

**PUBLIC ENGAGEMENT  
WITH HEALTH RESEARCH:  
DEVELOPMENT OF KNOWLEDGE  
AND ATTITUDE SCALES**

A Dissertation  
presented to the Faculty of the Graduate School  
of Cornell University  
in Partial Fulfillment of the Requirements for the Degree of  
Doctor of Philosophy

by  
Andrew Franklin Pleasant  
January 2005.

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Andrew Franklin Pleasant, Ph.D.

Cornell University 2005

This dissertation reports on the development of two measures useful to help understand how health research does – and does not – get used by the public. This project is important for several reasons. First, most major advances in health since the beginning of the 20th century are due to the application of new knowledge and technologies such as immunizations and preventive medicine. Also, there is an ongoing shift in the burden of disease away from infectious diseases and toward chronic diseases requiring increased patient self-management as well as behavior and lifestyle changes. Finally, a continuing emergence of self-care protocols as basic treatment practices combined with cutbacks in health services compound the need for a public that is fully engaged with the products of health research.

This work is conducted within a theoretical framework that posits health literacy as a primary tool individuals use to engage with the products of scientific research on health. Building upon that theoretical framework, this dissertation reports on the development of a method to assess the level of knowledge based on scientific research on health, or health research, that a person holds. Second, as attitudes are also important in terms of changing behavior to improve health, a measure to assess attitudes toward health research is developed. Both measures were tested in China, Mexico, Ghana, and India as part of a larger research effort conducted by the World Health Organization and local partners.

This work has developed two measures that will provide new information about public engagement with health research and health literacy. In addition to the central methodological developments, key lessons from this research are related to the role of health literacy in relation to the process of public engagement with health research, the design of international research projects, and the role of strict methodological guidelines to ensure validity and reliability. When applied, that knowledge can enhance efforts to promote public engagement with health research and, over the long-term, improve public health.

## **BIOGRAPHICAL SKETCH**

Andrew Pleasant has an A.A.S. from the Rochester Institute of Technology, a B.A. in Journalism from Arizona State University, and an A.M. in Environmental Studies from Brown University.

## **ACKNOWLEDGMENTS**

This dissertation was supported in part by the World Health Organization, Geneva, Switzerland. The views expressed herein do not necessarily reflect those of the World Health Organization or of any partnering organizations, individuals, or committee members. Pleasant acknowledges and thanks for their assistance, persistence, and patience committee members Jim Shanahan, Cliff Scherer, Stephen Hilgartner and, in particular, committee chair Bruce Lewenstein.

# TABLE OF CONTENTS

<b>CHAPTER 1.....</b>	<b>1</b>
<b>PUBLIC ENGAGEMENT WITH HEALTH RESEARCH .....</b>	<b>1</b>
GROWING RECOGNITION OF PUBLIC ENGAGEMENT WITH HEALTH RESEARCH ...	3
NEED FOR GREATER UNDERSTANDING.....	8
INTEGRATING THEORIES OF HEALTH LITERACY .....	11
TOWARD A DEFINITION OF PUBLIC ENGAGEMENT WITH HEALTH RESEARCH ...	17
<b>CHAPTER 2.....</b>	<b>23</b>
<b>THE ROLE OF KNOWLEDGE AND ATTITUDES .....</b>	<b>23</b>
THE ROLE OF KNOWLEDGE .....	23
<i>Measuring scientific literacy.....</i>	<i>24</i>
<i>Specific disease, condition or health issue knowledge scales.....</i>	<i>29</i>
<i>Measuring health literacy.....</i>	<i>36</i>
THE ROLE OF ATTITUDES .....	39
<b>CHAPTER 3.....</b>	<b>48</b>
<b>METHODOLOGY.....</b>	<b>48</b>
ISSUES IN SCALE DEVELOPMENT .....	48
CONTENT VALIDITY .....	49
<i>Face validity.....</i>	<i>50</i>
<i>Criterion validity.....</i>	<i>51</i>
<i>Construct validity.....</i>	<i>51</i>
<i>Discriminate validity.....</i>	<i>52</i>
<i>Reliability.....</i>	<i>53</i>
SURVEY ADMINISTRATION .....	57
THE COUNTRY SETTINGS AND STUDY PARTICIPANTS .....	61
<b>CHAPTER 4.....</b>	<b>64</b>
<b>THE KNOWLEDGE BASED ON HEALTH RESEARCH SCALE.....</b>	<b>64</b>
BUILDING THE SCALE.....	64
<i>Content validity.....</i>	<i>64</i>
<i>Construct validity.....</i>	<i>68</i>
<i>Discriminate validity.....</i>	<i>70</i>
RESULTS .....	71
<i>Face validity.....</i>	<i>71</i>
<i>Frequency of responses.....</i>	<i>72</i>
<i>Construct validity.....</i>	<i>76</i>
<i>Discriminate validity.....</i>	<i>78</i>
<i>Reliability.....</i>	<i>80</i>
ANALYSIS .....	86
CONCLUSION .....	89

<b>CHAPTER 5.....</b>	<b>91</b>
<b>THE ATTITUDES TOWARD HEALTH RESEARCH SCALE .....</b>	<b>91</b>
BUILDING THE SCALE.....	91
<i>Content validity</i> .....	91
<i>Construct validity</i> .....	97
<i>Discriminate validity</i> .....	98
RESULTS .....	99
<i>Face validity</i> .....	99
<i>Frequency of responses</i> .....	100
<i>Reliability</i> .....	102
<i>Construct validity</i> .....	104
<i>Discriminate validity</i> .....	105
<i>Exploratory factor analysis</i> .....	107
ANALYSIS .....	110
CONCLUSION .....	111
<b>CHAPTER 6.....</b>	<b>113</b>
<b>CONCLUSION .....</b>	<b>113</b>
<b>REFERENCES .....</b>	<b>117</b>

## LIST OF TABLES

Table 1. Approaches to validity and reliability. ....	55
Table 2. Location and size of sample by country. ....	61
Table 3. Economic and health system data .....	62
Table 4. Demographics of participants. ....	63
Table 5. Responses to health research statements. ....	73
Table 6. Responses to scientific knowledge statements.....	75
Table 7. Comparing science and health knowledge scales .....	77
Table 8. Correlation between science and health knowledge.....	77
Table 9. Comparison of experts and public responses .....	79
Table 10. Optimized scales for each country and corresponding alpha .....	81
Table 11. Final health knowledge scale (final items in bold).....	83
Table 12. Domains of outcomes from health research .....	93
Table 13. Frequency of responses .....	100
Table 14. The attitudes toward health research scale .....	103
Table 15. Attitudes toward health research scale descriptives .....	104
Table 16. Difference between experts and the public. ....	106
Table 17. Number and structure of factors.....	108
Table 18. Factor loadings: China and Mexico .....	109
Table 19. Factor loadings: India and Ghana.....	109
Table 20. Factor loadings: Aggregate.....	110

## **LIST OF FIGURES**

Figure 1. An intervention based model of the relationship between public engagement with health research and health literacy. ....	17
Figure 2. Health research system.....	69

## LIST OF ABBREVIATIONS AND ACRONYMS

ACP-ASIM	
American College of Physicians - American Society of Internal Medicine	
AIDS	Acquired Immune Deficiency Syndrome
Ch	China
In	India
GDP	Gross Domestic Product
Gh	Ghana
HIV	Human Immunodeficiency Virus
MDA	Muscular Dystrophy Association
Mx	Mexico
NHS	U.K. National Health Services
NIH	U.S. National Institutes of Health
NSB	U.S. National Science Board
OECD	Organization for Economic Co-operation and Development
REALM	Rapid Estimate of Adult Literacy in Medicine
SD	Standard Deviation
TOFHLA	Test of Functional Health Literacy in Adults
UNCED	
	United Nations Conference on Environment and Development
USDHHS	U.S. Department of Health and Human Services
WHO	World Health Organization

# **CHAPTER 1**

## **PUBLIC ENGAGEMENT WITH HEALTH RESEARCH**

Every day around the world about 15 billion cigarettes are smoked, poor use of antibiotics increases the likelihood of antibiotic resistance, and HIV/AIDS continues to spread (ACP-ASIM, 2000; Mackay & Eriksen, 2002; WHO, 2004). Every day around the world, health research that could help combat these and many other threats to human health lies underutilized or neglected altogether.

This dissertation addresses that issue by reporting on the development of tools to investigate the gap between what is known through scientific research about health, referred to as health research in this dissertation, and what is done in actual practice – sometimes called the “know-do” gap (Bailey & Pang, 2004). The tools developed are a scale to assess the level of knowledge based on health research held by individuals and a scale to assess attitudes toward health research.

Health literacy is a core set of skills and abilities that individuals employ in engaging with the varied products of scientific research on health. As health literacy is generative – in that it allows individuals to apply existing knowledge and skills to new situations as they arise – the possession of knowledge produced by scientific research on health, or health research, and positive attitudes toward such research is

postulated in this dissertation to indicate as well as predict increased engagement with health research (Zarcadoolas et al., 2003; in press).

This project is important for several reasons. First, most major advances in health since the beginning of the 20th century are due to the application of new knowledge and technologies such as immunizations and preventive medicine (World Bank, 2002). Also, there is an ongoing shift in the burden of disease away from infectious diseases and toward chronic diseases requiring increased patient self-management as well as behavior and lifestyle changes (Resnik, 2001). This shift indicates a tangible need for an active and informed public to assure, for example, patient compliance and proper self-care (Karmaus, 2001; Resnik, 2001; Stokols, 1992). Further, a continuing emergence of self-care protocols as basic treatment practices combined with cutbacks in health services (furthering the need for self-care) compound the need and utility of an informed and active public fully engaged with the products and processes of health research (Haynes & Haines, 1998). Finally, the continuing emergence of information and communication technologies has increased access to often disagreeing sources of information about health, thereby increasing the demands on health literacy skills of patients and health care providers alike and creating a new set of challenges to and opportunities for public engagement with health research (Eng, et al., 1998).

## ***Growing recognition of public engagement with health research***

Support for some notion of public engagement is found in almost every major contemporary public document that addresses health, development, or the environment. The 1987 report, *Our Common Future: The Report of the World Commission on Environment and Development*, also referred to as *The Brundtland Report* acknowledging then UNCED chairperson Gro Harlem Brundtland, concludes that, in part, the pursuit of sustainable development requires “a political system that secures effective citizen participation in decision-making” (*World Commission on Environment and Development*, 1987). Building on that lead, Principle 10 of the *Rio Declaration on Sustainable Development* calls on states to enhance participation and access to information (UNCED, 1992).

Public engagement is taken as a good in and of itself in the *World Health Organization's (WHO) Alma Ata declaration*, which states, “The people have the right and duty to participate individually and collectively in the planning and implementation of their health care” (*International Conference on Primary Health Care*, 1978). One of the five action strategies of the *Ottawa Charter for Health Promotion* is to strengthen community participation (*First International Conference on Health Promotion*, 1986; WHO, 1998). The U.S. National Institutes of Health (NIH) *Healthy People 2010 plan* explicitly addresses goals of

mobilizing community partnerships to identify and solve health problems and to inform, educate, and empower people about health issues (USDHHS, 2000). The U.K. National Health Services (NHS) plan argues, “The NHS of the 21st century must be responsive to the needs of different groups and individuals within society” (NHS, 2000).

Finally, the constitution of the World Health Organization states “An informed opinion and active co-operation on the part of the public are of the utmost importance in the improvement of the health of the people”.

Public engagement can address a fear that countries with marginalized populations and a lack of participatory democracy may suffer further inequalities if the products and direction of health research are not appropriately guided by ethical concerns (Bhutta, 2001; V. Wiseman, Mooney, Berry, & Tang, 2003). Health policymakers argue that indigenous involvement in the health care decision-making process is required in order to achieve equity. Thus, in many countries public representation is required in the membership of ethical review committees. For example, New Zealand requires that 50 percent of the membership of such boards must be lay people, including the chairperson, and at least two members must be Maori (New Zealand Ministry of Health, 2002). Most aboriginal organizations and policymakers in Australia are reported as arguing that indigenous involvement in the health care decision-making process "is a basic pre-

requisite for the achievement of equity" (V. Wiseman et al., 2003, p. 1003).

Legislation establishing regulatory systems of health care professionals often mandates community representation and the proportion of such representation has generally increased over time (Bastian, 1994). In the United Kingdom, either the chairperson or vice chairperson of medical review boards is required to be a layperson (McNeil, 1993). The U.S. Federation of State Medical Boards has proposed that at least a quarter of all medical review board members be public representatives (Federation of State Medical Boards of the United States, 1998).

Broad public engagement in research priority setting has a potential to highlight the global burden of disease in the decision-making process by including those directly affected. Therefore, public engagement is also seen as one of the means to reduce inequity in health research funding as indicated by the 10/90 gap – wherein 90 percent of the world's health research spending goes toward 10 percent of the problems (Global Forum for Health Research, 2000, 2002).

Despite the immense challenge, well-documented examples of public engagement changing health research policy and the level and direction of funding for the health research system do exist. Epstein documents how AIDS activist movements have changed the practice of

biomedical research as well as the therapeutic techniques of medical care (Epstein, 1995). Those changes were achieved not through sheer political power but through an intensity of engagement that resulted in activists claiming credibility within the discourse of health research, altering traditional perspectives on expertise.

Other examples of the role of public engagement in influencing the direction of health research include influencing the flow of funding to disease related research. The Jerry Lewis MDA Labor Day Telethon is an example in the United States that has existed since 1966. The 2003 telethon involved more than one million volunteers and raised \$60.5 million (Muscular Dystrophy Association, 2004). The growth and influence of organizations like the American Cancer Society, the March of Dimes, and a host of disease related non-governmental and advocacy organizations are further examples of the impact of public engagement (Starr, 1982).

In an historical example, the National Tuberculosis Association (NTA), the first voluntary health-organization formed in the United States to fight a specific disease at the national level, launched the Christmas Seal Campaign in 1907 to raise funds to finance an educational approach to combating tuberculosis. The sale of the annual seal helped to educate the public about tuberculosis by creating institutional value, being widely distributed, and increasing commitment among purchasers (Jacobs, 1940). Additionally, exposure

to such programs was related to greatly increased levels of participation in x-ray screening programs (Jacobs, 1940; Chadwick & Pope, 1946; Starr, 1982).

Public engagement can also be pursued as a social technology of legitimization in attempts to enhance the credibility of research commissioning organizations (Harrison, Barnes, & Mort, 1997). At times, that end has been sought without actual sharing of decision-making power from the central authority (Rowe & Frewer, 2000). Many attempts at involving the public in research are limited to short-term efforts (Stevens, Wilde, Hunt, & Ahmedzai, 2003) or are not as "public" as they claim (Ard & Natowicz, 2001). For example, Ard and Natowicz (2001) reviewed the data in a U.S. National Institute of Medicine report that contains a strong rhetorical claim of the value of consumer involvement in policy decisions. Their review found that, despite the rhetorical claim, fewer than 5 percent of individuals serving on advisory committees were consumer advocates or lay members.

Public engagement with health research can also provide new knowledge to the health research system. An example is the development of "new" drugs based on traditional knowledge of the medicinal properties of plants and animals. For example, South Africa's Commission on Scientific and Industrial Research has established a database of information on traditional uses of South African plants (Artuso, 2002). The importance of public access to the

formation and management of agreements to 'prospect' indigenous knowledge as well as biological resources is highlighted by the possibility of an inequitable distribution of the benefits created by such activities (Artuso, 2002; WHO Advisory Committee on Health Research, 2002).

Finally, health economists are also beginning to use and value various forms of public engagement, indicating that it can bring new resources to efforts to improve health and can increase cost-effectiveness (Jewkes & Murcott, 1998; Wiseman et al., 2003). For instance, Wiseman and Jan (2000) developed a community participation effort that incorporated differing cultural interpretations of health and what it means to be healthy into an attempt to redress historical inequities in health care provision and decision-making about the allocation of resources for health. Such efforts introduce equity into a process traditionally dominated by goals of relatively short-term economic efficiency.

### ***Need for greater understanding***

Meeting social goals through shared decision-making relies on societies being held together and defined by a shared and integrated system of behavior, stories, and symbols that are socially learned and communicated (Fisher, 1984; Labov, 1997; Nieva & Hickson III, 1996; Ochs, 1997).

Increasing individualization, withering of traditional community structures, and accompanying reductions in social capital and trust in social institutions challenge efforts to create shared decision-making processes (Buchecker, Hunziker, & Kienast, 2003; Gerbner, 1999; Jasanoff, 1997; Putnam, Leonardo, & Nanetti, 1993). Further challenging efforts to enhance public engagement, most members of society have reduced access to the stories of health research and science. This differential access to knowledge can have serious ramifications – as Wertheim cautions,

"As long as our culture continues to refract reality through the lens of science there is an obligation to make the science accessible to everyone. What is at stake here is not just individual sanity, but ultimately social cohesion" (Wertheim, 1996).

Many researchers have repeatedly called for building up a body of empirical evidence of the relationships between the public and science, including health research. For example, Litva et al. (2002) assert that there is little systematic research looking at where and how the public prefers to be involved in rationing decisions. Ard and Natowiz (2001, p. 787) found that “there has been only limited scholarly research regarding the composition of federal medical and scientific policy-making advisory committees and whose interests committee members

represent.” von Grote & Dierkes (2000, p. 356) highlight the need for research exploring how the public understands, accepts, and uses science and technology. They argue that the “interactive elements in the process of negotiating and acquiring knowledge that is used should become a major focus of study, as should the social contexts in which knowledge is produced.” Finally, in one of the few attempts at systematic review of the public participation literature, Abelson et al. (2003) note a “paucity of rigorous evaluations”.

A lack of systematic assessment is a strong contributing factor to the poor understanding of the mismatch between the knowledge produced by the health research system and the public awareness and use of that knowledge. Systematic assessment of efforts to improve public engagement with health research will create a valid and reliable evidence base related to the successes and failures of differing interventions and the obstacles and incentives to public engagement with health research. That evidence can contribute to greater understanding of the relevance, context, and outcomes of health research for various audiences, contribute to effective communication strategies, support further monitoring of efforts to enhance engagement with health research, and inform effective and equitable investment and policy decisions (Bero et al., 1998; Comroe & Drips, 1976; Haines & Jones, 1994; S. Hanney, Gonzalez-Block, Kogan, & Buxton, 2003; Patton, 2002). Systematic assessment requires valid and reliable tools of social research. Filling gaps in the toolbox of

research methods is the goal of the research reported in this dissertation.

A complete discussion of how the public engages with health research must address accounts of knowledge absent when needed, ignored when relevant, or known but not transmitted to those in need (Adams & Corrigan, 2002; Gross & Sepkowitz, 1998; Mosteller, 1981; WHO, UNAIDS, & UNICEF, 2002). To identify and address such gaps between knowledge produced and the extent that knowledge is used, a greater understanding of the forms, intensity, obstacles, incentives, and the process of public engagement with health research is needed (Bastian, 1994; Pleasant et al., 2003).

### ***Integrating theories of health literacy***

Health literacy is a key component of the complex relationship between knowledge, attitudes, behavior, and health outcomes (Nielsen-Bohlman et al., 2004). A health literate person is able to improve health decision-making and benefits from healthier lifestyle choices; but in addition, a health literate individual can better participate in the “social, economic and environmental determinants of health, and be directed towards the promotion of individual and collective actions which may lead to modification of these determinants” (Nutbeam, 1999, p.49). Health literacy is defined as the wide range of skills and competencies that people develop to seek out, comprehend, evaluate,

and use health information and concepts to make informed choices, reduce health risks, and increase quality of life (Zarcadoolas et al., 2003; in press).

Within the context of public engagement with health research, this research incorporates and builds upon two theoretical constructs of health literacy. First, the model put forth by Zarcadoolas, Pleasant, & Greer (2003; in press) posits four conceptual domains of health literacy:

- Fundamental - the skills and strategies involved in reading, speaking, writing, and interpreting numbers (numeracy).
- Scientific - levels of competence with science and technology, including some awareness of the process of science.
- Civic - abilities that enable citizens to become aware of public issues and to become involved in the decision-making process.
- Cultural - abilities to recognize and use collective beliefs, customs, world-view, and social identity in order to interpret and act on health information.

Second, this research incorporates the model of health literacy suggested by Nutbeam (2000). That model of health literacy proposes

levels of health literacy, versus cognitive domains of health literacy as theorized in the Zarcadoolas et al. model. The levels of health literacy Nutbeam proposed are:

- Functional – basic skills in reading and writing to be able to function effectively in everyday situations
- Communicative – cognitive, literacy, and social skills used to participate in everyday activities including the ability to apply new information to changing circumstances.
- Critical – advanced cognitive and social skills applied to critically analyze information and use information to exert greater control over life's events and situations.

Combining the two theories creates a more complete conceptual framework that outlines the areas of content that should be addressed by a valid and reliable methodology to assess health literacy; a key tool individuals use when engaging with health research (Figure 1).

The combination of theories of health literacy from Zarcadoolas et al., and Nutbeam posits that within each conceptual domain established by Zarcadoolas et al., there will be three levels of skills and abilities as described by Nutbeam. For example, within the scientific domain of health literacy as proposed by Zarcadoolas et al., the theoretical

foundation requires the methodology of assessment to explicitly incorporate measures of:

- Functional scientific literacy – This level will reflect the possession of knowledge based on health research. This dissertation, in part, reports on the development and testing of a scale to assess this component of the overall theoretical framework.
- Communicative scientific literacy – This level will reflect the ability to discuss the implications of basic scientific facts for individual lifestyles, which begins to move into the domain of behavior change based on the possession of information.
- Critical scientific literacy – This level will reflect higher abilities to deal with information produced by health research such as an understanding of the scientific process itself and some understanding of evidence-based medicine. Possession of skills and abilities in this area will directly produce an improved ability to critically interact with medical professionals in terms of questioning and understanding proposed treatments and their efficacy.

A strong source of motivation and justification for this dissertation is to develop a methodology useful for informing and improving efforts to

enhance public engagement with health research. The goal of supporting and informing better knowledge-based interventions is reinforced by, for example, the WHO Commission on Macroeconomics and Health's reports that indicate such interventions – including traditional health education, community-based education and information, or social marketing – designed to stimulate demand by specific target populations for health services are required in order to improve the health of the global poor (Jha et al., 2002). Also, a recent U.S. Institute of Medicine report demonstrates that health literacy is a critically important tool for individuals to use in that process and that successful interventions are those that address health literacy (Nielsen-Bohlman et al., 2004). Therefore, an intervention-based approach to the theoretical framework put forth here is perhaps the most explicatory and useful (Figure 1).

From the perspective of an intervention – be it focused on health education, health promotion, or direct activism – the effort must meet the health literacy skills and abilities of targeted populations and individuals if it is to have the desired effect. This notion is well encapsulated in theories of and approaches to social marketing (Lefebvre & Rochlin, 1997). Social marketing is the "application of commercial marketing technologies to the analysis, planning, execution, and evaluation of programs designed to influence the voluntary behavior of target audiences in order to improve their personal welfare and that of their society" (Andreason, 1995, p. 6).

The WHO Commission on Macroeconomics and Health and other efforts to assess the impact of health care systems repeatedly demonstrate a link between long-term health and social outcomes and health literacy and increased engagement with health research (Jha et al., 2002; WHO 2000). The status of health and society determines the need and development of future interventions as they become relevant and necessary.

As depicted in Figure 1, the theoretical basis for this work predicts that complex social interventions attempting to improve public engagement with health research are ‘translated’ through an individual’s health literacy. According to the theoretical framework employed in this work, that will occur in multiple levels within multiple conceptual domains. As engagement through health literacy advances to the critical level, an individual’s ability to engage with the products of health research increases. In turn, the theoretical model predicts that individuals will adopt healthier behaviors, make more effective use of health services, and demand effective health services, improved health policy, and a healthy environment.

In order to develop a methodology that will allow testing of this theoretical framework, the process of public engagement must first be further explored.

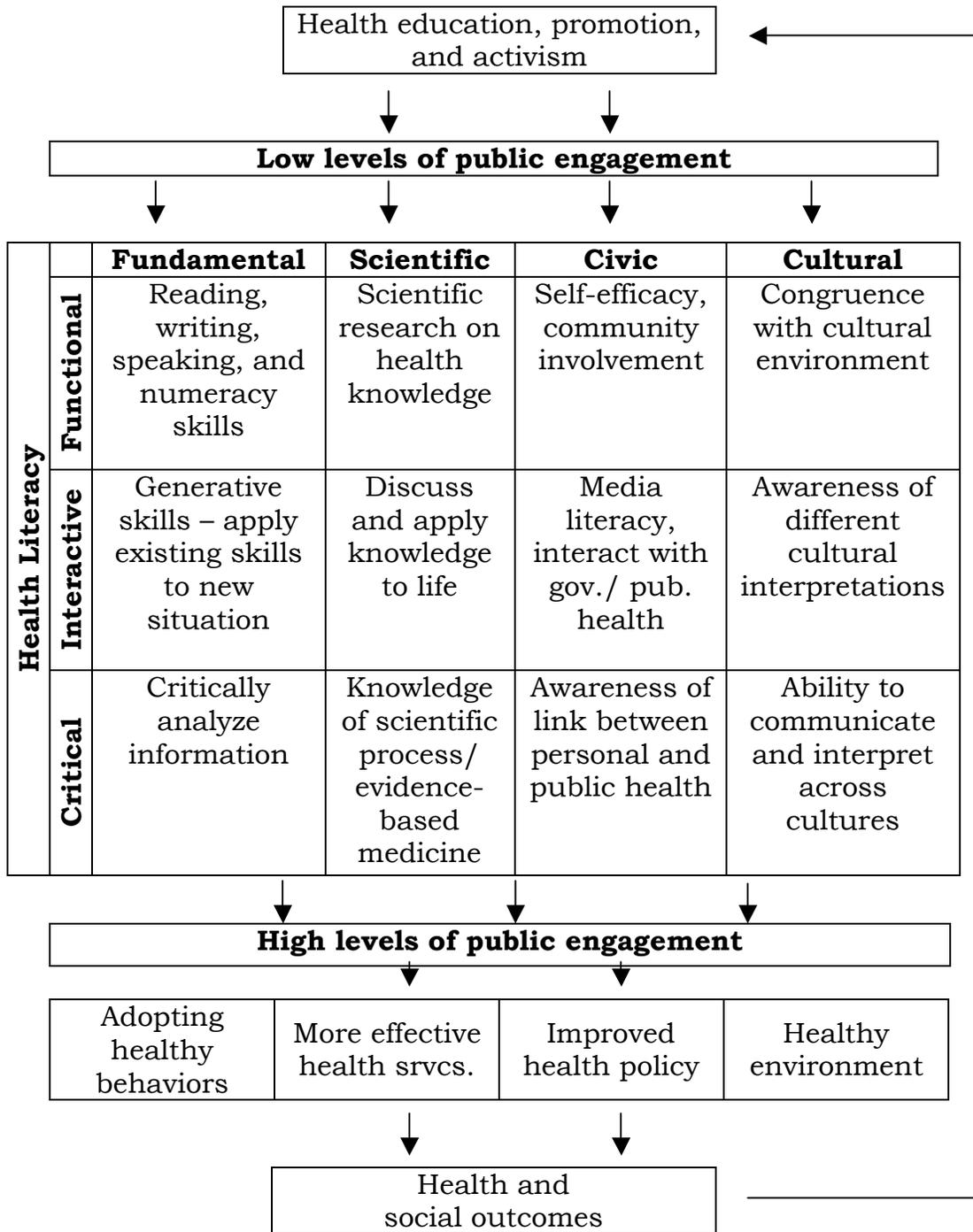


Figure 1. An intervention based model of the relationship between public engagement with health research and health literacy.

### ***Toward a definition of public engagement with health research***

Public engagement is used as a means to incorporate both the concept of an informed public, as reflected in the many studies of public understanding of science and technology, and the concept of an actively involved public as reflected in advocacy of and academic research on public participation. Understanding and participation are incorporated within the term engagement because while both a fully informed yet inactive individual and a fully active yet uninformed individual are possible, neither reflects the ideal (Frankish, Kwan, Ratner, Higgins, & Larsen, 2002; Pardo & Calvo, 2002).

High-levels of engagement can be considered an ideal as the concept implies that individuals so engaged will have the skills and inclination to question as well as to utilize the products and processes of health research. In that sense, the potential for high-levels of engagement with health research are created by the presence of high levels of health literacy. Ultimately, this relationship is predicted to produce increased public demand for relevant and appropriate health services (Figure 1).

Thus, public engagement as used in this work refers to a process that can be configured in a number of ways – ranging from the deliberately

planned consensus conference to an individual encountering health research based information in the mass media. The process of engagement is not a single discrete event but is composed of multiple events including the transfer, reception, understanding, and use of knowledge as well as feedback and the production of information by the public (Rich, 1991).

While other researchers have used a variety of terms and overlapping concepts such as civic engagement, public participation, or public understanding to refer to the process of public engagement, common to all approaches is a core element of communication – though the understanding of the complexity of communication varies.

The most commonly encountered and historically dominant models of participation and understanding are linear from input to output. Those echo the mathematical model of communication developed by Claude Shannon that depicts a unidirectional flow from sender – of a message through a channel – to a receiver (Shannon & Weaver, 1949). However, most contemporary models of communication acknowledge a more complex and iterative process involving feedback, potential misinterpretation at the message at encoding and decoding stages, as well as multiple influences at social and individual levels (Glanz, Lewin, & Rimer, 1997; Kreps & Thornton, 1992; Salwen & Stacks, 1996; Shinn & Whitley, 1985). For example, Lewenstein advances a complex web of science communication that, while focusing on

communication within science, clearly depicts connections outside of science and multi-directional flows of information and feedback (Lewenstein, 1995; Brossard & Lewenstein, 2004).

Four core models of science communication are found within the public understanding of science literature: the deficit model, the lay knowledge/ expertise model, the contextual model, and the public participation model (Wynne, 1992; Yearley, 2000; Ziman, 1992). The deficit model depicts a communication relationship that is one-way from science to the public. The lay expertise model depicts a relationship mainly determined by lay knowledge flowing into science, but science generally selects from that body of information. The contextual model depicts a communicative relationship in which the public selects from science as that information is determined to be useful and relevant to the particular context. The public participation model depicts a more complex communicative relationship involving transparency, openness, and two-way dialogue between the public and science.

As a process of communication, public engagement with health research can occur in line with those theoretical models as well as in combinations of those models and in ways those models do not depict. Therefore, public engagement should not solely be conceived using a model of one-way communication from health research to fill the knowledge gaps of the public – the ‘deficit model’ – despite the

historical dominance of that conceptualization (Hilgartner, 1990; Irwin, 2001; Lewenstein, 1995).

The most effective efforts to promote engagement will inherently involve feedback on the content and the process. Stevens et al. (2003, p. 83) argue, "the most powerful way of involving consumers is to engage them at the beginning of the research process and then continue to maintain contact with consumers through the duration of the study." Therefore, participants in such efforts must have or achieve some level of understanding of the content as well as motivation and means to engage and provide feedback. As a result, public engagement with health research also refers to the ability and the nature of engagement in decision-making involving health research in regard to individual, family, and public health.

Public engagement with health research, then, is a communicative process relying on the skills and abilities of health literacy that can be internal to an individual or can occur between individuals in larger groups (Abelson et al., 2003; Fearon, 1998). Engagement can occur in fairly simple moments such as during a brief encounter with health research based information in the mass media, or in the highly complex process that, for example, could occur during a planned deliberative event such as a citizens jury or when individuals decide whether to participate in a clinical trial.

While broad outlines can be drawn around the concept of public engagement, there is a clear need for further research and the development of a targeted set of research tools to help better understand public engagement with health research.

## CHAPTER 2

### THE ROLE OF KNOWLEDGE AND ATTITUDES

#### *The role of knowledge*

Researchers in the World Bank's department on social capital argue, "One of the most important factors in improving health outcomes is the diffusion and spread of knowledge" (World Bank, 2002). For example, from the first use of dapsone to treat leprosy in 1941 to the development of multi-drug therapy in 1981, initially only a few people in society were aware of treatments for leprosy. Over time, awareness and use grew and then spread quite rapidly and is approaching complete diffusion and the goal of eliminating leprosy (Global Alliance for Elimination of Leprosy, 2001). Attempts to replicate the process are ongoing on a global level for multiple health concerns including polio, tuberculosis, and HIV/AIDS.

This research explicitly incorporates knowledge as part of the larger concept of public engagement with health research (i.e. an *informed* and active public). Therefore, there is a need to understand the role of knowledge based on health research, especially in relation to attitudes and behavior choices. One explanation for the inconsistent associations found by other researchers investigating the relationship between knowledge, attitudes, and behavior is that knowledge may be poorly assessed (Parmenter & Wardle, 1999). Thus, there is a clear

need for a valid and reliable measure of knowledge based on health research in order to better understand the process of public engagement with health research and the disconnects often encountered between knowledge, attitudes, and behaviors.

In building an evidence base upon which to build a scale assessing knowledge based on health research, it is helpful to review previous efforts in the area of assessing scientific literacy, knowledge of specific diseases or health issues, health literacy, and the role of attitudes in shaping knowledge.

### ***Measuring scientific literacy***

The largest effort to measure the level of scientific literacy is a series of surveys in the United States primarily developed by Jon Miller and adopted by the National Science Board (NSB). Beginning with the 1979 version, the NSB survey measures scientific literacy as the possession of a vocabulary of scientific terms and concepts, an understanding of the process of science, and an awareness of the impact of science and technology (Miller, 1992). That basic approach continued on a biannual basis in the U.S. until 2001 and has been used in over 20 countries, including in several Eurobarometer studies. The measures include a series of true/false statements such as, "Antibiotics kill viruses as well as bacteria" and "The earliest humans lived at the same time as the dinosaurs." Open-ended questions including those directed

at measuring an understanding of the nature of the scientific process are also included.

Miller argues that this approach to measuring what he terms civic science literacy is based on a two-dimensional approach: a construct vocabulary dimension and an understanding of scientific inquiry dimension (Miller, 1998).

More recently, Miller and Kimmel (2001) have also suggested an explicitly biomedical science literacy measure. The effort is a significant addition to the ongoing effort to build successful measures of public understanding of science. However, several statements in this scale are subject to criticism based on the high level of complexity and relatively low relevance to daily decisions about health (Pleasant et al., 2003). For example, the biomedical science methodology includes an open-ended question about the definition of a molecule and asks for agreement/disagreement with the statement, “The earliest humans lived at the same time as dinosaurs.”

Overall, there are several notable critiques of the basic approach to measuring what has been called the “deficit model” pioneered by Miller. In an ongoing body of work, Wynne has pointed out the assumptions underlying the survey-based method of measuring the deficit in information that, he argues, diminish the usefulness and relevance of the results (Wynne, 1995). His critique focuses on:

- the lack of uncertainty incorporated into the measure despite the uncertainty inherent to many of the scientific concepts measured,
- a heavy reliance on a "Popperian model of science" which is defined by an emphasis on falsification,
- a reliance on measuring science without context,
- a simplistic interpretation of results, and
- a failure to address the multidimensional nature of science.

Additionally, Bauer and Schoon (1993) offer a critique and suggest improvements to the open-ended question on scientific process included in the basic measurement approach. They point out that the largest percentage of responses, using the original method of analysis, for multiple years and multiple surveys fell into an "other answers" category. Further, Bauer and Schoon (1993, p. 144) argue that the original analytical method does not measure public understanding but "the diffusion of a particular notion of science among the general public." Finally, the authors found in their reanalysis that the reliability of the original coding framework is unacceptably low, with two coders producing an intercoder reliability kappa of 0.44.

In turn, Miller responded that "Bauer and Schoon attempted to apply a multi-dimensional coding scheme to these data, but the limited number of probes in the original interviews and the large number of

very short answers negates the feasibility of this approach for these data” (Miller, 1998, p. 213). Miller’s response is understandable, but the success of Bauer and Schoon’s coding scheme cannot be ignored.

In response to the general critique of the deficit model, Kallerud and Ramberg (2002) proposed that adding questions related to civic scientific literacy, or at least the civic nature of science, would help broaden the approach of the traditional knowledge deficit measuring survey. In particular, the authors argue for inclusion of items related to the trustworthiness of science, the precautionary principle, and science in politics.

Miller (1998, p. 208) wrote that, in his assessment at least, “In general, open-ended questions provide a better measure of understanding than close-ended questions.” As the above review of the critiques indicates, both open and closed question forms have been subject to their share of criticism. In general, the critique of close-ended T/F statements used in this approach is that they present science as much more certain than is true and may often lack relevance to the survey respondents. In response, Miller (1998, p. 208) points out that, “each of these sets of items should be viewed as a sample of constructs from a universe of perhaps a hundred or more constructs that are important to civic scientific literacy.” The general critique of the open-ended aspect of this methodology is that it is subject to varying interpretations and that the interpretation of responses tends to

promote one view of science. Miller, in turn, points to his confirmatory analysis of both U.S. and Eurobarometer data using both open and closed ended questions (Miller, 1998). In essence, Miller argues that his analysis proves the utility of his basic approach whereas the critiques suggest a more complex interpretation of science and the relationship between science and society is possible at least in theory. Nonetheless, the critiques do not so much disprove Miller as they do argue for extending the methodology.

Every effort to measure some aspect of scientific literacy is subject to a growing number of critics and their re-analysis of the data, in particular over the past two decades. That criticism often loses sight of the simple fact that Miller's approach to measuring scientific literacy was the critically important first step in a broader scientific enterprise investigating the relationship between science and society and moving that relationship toward a higher visibility on the public policy agenda.

The research efforts reviewed here have brought a spotlight onto the issues of the relationship between science and the public and the complex nature of developing research tools in this area. An important driver for that process was the collection, aggregation, and presentation of usable information in a policy-forum relevant manner in publications such as the U.S. National Science board's Science and Engineering Indicators series. In society, the importance of public engagement with science was reinforced each time the basic approach,

in its various configurations, was administered and results published. In turn, that process has clearly contributed to a general upsurge of activities promoting public engagement with science. Perhaps the same can be true if a similar effort is initiated specifically in regard to health research.

In regard to the construction of a scale assessing the level of knowledge based on health research, there are lessons to be gleaned from these efforts to establish a measure of general scientific literacy. For example, and perhaps most importantly, in regard to developing a scale to explicitly measure knowledge based on health research, that first step has not yet been taken. Secondly, it is clear from Miller's experience that while there is utility in both closed and open-ended questions, there are practical advantages to taking that first step with the use of closed-ended true/false statements including the relative clarity of the results and increased cost-effectiveness.

***Specific disease, condition or health issue  
knowledge scales***

To further assist in developing a scale to assess the level of general knowledge based on health research that individuals possess, I conducted a review of scale development efforts targeting knowledge about specific diseases or health issues. A plethora of health knowledge scales have been developed in relation to specific diseases,

health conditions, and issues related to health. For example, over 200 articles were identified and reviewed by using a key word search (e.g., “health” and “knowledge” and/or “information” and “scale”) via the PubMed, ProQuest, PsycINFO, ArticleFirst, Ingenta, and the OCLC databases. Specific examples include scales to measure the amount of knowledge about HIV/AIDS (Vogels, Brugman, & van Zessen, 1999), ocular diseases (Pardhan, Mughal, & Mahomed, 2000), breast cancer (Suarez-Perez et al., 1999), osteoporosis (Pande et al., 2000), diabetes (Nicolucci et al., 2000), and nutrition (Parmenter & Wardle, 1999).

Three themes emerge from this review. Most encouragingly, the literature review encountered sound research from around the world, indicating the growth of interest in the impacts of knowledge based on health research and a desire to produce valid and reliable scales to perform that work on an international basis. This body of research also provides some insight into the potential impacts of knowledge based on health research in a variety of countries and contexts. A consistent issue is the relationships between knowledge, behaviors, and health status. Finally, this review indicates the potential utility of a scale assessing the level of knowledge based on health research held by individuals.

For example, there are a number of studies investigating the role of knowledge about HIV/AIDS and treatment options. Much as has been the case for scientific literacy studies, research into the role of

knowledge about HIV/AIDS generally finds a complex relationship between knowledge and behaviors. Often, knowledge related to HIV/AIDS is related to but not sufficient to create behavior change.

For example, in setting the stage for research into the knowledge and risk perceptions of male sex workers in Australia Minichiello et al. (2001) report that while knowledge has traditionally been described as affecting safe sex behavior, it is not clear if knowledge alone is sufficient to increase safe sex behaviors.

Compounding the complexity of the equation regarding the role of knowledge, are findings such as Vogels et al. (1999) who found no statistically significant difference in knowledge levels between Dutch students and individuals who dropped out of school in the Netherlands despite what they report as an active sexual education program in the schools. On a first level of analysis they did find a significant difference in knowledge about HIV prevention that disappeared after controlling for age and education. As age and education are both expected to positively correlate with scores on a general knowledge based on health research scale, the use of such a scale in this case may have given researchers further insight into the role of the various forms and levels of knowledge based on health research. Dropouts and students may, for instance, have the same knowledge about HIV/AIDS because of its high relevance to their

lifestyle but differences in behaviors could be related to the level of knowledge based on health research individuals possess.

The body of research assessing HIV/AIDS knowledge tends to rely on a similar set of statements or questions to assess knowledge. Most commonly encountered are those targeting knowledge about how HIV/AIDS can be transmitted. Commonly used questions inquire whether HIV/AIDS can be transmitted through blood transfusion, unprotected sex, protected sex, kissing, using the same bathroom, or eating off the same plates. That commonality does allow some level of comparability across studies – to the extent that the statements are similar. However, when research turns to other diseases or health issues, there is an appropriate shift in content that limits direct comparability.

In researching the impact of knowledge about breast cancer, Suarez-Perez et al., (1999, p. 367) relied on statements such as “Women who have had breast cancer have more possibilities of developing it a second time” and “to hit, bruise or hurt the breast can cause breast cancer” or “Thin women have a higher possibility of developing breast cancer.” In their analysis, the authors identified three domains of breast cancer knowledge – risks, symptoms, and detection – with corresponding Cronbach’s alpha scores of 0.3069, 0.4339, and 0.4098. As will be discussed in more detail later, those scores are quite

low despite the author's claim that an alpha value of 0.20 is acceptable.

In contrast, Ondrusek, Warner and Goel (1999) used neither of the two statements used as examples above in their final version of an 11-item scale they call the Breast Cancer and Heredity Knowledge Scale. In their analysis, Ondrusek et al. (1999) also argue that there are multiple domains to knowledge about breast cancer as their scale demonstrates that women may know many facts about mammography, but may know virtually nothing about hereditary breast cancer or other risk factors.

That comparison of results and analysis found in Ondrusek et al. (1999) and Suarez-Perez et al. (1999) indicate that even within research addressing the role of knowledge about the same issue there is a lack of consistency in method and results not only between studies but also, at times, within studies. Further, there is no evidence whether knowledge about breast cancer has any relation to knowledge of other diseases or health issues. Therefore, it remains an unanswered question if researchers are finding consistent results in terms of the impact of knowledge upon behavior, attitudes, or health status across various issue areas. The development of a research tool that allows comparison across such dissimilar health issues would help answer that question.

This review indicates utility for a scale that can assess knowledge based on health research that is not based on any particular disease, condition, or health issue. Current research efforts are by and large incommensurate as the specific statements or questions used to measure knowledge are, appropriately, as distinct as the diagnostic methods used to assess health status in relation to the specific health issue. While that difference is entirely appropriate, it creates a need for a valid and reliable measure – especially one proven in a variety of cultural contexts and languages – that could allow researchers to compare results by including a scale assessing knowledge based on health research in general within their projects targeting particular health issues. That step would create evidence to help answer critical questions such as “Do individuals know more about a specific health condition because they are at greater actual or perceived risk, or is it because they possess more knowledge based on health research in general?”

A general measure of knowledge based on health research, which would allow for comparison across studies, would also prevent a situation akin to what Brossard and Shanahan (2003) encountered in their study of authoritarian views toward science. Their use of a scale specifically to assess authoritarianism in regard to biotechnology, without the inclusion of a measure of authoritarianism in general “rendered it impossible to isolate effects due uniquely to the scientific context” (Brossard & Shanahan, 2003, p. 307).

In addition to reinforcing the utility of a general knowledge based on health research scale, assessing knowledge of particular diseases, conditions, or health issues is also a guide to widely accepted methodological practices in scale development. In terms of methodology, the dominant concerns that emerge are issues of reliability and validity. Articles reporting on the development of a new scale assessing knowledge – when the article contained a report of a measure of internal reliability – exclusively reported using Cronbach's alpha (including KR-20). Validity concerns in their various forms were most often addressed through focus groups or participant' comments, expert review, literature reviews, confirmatory factor analysis, and correlations between factors.

Another strong area of methodological agreement emerged in that almost all scales assessing knowledge of a specific disease, condition, or health issue employed response categories of true, false, and don't know. These categories were generally recoded for analysis as either correct or incorrect. The few exceptions using a Likert type scale tended to also recode responses into a dichotomous scheme.

Therefore, based partly upon the preponderance of acceptance within the professional academic community, Cronbach's alpha will be used as an indicator of internal reliability. Cronbach's alpha is an assessment of reliability based on variation accounted for by the true

score of the underlying construct which is the hypothetical variable measured by the formula (Cronbach, 1951). As the underlying construct being measured by, for instance, a scale assessing knowledge based on health research (as expressed previously a shorthand for scientific research on health) will, drawing on the work of Miller discussed earlier, be built of a sample of a larger pool of possible items, there is no reason to expect more than one underlying construct. Additionally, if the sample of items to include in a uni-dimensional, or for each dimension if multi-dimensional, scale is appropriately selected then responses should exhibit a high correlation. Therefore, Cronbach's alpha is an appropriate methodology to assess internal consistency.

### ***Measuring health literacy***

Health literacy is defined as the wide range of skills and competencies that people develop to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life (Zarcadoolas, Pleasant, & Greer, 2003; in press).

The term 'health literacy' and the field of study developed through a convergence of patient comprehension and compliance studies generally conducted by physicians and health education and adult literacy specialists looking at the mismatch between print materials

and patient reading abilities. During the past two decades, a growing number of researchers focusing on health literacy have attempted to measure the ability of individuals to interact with the health care system and, by extension, the products of health research. Therefore, this provides a third area of review to support the development of a scale assessing the level of knowledge based on health research that individuals hold.

One approach to measuring health literacy focuses on an individual's ability to interact with health care providers and has made advances in measuring and analyzing the relationship between health literacy and health in the United States while predominantly focusing on an individual's ability to read (Nielsen-Bohlman, Panzer, & Kindig, 2004). These measures, in particular the Test of Functional Health Literacy in Adults (TOFHLA) and the Rapid Estimate of Adult Literacy in Medicine (REALM), produce statistically significant yet small correlations with factors such as the likelihood of possessing health information and being able to act on knowledge about health (Baker, Parker, Williams, Clark, & Nurss, 1997; Baker, Williams, Parker, Gazmarian, & Nurss, 1999; Davis, Michielutte, Askov, Williams, & Weiss, 1998; Gazmarian et al., 1999; Parker, Baker, Williams, & Nurss, 1995; Schillinger et al., 2002; Williams, Baker, Parker, & Nurss, 1998; Williams et al., 1995).

The REALM consists of 66 health or medical related words arranged in progressive difficulty and can generally be completed in two minutes.

The REALM does not address numeracy skills or any of the more complex concepts making up health literacy.

The TOFHLA is available in English and Spanish, large-print, and a commonly used shortened version (S-TOFHLA). According to the developers, “The S-TOFHLA appears to have good reliability (internal consistency) and is a valid measure of patients’ ability to read the materials they are likely to encounter in the health care setting (i.e. health literacy)” (Baker et al., 1999, p. 38).

Evidence produced by these scales demonstrating that many people who are low literate cannot understand and act on health information has led to a “clear language” movement focusing on the simplification of language. However, these measures remain relatively unused in an international context and sparsely tested or successfully adapted to different languages and contexts other than the American health care system for which they were explicitly devised.

While they are perhaps the best measures of functional health literacy currently available, the REALM and TOFHLAs are most limited in that they do not address the multiple domains of health literacy. In a recent review, Rogers, Ratzan & Payne (2001, p. 2184) concluded, “The ideal measure of health literacy would be short and quick, include both numeracy as well as reading ability, and also deal with the ability to think critically about the medical/health system. Furthermore, an

ideal measure would not be offensive or embarrassing to patients. Our review of literature did not disclose a health literacy measure that met all of these criteria, so further effort is needed to develop improved measures.”

The development an internationally valid and reliable scale to measure the level of general knowledge based on health research, then, can also be of use, and build upon past efforts, in the field of health literacy. The ability to understand knowledge based on health research – an aspect of health literacy – would be indicated by the results of such a scale.

Therefore, this review further demonstrates a role and need for a scale to assess the level of general knowledge based on health research held by individuals.

### ***The role of attitudes***

The impact of knowledge upon behavior is far from always direct or present. Thus, it is equally important to assess attitudes (Galli, 1978; Azjen & Fishbein, 1980; Becker & Rosenstock, 1984; Durant, Evans, & Geoffrey, 1992).

While there is a scarcity of established methods to measure attitudes toward health research, various attitudinal scales have been developed

toward science. For instance, there are attitudinal scales that claim to focus on the attentiveness to science (Miller, 1992), the institution and nature of science (Bauer, Petkova, & Boyadjieva, 2000; Kimball, 1967), the nature of scientific knowledge (Rubba & Andersen, 1978), the relationship between science, technology and society (Aikenhead & Ryan, 1992), and attitudes toward organized science (NSB, 1993). Many of these scales suffer from weak construction and methodology (Pardo & Calvo, 2002) and all ask for relatively complex assessments of science and technology even though accompanying measures of scientific information held or scientific literacy consistently yield low scores.

Typical of the approach toward assessing attitudes toward science in education, Francis and Greer (1999) developed and tested a scale with over 2,000 secondary students in Northern Ireland. The authors assert their scale emphasizes what they call the 'affective' domain of attitudes toward science versus the cognitive or behavioral domains.

The scale developed consists of 20 statements that treat science in the abstract but ask for responses in a range of domains. For instance, "Science has ruined the environment", "Science is a difficult subject", "Science is relevant to everyday life" or "I do not have much interest in science". While Cronbach's alpha coefficients were in the acceptable range, between .88 and .91, the scale itself is based strictly on a 'deficit model' theory of engagement with science. In this instance, that

approach may well be appropriate as formal education is strongly rooted in the deficit model and students are the target population for such efforts. Indicative of a deficit model approach, the authors report, “although there is no simple or unambiguous relationship between science-related attitudes and science-related behaviour, construct validity is supported by significant positive correlation between scores on the attitude scale and the number of science-related subjects studied” (Francis & Greer, 1999, p. 222).

The work to develop scales for use within education to assess attitudes toward science such as that by Francis et al. (1999), Rubba and Andersen (1978), Aikenhead and Ryan (1992), or Lederman et al. (2002) share at least one of two common approaches that limit their broader utility. One, these scales use statements that treat science as a career field rather than a body of knowledge with the potential to interact with and improve the day-to-day decisions of life. Or, second, their goal and design is meant to inform specific interventions within the classroom or educational environment to improve instruction about science.

Additionally, no agreement has emerged about which, if any of these scales is successful. Lederman et al. (2002, p. 502) illustrate this point with their finding that “During the past 40 years, more than 20 standardized and convergent paper and pencil instruments have been developed to assess learners’ NOS views, such as the Test on

Understanding Science (Cooley & Klopfer, 1961), Nature of Science Test (Billeh & Hasan, 1975), and Conceptions of Scientific Theories Test (Cotham & Smith, 1981).”

Perhaps the single most referenced body of work assessing attitudes toward science is that initiated by Miller and continued by the U.S. National Science Board in the Science and Engineering Indicator series. Miller argues that his attitudinal scale identifies two factors, or schema, through which members of the public receive and process information about science and technology (Miller, Pardo, & Niwa, 1997). One factor, or attitude construct, reflects the promise of science and technology and focuses on the potential for science to develop useful outcomes and products. The second factor Miller has identified reflects reservations about science and technology, focusing on the speed of development prompted by science and technology and resulting conflicts with traditional values and beliefs.

A primary use of attitudinal scales is to assess the relationship between knowledge and attitudes. Although early assumptions predicted a positive linear relationship between possession of knowledge and positive attitudes toward science – the “deficit model” supports such an assumption – that is not always the case (Pardo & Calvo, 2002). For example, Bauer, Durant and Evans (1994) argue for a curvilinear relationship between knowledge and attitudes toward

science that corresponds to the level of modern industrial development when examining data from several European countries.

In another example, Bak (2001) reviewed data from over a decade's worth of the NSB's surveys. This analysis found that the level of education, versus knowledge, does influence attitudes toward science in general, but that influence was much weaker when attitudes toward controversial scientific research were assessed versus attitudes toward science as an abstract concept.

Bak (2001) found that the general level of education and the level of scientific knowledge made independent contributions to attitudes toward science. For instance, Bak found that while the more educated have more positive attitudes toward science the less educated possess basically the same levels of scientific knowledge. Bak's analysis suggests the less educated may be less likely to see themselves as benefiting from science.

In New Zealand, researchers have found equally complex relationships between attitudes toward science and level of scientific knowledge, but the studies also suffer from some of the same methodological shortcomings encountered in other efforts (Hipkins, Stockwell, Bolstad, & Baker, 2002). Using a series of 29 statements, Hipkins et al. (2002) report that they were able to identify six segments within their respondents, a representative random sample of the New Zealand

population. Through exploratory factor analysis the researchers identified seven underlying factors that accounted for 47 percent of the variance – meaning that more than half of the variance responses remains unaccounted for or is due to error. Clustering the factor scores, the authors identified the following six typologies, the “confident science believers,” “educated cynics,” “concerned science supporters,” “confused and suspicious,” “uninformed individualists,” and a group the authors labeled “left behind”. Those results map fairly well but not perfectly upon those reported by an earlier research effort in the UK that also identified six attitudinal groups labeled “confident believers,” “technophiles,” “supporters,” “concerned,” “not sure,” and “not for me” (Office of Science and Technology and the Wellcome Trust, 2000).

While the groups “confident science believers” and “uninformed individualists” align fairly closely with the top and bottom of the deficit model’s theory, the presence of groups like the educated cynics point to a more complex relationship between attitudes and knowledge in regard to science.

Investigating the commonly encountered claim that gender differences account for differences in attitudes toward science, Hayes and Tariq (2000) analyzed survey data from the U.S., Canada, Great Britain, and New Zealand. The analysis did find lower knowledge and less favorable attitudes toward science among women, but the authors argue that

the data demonstrate those differences are due to disparities in educational background and religious belief – not variations in scientific knowledge – in all countries but the United States where differences in level of scientific knowledge – but not gender – explain the difference in attitudes (Hayes & Tariq, 2000).

In their research design, Hayes and Tariq relied on three statements to assess attitudes toward science:

- We believe too often in science, and not enough in feelings and faith
- Overall, modern science does more harm than good
- Any change humans cause in nature – no matter how scientific – is likely to make things worse.

In their analysis, only one factor emerged, explaining slightly over 50 percent of the variance with a Cronbach's alpha of 0.635 which is somewhat low but acceptable as, for example, Pardo and Calvo (2001) suggest a guideline of low 0.47, median 0.79, and high 0.98 for Cronbach's alpha scores. The second statement loaded the strongest on the single factor that emerged, reflecting a common finding that attitudes toward science are strongest in regard to an expectation of benefits.

Overall, Pardo and Calvo (2001) put forth a strong argument that most of the scales currently in use were not created by following rigorous methodologies, are based on little or no theoretical foundation, rarely went through pre-testing or piloting, and as a result tend to exhibit less than acceptable levels of reliability. As a result, there is currently no single scale that is an agreed upon best measure of attitudes toward the scientific enterprise in general.

Despite the conflicting findings, a universal finding that does emerge is in terms of what aspects of science people regard with the most interest. The highest level of interest is toward health and medicine, to the point of being called by one researcher “paradigmatic for the popular representation of science” (Durant et al., 1992; Office of Science and Technology and the Wellcome Trust 2000).

Overall, differences in methodology and theory – indicating the lack of an agreed upon gold standard – is one of the few defining elements of the continuing investigations of attitudes toward science. Further arguing for the need for development of an attitudinal scale specifically about health research, this history of methodological development of measuring attitudes toward science in general does not extend to attitudes toward health research in particular, where there is a scarcity of attitudinal measures. The combination of the predominance of health and medicine in public viewpoints and the lack of an agreed upon gold standard in regard to measuring attitudes toward science in

general and health research in particular further justifies the development of a scale specifically targeting attitudes toward health research.

## **CHAPTER 3**

### **METHODOLOGY**

Developing and testing scales to measure the level of knowledge based on health research and a scale to assess attitudes toward health research was conducted within the context of a larger cross-national survey project sponsored by the World Health Organization. Therefore, the overall methodological concerns and practices related to both scales are presented first, followed by more specific approaches and the results for each scale.

#### ***Issues in scale development***

The primary goals during the development and testing of the scales were to address the critical methodological issues of validity and reliability. To confidently identify a relationship between change in scale results to, for instance, effects of a health promotion, education or communication program rather than measurement error, a valid and reliable measure is required. Validity refers to the agreement between the scale and the concept it is supposed to reflect. Reliability refers to the likelihood that consistent results will be obtained if the measure, test, or experiment is repeated.

There are several types of validity – construct validity, face validity, criterion (predictive) validity, and content validity – each of which is

best considered as a piece of evidence arguing for or against the overall validity of a scale (Carmines & Zeller, 1979; DeVillis, 1991; Streiner & Norman, 1995). Additionally, scales should be assessed on their ability to discriminate between respondents, or discriminate validity, which is in part indicated by the percent of respondents who select a particular response. For example, in knowledge scales, correct endorsement is a direct indication of the difficulty of the item (Streiner & Norman, 1995).

### ***Content validity***

Content validity requires that the items of a scale should adequately sample the domain in question. For example, the health literacy scales such as the REALM and the TOFHLA discussed above appear to have poor content validity as they purport to measure a multi-dimensional construct but predominantly measure the ability to read (Zarcadoolas, Pleasant, & Greer, 2003; in press).

In theory, the best approach to assuring content validity is to determine all of the potential items that reflect the domain in question and then randomly select from those. That is only possible, however, when the entire domain is known and fixed – as would be the case when building a measure to assess knowledge of the names of U.S. states. That is not the case with domains such as attitudes or with expansive and changing bodies of knowledge as is the case with health

research. In these cases, content validity is built into the measure during the statement selection process through expert review in an attempt to assure that the scale statements accurately reflect the domain of interest (DeVillis, 1991).

### ***Face validity***

Face validity requires that the scale be phrased simply and unambiguously. Items on a scale must find an appropriate balance, based on the content and desired use of the scale, between relevance and simplicity and not allowing respondents to so easily understand the nature of the scale as to allow 'faking' of answers to produce desired results (Streiner & Norman, 1995).

The basic elements of written language that combine to determine the complexity of text are vocabulary, sentence structure, cohesion, relevance, and context. Quantitatively, a number of readability formulas (e.g., SMOG, Flesch-Kincaid) focus on measuring difficulty of vocabulary and sentence structure. Issues of cohesion, relevance, and context and best assessed through qualitative expert appraisal and feedback from participants during piloting (Zarcadoolas et al., 2003; in press).

### ***Criterion validity***

Criterion validity requires that the measure predict a practical outcome, usually assessed by comparing the results of a new scale with a 'gold standard' that currently exists. However, as this seems to be the first effort at developing scales explicitly and exclusively measuring knowledge based on health research and attitudes toward health research, no gold standard or comparable measures exist.

### ***Construct validity***

Construct validity is assessed by the extent the measure relates to other measures in a manner consistent with the theoretical foundation. Therefore, addressing construct validity requires returning to the theoretical framework supporting the scale. Construct validity is the first test of a scale addressed in this section that can be entirely assessed using quantitative methods. Establishing validity is an ongoing process. While no single test can individually prove a construct, negative findings in a well-designed experiment can call the entire construct into question (Streiner & Norman, 1995). Lederman et al. (2002) assert it is incorrect to speak of validity as ever being permanently established but that evidence of an instrument's efficacy in measuring what it is designed to measure can be provided.

### ***Discriminate validity***

The discriminate validity of a scale refers to the scale's ability to distinguish between groups. Individual items should generally not be so easy that nearly everyone responds correctly, nor too difficult. Generally, if the percent of correct answers, on a true false scale, is over 80% or under 20% the item is removed from a scale (Streiner & Norman, 1995). However, the knowledge based on health research scale is hoped to be applicable in a wide range of settings, including low-income countries where literacy rates can be extremely low. Thus, it is predicted that some statements on the health research produced knowledge scale will need to be constructed to distinguish between individuals who may not have much success correctly responding to the statements in general. Therefore, it is anticipated that a cutoff point may well need to rise to the region of 90 percent correct responses on some statements.

One approach to discriminate validity is to compare the scores of so-called 'extreme' groups that should be different in their response. In this research design, discriminate ability tests will come from comparing the results between countries that, due to differences in culture, the burdens of disease, and the nature of the health care systems should perform differently. At this point, however, too little is known about the relationship between the possession of knowledge based on health research, attitudes toward health research, and the

performance of national health care systems, cultures, the burden of disease, and individual characteristics to support a hypothesis about the direction of those differences. As the scales developed in this effort are further validated through replication, this will be an area of future interest.

Additionally, in another component of the overall World Health Organization effort, health care practitioners and health researchers will be asked to respond to the same scales. If sufficient numbers of those individuals are obtained, it is predicted that the scales will be able to discriminate between the broader samples drawn from the general public and these experts in various areas of health care.

### ***Reliability***

Fundamentally, reliability measures assess the amount of random and systematic error of any measurement in relation to the population of interest. There are several approaches to assessing reliability of a scale. Cronbach's alpha is a statistical measure of the internal reliability of a scale, test-retest designs can be used to assess reliability over time, or researchers can split a scale between groups of respondents in what is called a split-halves design (Carmines & Zeller, 1979; Streiner & Norman, 1995).

The overarching WHO project goal was methodology development and testing, versus assessment of a specific intervention that would argue for an experimental or quasi-experimental design. Thus, the consensus of participating researchers was to employ a one-time survey with a small test-retest component. Within that framework, the scale development efforts reported in this dissertation assess internal reliability using item-total correlation and Cronbach's alpha. These choices are based upon the predominantly accepted practices identified earlier in the literature review and explicitly identified and outlined in basic texts on scale development (Devillis, 1991; Streiner & Norman, 1995).

Individual items on an internally reliable scale should correlate with each other and with the total scale score with that item removed. Internal consistency of dichotomous items, as is the case for the knowledge scale with true/false response categories, can be measured with Cronbach's alpha as it incorporates Kuder-Richardson formula 20 (KR-20) and the results will be identical (DeVillis, 1991). Generally, an alpha of between 0.70 and 0.90 is desired. However, Pardo and Calvo (2001) report their review of attitudinal scales suggests that, in practice, a Cronbach's alpha of 0.47 is considered low, 0.79 is the median, and 0.98 is high. Item-total correlation can be assessed using Pearson's  $r$  correlation, generally with a score of no lower than 0.20 being judged acceptable.

A reliable scale will also produce scores that remain stable when the test is completed twice over a reasonable time period – long enough for answers to be forgotten yet short enough to reduce the opportunities for change in the measured attribute to occur. Such test-retest scores can be measured by simple agreement of responses between tests. However, and especially in the case of dichotomous responses, the recommended approach is to employ the kappa coefficient as that measure addresses the distribution of responses and corrects for chance. The literature review of health knowledge scales found that a kappa of no lower than 0.60 should be expected, 0.70 being a better target.

Thus, quantitative tests the scales will be assessed with are a test-retest kappa value of at least 0.60, a item-total correlation for individual statements using a Pearson's  $r$  of no lower than 0.20, and a Cronbach's alpha value preferably between 0.70 and 0.90 though broader ranges of acceptability have been identified. (Table 1)

Table 1. Approaches to validity and reliability.

<b>Measure</b>	<b>Method</b>	<b>Used for knowledge scale?</b>	<b>Used for attitudinal scale?</b>
Face validity	Readability assessment	√	√
	Expert consultation	√	√
	Pre-test with students		√
	Participant feedback	√	√
Content validity	Expert consultation	√	√
	Participant feedback	√	√

Table 1 (Continued)

Criterion validity	Compare to a 'gold standard'.	There is no gold standard for measuring general health research produced knowledge, yet. Thus, not applicable.	There is no gold standard for measuring attitudes toward health research, yet. Thus, not applicable.
Construct validity	Predicted that individuals will score higher on the health research information scale than on the scientific literacy scale.	√	
	Predicted a positive, but weak, correlation between total scores on the health research information scale and the scientific literacy scale.	√	
	Predict a positive but weak correlation between knowledge and attitudes (in aggregate but not across subgroups)		√
Discriminate validity	Only accept statements with above 20 percent correct responses.	√	√
	Predicted difference between experts and general public.	√	√
	Predicted difference between counties.	√	√

Table 1 (Continued)

Reliability - Internal consistency	Item-total correlation (Pearson's r) of over 0.20.	√	√
	Internal consistency (Cronbach's alpha/KR- 20), prefer between 0.70 and 0.90. (0.47- 0.98 per Pardo & Calvo (2001))	√	√
Reliability - Test-retest method	Test-retest (kappa coefficient) - expect between 0.60 and 0.70.	√	√

### ***Survey administration***

Once the preliminary scales were developed and the theoretical and methodological basis to assess their performance were established, the scales was piloted as part of a larger survey effort conducted by the World Health Organization (WHO) in cooperation with local partners in Mexico, China, Ghana, and India. In each of those countries, a researcher at a WHO collaborating center with experience in the social sciences and surveying was selected to lead the study locally. All were supplied with the same protocol for survey administration.

One concern that is universal to scale development is the structure of response categories. For the knowledge scale, true/false/don't know responses were utilized. This decision was based on a concern that the project not allow the uncorrect perception that, for example, the use of condoms may not prevent HIV/AIDS. A true/false response is

unambiguous in that respect. The use of dichotomous response items, however, calls the use of factor analysis into question even though it is frequently encountered (Streiner & Norman, 1995). That is because factor analysis, based on a correlation (or covariance) matrix, assumes continuous measures that are distributed normally and that associations among indicators are linear (DeVellis, 1991). Applying factor analysis to dichotomous, non-continuous data such as correct/incorrect responses can, therefore, result in “quite anomalous results” (Streiner & Norman, 1995 p. 65). For the attitude scale, a six-category response scale labeled from strongly agree to strongly disagree with a separate don’t know category was used.

After receiving institutional and ethical reviews, local partners were requested to translate and back-translate the statements into local languages as required. Back-translation has been shown to be an important step in assuring that translation captured the intended meaning of the original (Zarcadoolas et al., in press). Initial translation was to be performed by native speakers in the local language and back translations were to be performed by fluent English speakers. When interviewing respondents from the public sample of the overall survey project, questions were read aloud and, if necessary, explained to the participants.

The local research partners were requested to survey 200 members of the general public and conduct a retest with at least 50 of those

individuals between two weeks to one month after the initial survey. A small number of participants (approx. 10) were selected for an initial round of cognitive interviewing in a focus group format to gauge face and content validity.

Local partners were recommended to follow a uniform stratified sampling strategy with specific expectations that the sample developed reflect the larger population as best as possible. In particular, a sampling strategy suggested to the country partners was to:

1. Select one or more sub-national/ geographical units based on sample size required.
2. Stratify the sub-national unit by socio-demographic criteria, e.g. high, upper-middle, lower-middle, and low income households OR elite, mixed, migrant, and traditional population households OR urban, rural OR other appropriate socio-demographic strata
3. Assemble household lists from the socio-demographic strata, and randomly select 200 participating households. Also, select a back up sample.
4. In each household, all adults within the study's age limits - 15 to 65 years - are listed, and one among them randomly selected for the interview (or, in another method, selecting the person with the most recent birthday). If the selected respondent is not available, interviewers are instructed to make two returns before selecting an alternate respondent from the same household. If

no respondents from the household are available, a household from the back-up sample should be selected.

In practice, and in alignment with core operating principles of cooperation and coordination as outlined in the WHO Constitution, the sampling methodologies experienced some variation from country to country reflecting local practices, preferences, and conditions. (Table 2)

For example, some partners selected one city (e.g. Mexico) while others selected multiple cities as research sites. Some attempted with varying levels of success to obtain a representative sample of respondents whereas others took a more opportunistic route and surveyed whomever was willing and available without great regard to the diversity or representative nature of the sample. Finally, one partner (India) did not conduct the test-retest portion of the project. As the larger WHO project these scale development efforts were nested within experienced a transition of staff, willingness and ability to push country partners to extend their capacity diminished.

Table 2. Location and size of sample by country.

<b>Country</b>	<b>Location(s)</b>	<b>N</b>	<b>N for retest</b>
Mexico	City of Cuernavaca (State of Morelos)	200	50
China	Chengdu City of Sichuan Province, Dalian City of Liaoning Province, Shanghai Municipal, Xi'an City of Shaanxi Province and, Wuhan City of Hubei Province. 40 individuals from each were selected, with 10 from each for the retest stage.	220	50
Ghana	City of Accra	204	50
India	City of Mumbai, including New Mumbai, Dahisar, Malwani, Northwestern Mumbai, Chembur, South Mumbai, Vasai, and Turbhe.	205	0
Total		829	150

The same local partners conducted similar surveys that included the health knowledge and attitude scales with smaller numbers of health policy-makers health researchers, and health practitioners according to a separate sampling strategy. Country partners manually entered data into the statistical software package SPSS and resulting files were forwarded for analysis. As the desire is to develop scales that are valid and reliable internationally, analysis will be conducted using both aggregated data from all countries as well as within each country.

### ***The country settings and study participants***

Mexico, China, Ghana, and India present a wide range of social, political, and cultural settings to test the scales within. Literacy levels,

for example, range from a high of 92 percent in Mexico to a low of 59 percent in India with China at 86 percent and Ghana at 74 percent (World Bank, 2004).

In terms of the urban/rural setting of the population, 75 percent of Mexico's population lives in an urban setting, 38 percent of China's, 37 percent of Ghana's, and only 28 percent of India's population live in an urban setting (World Bank, 2004). Other relevant indicators of each country's economic status, expenditures on health, and health status are reported in Table 3.

Table 3. Economic and health system data (WHO, 2003).

<b>Country</b>	<b>GDP per capita<sup>1</sup></b>	<b>% GDP spent on health<sup>1</sup></b>	<b>Total health spending per capita<sup>1</sup></b>	<b>Healthy average life expectancy (HALE)</b>	<b>Child mortality per 1,000</b>
Mexico	8903	6.1	544	65.5	27
China	4095	5.5	224	64.1	36
Ghana	1272	4.7	60	49.75	102.5
India	1560	5.1	80	53.45	91

1. In U.S. dollars, 2002.

The participants in this study are not representative of the larger populations they are drawn from. For example, the samples from Mexico and Ghana are drawn almost entirely from an urban setting while 25 percent of the residents of Mexico and 63 percent of Ghana live in a rural setting. The results from India indicate a sample heavily swayed toward the urban population as well. However, as is true for

many urban areas in India, Mumbai attracts workers from a broad range of backgrounds. For example, Vashi (often called New Mumbai) has many low-income settlers and work-seekers regularly arriving directly from rural regions. (Table 4)

Table 4. Demographics of participants.

	<b>Sex (%)</b>		<b>Urban or rural residence (%)</b>		<b>Av. age</b>	<b>Av. years of formal education</b>	<b>Average household income<sup>1</sup></b>
	F	M	U	R			
Mexico	66	34	99.5	0.5	32	11	314
China	52	48	48	52	47	8	1,570
Ghana	43	57	94	6	32	16	1.64
India	56	44	98	2	37	15	4,181
All	54	46	85	15	37	12.5	1,517

1. For 2002, in U.S. dollar.

Additionally, for example, the reported median age in China during 2002 was 31.5 versus the participant's median age of 47; in Ghana median age is 19.2 versus the participant's 32 years; in India 24.1 versus 37; and in Mexico the media age in 2002 was 23.8 versus 32 in the sample (U.S. Central Intelligence Agency, 2004). As an aggregate group, however, the participants in this study do represent a wide range of life experience in a variety of settings.

# **CHAPTER 4**

## **THE KNOWLEDGE BASED ON HEALTH RESEARCH SCALE**

### ***Building the scale***

In reporting on the development and testing of the knowledge based on health research scale, issues of building individual scale items to meet the validity and reliability criteria established above are first discussed. That is followed by the results from testing the scale in Mexico, China, Ghana, and India.

### ***Content validity***

In addressing content validity concerns, the World Health Organization sponsored teams of researchers to identify areas of expert agreement through literature reviews encompassing the core project themes of public, health research, health research systems, public engagement, and assessing the utilization of health research (Hanney et al., 2003; Pang et al., 2003; Pleasant et al., 2003).

One area of agreement emerging from the reviews is that no universally accepted approach to assessing the utilization of health research currently exists. Therefore, in building this scale the first

challenge was to determine what knowledge based on health research to use. Researchers could ask, as Miller and Kimmel do in their biomedical scientific literacy measure, for a definition of DNA or a molecule. However, as health literacy studies have demonstrated that context and relevance are critical issues, statements based in health research but directly applicable to the basic conditions of living around the world are desired.

To that end, and to further address concerns of content validity, the product of a broad consortium of international health agencies – a collection of health research knowledge called the Facts for Life – was selected as the core content for this scale development effort. The Facts for Life are one of the only sources of health research produced knowledge that has been vetted by a range of health care professionals working in a variety of international contexts – in this case, from the sponsoring organizations: UNICEF, WHO, UHESCO, UNFPA, UNDP, UNAIDS, WFP, and the World Bank. There are thirteen core topics ranging from the timing of birth, to immunization, nutrition and growth, and diarrhea. The ultimate goal of the Facts for Life is to make life-saving knowledge easily available to everyone (UNICEF, 2002).

Through a consultative process with experts involved in the overall World Health Organization project, a preliminary set of 18 statements adapted from the Facts for Life were developed as a core measure of the level of knowledge based on health research. After the initial

crafting, these statements were subjected to review by the same body of experts who contributed to the initial conceptual foundations of this project.

The statements developed, and the correct response, are:

- To improve the health of mothers and children, women should be at least 18 years old before becoming pregnant for the first time. (T)
- Siblings with less than two years between their births have fewer health risks than siblings with more than two years between their births. (F)
- For a healthy pregnancy and birth, all pregnant women should visit a health worker before the baby is born. (T)
- Births that are not assisted by a skilled birth attendant are as safe as births that are assisted by a skilled birth attendant. (F)
- Breast milk is the only food and drink babies need for the first six months. (T)
- It is normal if children below the age of one year to weigh the same over a two-month period. (F)
- Children who are vaccinated are protected from dangerous diseases. (T)
- Overall, vaccination has more risks than benefits. (F)
- Children learn a lot by playing. (T)
- Most injuries and accidents cannot be prevented. (F)

- In emergency situations, it is preferable if parents take care of their own children. (T)
- If a child is breathing rapidly or has difficulty breathing, the child should be taken immediately to a health care provider. (T)
- Many diseases can be prevented by washing hands before touching food. (T)
- Using condoms when having sex can prevent the spread of AIDS. (T)
- Using mosquito nets helps prevent malaria. (T)
- A child with diarrhea should drink extra fluids and continue to eat as usual. (T)
- Exercise helps prevent heart disease. (T)
- Coughs and colds only get better with medicine. (F)

Additionally, statements about knowledge based on health research adapted from NSB and Eurobarometer measures of scientific literacy are included in the analysis. These statements are:

- It is the father's gene that decides whether the baby is a boy or a girl. (T)
- Antibiotics kill viruses as well as bacteria. (F)
- Cigarette smoking causes lung cancer. (T)
- Radioactive milk can be made safe by boiling it. (F)
- All bacteria are harmful to humans. (F)
- Senility is inevitable as the brain ages and loses tissue. (F)

- Human beings can survive on almost any combination of foods, provided the total diet has enough calories. (F)

### ***Construct validity***

The theoretical base for the overall WHO project defines a health research system as the “people, institutions, and activities whose primary purpose in relation to research is to generate high-quality knowledge that can be used to promote, restore, and/or maintain the health status of populations” (Pang et al., 2003, p. 81). This includes mechanisms adopted to encourage engagement and use of health research.

A health research system can produce a variety of goods, including drugs, devices, information about diseases and their causes, new medical procedures, and the process of health research itself. The products of the health research system are often not the sole property of research scientists, the funders, or the participants in the research but can be considered part of a larger, shared body of information, at times referred to as the global pool of knowledge, leading to a better understanding of health and how to improve health (Lewando-Hundt & Al Zaroo, 2000).

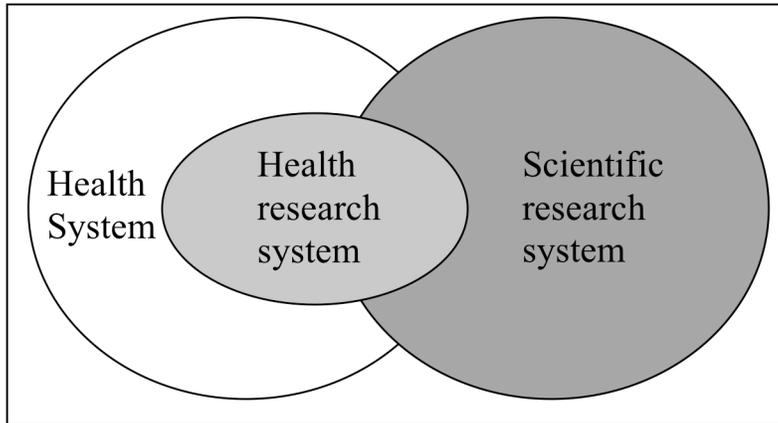


Figure 2. Health research system.

A health research system can be visualized as operating at the intersection of a large and complex scientific research system and a health system (Pang et al., 2003) (Figure 2). Therefore, as a measure of construct validity, there should be a moderate correlation between a scale assessing the possession of knowledge based on health research and the portion of the scientific literacy scales explicitly measuring scientific knowledge.

Based on issues identified during the literature review of the importance of context and relevance of scale items toward the daily life experiences of individuals, and the predominance of health and medicine in the perception of science among a variety of populations, scores should be higher on the statements about knowledge based on health research than they are on the scientific knowledge statements. That is to say, the items on the knowledge based on health research scale are much more likely to have been encountered through daily life experience by participants than items on the science literacy scale.

Therefore, the following two hypotheses will serve as key tests of construct validity.

Hypothesis 1: Individuals will score higher on the knowledge based on health research scale than on the scientific knowledge scale.

Hypothesis 2: There will be a positive, but weak, correlation between scores on the knowledge based on health research scale and the scientific knowledge scale.

### ***Discriminate validity***

In addition to analyzing the pattern of responses to eliminate poor performing statements in regard to their ability to discriminate between respondents, two hypotheses are possible in regard to the knowledge based on health research scale's ability to discriminate between audiences given the design of the research project.

Hypothesis 3 - Expert groups will score higher than the general public.

Hypothesis 4 - Country level data will reveal significant differences between countries.

## ***Results***

Results of particular interest are the frequency of responses to the scale items and the assessment of the validity and reliability measures and their contribution to the development of a final version of the scale.

### ***Face validity***

A Flesch-Kinkaid readability formula assessment of the piloted scale items, in the English version, rated the scale at a 7th grade reading level. Reports from the field indicate that researchers in India felt the overall survey (consisting of many more questions than the scales reported on here) was difficult for members of the public as some words had no translation into some local dialects. As a result don't know/non-response rates to some of the statements being tested was over 10 percent, in particular among participants with the lowest levels of education and those older in age. From Mexico, the participating researchers reported that the word "senility" was not well understood by all participants. On the other hand, in China researchers rated all statements as either easy or of medium difficulty. Overall, however, the scales being tested seemed understandable to a majority of the participants.

### ***Frequency of responses***

In both the aggregate and by country, some statements received over 90 percent correct responses. The lowest percent of correct responses to any statement in the “Facts for Life” based scale was 25 percent in China in response to the statement, “Exercise helps prevent heart disease”. Don’t know or non-responses were scored as incorrect, when necessary false statements scores were reversed from their original T/F coding so all calculations are based on a correct/incorrect coding. (Table 5)

In the aggregate, 75 percent of the responses to the “Facts for Life” statements were correct on average. Participants in Mexico, on average, offered 81 percent correct responses, while participants in China responded correctly 67 percent of the time, in Ghana correct responses were given 81 percent of the time, and respondents in India responded correctly 71 percent of the time. (Table 5) The standard deviation of correct responses to the “Facts for Life” statements was 3.2 in the aggregate, 1.8 for Mexico, 2.4 in China, 2.2 in Ghana, and 4.8 in India.

The poorest overall performance to statements derived from the “Facts for Life” was in response to “Coughs and Colds only get better with medicine”, where less than half (41%) of the participants responded correctly that the statement is false. Four of the “Facts for Life”

statements received a correct response rate equal to or greater than 90 percent correct – those relating to women visiting a health worker when pregnant, children learning by playing, children experiencing difficulty in breathing, and personal hygiene. (Table 5)

Table 5. Responses to health research statements.

Statement	Percent correct responses				
	All	Mx	Ch	Gh	In
To improve the health of mothers and children, women should be at least 18 years old before becoming pregnant for the first time. (T)	80	86	63	88	84
Siblings with less than two years between their births have fewer health risks than siblings with more than two years between their births. (F)	54	40	58	70	50
For a healthy pregnancy and birth, all pregnant women should visit a health worker before the baby is born. (T)	91	97	90	98	82
Births that are not assisted by a skilled birth attendant are as safe as births that are assisted by a skilled birth attendant. (F)	80	84	80	89	70
Breast milk is the only food and drink babies need for the first six months. (T)	72	84	63	82	62
It is normal if children below the age of one year to weigh the same over a two-month period. (F)	66	77	79	58	50
Children who are vaccinated are protected from dangerous diseases. (T)	88	89	85	93	84
Overall, vaccination has more risks than benefits. (F)	77	82	65	90	75

Table 5 (Continued)

Children learn a lot by playing. (T)	90	94	88	92	85
Most injuries and accidents cannot be prevented. (F)	59	58	36	76	67
In emergency situations, it is preferable if parents take care of their own children. (T)	65	61	88	48	61
If a child is breathing rapidly or has difficulty breathing, the child should be taken immediately to a health care provider. (T)	91	99	87	92	85
Many diseases can be prevented by washing hands before touching food. (T)	92	95	92	97	84
Using condoms when having sex can prevent the spread of AIDS. (T)	81	94	60	86	86
Using mosquito nets helps prevent malaria. (T)	82	88	71	93	79
A child with diarrhea should drink extra fluids and continue to eat as usual. (T)	65	86	44	79	55
Exercise helps prevent heart disease. (T)	72	96	25	94	80
Coughs and colds only get better with medicine. (F)	41	45	43	35	41
<b>AVERAGE PERCENT CORRECT TO “FACTS FOR LIFE” STATEMENTS</b>	<b>75</b>	<b>81</b>	<b>67</b>	<b>81</b>	<b>71</b>

The adapted scientific knowledge statements, in general, seemed more difficult for participants, this is indicated not only by the scores but also by reports from country partners. Overall, the average correct percent of responses to the scientific knowledge statements was 44 percent. Statements that received very low correct responses, by country, included those related to nutrition (3% correct in Mexico), senility (8% in Mexico and China). Statements that received a high

level of correct responses include cigarette smoking causing lung cancer (86% overall) and oxygen coming from plants (93% in Mexico). (Table 6)

Table 6. Responses to scientific knowledge statements

Statement	Percent correct responses				
	All	Mx	Ch	Gh	In
The earliest humans lived at the same time as the dinosaurs. (F)	39	58	28	25	48
The continents on which we live have been moving their location for millions of years and will continue to move in the future. (T)	54	75	35	44	63
The center of the Earth is hot. (T)	62	78	38	59	77
All radioactivity is man-made. (F)	42	29	44	43	52
Electrons are smaller than atoms. (T)	40	44	22	40	54
The oxygen we breathe comes from plants. (T)	72	93	49	78	69
It is the father's gene that decides whether the baby is a boy or a girl. (T)	62	58	46	77	66
Lasers work by focusing sound waves. (F)	25	28	12	23	38
Antibiotics kill viruses as well as bacteria. (F)	24	20	25	30	22
The universe began with a huge explosion. (T)	41	60	25	17	64
Human beings, as we know them today, developed from earlier species of animals. (T)	58	67	55	36	75
Cigarette smoking causes lung cancer. (T)	86	99.5	73	94	86
Radioactive milk can be made safe by boiling it. (F)	33	65	37	30	40
All bacteria are harmful to humans. (F)	48	33	42	51	68

Table 6 (Continued)

Senility is inevitable as the brain ages and loses tissue. (F)	11	8	8	14	16
Ordinary tomatoes do not contain genes while genetically modified tomatoes do. (F)	30	30	26	28	39
Human beings can survive on almost any combination of foods, provided the total diet has enough calories. (F)	15	3	17	24	15
AVERAGE PERCENT CORRECT TO ALL SCIENCE KNOWLEDGE	44	50	32	42	52
TOTAL AVERAGE PERCENT CORRECT ON BOTH SCALES	60	54	50	62	62

### ***Construct validity***

As there were different numbers of statements in the health and scientific knowledge sections in the overall survey (18 and 17 respectively), statistical significance of the difference is determined by using the mean percent correct response for each scale. Using a paired sample t-test, the difference between the “Facts for Life” based statements and the scientific knowledge statements adapted from other research efforts was significant. Thus, hypothesis one, that the knowledge based on health research scale would produce significantly different and higher scores than the scientific knowledge scale is accepted for the aggregated data as well as for each country. (Table 7)

Table 7. Comparing science and health knowledge scales

Country	Mean % correct health knowledge	Mean % correct science knowledge	Difference	Paired sample t score
Mexico	81	50	31*	22.4
China	67	32	35*	23.9
Ghana	81	42	39*	29.8
India	71	50	21*	13.0
All	75	44	31*	38.8

\*Significant at the 0.01 level

Pearson's correlation between the mean percent correct scores on the knowledge based on health research and the scientific knowledge scales were positive in every country. India has the highest correlation at 0.609 and Mexico the smallest at 0.121. The correlations were significant in all countries except Mexico. Thus, hypothesis 2, that there will be a positive, but weak, correlation between total scores on the knowledge based on health research and the scientific knowledge scales, is accepted for all but Mexico. (Table 8)

Table 8. Correlation between science and health knowledge

Country	n	Pearson's Correlation
Mexico	200	0.121
China	220	0.217*
Ghana	204	0.273*
India	205	0.609*
All	829	0.391*

\*Significant at the 0.01 level

### ***Discriminate validity***

As reported, several statements received over 90 percent correct responses and, thus, are identified as potential statements to be removed from further consideration. Given the need to discriminate between potentially low levels of knowledge based on health research, such high scoring statements may well be left in the final version of the scale. Two of the statements related to knowledge based on health research contained within the adapted scientific knowledge statements received below 20 percent correct responses and, thus, are removed from further consideration for inclusion into this scale.

Additionally, it was predicted before testing that the health knowledge statements would receive significantly different levels of correct responses from experts such as health care researchers and practitioners in comparison to the general public. In a complementary aspect of the overall World Health Organization project, a total of 357 individuals identified as either health researchers or health care practitioners responded to the same set of T/F statements. A t-test comparison of the mean scores revealed significant differences between the experts and the public sample at the 0/01 level.

There is an unpredicted aspect to the comparison of experts and the public. The average score for experts was 12.6 with a standard

deviation of 3.7. For the public, the average score was higher at 13.8 with a standard deviation of 2.5. Country level data reveals that the lowest performance of experts was from China, but that Mexico experienced the same basic relationship, the performance of both groups from Ghana was quite similar, and only in India did experts offer more correct responses than did the public sample. (Table 9)

Table 9. Comparison of experts and public responses

	<b>All</b>	<b>Mx</b>	<b>Ch</b>	<b>Gh</b>	<b>In</b>
Public average score / SD	13.8 2.5	14.5 1.8	12.1 2.4	14.6 2.2	12.8 4.8
Experts average score / SD	12.6 3.7	12.5 5.6	9.5 1.7	14.5 2.1	13.9 5.8

Therefore, the hypothesis that experts would score higher than the general public cannot be accepted. The data do exhibit a significant difference between the two extreme groups, but not in the direction predicted.

Finally, a one-way ANOVA analysis of the mean correct responses from the four countries revealed a significant difference at the 0.01 level between countries ( $F = 35.0$ ) Thus, the hypothesis of a significant difference between countries is accepted.

## ***Reliability***

A retest of members of the public was performed in 3 of the 4 countries with India being the exception as previously reported. Kappa values (N=50) for the scale statements are 0.89 from Mexico, 0.67 from China, and 0.71 from Ghana indicating an acceptable level of test-retest reliability.

Assessing internal reliability of the potential scale components involved assessing the performance of the items on a country-by-country basis as well as in the aggregate. A scale with a Cronbach's alpha of over .7 meeting all criteria previously discussed emerged for each country except Mexico. However, the scales optimized for each country do not consist of the same statements. Scales individually tailored for each country produced alphas of 0.8137 for the aggregated data (14 statements); for Mexico 0.5423 (10 statements); for China 0.7321 (11 statements); for Ghana 0.6861 (14 statements); and for India 0.9322 (15 statements). (Table 10)

Table 10. Optimized scales for each country and corresponding alpha

<b>Statement</b>	<b>All</b>	<b>Mx</b>	<b>Ch</b>	<b>Gh</b>	<b>In</b>
To improve the health of mothers and children, women should be at least 18 years old before becoming pregnant for the first time. (T)	√				√
Siblings with less than two years between their births have fewer health risks than siblings with more than two years between their births. (F)				√	
For a healthy pregnancy and birth, all pregnant woman should visit a health worker before the baby is born. (T)	√		√	√	√
Births that are not assisted by a skilled birth attendant are as safe as births that are assisted by a skilled birth attendant. (F)	√	√	√		√
Breast milk is the only food and drink babies need for the first six months. (T)					
It is normal if children below the age of one year to weigh the same over a two-month period. (F)		√			
Children who are vaccinated are protected from dangerous diseases. (T)	√			√	√
Overall, vaccination has more risks than benefits. (F)	√	√	√	√	√
Children learn a lot by playing. (T)	√			√	√

Table 10 (Continued)

Most injuries and accidents cannot be prevented. (F)	√		√	√	√
In emergency situations, it is preferable if parents take care of their own children. (T)					
If a child is breathing rapidly or has difficulty breathing, the child should be taken immediately to a health care provider. (T)	√			√	√
Many diseases can be prevented by washing hands before touching food. (T)	√	√	√	√	√
Using condoms when having sex can prevent the spread of AIDS. (T)	√	√	√		√
Using mosquito nets helps prevent malaria. (T)	√	√	√		√
A child with diarrhoea should drink extra fluids and continue to eat as usual. (T)				√	
Exercise helps prevent heart disease. (T)	√	√		√	√
Coughs and colds only get better with medicine. (F)					
It is the father's gene that decides whether the baby is a boy or a girl. (T)	√		√	√	√
Antibiotics kill viruses as well as bacteria. (F)		√	√	√	
Cigarette smoking causes lung cancer. (T)	√	√	√	√	√
All bacteria are harmful to humans. (F)		√	√	√	√
Number of items	14	10	11	14	15
Alpha	.8137	.5423	.7321	.6861	.9322

√ indicates statement is used in this version of the scale.

Further analysis of the country level and aggregated data identified a scale that produces an acceptable alpha for the aggregated data and the highest possible alpha for the individual countries. (Table 11) Relying primarily on item-total correlation and Cronbach's alpha as decision points, that scale consists of 16 statements. In the aggregate of all country data alpha is 0.7973; for Mexico 0.4582; for China 0.7176; for Ghana 0.6384; and for India 0.9151. Pardo and Calvo (2001) suggest a guideline of low 0.47, median 0.79, and high 0.98 for Cronbach's alpha scores.

Table 11. Final health knowledge scale (final items in bold)

<b>Facts for Life and Health- related NSF scale Statements</b>	<b>Results for aggregated data</b>		
	Percent Correct	SD	Corrected Item-total correlation
To improve the health of mothers and children, women should be at least 18 years old before becoming pregnant for the first time. (T)	80	.44	*
Siblings with less than two years between their births have fewer health risks than siblings with more than two years between their births. (F)	54	.50	*
<b>For a healthy pregnancy and birth, all pregnant women should visit a health worker before the baby is born. (T)</b>	<b>91</b>	<b>.28</b>	<b>.4992</b>
<b>Births that are not assisted by a skilled birth attendant are as safe as births that are assisted by a skilled birth attendant. (F)</b>	<b>80</b>	<b>.40</b>	<b>.4027</b>

Table 11 (Continued)

Breast milk is the only food and drink babies need for the first six months. (T)	72	.45	+
<b>It is normal if children below the age of one year to weigh the same over a two-month period. (F)</b>	<b>66</b>	<b>.47</b>	<b>.2045</b>
<b>Children who are vaccinated are protected from dangerous diseases. (T)</b>	<b>88</b>	<b>.33</b>	<b>.4271</b>
<b>Overall, vaccination has more risks than benefits. (F)</b>	<b>77</b>	<b>.42</b>	<b>.4914</b>
<b>Children learn a lot by playing. (T)</b>	<b>90</b>	<b>.31</b>	<b>.4452</b>
<b>Most injuries and accidents cannot be prevented. (F)</b>	<b>59</b>	<b>.49</b>	<b>.3551</b>
In emergency situations, it is preferable if parents take care of their own children. (T)	65	.48	*
<b>If a child is breathing rapidly or has difficulty breathing, the child should be taken immediately to a health care provider. (T)</b>	<b>91</b>	<b>.29</b>	<b>.4333</b>
<b>Many diseases can be prevented by washing hands before touching food. (T)</b>	<b>92</b>	<b>.27</b>	<b>.5363</b>
<b>Using condoms when having sex can prevent the spread of AIDS. (T)</b>	<b>81</b>	<b>.39</b>	<b>.4964</b>
<b>Using mosquito nets helps prevent malaria. (T)</b>	<b>82</b>	<b>.38</b>	<b>.4433</b>
A child with diarrhoea should drink extra fluids and continue to eat as usual.(T)	65	.48	+
<b>Exercise helps prevent heart disease. (T)</b>	<b>72</b>	<b>.45</b>	<b>.4248</b>
Coughs and colds only get better with medicine. (F)	41	.49	*
<b>It is the father's gene that decides whether the baby is a boy or a girl. (T)</b>	<b>62</b>	<b>.49</b>	<b>.3829</b>

Table 11 (Continued)

<b>Antibiotics kill viruses as well as bacteria. (F)</b>	<b>24</b>	<b>.43</b>	<b>.2494</b>
<b>Cigarette smoking causes lung cancer. (T)</b>	<b>86</b>	<b>.34</b>	<b>.5262</b>
<b>All bacteria are harmful to humans. (F)</b>	<b>48</b>	<b>.50</b>	<b>.3104</b>
Senility is inevitable as the brain ages and loses tissue. (F)	11	.32	*a
Human beings can survive on almost any combination of foods, provided the total diet has enough calories. (F)	15	.35	*a

\*Item-total correlation below .2, removed from scale.

+ Cronbach's alpha increased by removing from scale.

a Correct response rate below 20 percent, removed from scale.

Therefore, the final version of a scale to measure knowledge based on health research consists of the following 16 statements:

- For a healthy pregnancy and birth, all pregnant women should visit a health worker before the baby is born. (T)
- Births that are not assisted by a skilled birth attendant are as safe as births that are assisted by a skilled birth attendant. (F)
- It is normal if children below the age of one year to weigh the same over a two-month period. (F)
- Children who are vaccinated are protected from dangerous diseases. (T)
- Overall, vaccination has more risks than benefits. (F)

- Children learn a lot by playing. (T)
- Most injuries and accidents cannot be prevented. (F)
- If a child is breathing rapidly or has difficulty breathing, the child should be taken immediately to a health care provider. (T)
- Many diseases can be prevented by washing hands before touching food. (T)
- Using condoms when having sex can prevent the spread of AIDS. (T)
- Using mosquito nets helps prevent malaria. (T)
- Exercise helps prevent heart disease. (T)
- It is the father's gene that decides whether the baby is a boy or a girl. (T)
- Antibiotics kill viruses as well as bacteria. (F)
- Cigarette smoking causes lung cancer. (T)
- All bacteria are harmful to humans. (F)

### ***Analysis***

The overriding issue that emerges from this effort to develop an internationally reliable and valid scale to assess the amount of knowledge based on health research held is the quality of the sample collected by some country partners. In particular, the samples from Mexico and Ghana are more homogenous than appropriate, especially in regard to basic demographic and socio-economic characteristics as identified earlier.

The approach of a stratified random sample taken from a selected block/geographic region in each country is frequently used. However, more oversight and enforcement of desired goals appears to have been necessary. A larger sample size may well have overcome the limitations previously noted in terms of the homogeneity, but sample size isn't as directly causal as is the manner of selection. The emergence of this issue reflects the variation of basic approaches to social science between individuals and countries in combination with a strategy of enhancing capacity within countries while respecting the expert status and participation of project partners, as noted above.

Ideally, the same set of statements would emerge as an internally consistent scale across countries and in the aggregate. The homogenous nature of some country samples combined with the fact that Cronbach's alpha is most strongly a function of the number of the statements and the standard deviation of responses (thus as a sample is more homogenous, no matter the size, the standard deviation will decrease reducing Cronbach's alpha in turn) made that ideal an unlikely outcome which, in fact, did not entirely occur. However, the fact that the homogeneity of samples is most notable in the countries with the lowest Cronbach's alpha scores for the final scale is an indication that the scale itself is acceptable. As this is an effort to develop a valid and reliable scale that will work across countries, the nature of the samples also provides further justification at this stage

to place priority on the results from the aggregated data where the scale is entirely acceptable according to the criteria outlined.

Perhaps most surprising is the relationship of results from experts and the public. This was noted by the country partner in China, where expert responses were the poorest, who speculated, “We wonder if respondents did not understand the meaning of the questions or they respond carelessly.” However, in China and other countries, these statements were not reported as being too difficult to understand for a majority of the public participants. Therefore, the first suggestion of experts not understanding the statements (especially in light of their advanced educational backgrounds in health and medicine) can be discarded. The level of attention that expert participants gave their responses to the statements is impossible to accurately assess.

Perhaps as importantly, it should be noted that the expert component of the overall project was not administered in person whereas the public data was collected in face-to-face interviews. That basic methodological difference may account for some part of this difference and could contribute to a reduced attention being given the survey by experts.

Additionally, an expert status is often accompanied by a higher understanding of the uncertainty associated with the results of health research. In this instance, given the nature of the statements, that

heightened awareness of uncertainty was perhaps compounded by the power of day-to-day experience to affect perception. There is no doubt that physicians in these countries have had personal experiences in their communities that contradict the statements. For example, many healthy births have occurred without the presence of a health worker or a visit to a health worker during pregnancy just as there are individuals who have smoked for decades without developing lung cancer. This simply points out the strong difference between medical decisions based on personal experience versus those based on evidence-based medical knowledge which, in fact, this scale was designed to do.

### ***Conclusion***

An internationally valid and reliable scale to assess the level of knowledge based on health research held by individuals has been successfully constructed. This scale can meet the needs for health researchers concerned with the access and use of health research and advocacy efforts to improve the flow of health research into practice and to promote healthy behaviors.

This work points out the challenges inherent in international survey projects while respecting local partner autonomy and expert status. More importantly, the challenge of developing an internationally reliable and valid scale related to health given the wide disparities in

health care systems and health status have been identified and met. This work should be replicated in more countries, with larger samples, and especially with samples more reflective of the diversity of larger populations they are drawn.

# **CHAPTER 5**

## **THE ATTITUDES TOWARD HEALTH RESEARCH**

### **SCALE**

#### ***Building the scale***

Issues in scale building and design will be reported first, followed by results from piloting the scale in Mexico, China, Ghana, and India.

#### ***Content validity***

Based on the finding from the literature review discussed that perceptions of benefits are generally among the stronger determinants of individual's attitudes toward science and the finding that health and medicine dominate perceptions of science, the decision was made to base a scale assessing attitudes toward health research on the potential outcomes of health research. Thus, a first step of developing this scale was a continued literature review and expert consultation to identify the potential outcomes of health research.

The most productive body of literature useful for supporting decisions about what outcomes are possible from health research is that focusing on assessing the impacts of health research. Of most utility from this research program was the work of Buxton and Hanney (1996) and continuing in Hanney et al. (2004). When reviewing the

'paybacks' from health research, they identified outcomes related to knowledge production, research capacity building, informed policy and product development, health benefits, and economic benefits.

The utility of science and technological development in regard to strengthening national defense and improving a nation's position of power and strength within the global community has been identified by a wide variety of authors both from appreciative and critical viewpoints. This outcome area is generally included in research and development measurement approaches such as the Organization for Economic Co-operation and Development's Frascati and Oslo Manuals (OECD, 1993,1997).

Efforts such as the Eurobarometer and NSB surveys previously mentioned have clearly identified outcomes such as relevance and responsiveness to needs as influencing the public's attitude toward science and technology (Durant et al., 1992; NSB, 1993).

The work of several scholars from a range of disciplines, for example Sen (1999), Chen (2001), and Shiva (2000) have pointed out the critical role equity plays, both normatively and positively, in the distribution of benefits from science and technological developments. Shiva (2000), for example, points out the inequitable impacts on small farmers in low-income nations resulting from the utilization of scientific developments in agriculture over the past three decades.

An initial list of potential areas of outcomes from health research were presented to the team of social scientists, physicians, and leading health professionals taking part in the larger exercise organized by the World Health Organization. As a result of that exercise, twelve domains of potential outcomes from health research were developed. These areas of domains are not expected to identify underlying factors that may emerge through exploratory factor analysis. (Table 12)

Table 12. Potential areas of outcomes from health research

Political autonomy/ stability	Knowledge production	Relevance/ responsiveness
Health benefits	Morality/ ethics	Research production
Economic benefits	Policy	Science culture/ Ways of knowing
Equity	Practice/ service provision	Uncertainty reduction

Initial rounds of statement writing produced 52 statements, roughly 4 statement per outcome area. These statements were subjected to a round of pre-testing with 90 undergraduates at a medium-sized research university in the northeastern United States. The students were unpaid and unrewarded volunteers from a large undergraduate introductory class in environmental studies, thus there is no reason to expect any special status of knowledge or attitudes toward health research.

The students were asked to review the statements for clarity as well as respond to the statements on a 6-point agreement scale with an additional category for don't know responses. A combination of item/total correlation and impact on Cronbach's alpha was used to reduce the number of statements to 35, roughly three per each domain except for political autonomy/stability where only two statements emerged. The organizing domains and the 35 statements that resulted from this development and pre-testing effort that were incorporated in the full piloting stage in Mexico, China, Ghana, and India are:

#### POLITICAL AUTONOMY/STABILITY

- Health research results are shared with the world.
- Health researchers do not share their findings with foreigners for reasons of national security.

#### HEALTH BENEFITS

- The health benefits of health research are greater than any harmful effects it may have.
- Because of health research we live healthier lives than our ancestors
- Health research provides hope to those with health problems that are currently untreatable.

#### ECONOMIC BENEFITS

- Health research creates jobs in the country.

- The economic benefits of health research are less than the cost.
- The benefits of health research are greater than any harmful effects.

#### EQUITY

- Men and women benefit equally from health research
- Health research benefits only the rich.
- Everyone equally benefits from health research.

#### KNOWLEDGE PRODUCTION

- Health research helps us better understand illness and health.
- Health research produces new knowledge about health.
- Health research does not teach us anything new about health.

#### MORALITY/ETHICS

- Health research is not influenced by ethics.
- Health research is conducted ethically.
- For ethical reasons, some types of health research should not be allowed.

#### POLICY

- The results of health research are immediately applied to policy.
- Health research helps government officials make better health policies.

- The government uses health research to solve the country's health problems.

#### PRACTICE/SERVICE PROVISION

- Doctors use health research to keep up to date on the best treatments available.
- Health research improves the service hospitals provide.
- Health research helps doctors provide better health care.

#### RELEVANCE/RESPONSIVENESS

- Health research does not deal with current health problems.
- Health research improves my life.
- Health research focuses where there is the greatest need.

#### RESEARCH PRODUCTION

- Health researchers learn from previous research.
- Health research done in the past influences current health research.
- The more health research a country does, the better its research becomes.

#### SCIENCE CULTURE/WAYS OF KNOWING

- We depend too much on science and not enough on spirituality.
- There are some good ways of treating sickness that medical science does not recognize.

- Health research is the best way to understand illness and health.

#### UNCERTAINTY REDUCTION

- Health research makes me more confused about health.
- Health research helps me make better decisions about health.
- Health research reduces my worries.

The next sections report results from the full piloting stage.

### ***Construct validity***

The literature review supporting the theoretical basis for this effort revealed an incomplete and inconclusive body of knowledge about the complex relationship between attitudes toward health research and knowledge based on health research. However, in simple analyses of that relationship there is a trend toward finding positive linear relationships between knowledge and attitudes toward science. That relationship becomes more complex when analysis advances to subgroups or begins to incorporate factors such as education, age, gender, or number of previous science classes taken.

In low-income settings where the percent of gross domestic product (GDP) spent on health can produce significant outcomes on health status (WHO, 2000), there is evidence to support a hypothesis that

there will be a positive correlation between attitudes toward health research and the level of health spending as a percent of GDP.

Therefore, for the purposes of scale development and establishing construct validity measures and considering the nature of the sample, two hypotheses can be advanced to test construct validity of this attitudinal scale.

Hypothesis 5 – There will be a positive correlation between the level of knowledge based on health research and attitudes toward health research.

Hypothesis 6 - Mean attitudinal scores by country will positively correlate with per capita GNP spent on health.

### ***Discriminate validity***

In addition to analyzing the pattern of responses to eliminate poor performing statements in regard to their ability to discriminate between respondents, two hypotheses are possible in regard to the scale assessing attitudes toward health research to test discriminate validity.

Hypothesis 7 - Expert groups will exhibit more positive attitudes toward health research than the general public.

Hypothesis 8 - Significant differences in attitudes toward health research will exist between countries.

## ***Results***

Results of particular interest are the frequency of responses to the scale items and the assessment of the validity and reliability measures and their contribution to the development of a final version of the scale. In the following sections, results regarding face validity, frequency of correct responses, criterion validity, construct validity, discriminate validity, and reliability are reported.

### ***Face validity***

A Flesch-Kinkaid readability formula assessment of the piloted scale items, in the English version, rated the scale at a 6th grade reading level (Score = 6.3). Reports from the field indicate only one area of difficulty in regard to face validity and that was in regard to the use of the word “ethical”. This occurred during the initial round of cognitive interviews with individual participants in every country and as well as in the field during piloting. Due to such consistency across countries that the word ‘ethical’ was difficult to interpret by participants, corresponding statements were removed from further analysis.

### ***Frequency of responses***

A first level of criteria is the percent of total non-responses to statements combined with Don't Know responses. Any statement receiving more than 20 percent "Don't Know" or non-response was removed from further analysis. All statements that received more than 20 percent at the individual country level also performed as poorly at the aggregate level. Therefore, only aggregate data is reported. (Table 13)

The statements in bold face type in table 13 are those removed from further consideration. For confirmation purposes, the response levels to statements using the word 'ethical' or 'ethics' are also included. The descriptive statistics confirm the decision to remove those statements.

Table 13. Frequency of responses

6	Health research helps us better understand illness and health.	811	9.8	4.72 1.7
<b>7</b>	<b>The economic benefits of health research are less than the cost.</b>	<b>813</b>	<b>20.2</b>	<b>3.30</b> <b>2.2</b>
<b>8</b>	<b>Health research is conducted ethically.</b>	<b>811</b>	<b>28.3</b>	<b>3.20</b> <b>2.3</b>
9	Health research results are shared with the world.	815	12.0	4.21 1.9
10	Men and women benefit equally from health research	812	8.4	4.73 1.6
11	Health research helps doctors provide better health care.	813	7.0	4.80 1.5
12	Health research reduces my worries.	813	10.1	3.87 1.9

Table 13 (Continued)

30	Health research helps government officials make better health policies.	814	14.5	4.07 2.0
31	Health research produces new knowledge about health.	814	10.3	4.69 2.0
32	Health research provides hope to those with health problems that are currently untreatable.	814	8.9	4.74 1.6
33	Health research focuses where there is the greatest need.	813	13.8	4.14 1.8
34	Health research is the best way to understand illness and health.	815	8.2	4.51 1.7
35	Health research benefits only the rich. country.	814	8.1	2.31 1.6 2.0
20	Everyone equally benefits from health research.	811	10.9	3.97 1.9
21	Health research does not deal with current health problems.	812	16.7	2.67 1.9
22	Health researchers learn from previous research.	811	11.2	4.47 1.8
<b>23</b>	<b>For ethical reasons, some types of health research are not allowed.</b>	<b>809</b>	<b>30.5</b>	<b>3.04</b> <b>2.3</b>
24	Because of health research we live healthier lives than our ancestors	813	10.1	4.40 1.9
25	Health research improves my life.	813	9.6	4.36 2.6
<b>26</b>	<b>Health researchers do not share their findings with foreigners for reasons of national security.</b>	<b>813</b>	<b>26.4</b>	<b>2.39</b> <b>2.1</b>
<b>27</b>	<b>The results of health research are immediately applied to policy.</b>	<b>913</b>	<b>21.7</b>	<b>2.90</b> <b>2.1</b>
28	The benefits of health research are greater than any harmful effects.	812	15.1	4.15 2.0
29	The government uses health research to solve the country's health problems.	813	13.8	4.06 2.0

(Bold faced statements were removed from further analysis.)

## ***Reliability***

Test-retest reliability was assessed using kappa rather than the simpler percent agreement method as kappa accounts for chance. In this section of the larger survey, kappa values (N=50) were in an acceptable range from a low of 0.69 in China, 0.74 in Ghana, and a high of 0.89 in Mexico.

To further reduce the number of statements and to assess internal reliability, Cronbach's alpha scores and item/total correlation values were used for the decision analysis. First, all statements at the country level or the aggregate of all country level data with an item/total correlation below 0.20 were removed from further analysis. Second, if Cronbach's alpha increased when any statement was removed, that statement was removed from further analysis. That was performed individually at the country level and with the aggregated data from all countries.

A scale consisting of 11 statements, meeting the criteria described above based on accepted social science methodology, emerged that includes one statement in each of the outcome areas built into the scale. (Table 14)

Table 14. The attitudes toward health research scale

	<b>All</b>	<b>Mexico</b>	<b>China</b>	<b>Ghana</b>	<b>India</b>
<b>Statement (numbered by order as tested)</b>	<b>Mean SD</b>	<b>Mean SD</b>	<b>Mean SD</b>	<b>Mean SD</b>	<b>Mean SD</b>
2. The health benefits of health research are greater than any harmful effects it may have.	4.71 1.31	5.07 1.10	4.42 1.66	4.78 0.91	4.57 1.40
6. Health research helps us better understand illness and health.	5.12 1.05	5.23 0.86	5.06 1.22	5.20 0.74	4.99 1.30
9. Health research results are shared with the world.	4.70 1.34	4.48 1.60	5.25 1.07	4.69 1.05	4.43 1.40
15. Health research improves the service hospitals provide.	4.86 1.15	4.94 1.10	5.04 1.10	4.79 0.94	4.66 1.40
17. Health research helps me make better decisions about health.	4.86 1.10	5.12 0.90	4.96 1.24	4.79 0.80	4.57 1.3
20. Everyone equally benefits from health research.	4.36 1.49	4.51 1.50	4.64 1.40	4.02 1.40	4.28 1.70
22. Health researchers learn from previous research.	4.93 1.09	5.03 1.20	5.14 0.97	4.89 0.76	4.66 1.30
28. The benefits of health research are greater than any harmful effects.	4.79 1.15	4.68 1.40	5.25 0.93	4.71 0.88	4.51 1.20
30. Health research helps government officials make better health policies.	4.67 1.30	4.36 1.50	5.17 1.13	4.70 0.95	4.46 1.40

Table 14 (Continued)

33. Health research focuses where there is the greatest need.	4.58 1.34	4.40 1.609	4.85 1.39	4.73 0.88	4.35 1.40
34. Health research is the best way to understand illness and health.	4.83 1.22	5.21 1.01	4.55 1.57	4.82 0.91	4.71 1.20

Note: Numbers reflect ordering during piloting.

This 11-statement scale produced a range of Cronbach's alpha scores, all acceptable, and means at the country and aggregate level. (Table 15)

Table 15. Attitudes toward health research scale descriptives

	<b>Mexico</b>	<b>China</b>	<b>Ghana</b>	<b>India</b>	<b>All</b>
N	199	208	199	199	805
Cronbach's alpha	0.8274	0.8410	0.7659	0.8449	0.8328
Scale mean	4.80	4.83	4.70	4.54	4.73
Standard deviation	0.78	0.92	0.53	0.83	0.79

### ***Construct validity***

For all data aggregated, the Pearson's correlation between the mean score on the attitudinal scale and the average percent correct on the knowledge based on health research scale was 0.237. For Mexico that correlation was 0.268, for china 0.274, for Ghana 0.187, and for India 0.297. All correlations are significant at the 0.01 level. Therefore, hypothesis five, that there will be a positive linear relationship between the two scales is accepted.

The literature review also indicated that this relationship may change when analysis moves to sub-groups based on possession of knowledge based on health research. For individuals scoring equal to and above the mean (N=501) on the knowledge based on health research scale, the correlation shrinks to 0.092 and significance disappears. For those below the mean (N=304) on the knowledge based on health research scale the correlation is significant and positive at 0.212.

No statistically significant correlations exist between attitudes and percent of GDP spent on health at the country level. However, further analysis found that scores on the attitude scale positively correlate at the aggregate level with the percent of GDP spent on health (0.574) and total health spending per capita (0.625), and healthy average life expectancy (0.739). There is a negative correlation between attitudes toward health research and child mortality per 1,000 (-0.780).

Therefore, hypothesis six, that mean attitudinal scores will positively correlate with per capita GNP spent on health cannot be accepted due to the lack of statistical significance at the country level although the direction of the correlation is as predicted.

### ***Discriminate validity***

Between country differences were tested using a one-way ANOVA analysis of the mean scores from the four countries. This revealed a

significant difference between countries ( $F = 5.376$ ). Thus, hypothesis seven that a significant difference in responses to attitudes toward health research scale would exist between countries is accepted.

Differences between experts and the public sample were analyzed using an independent sample t-test. At a 95% and a 99% confidence interval, differences were significant in the aggregate and in every country except India. (Table 16)

Table 16. Difference between experts and the public.

		<b>Public</b>	<b>Experts</b>
<b>Mexico</b>	N	199	69
	mean	4.80*	4.40*
	SD	1.11	0.78
<b>China</b>	N	208	159
	mean	4.83**	5.00**
	SD	0.92	0.69
<b>Ghana</b>	N	199	100
	mean	4.73**	5.38**
	SD	0.53	0.16
<b>India</b>	N	199	57
	mean	4.54	4.70
	SD	0.83	1.02
<b>Aggregate</b>	N	805	385
	mean	4.73**	4.95**
	SD	0.79	0.83

\* = significant difference at 95% CI.

\*\* = significant difference at 99% CI.

Therefore, the results reveal strong, but not complete, support for hypothesis eight that there would be significant differences in scores between experts and the public samples.

### ***Exploratory factor analysis***

While acknowledging the potential for difficult interpretation of factor analysis discussed earlier, I chose to conduct exploratory factor analysis using Varimax rotation. Factors identified are those with an Eigen value over 1.0. However, in Mexico and Ghana, using the scree plot shoulder technique to identify factors would have identified one fewer factor; in China that technique would identify one additional factor, and in India and in the aggregate the number of factors would remain unchanged.

Somewhat similar factors, in concept, emerged in each country and in the aggregate, yet the exact structure of the factors changes between countries. Three factors emerged from the analysis of data from Mexico and Ghana, while two factors emerged from the analysis of data from China, India, and in the aggregate. (Table 17)

Table 17. Number and structure of factors.

	<b>Percent variance explained</b>	<b>Factor 1 statements</b>	<b>Factor 2 statements</b>	<b>Factor 3 statements</b>
Mexico	59.4	2, 9, 15, 17, 20,	28, 30, 33, 34	6, 22
China	57.1	9, 15, 17, 20, 22, 28, 30	2, 6, 34, 33	NA
Ghana	52.9	15, 17, 20, 22, 28	9, 30, 33, 34	2, 6
India	50.8	9, 20, 22, 28, 30, 34	2, 6, 15, 17, 33	NA
All	47.8	9, 15, 17, 20, 22, 28, 30, 33, 34	2, 6	NA

In regard to the participants in this exercise in scale development, two factors consistently emerged that explain roughly half of the variance in responses. When a third factor did emerge, that factor on its own never accounted for more than 10 percent of the variance. However, given the sample size and the lack of representative nature of the samples in some countries as noted earlier, caution must be taken in assessing the results of this factor analysis. For example, no sample size at the country level exceeds 200 individuals for this 11-item scale. DeVellis (1991) reports guidelines for sample size for factor analysis, one of such suggests a ratio of 5-10 individuals per item yet another which calls a sample size of 200 as fair. Therefore, the country level

data can be described as adequate but not an ideal sample size for factor analysis.

Table 18. Factor loadings: China and Mexico

Statement	China		Mexico		
	Factor 1	Factor 2	Factor 1	Factor 2	Factor 3
2		.613	.671		
6		.717	.552		.624
9	.722		.543	.446	
15	.626		.685		
17	.717		.616		
20	.500		.690		
22	.829				.741
28	.835			.651	
30	.828			.573	
33		.729		.885	
34		.843		.522	

Table 19. Factor loadings: India and Ghana

Statement	India		Ghana		
	Factor 1	Factor 2	Factor 1	Factor 2	Factor 3
2		.714			.803
6		.837			.703
9	.516			.684	
15		.512	.510		
17		.682	.776		
20	.696		.657		
22	.603		.518		.411
28	.705		.473		
30	.646		.344	.381	
33		.597		.739	
34	.684			.748	

Table 20. Factor loadings: Aggregate

<b>Aggregate</b>		
Statement	Factor 1	Factor 2
2		.805
6		.778
9	.637	
15	.587	
17	.547	.446
20	.586	
22	.552	
28	.715	
30	.735	
33	.515	
34	.502	.480

Statements generally loading on factor one are related to equity, policy, practice, uncertainty reduction, research production, economic, and political autonomy/stability. Statements generally loading on the second factor are related to relevance/responsiveness, knowledge production, and ways of knowing. Thus, while more research is needed to confirm and replicate these findings, it tentatively seems that factor one relates more to immediate benefits that can emerge from health research and factor two relates to the process of health research. (Tables 18, 19, 20)

### ***Analysis***

Higher mean scores on the attitude toward health research scale can be taken to indicate a more positive set of attitudes and expectations. Thus, it is worth noting that mean scores in all countries and the

aggregate were higher than the mean point on the 6-point scale that was used indicating, and confirming previous research, that health research is generally well regarded.

Certainly, there are broad differences in culture, political setting, and nature of the health care systems between countries. At the same time, there are fundamental relationships between individuals and health that do cross over cultural and political borders. Additionally, the nature of health research, while it is subject to social construction and varying boundaries, is more rather than less consistent internationally. This situation seems to be reflected in the nature and changing structure of the factors that did emerge in this preliminary analysis. However, further testing of the scale with larger, representative samples in more countries is suggested.

### ***Conclusion***

A valid and reliable scale that can be used in international contexts to measure attitudes toward health research based on the expected outcomes of health research has been constructed.

An important utility of this measure, when replicated and used with more robust and representative samples, will be to contribute to the continued development of theory about the relationship between attitudes toward health research, knowledge based on health research,

health literacy, the adoption of healthy behaviors based on health research, and the nature and impacts of public engagement with health research.

## **CHAPTER 6**

### **CONCLUSION**

This dissertation reports on a research effort with explicit goals of methodology development and testing. Therefore, results reported here reflect the performance of the scale from a methodological perspective and, importantly, should in no way be taken to reflect the knowledge levels or attitudes of the larger populations the samples were drawn from. Further limitations to the implications of this work result from the sampling issues discussed previously.

Overall, this research effort has developed and tested successful scales useful in international contexts to measure knowledge based on scientific research on health, or more simply health research, and attitudes toward health research. This work will contribute to greater understanding of the relevance, context, and outcomes of health research for various audiences, contribute to effective communication strategies, support further monitoring of efforts to enhance engagement with health research, and inform effective and equitable investment and policy decisions.

Key lessons learned from this dissertation process include the need for strict and stringent supervision of international research partnerships that maintain a balance respecting the independent professionalism of all partners. Open and loose research collaborations are useful when

conducting exploratory research as it allows local input to be maximized. However, when research methodologies and goals are well defined, there is perhaps greater utility for a centralized and stronger decision-making authority. However, that authority can occur at the loss of a sense of local empowerment which, justifiably so, is sought after by qualified international researchers and may well be a requisite for their participation. This is an area where a balanced approach is required that develops from personality and personal experience rather than a research methodology textbook or classroom learning. Unfortunately, academic practices in the United States currently tend to diminish or disregard personal experience in favor of statistics and rules.

Nonetheless, this dissertation is important and justified as many if not most of the advances in health are related to the development and uptake of new knowledge and technologies. General criticism and questions of the value of efforts to develop and test measures such as the two put forth in this work are at least partially based on an incomplete or naive understanding of the potential of health research – scientific research on health – to improve public health. The concept of public engagement is the conceptual rubric for this research as well as the process of improving health through the uptake of new knowledge and technologies. Health literacy is the key set of skills and abilities that individuals use in the process of engaging with health research.

Combining health literacy with notions of public engagement is an advance to the scholarly body of knowledge in this area.

Marrying health literacy with the concept of public engagement directly incorporates a key lesson learned from decades of research – that behavior change for health involves both awareness and action. An individual must first be aware of a choice that could result in better health and, then, must take action to adopt that behavior. That process is not always as direct as early theories, such as the so-called deficit model, put forth. It is perhaps that a priori need for awareness before change that led earlier theories to overly rely on the deficit model's approach.

In any case, further research on the complex relationships between knowledge, attitudes, and behaviors requires appropriate methodological tools, many of which are currently lacking. This work begins to meet those needs and should be continued so that, for instance, a complete measure of health literacy as an important tool in public engagement is developed.

Future research activities should also be conducted to, first, continue to compile evidence as to the validity and reliability of the scales in a variety of settings. Second, these scales can be productively used within research looking at the variety of diseases, conditions, or health issues to add another layer of analysis within those research efforts as

well as creating a tested means of comparability across such dissimilar efforts. Finally, if the political will were to emerge, these scales could be used as the core measures for large national survey efforts like the aforementioned NSB and Eurobarometer efforts. One of the practical outcomes of those efforts has been to highlight science and the interplay between science and society in the mass media and in policy settings. The same impact could be minimally anticipated in relation to health research given the higher level of salience for health, versus science in general.

Health is one of the strongest determinants of individual and community well being and patterns of development. Unfortunately, we do not have complete knowledge of how individuals make decisions related to their own, their families', and their communities' health. These scales hold the promise to be useful to researchers investigating the complex relationships surrounding health-related decisions. As a result, researchers will hopefully be able to contribute informed recommendations to practitioners and policy-makers producing positive outcomes on individual and public health.

## REFERENCES

- Abelson, J., Forest, P., Eyles, J., Smith, P., Martin, E., & Gaubin, F. (2003). Deliberations about deliberative methods: Issues in the design and evaluation of public participation processes. *Social Science & Medicine*, 57(2), 239-251.
- American College of Physicians – American Society of Internal Medicine (ACP-ASIM) (2000, 1-15-02). *Emerging antibiotic resistance: Appropriate use of antibiotics and immunization*. Retrieved 3-15-2003, 2003, from <http://www.acponline.org/ear/index.html>.
- Adams, K., & Corrigan, J. M. (Eds.). (2002). *Priority areas for national action: Transforming health care quality*. Washington, D.C.: The National Academies Press.
- Aikenhead, G. S., & Ryan, A. G. (1992). The development of a new instrument: "Views on Science-Technology-Society" (VOSTS). *Science Education*, 76(5), 477-491.
- Andreason, A. R. (1995). *Marketing social change: Changing behavior to promote health, social development, and the environment*. San Francisco: Jossey-Bass.
- Ard, C., & Natowicz, M. R. (2001). A seat at the table: Membership in federal advisory committees evaluating public policy in genetics. *American Journal of Public Health*, 91(5), 787-790.
- Artuso, A. (2002). Bioprospecting, benefit sharing, and biotechnological capacity building. *World Development*, 13(8), 1355-1368.
- Azjen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behavior*. Englewood Cliffs, NJ: Prentice Hall.

- Bailey, C., & Pang, T. (2004). Health information for all by 2015? *The Lancet*, 364(9430), 223-224.
- Bak, H.-J. (2001). Education and public attitudes toward science: Implications for the "Deficit Model" of education and support for science and technology. *Social Science Quarterly*, 82(4), 779-795.
- Baker, D., Parker, R., Williams, M., Clark, W. S., & Nurss, J. (1997). The relationship of patient reading ability to self-reported health and use of health services. *American Journal of Public Health*, 1997(87), 1027-1030.
- Baker, D., Williams, M., Parker, R., Gazmarian, J. A., & Nurss, J. (1999). Development of a brief test to measure functional health literacy. *Patient Education and Counseling*, 38, 33-42.
- Bastian, H. (1994, March 23, 1998). *The power of sharing knowledge: Consumer participation in the Cochrane Collaboration*. Retrieved June 10, 2004, 2004, from <http://www.informedhealthonline.org/item.aspx?tabid=37>.
- Bauer, M., Durant, J., & Evans, G. (1994). European public perceptions of science. *International Journal of Public Opinion*, 6(2), 163-186.
- Bauer, M., Petkova, K., & Boyadjieva, P. (2000). Public knowledge of and attitudes to science: Alternative measures that may end the 'science war'. *Science, Technology, & Human Values*, 25(1), 30-51.
- Bauer, M., & Schoon, I. (1993). Mapping variety in public understanding of science. *Public Understanding of Science*, 2, 141-155.

- Becker, M. H., & Rosenstock, I. M. (1984). Compliance with medical advice. In A. Steptoe & A. Matthews (Eds.), *health care and human behavior* (pp. 175-208). Orlando, FL: Academic Press.
- Bero, L. A., Grilli, R., Grimshaw, J. M., Harvey, E., Oxman, A. D., & Thomson, M. A. (1998). Getting research findings into practice: Closing the gap between research and practice: an overview of systematic reviews of interventions to promote the implementation of research findings. *BMJ*, *317*, 465-468.
- Bhutta, Z. A. (2001). *Ethics in international health research: A perspective from the developing world* (Report No. WG2\_4). Geneva, Switzerland: World Health Organization Commission on Macroeconomics and Health.
- Billeh, V. Y., & Hasan, O. E. (1975). Factors influencing teachers' gain in understanding the nature of science. *Journal of Research in Science Teaching*, *12*, 209-219.
- Brossard, D., & Lewenstein, B. (2004). Assessing models of outreach in ELSI projects – Report to the DOE's ELSI program. Ithaca, NY, USA: Cornell University, Department of Communication.
- Brossard, D., & Shanahan, J. (2003). Do citizens want to have their say? Media, agricultural biotechnology, and authoritarian views of democratic processes in science. *Mass Communication & Society*, *6*(3), 291-312.
- Buchecker, M., Hunziker, M., & Kienast, F. (2003). Participatory landscape development: Overcoming social barriers to public involvement. *Landscape and Urban Planning*, *973*, 1-18.
- Buxton, M., & Hanney, S. (1996). How can payback from health services research be assessed? *Journal of Health Services Research and Policy*, *1*(1), 35-43.

- Carmines, E. G., & Zeller, R. A. (1979). *Reliability and validity assessment*. Newbury Park: Sage Publications.
- Chadwick, H. D., & Pope, A. S. (1946). *The modern attack on tuberculosis*. New York, NY: The Commonwealth Fund.
- Chen, L. C., & Berlinguer, G. (2001). Health equity in a globalizing world. In T. Evans, M. Whitehead, F. Diderichsen, A. Bhuiya & M. Wirth (Eds.), *Challenging inequities in health: From ethics to action*. Oxford, UK: Oxford University Press.
- Comroe, J., & Drips, R. (1976). Scientific basis for the support of biomedical science. *Science*, 192(4235), 105-111.
- Cooley, W., & Klopfer, L. (1961). *Test on understanding science (Form W)*. Princeton, NJ: Educational Testing Service.
- Cotham, J., & Smith, E. (1981). Development and validation of the conceptions of scientific theories test. *Journal of Research in Science Teaching*, 18, 387-396.
- Cronbach, L.J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika*, 16:297-334.
- Davis, T. C., Michielutte, R., Askov, E. N., Williams, M., & Weiss, B. D. (1998). Practical assessment of adult literacy in health care. *Health Education and Behavior*, 25(5), 613-624.
- DeVillis, R. F. (1991). *Scale Development: Theory and applications* (Vol. 26). Newbury Park: Sage Publications.
- Durant, J., Evans, G., & Geoffrey, T. (1992). Public understanding of science in Britain: The role of medicine in the popular representation of science. *Public Understanding of Science*, 1(1), 161-182.

- Eng, T.R., Maxfield, A., Patrick, K., Deering, M.J., Ratzan, S.C., & Gustafson, D.H. (1998). Access to health information and support: A public highway or private road? *JAMA*, 28-(15) 1371-1375.
- Epstein, S. (1995). The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology & Human Values*, 20(4), 408-437.
- Fearon, J. D. (1998). Deliberation as discussion. In J. Elster (Ed.), *Deliberative Democracy* (pp. 44-68). Cambridge: Cambridge University Press.
- Federation of State Medical Boards of the United States, Inc. (1998). *Elements of a modern state medical board*: Federation of State Medical Boards of the United States, Inc.
- First International Conference on Health Promotion. (1986, November 21, 1986). *Ottawa charter for health promotion*. Retrieved 3-10-2003, 2003, from <http://www.who.int/hpr/archive/docs/ottawa.html>.
- Fisher, W. R. (1984). Narration as a human communication paradigm: The case of public moral argument. *Communication Monographs*, 51(1), 1-22.
- Francis, L. J., & Greer, J. E. (1999). Measuring attitude toward science among secondary school students: The affective domain. *Research in Science & Technological Education*, 17(2), 219-226.
- Frankish, C. J., Kwan, B., Ratner, P. A., Higgins, J. W., & Larsen, C. (2002). Challenges of citizen participation in regional health authorities. *Social Science & Medicine*, 54, 1471-1480.

- Galli, N. (1978). *Foundations and principles of health education*. New York, NY: Wiley.
- Gazmarian, J. A., Baker, D., Williams, M., Parker, R., Scott, T. L., Green, D. C., et al. (1999). Health literacy among Medicare enrollees in a managed care organization. *Journal of the American Medical Association*, 281(6), 545-551.
- Gerbner, G. (1999). The stories we tell. *Peace Review*, 11(1), 9-16.
- Glanz, K., Lewin, K. M., & Rimer, B. K. (Eds.). (1997). *Health behavior and health education: Theory, research, and practice* (Second ed.). San Francisco, CA: Jossey-Bass.
- Global Alliance for Elimination of Leprosy (2001). *Leprosy: Learning from success* (Report). Geneva, Switzerland: World Health Organization.
- Global Forum for Health Research. (2000). *The 10/90 report on health research* (Report). Geneva: Global Forum for Health Research.
- Global Forum for Health Research. (2002). *The 10/90 report on health research, 2001-2002* (Report). Geneva, Switzerland: Global Forum for Health Research.
- Gross, C., & Sepkowitz, K. (1998). The myth of medical breakthrough: Smallpox, vaccination, and Jenner reconsidered. *International Journal of Infectious Disease*, 3(1), 54-60.
- Haines, A., & Jones, R. (1994). Implementing findings of research. *BMJ*, 308, 1488-1492.
- Hanney, S., Gonzalez-Block, M., Kogan, M., & Buxton, M. (2003). The utilisation of health research in policy-making: Concepts,

examples and methods of assessment. *Health Research Policy and Systems*, 1(2).

- Hanney, S. R., Grant, J., Wooding, S., & Buxton, M. J. (2004). Proposed methods for reviewing the outcomes of health research: The impact of funding by the UK's 'Arthritis Research Campaign'. *Health Research Policy and Systems*, 2(4).
- Harrison, S., Barnes, M., & Mort, M. (1997). Praise and damnation: Mental health user groups and the construction of organizational legitimacy. *Public Policy and Administration*, 12(2), 4-6.
- Hayes, B. C., & Tariq, V. N. (2000). Gender differences in scientific knowledge and attitudes toward science: A comparative study of four Anglo-American nations. *Public Understanding of Science*, 9, 433-447.
- Haynes, B., & Haines, A. (1998). Getting research findings into practice: Barriers and bridges to evidence based clinical practice. *BMJ*, 317, 273-276.
- Hilgartner, S. (1990). The dominant view of popularization: Conceptual problems, political uses. *Social Studies of Science*, 20, 519-539.
- Hipkins, R., Stockwell, W., Bolstad, R., & Baker, R. (2002). *Commonsense, trust and science* (Technical Report): New Zealand Ministry of Research, Science, and Technology.
- International Conference on Primary Health Care. (1978). *Declaration of Alma-Ata*. Retrieved 1-21-2003, 2003, from <http://www.who.int/hpr/archive/docs/almaata.html>.
- Irwin, A. (2001). Constructing the scientific citizen: Science and democracy in the biosciences. *Public Understanding of Science*, 10, 1-18.

- Jacobs, P. P. (1940). *The control of tuberculosis in the United States*. New York, NY: National Tuberculosis Association.
- Jasanoff, S. (1997). Civilization and madness: The great BSE scare of 1996. *Public Understanding of Science*, 6(3), 221-232.
- Jewkes, R., & Murcott, A. (1998). Community representatives: Representing the "community"? *Social Science & Medicine*, 46(7), 843-858.
- Jha, P., Mills, A., Hanson, K., Kumaranayake, L., Conteh, L., Kurowski, C., Nguyen, S. N., Cruz, V. O., Ranson, K., Vaz, L. M. E., Yu, S., Morton, O., & Sachs, J. D. (2002). Improving the health of the global poor. *Science*, 295, 2036-2039.
- Kallerud, E., & Ramberg, I. (2002). The order of discourse in surveys of public understanding of science. *Public Understanding of Science*, 11(3), 213-224.
- Karmaus, W. (2001). Of jugglers, mechanics, communities, and the thyroid gland: How do we achieve good quality data to improve public health? *Environmental Health Perspectives Supplements*, 109(6), 7.
- Kimball, M. E. (1967). Understanding the nature of science: A comparison of scientists and science teachers. *Journal of research in science teaching*, 5, 110-120.
- Kreps, G. L., & Thornton, B. C. (1992). *Health communication: Theory & practice* (Second ed.). Prospect Heights, IL: Waveland Press, Inc.
- Labov, W. (1997). Some Further Steps in Narrative Analysis. *The Journal of Narrative and Life History*. Retrieved 8-19-2004, from <http://www.ling.upenn.edu/~labov>.

- Lederman, N. G., Abd-El-Khalick, F., Bell, R. L., & Schwartz, R. S. (2002). Views of nature of science questionnaire: Toward valid and meaningful assessments of learners' conceptions of nature of science. *Journal of Research in Science Teaching*, 39(6), 497-521.
- Lefebvre, R. C., & Rochlin, L. (1997). Social marketing. In K. Glanz & F. M. Lewis & B. K. Rimer (Eds.), *Health behavior and health education: Theory, research, and practice* (pp. 384-402). San Francisco, CA: Jossey-Bass.
- Lewando-Hundt, G., & Al Zaroo, S. (2000). Evaluating the dissemination of health promotion research. In M. Thorogood & Y. Coombes (Eds.), *Evaluating health promotion: Practice and methods* (pp. 151-163). Oxford, UK: Oxford University Press.
- Lewenstein, B. V. (1995). From Fax to Facts: Communication in the Cold Fusion Saga. *Social Studies of Science*, 25, 403-436.
- Litva, A., Coast, J., Donovan, J., Eyles, J., Shepherd, M., Tacchi, J., et al. (2002). 'The public is too subjective': Public involvement at different levels of health-care decision making. *Social Science & Medicine*, 54, 1825-1837.
- Mackay, J., & Eriksen, M. (2002). *The tobacco atlas*. Retrieved 3-23-2003, 2003, from [http://www.who.int/tobacco/resources/publications/tobacco\\_atlas/en/](http://www.who.int/tobacco/resources/publications/tobacco_atlas/en/).
- McNeil, P. M. (1993). *The ethics of human experimentation*. Cambridge: Cambridge University Press.

- Miller, J. D. (1992). Toward a scientific understanding of the public understanding of science and technology. *Public Understanding of Science*, 1(1), 23-26.
- Miller, J. D. (1998). The measurement of civic scientific literacy. *Public Understanding of Science*, 7, 203-223.
- Miller, J. D., & Kimmel, L. G. (2001). *Biomedical communications*. New York: Academic Press.
- Miller, J. D., Pardo, R., & Niwa, F. (1997). *Public perceptions of science and technology: A comparative study of the European Union, the United States, Japan, and Canada*. Madrid, Spain: Fundacion BBV.
- Minichiello, V., Marino, R., & Brown, J. (2001). Knowledge, risk perceptions and condom usage in male sex workers from three Australian cities. *AIDS Care*, 13(3), 387-492.
- Mosteller, F. (1981). Innovation and evaluation. *Science*, 211(4485), 881-886.
- Muscular Dystrophy Association. (2004). *MDA Telethon: Answers to frequently asked questions*, 2004, from <http://www.mdausa.org/telethon/faqs.cfm>.
- National Science Board (NSB). (1993). *Science and Engineering Indicators*. Retrieved 3-5-2003, 2003, from <http://www.nsf.gov/sbe/srs/seind93/chap7/doc/7d1a93.htm>.
- New Zealand Ministry of Health (2002, March, 2002). Operational standard for ethics committees. Retrieved 3-10-2003, 2003, from <http://www.moh.govt.nz>.

- Nicolucci, A., Ciccarone, E., Consoli, A., Di Martino, G., La Penna, G., Latorre, A., et al. (2000). Relationship between patient practice-oriented knowledge and metabolic control in intensively treated Type I diabetic patients: Results of the validation of the knowledge and practices diabetes questionnaire. *Diabetes, Nutrition & Metabolism*, 13(5), 276-283.
- Nielsen-Bohlman, L., Panzer, A. M., & Kindig, D. A. (Eds.). (2004). *Health literacy: A prescription to end confusion*. Washington, D.C.: Institute of Medicine of the National Academies. Available: <http://www.iom.edu/report.asp?id=19723>.
- Nieva, E., & Hickson III, M. (1996). Modeling cultures: Toward grounded paradigms. In M. Salwen & D. W. Stacks (Eds.), *An integrated approach to communication theory and research* (pp. 297-316). Mahwah, NJ: Lawrence Erlbaum Associates.
- Nutbeam, D. (1999). Literacies Across the Lifespan: Health Literacy. *Literacy & Numeracy Studies*, 9(2), 47-55.
- 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.
- Ochs, E. (1997). Narrative. In T. A. van Dijk (Ed.), *Discourse as structure and process: A multidisciplinary introduction* (Vol. 1, pp. 185 - 207). London: Sage Publications Ltd.
- Office of Science and Technology and the Wellcome Trust. (2000, October, 2000). *Science and the public: A review of scientific communication and public attitudes toward science in Britain*. Retrieved Aug. 8, 2004, 2004, from <http://www.wellcome.ac.uk/en/1/pinpubactconpubpat.html>.

- Ondrusek, N., Warner, E., & Goel, V. (1999). Development of a knowledge scale about breast cancer and hereditary (BCHK). *Breast Cancer Research and Treatment*, 53, 69-75.
- Organization for Economic Co-operation and Development (OECD). (1993). *Frascati Manual*. Paris: OECD.
- Organization for Economic Co-operation and Development (OECD). (1997). *Oslo Manual*. Paris: OECD.
- Pande, K. C., de Takats, D., Kanis, J. A., Edwards, V., Slade, P., & McCloskey, E. V. (2000). Development of a questionnaire (OPQ) to assess patient's knowledge about osteoporosis. *Maturitas*, 237, 75-81.
- Pang, T., Sadana, R., Hanney, S., Bhutta, Z., Hyder, A., & Simon, J. (2003). Knowledge for better health - A conceptual framework and foundation for health research systems. *Bulletin of the World Health Organization*, 81(11), 815-820.
- Pardhan, S., Mughal, N., & Mahomed, I. (2000). Self-reported eye disease in elderly South Asian subjects from an inner city cluster in Bradford: A small-scale study to investigate knowledge and awareness of ocular disease. *Eye*, 14(5), 620-624.
- Pardo, R., & Calvo, F. (2002). Attitudes toward science among the European public: a methodological analysis. *Public Understanding of Science*, 11, 155-195.
- Parker, R., Baker, D., Williams, M., & Nurss, J. (1995). The test of functional health literacy in adults: A new instrument for measuring patients' health literacy. *Journal of General Internal Medicine*, 10, 537-541.

- Parmenter, K., & Wardle, J. (1999). Development of a general nutrition knowledge questionnaire for adults. *European Journal of Clinical Nutrition*, 53, 298-308.
- Patton, M. Q. (2002). *Qualitative research & evaluation methods* (Third ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Pleasant, A., Kuruvilla, S., Zarcadoolas, C., Shanahan, J., & Lewenstein, B. (2003). *A framework for assessing public engagement with health research*. Geneva: World Health Organization.
- Putnam, R. D., Leonardo, R., & Nanetti, R. Y. (1993). *Making democracy work: Civic traditions in modern Italy*. New Jersey: Princeton University Press.
- Resnik, D. (2001). Setting biomedical research priorities: Justice, science, and public participation. *Kennedy Institute of Ethics Journal*, 11(2), 181-204.
- Rich, R. F. (1991). Knowledge creation, diffusion, and utilization: Perspectives of the founding editor of Knowledge. *Knowledge: Creation, Diffusion, Utilization*, 12(3), 319-337.
- Rogers, E. M. R., Scott C. Payne, J. Gregory. (2001). Health Literacy: A nonissue in the 2000 presidential election, *American Behavioral Scientist* (Vol. 44, pp. 2172): Sage Publications Inc.
- Rowe, G., & Frewer, L. J. (2000). Public participation methods: A framework for evaluation. *Science, Technology, & Human Values*, 25(1), 3-29.
- Rubba, P. A., & Andersen, H. O. (1978). Development of an instrument to assess secondary school students' understanding of the nature of scientific knowledge. *Science Education*, 62(4), 449-458.

- Salwen, M. B., & Stacks, D. W. (Eds.). (1996). *An integrated approach to communication theory and research*. Mahwah, NJ: Lawrence Erlbaum Associates, Publishers.
- Schillinger, D., Grumach, K., Piette, J., Osmond, D., Daher, C., Palacios, J., et al. (2002). Association of health literacy with diabetes outcomes. *Journal of the American Medical Association*, 288(4), 475-482.
- Sen, A. (1999). *Development as freedom*. New York, New Delhi: Oxford University Press.
- Shannon, C., & Weaver, W. (1949). *The mathematical theory of communication*. Urbana, IL: University of Illinois Press.
- Shinn, T., & Whitley, R. (Eds.). (1985). *Expository science: Forms and functions of popularisation*. Dordrecht, Holland: D. Reidel Publishing Co.
- Shiva, V. (2000). *Stolen harvest*. Cambridge, MA: South End Press.
- Starr, P. (1982) *The social transformation of American medicine*. New York, NY: Basic Books.
- Stevens, T., Wilde, D., Hunt, J., & Ahmedzai, S. H. (2003). Overcoming the challenges to consumer involvement in cancer research. *Health Expectations*, 6, 81-88.
- Stokols, D. (1992). Establishing and maintaining healthy environments: Toward a social ecology of health promotion. *American Psychologist*, 47(1), 6-22.

- Streiner, D. L., & Norman, G. R. (1995). *Health measurement scales: A practical guide to their development and use*. Oxford: Oxford University Press.
- Suarez-Perez, E., Sanchez-Ayendez, M., Oliver-Vazquez, M., Almodovar, H. V., Rosario-Rosado, R., & Nazario-Delgado, C. (1999). Knowledge and beliefs of breast-cancer among elderly Puerto Rican women: Validation process of scales. *Puerto Rico Health Sciences Journal*, 17(4), 365-373.
- UK National Health Service (NHS). (2000). *NHS core principle*. Retrieved 2-21-2003, 2003, from [http://www.nhs.uk/patientsvoice/core\\_principles.asp](http://www.nhs.uk/patientsvoice/core_principles.asp).
- United National Conference on Environment and Development (UNCED). (1992, May 7, 1998). *Rio declaration on environment and development*. Retrieved 11-3-2001, 2001, from <http://www.unep.org/unep/rio.htm>.
- UNICEF, WHO, UNESCO, UNFPA, UNDP, UNAIDS, WFP & World Bank. (2002). *Facts for Life*. New York, NY: United Nations Childrens Fund.
- U.S. Central Intelligence Agency. (2004). *World Fact Book*. Retrieved 6-1-04, 2004, from <http://www.odci.gov/cia/publications/factbook>.
- U.S. Department of Health and Human Services (USDHHS). (2000). *Healthy People 2010: Understanding and improving health*. Washington, D.C.: U.S. Department of Health and Human Services.
- Vogels, T., Brugman, E., & van Zessen, G. (1999). AIDS-related knowledge, attitudes, and behavior: A comparison of Dutch students and dropouts. *Adolescence*, 34(134), 360-379.

von Grote, C., & Dierkes, M. (2000). Public understanding of science and technology: State of the art and consequences for future research. In M. Dierkes & C. von Grote (Eds.), *Between understanding and trust: The public, science and technology* (pp. 341 - 362). Amsterdam: Harwood Academic Publishers.

Wertheim, M. (1996). *Pythagoras' trousers: God, physics, and the gender wars* (First ed.). New York: W.W. Norton & Co.

World Bank (2002, May 9, 2003). *Social capital and health*. Retrieved March 1, 2003, 2003, from <http://www.iris.umd.edu/socat/topics/health.htm>.

World Bank (2004). *Country at a Glance*. Retrieved 6-2-04, 2004, from <http://www.worldbank.org/data/countrydata/countrydata.html>

World Commission on Environment and Development (1987). *Our Common Future*. Oxford, New York: Oxford University Press.

World Health Organization (WHO). (1998). *Health promotion glossary*. Retrieved Sept. 25, 2002, 2002, from <http://www.who.int/hp4/hpbackground/glossary/glossary.pdf>.

World Health Organization (WHO). (2000). *World Health Report 2000: Health Systems*. Geneva, Switzerland: World Health Organization.

World Health Organization (WHO). (2003). *The World Health Report 2002*. Geneva, Switzerland: World Health Organization.

World Health Organization (WHO). (2004). *World Health Report 2004 - Changing history*. Retrieved 5/31/04, 2004, from <http://www.who.int/whr/en>.

- World Health Organization (WHO) Advisory Committee on Health Research. (2002). *Genomics and world health*. Geneva, Switzerland: World Health Organization.
- World Health Organization (WHO), UNAIDS, & UNICEF. (2002). *Coordinates 2002: Charting progress against AIDS, TB, and malaria* (Report). Geneva, Switzerland: World Health Organization.
- Williams, M., Baker, D., Parker, R., & Nurss, J. (1998). Relationship of functional health literacy to patient's knowledge of their chronic disease: A study of patients with hypertension or diabetes. *Archives of Internal Medicine*, 158, 166-172.
- Williams, M., Parker, R., Baker, D., Parikh, K., Coates, W., & Nurss, J. (1995). Inadequate functional health literacy among patients at two public health hospitals. *Journal of the American Medical Association*, 271(21), 1677-1682.
- Wiseman, V., & Jan, S. (2000). Resource allocation within Australian Indigenous communities: A program for implementing vertical equity. *Health Care Analysis*, 8, 217-233.
- Wiseman, V., Mooney, G., Berry, G., & Tang, K. C. (2003). Involving the general public in priority setting: Experiences from Australia. *Social Science & Medicine*, 56, 1001-1012.
- Wynne, B. (1992). Public understanding of science research: New horizons or hall of mirrors? *Public Understanding of Science*, 1(1), 37-43.
- Wynne, B. (1995). Public understanding of science. In S. J. e. al (Ed.), *Handbook of Science and Technology Studies* (pp. 361-388). Thousand Oaks, CA.

Yearley, S. (2000). Making systematic sense of public discontents with expert knowledge. *Public Understanding of Science*, 9, 105-122.

Zarcadoolas, C., Pleasant, A., & Greer, D. (2003). Elaborating a Definition of Health Literacy: A Commentary. *Journal of Health Communication*, 8, Supplement 1, June 2003, 119-120.

Zarcadoolas, C., Pleasant, A. & Greer, D. (In press). Understanding Health Literacy: An expanded model. *Health Promotion International*.

Zarcadoolas, C., Pleasant, A., & Greer, D. (In press). *Health literacy: An introductory textbook*. Baltimore: Johns Hopkins University Press.

Ziman, J. (1992). Not knowing, needing to know, and wanting to know. In B. Lewenstein (Ed.), *When Science Meets the Public* (pp. 13-20). Washington, D.C.: American Association for the Advancement of Science.