff team.
- ***Student support***
 - Stipends for participation in training and working sessions (time spent working on assessment of materials or walk-throughs of the hospital). \$15/hour is recommended.
 - Provision of food, childcare, and transportation (as needed) for each student advisor session.
- ***Literacy Organization Support***
 - Financial support is recommended for the literacy organization's administration and leadership. The literacy organization leadership is critical in recruiting students to participate in the project, communicating with them about the importance of the project and scheduled working sessions, administering project stipends to the students, and providing a supporting role.
- ***NCSALL Guide:*** free and available at www.hsph.harvard.edu/healthliteracy or www.ncsall.net

How to Begin

1. **Establish executive leadership support** for plain language¹³ initiatives and transformation to a plain language culture.

2. **Contact and establish a working relationship** with a local adult basic education or literacy provider in your hospital's service area. Wisconsin Literacy, Inc. is a statewide coalition of over 60 member agencies that are strengthening Wisconsin's workforce, families and communities through literacy. Local literacy agencies can be found by contacting Wisconsin Literacy, Inc: (608)-257-1655 or Info@WisconsinLiteracy.org

3. **Provide foundation training** on the impact of health literacy and benefits of plain language to the hospital leadership team and participating staff. Recommended topics for this overview include: defining health literacy and plain language, the impact of low health literacy, common barriers to health literacy and promising practices to improve health literacy. See "Resources" for training below.

4. **Consider how improved health literacy** among low literate adults affects the achievement of hospital goals. Where would a collaborative effort lead to better solutions? Jointly discuss points of leverage to strengthen buy-in from both the literacy organization and hospital. Examples include:

- a. Increased patient safety
- b. Decreased hospital re-admissions
- c. Increased patient satisfaction
- d. Reduction of health disparities
- e. Quality improvement initiatives
- f. Creation of a welcoming environment for all patients
- g. Appropriate utilization of health care services (reduced Emergency Room use, reduced hospitalizations, error reduction)
- h. Increased ability of patients to manage chronic conditions and health care needs
- i. Positive public relations
- j. Community benefit

5. **Designate a leader** and project team or charge an existing committee or team to assume responsibility for project planning, prioritizing, implementing and evaluating plain language initiatives. This team will work with the literacy organization leadership to mutually establish achievable goals and objectives for a collaborative project.

6. **Limit initial work** to only one or two areas of focus (e.g. navigation within certain areas of the hospital, evaluation of one or two important patient information documents).

7. **Mutually clarify roles and expectations** of the student advisors, hospital team, and project facilitator.

8. **Launch the project with an event** that recognizes the participation of the hospital, literacy organization and student advisors. A launch event sponsored by the hospital creates visibility and confirms leadership support of the work of the student community. A launch event could be a joint reception or an event at the literacy organization, such as a health fair.

9. **Begin the process of facilitated, independent assessments** of the focus areas by the student advisor team and the hospital staff team. The Health Literacy Environment of Hospitals and Health Centers, Partners for Action: Making Your Healthcare Facility Literacy-Friendly¹⁴ (NCSALL Guide) is highly recommended as a valuable resource and toolkit for beginning the assessment process.

10. Once the individual assessments are complete, **engage in roundtable dialogue** between the student advisors and hospital team to share findings (similar and dissimilar), explore barriers to health literacy, prioritize areas for improvement, and identify potential solutions.

11. The assessment process forms the basis for **subsequent follow up by the hospital team** and future continuing work with the literacy community. Opportunities exist for integration of input from the literacy community within the hospital's structures such as committees, programs, curriculum development, etc.

Lessons Learned

- *Start small.*
- **Recruitment** of participating students is best done by the Executive Director, Program Manager or tutors of the partnering literacy organization.
- **Plan ahead for student scheduling challenges:** schedule meetings in the evening, if possible to accommodate school, work, and child care needs; provide food, childcare, and compensation in the form of project stipends.
- **Focus the work of the students** within an academic calendar timeframe to maintain student continuity and improve project effectiveness.
- **Plan for student attrition.** Recruit for more students than you think you will need.
- **Consider needs of all stakeholders** so that they can be intentionally addressed through project design. Both the hospital and literacy organization will likely be challenged with competing priorities.
- **Authenticity of the assessment process** is very important. Focused selection and project design would ideally allow for student advisors to experience the hospital environment as if they were “real” patients. Evaluation of a hospital process that requires use of the registration system to create an authentic patient experience may create significant administrative barriers and is not recommended as an initial project.
- **Refer to and regard the students as “consultants” or “advisors.”**
- Through facilitated and effective community building, **offer a safe environment for student advisors to contribute the following:**
 - A description, in their own words, of the meaning of the information reviewed
 - Identification of confusing words/language
 - Barriers/obstacles to effective understanding
 - Suggestions for plain language substitutions
 - Feedback on communication strategies
 - Sharing of their own personal experiences within healthcare environments

- **Budget appropriately for human and financial resources** needed to implement and sustain improvements over time.
- **Prepare for recommendations** that extend beyond improving readability of documents.
- While orientation to the issues of “health literacy” is important to hospital and literacy staffs, **use of the term “plain language”** is preferred and less likely to invoke assumptions about patients with limited health literacy.
- **Create a sense of trust.** Both hospitals and literacy organizations feel vulnerable in a partnership. Teachers as well as students feel intimidated by the health care system. Hospital staff may feel their training in patient communication has been inadequate. Developing trust requires deliberate consideration. Your local literacy organization can help to identify the most effective ways of working with the literacy student community.
- **Commit to joint, in-person meetings** for major planning, scheduling meetings far in advance.
- **Determine methods for measurement of progress.**
- **Prepare both teams for a lot of rewarding work.**

RESOURCES

- *Confident Conversations, LLC*
- *Health Literacy Wisconsin, a division of Wisconsin Literacy, Inc.*
- *Literacy Assistance Center of New York*
- *Wisconsin Research and Education Network*

References

1. Kutner M, Greenberg E, Jin Y, and Paulsen C. The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy, Washington, DC: U.S. Department of Education, National Center for Education Statistics.
2. Nielsen-Bohlman L, Panzer A, Kindig D, ed. Health literacy: A prescription to end confusion. Washington, DC: National Academies Press, 2004.
3. Vernon J, Health policy brief: The high economic cost of low health literacy in Wisconsin, February 2009.
4. Engel K, Heisler M, Smith D, Robinson C, Forman J, Ubel P. Patient comprehension of emergency department care and instructions: Are patients aware of when they do not understand? *Annals of Emergency Medicine*. 2009; 53(4) 454-461.
5. Smith P, Grasmick M, O'Halloran P, Colombo C. Limited reading and english skills in the health care system: The patients' perspective (pending publication).
6. Smith P, Gaard S, Erikson M. Adult literacy students as hospital health literacy consultants- A pilot project, (pending publication)
7. Nielsen-Bohlman.
8. Rudd R. Navigating hospitals: Literacy barriers. Literacy Harvest, 2004.
9. Rudd R, Moeykens B, Colton T. Health and literacy: A review of medical and public health literature. *Annual Review of Adult Learning and Literacy*, 1999.
10. Vernon J, Trujillo A, Rosenbaum, S, DeBuono B. Low health literacy: Implications for national health policy. October 2007.
11. Rudd, R., et.al, Literacy Demands in Health Care Settings: The Patient Perspective. Schwartzberg J, VanGeest J, Wang C, eds. *Understanding Health Literacy: Implications for Medicine and Public Health*. Chicago, Ill: American Medical Association Press; 2004.
12. Mace R. The Center for Universal Design. Accessed August 25, 2010. http://www.design.ncsu.edu/cud/about_ud/about_ud.htm
13. Plain language: A promising strategy for clearly communicating health information and improving health literacy. Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services. November, 2005.
14. Rudd R., Anderson J. The health literacy environment of hospitals and health centers. *Partners for action: Making your healthcare facility literacy-friendly*. National Center for the Study of Adult Learning and Literacy and Health and Adult Literacy and Learning Initiative Harvard School of Public Health, 2006.

Acknowledgements

The authors wish to thank the following people and organizations for their help with this project:

Chris Baker

Matt Albert

Oscar Mireles

The students and staff of Omega School, Madison, Wisconsin

Michael Grasmick

Carol Gabler

Rima Rudd

Winston Lawrence

Dana Richardson

Mary Kay Grasmick

St. Mary's Hospital, Madison, Wisconsin

Wisconsin Hospital Association

FUNDING PROVIDED BY:

American Academy of Family Physicians

MetaStar

St. Mary's Hospital

University of Wisconsin Institute for Clinical and Translational Research, funded through NIH grant number 1 UL1 RR025011.

My Notes

FOR MORE INFORMATION, CONTACT:

wisconsin  **literacy**

211 S. Paterson St., Suite 310

Madison, WI 53703

608.257.1655

www.healthliteracywisconsin.org

www.wisconsinliteracy.org
