

## Population Health Literacy: A NECON Proposal

### Background

Since Scott Simonds' seminal 1974 monograph,<sup>1</sup> approximately 700 articles focusing on health literacy have appeared in peer-reviewed journals.<sup>2</sup> The burgeoning literature on health literacy extends across educational, health care services, public health, health education, health promotion, clinical, and medical sociological disciplinary boundaries. Health literacy research has gained increasing currency during the last decade, especially with its inclusion as a separate objective in the U.S. *Healthy People 2010* objectives,<sup>3</sup> two related Institute of Medicine reports,<sup>4,5</sup> and in World Health Organization publications.<sup>6</sup> The breadth, depth, and variety of health literacy-related research are impressive. Yet despite the admirable quality and quantity of this literature, important questions remain unanswered.

### Problem

Within the U.S., health literacy research has focused largely on the interaction between individual patients and the health care system, including person-to-persons interactions and patient interactions with medical instructions. For example, *Healthy People 2010* defines health literacy 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>3</sup> U.S.-based research on health literacy has largely reflected this patient-health care system interaction, and especially a patient-provider focus.<sup>7,8</sup> This conceptual and research focus reflects the American "health-care nation"<sup>9</sup> ideological and political framework, with its emphases on health care rather than prevention, and individual health rather than population health.

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<sup>1</sup> Simonds SK (1974). Health education as social policy. Health Education Monograph 2:1-25.

<sup>2</sup> National Library of Medicine PubMed search for "health literacy" in citation title, English language only, dates from January 1, 1974 to present, conducted December 13, 2009, yields 666 citations. See: <http://www.ncbi.nlm.nih.gov/sites/entrez>.

<sup>3</sup> Objective 11-2, <http://www.healthypeople.gov/Document/pdf/uih/2010uih.pdf>.

<sup>4</sup> Nielsen-Bohman L, Panzer AM, Kindig D, editors (2004). Health Literacy: A Prescription to End Confusion. Washington (DC): National Academy of Sciences.

<sup>5</sup> Chao S, Anderson K, Hernandez L (2009). Toward Health Equity and Patient-Centeredness: Integrating Health Literacy, Disparities Reduction, and Quality Improvement. Washington (DC): National Academies Press.

<sup>6</sup> For example, see: World Health Organization (1998), Health Promotion Glossary. Geneva: World Health Organization.

<sup>7</sup> Rudd RE, Moeykens BA, Colton TC (1999). Health and literacy: a review of medical and public health literature. Annual Review of Adult Learning and Literacy.

<sup>8</sup> Rudd RE (2007). Health literacy skills of U.S. adults. American Journal of Health Behavior 31:S8-S18.

<sup>9</sup> Samuelson RJ. "Health-care nation." Washington Post, December 7, 2009.

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Internationally, and to a lesser extent in the U.S., definitions of health literacy have evolved within roughly the last decade.<sup>10,11,12</sup> While the core of health literacy definitions continue to revolve around the interactions between individual patients and health care providers, definitions have started to broaden to include the individual's capacity to manipulate the health-care system to his or her advantage and to advocate for him or herself, both in the immediate health care setting and in the broader context of health care and political system change. Additionally, the need to research health care system performance relating to promoting and enabling health literacy has also been recognized, as has the need to distinguish clearly between individual- and population-level measurements of health literacy. The expanded scope of health literacy conceptualization and research, while most predominant in Australia and Europe,<sup>13,14,15,16</sup> has also extended recently to the U.S.<sup>17,18</sup> However, this broadening of health literacy's scope has not been without controversy.<sup>19,20</sup>

After more than three decades of conceptualization, discussion, and research on health literacy, two core problems remain to be fully addressed.

One problem revolves around the predominant focus of health literacy research on *healthcare* services and *healthcare* activities.<sup>21,22</sup> This focus incompletely reflects our current understanding of the influences on health as multi-factorial and emanating from a variety of *distal population-level influences*—including the natural environment,

<sup>10</sup> Nutbeam D (2008). The evolving concept of health literacy. *Social Science and Medicine* 67:2072-2078.

<sup>11</sup> Peerson A, Saunders M (2009). Health literacy revisited: what do we mean and why does it matter? *Health Promotion International* 24(3):285-296.

<sup>12</sup> Wills J (2009). Health literacy: new packaging for health education or radical movement? *International Journal of Public Health* 54:3-4.

<sup>13</sup> Australian Bureau of Statistics (2006). *Health Literacy, Australia*. Canberra: Australian Bureau of Statistics.

<sup>14</sup> Nutbeam D (2000). Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21<sup>st</sup> century. *Health Promotion International* 15(3):259-267.

<sup>15</sup> Nutbeam D, Kickbusch I (2000). Advancing health literacy: a global challenge for the 21<sup>st</sup> century. *Health Promotion International* 15(3):183-184

<sup>16</sup> Nutbeam D (2009). Defining and measuring health literacy: what can we learn from literacy studies? *International Journal of Public Health* 54:303-305.

<sup>17</sup> Zarcadoolas C, Pleasant A, Greer DS (2005). *Health Promotion International* 20(2):195-203.

<sup>18</sup> Hernandez LM (2009). *Measures of Health Literacy: Workshop Summary*. Washington (D.C.): National Academies Press.

<sup>19</sup> Tones K (2002). Health literacy: new wine in old bottles? *Health Education Research* 17(3):287-290.

<sup>20</sup> Wills J (2009). Health literacy: new packaging for health education or radical movement? *International Journal of Public Health* 54:3-4.

<sup>21</sup> For example, see Department of Health and Human Services, Office of Disease Prevention and Health Promotion, Health Literacy Improvement. Available at:

<http://www.health.gov/communication/literacy/default.htm>. Cited December 13, 2009.

<sup>22</sup> For example, see Zorn M, Allen MP, Horowitz, AM (2004). *Understanding Health Literacy and Its Barriers*. Washington (DC): National Library of Medicine. Available at:

<http://www.nlm.nih.gov/pubs/cbm/healthliteracybarriers.html>. Cited December 13, 2009.

cultural context, political context, social attributes, biological characteristics, built environment, health services, economic resources, population-based health programs, and collective lifestyles and health practices—and more *proximate individual-level influences*. Figure 1 provides an abstracted view of distal population-level factors and more proximate individual-level factors that influence an individual's health. Figure 2 provides a more specific view of how these factors influence tobacco use and its related illnesses, again focusing on an individual's health.

A second problem revolves around the predominant focus of health literacy research on *individual* health to the exclusion of *population* health. Figure 3 summarizes the influences on population health, as opposed to individual health. For example, population health includes both the level *and the distribution* of disease, functional status, and well-being within a population.<sup>23</sup> Like the influences on individual health depicted in Figures 1 and 2, Influences on population health are multifactorial and include both the population's context and attributes, such as its political system and its income distributions, respectively.

### NECON's Capabilities

NECON is uniquely positioned to bring the Population Health Literacy project to fruition. A collaborative of the six New England state health departments, schools of public health, and federal health agencies led by Region I DHHS, as well as legislators and representatives of voluntary health associations, NECON has worked for the past 26 years to mobilize and convene regional policymakers to inform, develop, and enhance health promotion/disease prevention policies and practices. In cooperation with Region I and the six New England state departments of public health, NECON initiatives have consistently been complementary and adjunctive to the mission of the Healthy People and Healthy People 2010 objectives. Through NECON's efforts, successful prevention policies and models are shared in order to facilitate their adoption and replication throughout CT, MA, ME, NH, RI, and VT. The NECON coalition was designated as a model for the nation in 2006 by USDHHS.

One recent example of the NECON collaborative process in action — and itself part of NECON's ongoing charge from the New England Governors' Conference to "interact with the states' chief health officers and other health policymakers and to submit recommendations periodically for the improvement of the health status of the region" — has been the creation of a prototype Regional Health Trends Report for the six-state New England region. Based on the collaborative efforts of 17 senior health data and policy experts from the six New England states, 13 key indicators in eight behavioral, societal, and environmental categories of health promotion and disease

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<sup>23</sup> See Friedman DJ, Hunter EL, Parrish RG, *Shaping a Health Statistics Vision for the 21<sup>st</sup> Century*, Washington, DC: U.S. Department of Health and Human Services, 2002. Available from: <http://www.ncvhs.hhs.gov/21st%20final%20report.pdf>.

prevention have been proposed. The final indicators, as chosen, have had to meet several strict criteria. First, they had to be supported unambiguously by publicly available data sources that substantiate their intrinsic importance. Second, they had to be amenable to action, so that if people in their communities opt to make the necessary changes to their physical and social environments, altering established patterns of risky behaviors, etc., measurable improvements in promotion of wellness and the prevention of chronic disease will be achieved, and these results will be captured and reflected in the biennial Reports. Third, they had to be shapeable to a simple document that anyone can read and understand. The overriding idea is to spotlight salient problems and build the political will necessary to effect substantive change — in other words, to build a viable Prevention Movement across the six-state New England region that would stand as a model for the rest of the country. See Figure 4.

Within this context, “Population Health Literacy” constitutes a critical action item. The USDHHS includes health literacy as a component of its Healthy People 2010, but defines literacy narrowly, mostly in the context of preventive medicine. NECON proposes expanding the definition to include an understanding and internalization of the determinants of health, disease prevention, and wellness, which goes well beyond simply understanding the doctor’s instructions about medication dosages. Unless and until there is a massive population health literacy campaign whose effectiveness is measurable by key indicators, the epidemic of chronic diseases (e.g., Type II diabetes, cardiovascular illness, and many types of cancer) resulting from a demonstrated lack of knowledge about proper nutrition, the necessity of physical activity, the pervasive toxicity of tobacco, personal safety and injury control, and handling stress, can be expected to continue unabated. A comprehensive preventive policy built on and emanating from these proposed literacy indicators would continually monitor the quality of our social and built environments and the pernicious effects of poverty and inadequate education, which are the prime sources of disparities in health among our populations.

#### Project goals

Through this project, NECON proposes to accomplish six goals:

1. develop a definition of and a theoretical framework for *population* health literacy;
2. construct indicators of *population* health literacy;
3. develop instruments to measure and track population health literacy;
4. pretest instruments for measuring and tracking population health literacy;
5. based upon the pretests, revise the instruments for measuring and tracking population health literacy;
6. conduct initial telephone surveys of population health literacy.

In accomplishing these six goals, NECON would extend current definitions of health literacy to encompass population health and develop a system for measuring and then tracking population health literacy. A preliminary definition of health literacy could build on the Oxford English Dictionary's definitions of "literacy" as "the quality or state of being literate," and of "literate" as "acquainted with letters or literature; educated, instructed, learned."<sup>24</sup> Thus, a preliminary definition of population health literacy would entail knowledge and understanding of the distal and more proximate factors affecting individual and population health, and the distinction between individual and population health.

In meeting these six goals, NECON would bridge three disparate bodies of thought and research.<sup>25</sup> The first body of thought and research, as mentioned above, relates to the original concept of health literacy and recent expansions and re-examinations of this concept. The second relates to population-level influences on health, as perceived by the public, health care providers, and government and political leaders, and includes work conducted in Prince Edward Island,<sup>26</sup> Ontario,<sup>27</sup> Canada nationally,<sup>28</sup> western Scotland,<sup>29</sup> England, Scotland, and Wales;<sup>30</sup> and Wisconsin.<sup>31,32</sup> The third body of literature relates to the notion of "actual" causes of death.<sup>33,34,35</sup>

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<sup>24</sup> Oxford English Dictionary On-line. Available from:

[http://dictionary.oed.com.brkproxy.minlib.net/cgi/entry/50134123?single=1&query\\_type=word&queryw ord=literacy&first=1&max\\_to\\_show=10](http://dictionary.oed.com.brkproxy.minlib.net/cgi/entry/50134123?single=1&query_type=word&queryw ord=literacy&first=1&max_to_show=10) and

[http://dictionary.oed.com.brkproxy.minlib.net/cgi/entry/50134140?single=1&query\\_type=word&queryw ord=literate&first=1&max\\_to\\_show=10](http://dictionary.oed.com.brkproxy.minlib.net/cgi/entry/50134140?single=1&query_type=word&queryw ord=literate&first=1&max_to_show=10). Cited December 14, 2009.

<sup>25</sup> Ratzan SC (2001). Health literacy: communication for the public good. *Health Promotion International* 16(2):207-214.

<sup>26</sup> Eyles J, Brimacombe M, Chaulk P, Stoddart G, Pranger T, Moase O (2001). Who determines health? Attitudes towards the determinants of health among multiple stakeholder groups in Prince Edward Island, Canada. *Social Science and Medicine* 53:1611-1619.

<sup>27</sup> Collins PA, Abelson J, Eyles JD (2007). *Health Policy* 80(1):158-171.

<sup>28</sup> Canadian Institute for Health Information (2005). *Select Public Highlights on Public Views of the Determinants of Health*. Toronto (ON): Canadian Institute for Health Information.

<sup>29</sup> Macintyre S, McKay L, Ellaway A (2006). Lay concepts of the relative importance of different influences on health; are there major socio-demographic variations? *Health Education Research* 21(5):731-739.

<sup>30</sup> Blaxter M (1997). Whose fault is it? People's own conceptions of the reasons for health inequalities. *Social Science and Medicine* 44(6):747-756.

<sup>31</sup> Robert SA, Booske BC, Rigby E, Rohan AM (2008). Public views on determinants of health, interventions to improve health, and priorities for government. *Wisconsin Medical Journal* 107(3):124-130.

<sup>32</sup> Rigby E, Soss J, Booske BC, Rohan AMK, Robert SA (2009). Public responses to health disparities: how group cues influence support for government intervention. *Social Science Quarterly* 90(5):1321-1340.

<sup>33</sup> McGinnis JM, Foege WH (1993). Actual causes of death in the United States. *JAMA* 270(18):2207-2212.

<sup>34</sup> Mokdad A, Marks JM, Stroup DF, Gerberding JL (2004). Actual causes of death in the United States, 2000. *JAMA* 291(10):1238-1245.

<sup>35</sup> McGinnis JM, Foege WH (2004). The immediate vs the important. *JAMA* 291(10):1263-1264.

Project objectives

1. Goal: Develop a definition of and a theoretical framework for *population* health literacy:
  - a. Objective: Convene work group of population health and health literacy experts
  - b. Objective: Explore concept of population health literacy and develop preliminary definition
  - c. Objective: Review with work group concept and preliminary definition of population health literacy
  - d. Objective: Develop consensus concept and definition of population health literacy
2. Goal: Construct indicators of *population* health literacy:
  - a. Objective: Review extant indicators of health literacy and survey instruments measuring perceptions of influences on health
  - b. Objective: Based on indicators of health literacy, develop preliminary indicators of population health literacy
  - c. Objective: Review with work group conducts the preliminary indicators of population health literacy
  - d. Objective: Based upon work group review, revise preliminary indicators of population health literacy
3. Goal: Develop instruments to measure population health literacy
  - a. Objective: Develop population-based questionnaire
  - b. Objective: Develop state and local political leadership questionnaire
  - c. Objective: Develop health care provider questionnaire
  - d. Objective: Review with work group the three questionnaires
  - e. Objective: Revise three questionnaires based upon project work group review
4. Goal: Pretest instruments
  - a. Objective: Pretest population-based questionnaire through a random digit dial survey in New England states
  - b. Objective: Pretest state and local political leadership questionnaire through conducting telephone interviews in New England states
  - c. Objective: Pretest health care provider questionnaire through conducting telephone interviews in New England states
5. Goal: Refine population health literacy concept, definition, indicators, and questionnaires, based upon the pretests
  - a. Objective: Refine concept and definition of population health literacy to ensure their efficient and effective use
  - b. Objective: Refine indicators
  - c. Objective: Refine questionnaires
6. Goal: Conduct initial telephone surveys of population health literacy

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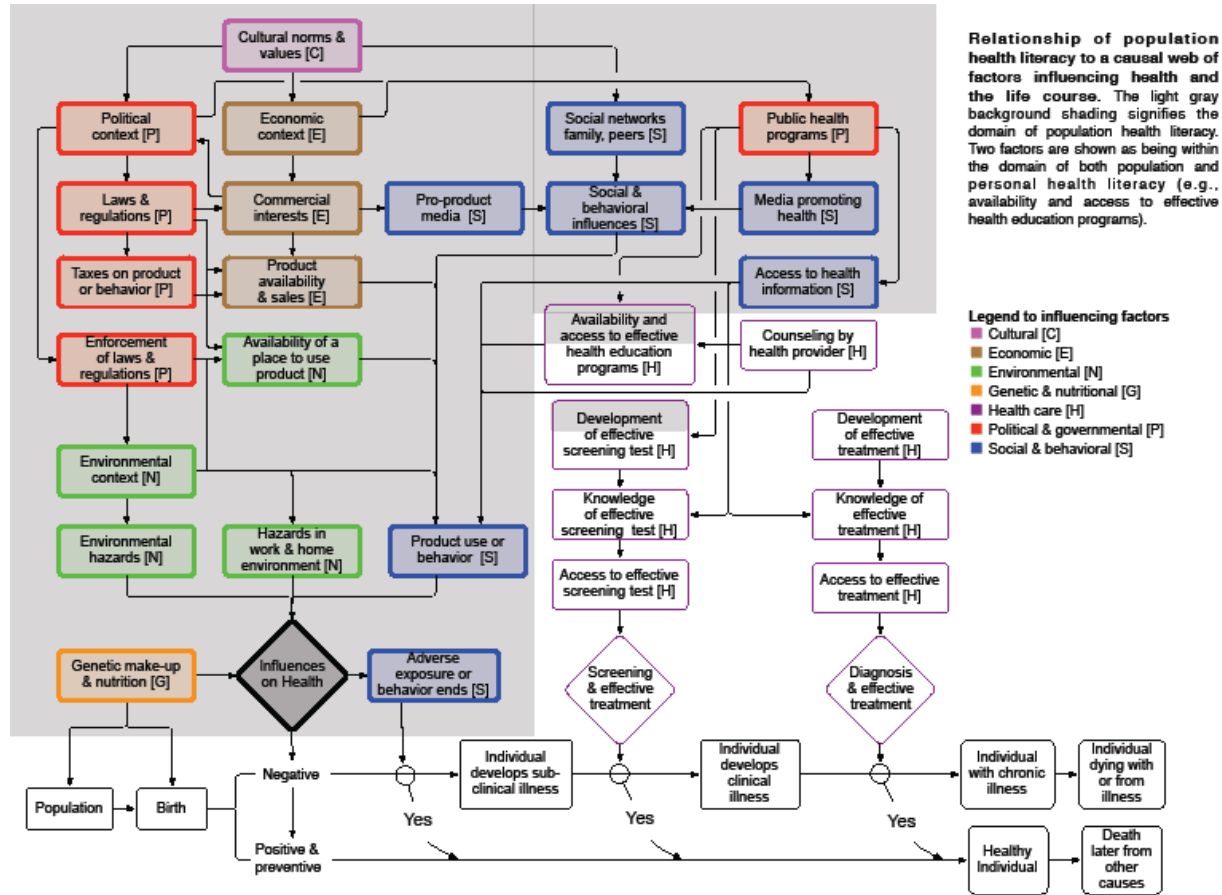
- a. Objective: Measure population health literacy in the six New England states through random digit dial interviews, with a sample capable of generalizing to New England as a whole and to each New England state
- b. Objective: Measure population health literacy among state and local political leadership in the six New England states through telephone interviews, with a sample capable of generalizing to New England as a whole and to each New England state
- c. Objective: Measure population health literacy among health care providers in the six New England states through telephone interviews, with a sample capable of generalizing to New England as a whole and to each New England state

#### Project products

This project will provide four final products:

1. Concept and definition of population health literacy for a NECON population health literacy Web site
2. Indicators of population health literacy for a NECON population health literacy Web site
3. Population health literacy questionnaires for random digit dial general population survey, state and local political leaders, and health care providers for a NECON population health literacy Web site
4. Project final report

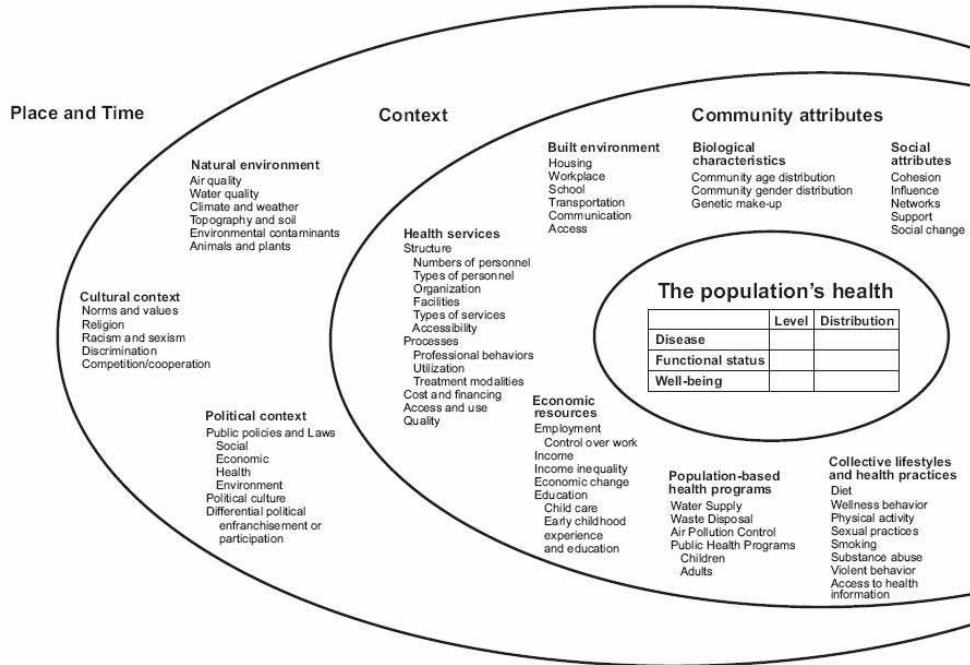
Figure 1: Relationship of population health literacy to causal web of factors influencing health and the life course



Adapted from Parrish RG, McDonnell SM, Rensington PL. Surveillance for Determinants of Population Health. In: Teutsch et al, Editors. Principles and Practice of Public Health Surveillance, 3rd edition. New York: Oxford; 2010.



Figure 3: Influences on population health



Source: Friedman DJ, Hunter EL, Parrish RG, editors. *Health Statistics: Shaping Policy and Practice to Improve the Population's Health*. New York, London, and San Francisco: Oxford University Press; 2005:18.

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Figure 4: NECON trends report indicators