

# Improving the Health Literacy of Hospitals

*A Collaborative Guide for Literacy Organizations*

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# 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 various signs and documents used in health care settings and to the overall literacy environment of hospitals. The aim of this project 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 a 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 U.S. adults are proficient in health literacy.<sup>1</sup> **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.<sup>2</sup>*

### 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.<sup>3</sup> While some have challenged 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.<sup>4</sup>

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 when attempting to understand complex health information, which resulted in withdrawal from further interaction.<sup>5</sup>

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 literacy organizations and health care systems.<sup>6</sup> 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 literacy organizations and hospitals

The demands placed on patients by complex health care systems exceed the health literacy skills of most adults in the United States.<sup>7</sup> 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.<sup>8</sup> 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.<sup>9</sup>

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.<sup>10</sup>

From the perspective of social justice and rights, patients experience unreasonable barriers and challenges. For example, patients participating in research may not be adequately informed of their risks and benefits because they cannot understand complex consent forms.<sup>11</sup> By not reducing the literacy demands of patients, hospitals may be at increased legal risk.

On the national front, The Joint Commission, a national accrediting body for health care organizations, 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 *National Action Plan* specifically recommends that those who develop health information involve persons with limited health literacy in the planning, developing, implementing, disseminating, and evaluating health and safety information.<sup>12</sup>

Literacy organizations are uniquely positioned to provide the perspective of those who disproportionately struggle with the challenges of health literacy. Literacy organizations can provide tangible assistance to hospitals in achieving their hospital accreditation goals and provide services of benefit to their respective communities.

# The Concept of Collaboration

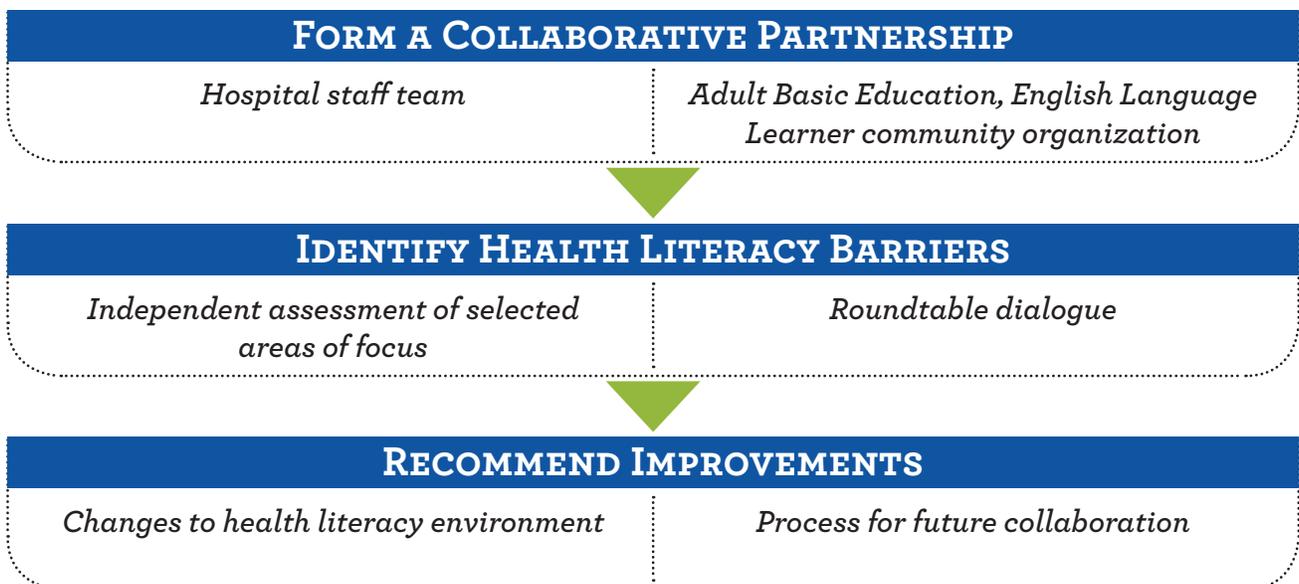
## *Literacy Organizations and Health Systems*

The collaborative model described in this project report 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 to 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.<sup>13</sup>

The health literacy needs assessment of the hospital will be best accomplished through the input of those with known literacy limitations. Adult Basic Education (ABE) and English Language Learners (ELL) 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 of 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*

- ***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](http://www.hsph.harvard.edu/healthliteracy) or [www.ncsall.net](http://www.ncsall.net)

# How to Begin

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1. **Establish a working relationship** with the public relations department of your local hospital. Provide a cogent business case and proposal for the hospital to consider. Suggest that the transformation to plain language occur as an incremental process, as it is integrated or infused into current patient communication projects and activities.
2. The hospital, in turn, will need to **establish executive leadership** support for plain language<sup>14</sup> initiatives and transformation to a plain language culture.
3. **Offer to 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 how it is different from low literacy), defining 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 literacy organization and hospital goals. Where would a collaborative effort lead to better solutions? Examples include:
  - a. Increased patient safety
  - b. Decreased hospital re-admissions
  - c. Increased patient satisfaction
  - d. Reduced health disparities
  - e. Patient-centered quality improvement initiatives
  - f. Improved patient experience through a more welcoming environment
  - g. Appropriate utilization of health care services (e.g. reduced Emergency Room use, reduced hospitalizations, error reduction)
  - h. Increased ability of patients to manage their chronic conditions and health care needs
  - i. Improved public relations
  - j. Improved health care communication skills of literacy students
5. **Work with the hospital’s designated leader** and project team 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 or 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. **Recruit students** to participate in the assessment process. Consider the student's ability to complete the work of the project, interest in the subject of health care, academic performance and motivation, demographics, and ability to contribute in a group setting. Prepare to provide support through frequent and ongoing communication about the project, financial incentives for project milestone completion, coordination and/or provision of transportation to training sessions, and provision of food and child care during sessions.

9. **Provide guidance** to the hospital in planning a launch 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. Students will especially want to learn about how their work will make a difference for the hospital and the patients it serves.



10. **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-Friendly*<sup>15</sup> (NCSALL Guide) is highly recommended as a valuable resource and toolkit for beginning the assessment process.

(Continued on next page)

# How to Begin *(continued)*

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The *NCSALL Guide* was developed as an assessment tool for hospitals by Rima Rudd and Jennie Anderson from the Harvard School of Public Health. The primary purposes of the guide are to generate dialogue within the hospital about health literacy, identify health literacy barriers, and reduce patients' obstacles to understanding health care information. The guide was rigorously tested prior to broad distribution. It has been translated into a number of languages and has been widely used by hospitals within the U.S. and in other countries.

Session content may look something like this for student advisor review of printed materials:

## ***Session 1: Project orientation***

- Community building activity (to establish trust and facilitate conversation)
- Introduction to the topic of health literacy
- Project goals
- Roles of students, project leaders, and facilitators
- Group ground rules
- Project timelines, tasks, and expectations
- Review skills necessary for project (listening, reading, asking questions, taking notes).

## ***Session 2: Establish baseline understanding***

- Community building activity
- Brief review of content covered in Session 1
- Complete definitions matching exercise. Students will be asked to match key words used in the selected patient materials with their respective definitions. Begin reading patient materials.

## ***Session 3: Baseline understanding (continued)***

- Complete initial read of the patient materials.
- Discuss overall reactions to the content.
- Discuss student perceptions of the meaning of the materials.

## ***Sessions 4-6: Content analysis of patient information materials***

- Review key points from sessions 2 and 3.
- Identify confusing words/language and barriers to effective understanding of content.
- Suggest plain language substitutions.

## ***Sessions 7-8: Redesign recommendations***

- Complete any unfinished tasks from sessions 4 to 6.
- Identify and discuss design and strategies for presentation of content.

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11. 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.
  12. 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, and current improvement projects.

## MY NOTES

# Lessons Learned

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- *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, child care, 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 the 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.
- **The authenticity of the assessment process** is very important. Designing the project to allow students to evaluate their experience as if they were real patients will provide the most accurate evaluation.

However, 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 health care environments

- **Budget appropriately for human and financial resources** needed to implement and sustain improvements over time.
- **Prepare for recommendations** that extend beyond improving the 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.**
- **Recognize** that through this type of collaboration, mutual long-term benefits may follow, including addressing the hospital’s need to better serve non-English speaking patients, training hospital staff with limited English proficiency, establishing a health literacy class for adult learners at the hospital, and connecting needs of the literacy organization with the hospital foundation.
- **Prepare both teams for a lot of rewarding work.**

## RESOURCES

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

# References

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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. U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. National Action Plan to Improve Health Literacy. Washington, DC; 2010.
13. Mace R. The Center for Universal Design. Accessed August 25, 2010. [http://www.design.ncsu.edu/cud/about\\_ud/about\\_ud.htm](http://www.design.ncsu.edu/cud/about_ud/about_ud.htm)
14. 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.
15. 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.

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