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Developing and testing the health literacy universal precautions toolkit

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ABSTRACT

The health literacy demands of the healthcare system often exceed the health literacy skills of Americans. This article reviews the development of the Health Literacy Universal Precautions (HLUP) Toolkit, commissioned by the Agency for Healthcare Research and Quality and designed to help primary care practices structure the delivery of care as if every patient may have limited health literacy. The development of the toolkit spanned 2 years and consisted of 3 major tasks: (1) developing individual tools (modules explaining how to use or implement a strategy to minimize the effects of low health literacy), using existing health literacy resources when possible, (2) testing individual tools in clinical practice and assembling them into a prototype toolkit, and (3) testing the prototype toolkit in clinical practice. Testing revealed that practices will use tools that are concise and actionable and are not perceived as being resource intensive. Conducting practice self-assessments and generating enthusiasm among staff were key elements for successful implementation. Implementing practice changes required more time than anticipated and some knowledge of quality improvement techniques. In sum, the HLUP Toolkit holds promise as a means of improving primary care for people with limited health literacy, but further testing is needed.

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The complexity of the healthcare system makes it difficult for many Americans to receive the best possible care. More than one-third of U.S. adults have limited health literacy—the ability to understand and use health information to make decisions. People with limited health literacy are less likely to engage in disease prevention behaviors, to know about their illness and medicines, and to manage and control a chronic disease. Limited health literacy is associated with multiple adverse outcomes including rates of hospitalization and mortality. Furthermore, the skills of patients, even those who have adequate health literacy skills, can decline when under the stress of illness or facing a new diagnosis.

On the demand side, medical care is complex. Routine healthcare activities such as receiving instructions at the doctor's office, taking medication, preparing for a screening test, and choosing a treatment option require sophisticated skills. Health information is often presented in such a way that proficiency in literacy and numeracy is needed to make informed health decisions. Developing systems of care that do not require advanced health literacy skills could improve the delivery of safe, timely, efficient, effective, equitable, and patient-centered care.⁵

Practicing universal precautions - structuring healthcare services to minimize risk for everyone when it is unclear which patients may have difficulty – is the best way to ensure that people have all the information they need to make appropriate health decisions. Research indicates that clinicians do not accurately identify people with limited health literacy.⁶ Screening for limited literacy in practice settings is often problematic, hampered by imprecise measurement tools and patient discomfort. At the same time, research indicates that materials prepared for people who do not read well are actually preferred by those who do read well.8 Although the most vulnerable stand to benefit the most from health literacy universal precautions, system and communication changes may lead to improved care for all patients.

Healthcare providers have become increasingly aware of the communication and navigation problems their patients experience. The simultaneous publication of the Institute of Medicine's report Health Literacy: A Prescription to End Confusion⁹ and the Agency for Healthcare Research and Quality's evidence report, Literacy and Health Outcomes, 10 brought national attention to health literacy. A variety of educational programs and resources to address health literacy have been developed. These approaches, however, have not integrated health literacy strategies into a quality improvement framework to assist practices with the redesign of processes and communication. Such an approach may help to increase adoption of best practices for the care of patients with limited health literacy.

The Agency for Healthcare Research and Quality (AHRQ) commissioned the development and validity testing of a Health Literacy Universal Precautions (HLUP) Toolkit to assist adult and pediatric primary care practices to implement such precautions. The HLUP Toolkit¹¹ was designed to build upon and adapt existing resources (eg, Rudd and Anderson's assessment of health centers¹²⁻¹³), identify and fill gaps, and create guidance for implementing tools. In this article, the development process and qualitative observations from implementation testing that occurred as part of the toolkit development are described.

HLUP Toolkit Development Overview

The HLUP Toolkit was developed over 2 years. The development process consisted of 3 major tasks: (1) developing individual tools (modules explaining how to use or implement a strategy to minimize the effects of low health literacy) using existing health literacy resources when possible, (2) testing individual tools in practice and assembling them into a prototype toolkit, and (3) testing implementation of the prototype toolkit in practice. The HLUP toolkit was designed for use by all staff at a practice, including physicians, nurses, receptionists, and business staff. Approval was granted by the office of Human Research and Ethics at the University of North Carolina to engage practices in the testing of the toolkit.

Advisory Panel

The study team received advice from a diverse expert advisory panel including physicians, nurses, health services researchers, quality improvement experts, and patients. Panelists identified health literacy resources for possible inclusion in the toolkit, reviewed drafts of individual tools, and reviewed the entire toolkit before it was tested in practices.

Participating Practices

This project was conducted through the North Carolina Network Consortium (NCNC), a consortium of 6 practice-based research networks (PBRNs) across the state of North Carolina. Six practices participated in the first phase of testing (Task 2). Four of these practices, plus 4 additional practices, participated in the testing of the prototype toolkit (Task 3). Practices varied in population served, size, practice type, location, and staff composition (see Table 1). All practices engaged members from all parts of the staff including nursing, physicians, practice management, and clerical staff. Representatives from all parts of the staff offered direct feedback on tools and attempted to implement tools appropriate for their position. For example, most practices that tested the teach-back tool used nurses and physicians in the testing.

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