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# Toward a Systems Approach to Health Literacy Research

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## Guest Editorial

# Toward a Systems Approach to Health Literacy Research

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Implementing the Affordable Care Act (ACA) requires a new commitment to "person-centeredness" as a central feature of health care. Person-centered health care means people have both the knowledge required to make decisions about their care and the support of providers and family who respect their needs and preferences (Hurtado, Swift, & Corrigan, 2001). To realize a person-centered health care system, the ACA and the HITECH Act,[1] two federal laws, promote new health care service delivery models and health information technologies that emphasize teams and people's engagement in information seeking, decision-making and self-management. These changes reflect the growing priority of health literacy.

Policy innovations present unique opportunities for research on health care systems and health literacy. Some prior research viewed health literacy as a matter of patients' deficits and focused on their lack of knowledge and skill to obtain, process, and understand health information and make appropriate health decisions. But the

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[1]See the Patient Protection and Affordable Care Act and the Health Information Technology for Economic and Clinical Health (HITECH) Act for the full legislation.

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growing complexity of modern day health care challenges virtually all patients. (Brach et al., 2012; Koh et al., 2012). In this context, we need research that investigates how health care organizations can make health information and services less complex and more adaptable for everyone (U.S. Department of Health and Human Services, 2010a).

In that spirit, health literacy experts now increasingly call for research exploring how health care organizations can effectively address health literacy (Koh et al., 2012; Nielsen-Bohlman, Panzer, & Kindig, 2004; Rudd, 2010; Rush & Paasche-Orlow, 2011; U.S. Department of Health and Human Services, 2003). This topic was the subject of a recent paper published by the Institute of Medicine. The authors propose that health care organizations become "health literate," taking steps to make it easier for everyone to navigate, understand, and use health information and services (Brach et al. 2012). Health literate organizations integrate health literacy into the organization's mission and all dimensions of planning, implementation, evaluation, and quality improvement activities. A "health literate" organization ensures that written materials are understandable and relevant; it also trains the workforce to meet the needs of people with a range of health literacy skills and relieves individuals of the challenge of coordinating their own care. Tools that offer practical guidance to organizations that aspire to be health literate include the Agency for Healthcare Research and Quality's (AHRQ) Health Literacy Universal Precautions Toolkit (DeWalt et al., 2010).

Health communication researchers can contribute to, and expand investigations of, the organizational changes and dynamics required for health care organizations to become "health literate." New models that coordinate care, use teams and information technologies, and partner with patients, such as Accountable Care Organizations (ACOs) and Patient Centered Medical Homes (PCMHs), should be particularly fertile areas for investigation of communication processes and outcomes.[2] To be person-centered, provider teams need to successfully engage everyone in prevention and self-management activities. Both providers and patients will need to shift their attitudes and expectations of traditional roles in order to create true partnerships. These provider teams may operate in the context of ACOs, adding another layer of interdependencies (i.e., ACO–provider and ACO–patient). The provider-patient dynamic should therefore be placed within the context of the broader health care system (Ferlie & Shortell, 2001; Reid, Compton, Grossman, & Fanjiang, 2005; Wynia, 2012).

Research in ACOs and PCMHs can begin by examining the *Healthy People 2020* goals and objectives related to health communication and health information technology (U.S. Department of Health and Human Services, 2012). Such goals and objectives present quantitative targets for shared decision-making between patients and providers, personalized self-management tools and resources for patients, improved health literacy skills, and accurate, accessible, and actionable health information that is targeted or tailored.

Researchers can use these objectives to generate research questions relevant to person-centered care, such as:

1. How does intra-organizational communication affect processes and outcomes for health care organizations that aim to be "health literate?"
2. How can health literacy principles and universal precautions be effectively diffused throughout an organization?

[2]See Centers for Medicare and Medicaid Innovation Center for information on these models http://innovations.cms.gov/.

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3. How can ACOs and PCMHs communicate with diverse individuals in ways that are understandable, actionable, and culturally relevant?
4. Which system-level changes—such as decision support systems, training, scheduling adjustments, and team handoffs—most effectively help care teams routinely confirm everyone's understanding of information and establish collaborative decision-making processes?
5. Which interpersonal and/or organizational communication strategies can help reduce the burden on individuals to coordinate their own care?
6. How can information systems best engage individuals with easily understandable personalized medical record data and other digital information?

With millions expected to gain health insurance in 2014 through Medicaid and new insurance marketplaces called exchanges, research questions about health care consumers could also include:

- What practices in mass communication can help insurance exchanges effectively reach and engage the public about insurance options?
- How can navigators associated with health exchanges most effectively reach people in ways to facilitate informed decision making about insurance options?

Health communication researchers who address these and other questions can help "connect the dots" to improve health literacy and person-centeredness. Some research has already explored health information–seeking, the impact of technology on care relationships and outcomes, the elements for productive interactions between providers and patients (Thompson, Parrott, & Nussbaum, 2011), and communication issues involving health care teams (Real & Poole, 2011). These investigations should expand to the entire organization and health care system to identify feasible and effective ways to overcome health literacy barriers that currently limit people's involvement in their own care (Johnson, Baur, & Meissner, 2011; Kennedy, et al., 2002; Wennberg, et al., 2010).

Several funding opportunities from the U.S. Department of Health and Human Services (HHS) support research. Since 2004, the National Institutes of Health (NIH) have funded more than 100 applications in response to three health literacy program announcements totaling $96 million of grant awards (U.S. Department of Health and Human Services, 2010b, 2010c, 2010d). Health literacy is also listed as an area of interest for the AHRQ Value, Prevention/Care Management, and Patient Safety Portfolios in AHRQ's small and large health services research program announcements (U.S. Department of Health and Human Services, 2008, 2010e). NIH's recent analysis of their health literacy research grant portfolio shows a shift from a predominance of descriptive work in the earlier grants to a greater focus on developing tools to address health literacy issues (e.g., improving comprehension, decision making, and medication adherence). NIH is planning to release a revised Funding Opportunity Announcement soon that should reflect some new directions, including more focus on "health literate" providers, organizations and systems.

These opportunities, among others, should generate more effective ways to engage and inform people, prepare care teams, and improve health outcomes and quality. The new service delivery models and health information technologies, based upon a systems approach, will be most successful when people understand their options and act as full partners. During this time of health care transformation, we can use health literacy

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research to help modernize a health system that finally establishes person-centeredness as the foundation for care that our nation has envisioned and desired for so long.

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