

**A REVIEW OF MEASURES EXAMINING THE ATTITUDES, BELIEFS, AND BEHAVIORS RELATED  
TO PHYSICAL HEALTH AND ILLNESS**

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**Abstract**

This paper seeks to answer the question, *how do we measure attitudes, beliefs, and behaviors related to physical health and illness*, within the context of the Committee on the Science of Changing Behavioral Health Social Norms at the National Academies of Science. Available literature was purposely reviewed for relevance to the question, diversity of health and illness conditions and novelty of the measures. Select measures were organized into one of five theoretical frameworks: Health Belief Model, Common Sense Model of Illness and Self-Regulation Theory, Theory of Reasoned Action, Stigmatizing or Social Distancing, and Social Representations. The reviewed measures represent a vast literature highlighting a number of decisions necessary in order to answer the above question. Those decisions, and their relationship to these frameworks and implications for measurement selection, are discussed in detail.

## Introduction

This paper seeks to answer the question, *how do we measure attitudes, beliefs, and behaviors related to physical health and illness?* As its purpose is ultimately to inform future messaging to improve social acceptance of people living with mental and substance use disorders, the scope of this project is to review and summarize the most relevant evidence that will achieve this goal. This review is not comprehensive of all evidence that may help answer this question; rather priority was given to (systematic) reviews, recent research, novel measures or frameworks, and research focusing on a variety of physical health and illness conditions. These criteria should help focus the literature on high-quality evidence the Committee need to help make its recommendations. It was beyond the scope of this review to consider mental illness or substance use, as other authors are focusing solely on this question.

In my initial search, the breadth of literature examining attitudes, beliefs, and behaviors related to physical health and illness was evident. I recognized a need to organize the literature in a meaningful way. Accordingly, this paper will be divided into three sections. The first will briefly discuss the attitudes, beliefs, and behaviors of people when they consider their own health and illness—where attitudes and beliefs are seen as the property of individuals. Within this section, the selected measures are framed within two dominant health behavior theories: Health Belief Model and the related Common Sense Model of Illness and Self-Regulation Theory. The second section addresses the attitudes, beliefs, and behaviors of people when considering the health and illness of others. This literature seems most consistent with the Committee’s purpose and is therefore emphasized more. This section is organized into three frameworks: Theory of Reasoned Action, Stigmatizing or Social Distancing, and Social Representations/ Constructions. Table one summarizes the measures of attitudes, beliefs and behaviors related to physical health and illness described in articles discussed. The final section will summarize my conclusions and implications.

## Measures of the Attitudes, Beliefs, and Behaviors of People When Considering Their Own Health and Illness

### *Health Belief Model (HBM)*

Developed and refined in the mid-late 20<sup>th</sup> century to help explain individual health behavior, this model argues that health behavior is a function of perceived susceptibility, perceived severity of the disease, perceived benefits of the behavior, and the perceived costs/barriers to the desired behavior. This value-based model has been widely applied to preventative health behavior, self-management of chronic disease behaviors, and sick-role behavior (seeking out health care). Quantitative measures grounded in this model tend to ask questions related to the four constructs specific to a health condition or illness. For example Tovar, Rayens, Clark, and Nguyen (2010) developed the Health Beliefs Related to Cardiovascular Disease Scale and posed questions related to one’s perceived susceptibility and severity of cardiovascular disease and benefits and barriers to diet and exercise. Interestingly they found two subscales (Susceptibility and Benefits) rather than the hypothesized four.

A review by Jones, Smith, & Llewellyn (2014) assessed 18 studies using the HBM to guide adherence interventions. Five studies measured health beliefs and all used different scales (Table 1). Though some were single item measures and others longer and with extensive psychometric testing, common themes among the tools included measures of perceived susceptibility and perceived severity (Jones, Smith, & Llewellyn, 2013). Many of these items were disease-specific statements of fact about, for example, the safety or efficacy of a treatment/procedure as well as some recall about past and expected future behaviors. Some scales ask questions about emotional aspects of a behavior, for example, carrying an auto-injector (for anaphylaxis) comforts the respondent. This pattern is consistent across scales and health conditions including vaccines and food allergies (Jones, Smith, Frew, Toit,

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Mukhopadhyay, & Llewellyn, 2014). A mixed-methods pilot study examining oral health practices to prevent dental caries in children framed qualitative questions within these four constructs related to oral health. There was no qualitative tradition guiding the qualitative component of the study, nor scenarios or education provided prior to asking the open ended questions; instead the questions relied on the prior knowledge of the children to describe perceived benefits, barriers, and susceptibility (Walker, 2015).

### *Common Sense Model of Illness and Self-Regulation Theory*

This model, developed by Leventhal and colleagues (1970, 1980), argues that illness representations (beliefs and expectations about the illness) determine one's appraisal of the illness context and related health behaviors. It emphasizes one's ability to process both cognitive and emotional aspects of a stimulus to behavior. *Illness representations are dynamic and develop from varied sources including direct experience with illness and health; indirect experience through family, friends, colleagues, and media; culture and language.* The components of illness representations include: 1) Identity (name or label of the symptom or illness); 2) Timeline (the illness' believed time trajectory); 3) Consequences (believed consequences of illness); 4) Cause (illness' casual mechanism); 5) Controllability (whether something can be done to control the illness; and 6) Illness coherence (whether a person thinks about the illness in a coherent way). This theory is widely used today, often in literature examining how to improve individual-level self-management behaviors (e.g. medication adherence, symptom management).

The review paper by Mass, Tal, van der Linden, & Boonen (2009) concisely summarizes the quantitative scales consistent with this model with most of the scales measuring the components of the illness representations. The Illness Perception Questionnaire and its related scales (brief, revised) elicit responses related to the illness-related symptom experience, the timeline, consequences, cause, and illness coherence. Items are scored on a 5 or 10 point Likert scale and all scales examine both the emotional and cognitive aspects of the illness. Though focused on applicability to those with rheumatoid arthritis, Mass et al (2009) discuss the diverse populations in which the five scales have been validated. These range from chronic fatigue syndrome to HIV to cardiovascular disease and has broad applicability across diseases. Qualitative work grounded in this model often attempts to understand illness perceptions in relation to a disease (cancer) and tends to use grounded theory methodology (Johansson, Axelsson, Berndtsson, & Brink, 2014). These data are reduced to conceptual categories consistent with components of illness representations.

As health behavior research has evolved, there have been other prominent theories that address attitudes, beliefs and behaviors related to health and illness. Social cognitive theory, transtheoretical stages of change theory, and the health action process model and their related measures all incorporate aspects of individual attitudes and beliefs when trying to explain and understand health behaviors. While there are aspects of this individually-focused literature that may be helpful in the Committee's charge, namely measures that emphasize the dynamic and multifactorial causes of attitudes and beliefs, measures examining the attitudes, beliefs and behaviors of people when considering the health and illness of others may be more fruitful. We turn to this literature next.

## **Measures of the Attitudes, Beliefs, and Behaviors of People when Considering the Health and Illness of Others**

### *Theory of Reasoned Action*

The Theory of Reasoned Action, developed by Ajzen and Fishbein (1980), aims to understand attitude and behavior. It has been applied to both individual's attitudes and behaviors towards *their own* health and of those considering the attitudes and behaviors of the health *of others*. Components of this

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theory tap both cognitive and emotional processing and include attitudes toward the behavior, subjective norms, and perceived behavioral control, influencing behavioral intentions, and ultimately behavior itself. It has been widely applied to health and disease phenomena and is the only theory discussed in this paper that incorporates the context of health or disease through subjective norms.

Siminoff, Burant and Younger (2004) developed a measure to help understand public beliefs and attitudes surrounding death, and the relationship of those beliefs and attitudes to organ procurement. After reviewing the literature and seeking the advice of the community advisory board, they developed an instrument to cover: attitudes toward organ donation, trust in the health care system, understanding of brain death, personal definitions of death, and three scenarios to measure the respondent's assessment of whether or not a person is dead and his or her willingness to donate organs based on the medical condition. The knowledge and attitude questions were assessed categorically based on statements of fact (i.e. the status of people declared brain dead is a) dead, b) as good as dead, or c) alive). They were then presented with three scenarios describing neurological conditions in lay terms. Respondents were asked to identify whether the person in the scenario was dead or alive (attitudes and beliefs) and if the respondent was willing to donate this person's (with the neurological condition) organs (behavioral intentions). The scenarios allowed the investigators to understand attitudes and beliefs as well as coherence in the respondent's knowledge, attitudes, beliefs and behavioral intentions and provided data for much of the discussion. This measure was a telephone interview conducted using random digit dialing, so was a bit more time consuming (20 minutes to administer) than a pen and paper measure. However, it provided rich data in a structured and reproducible way that could be adapted to other health and illness phenomena.

More commonly, investigators using this theory conducted focus groups or individual interviews using a semi-structured guide addressing general and disease-specific attitudes, knowledge and information sources and in some cases, behavioral intentions. Friedman and Sheppard (2007) did this on behalf of the Centers for Disease Control and Prevention when investigating attitudes towards Human papillomavirus (HPV). They developed open-ended interview guides for focus groups that tapped attitude (e.g., when asked what comes to mind when you hear the term sexually transmitted disease), knowledge (e.g. prevalence and transmission of genital warts; link to cervical cancer), and behavioral intent (e.g., what is the relationship between the HPV vaccine and health). Best strategies from this literature involve random sampling, matching on age and race, having trained moderators who were the same race and gender of participants, and pilot testing the semi-structured interview guide.

### *Stigmatizing and Social Distancing Framework*

Stigma and social distancing are widely applied to various conditions of health and illness. This framework suggests that stigmatizing starts with the identification of variations/differences, cultural norms labeling those variations as bad characteristics, individuals who have these characteristics are distinguished from those who do not, and ultimately those individuals experience status loss and discrimination (Link and Phelan, 2001). Corrigan and colleagues identified three types of stigma: public stigma, self-stigma, and structural stigma (Corrigan et al, 2012). Accordingly, in 2006 Van Brakel undertook a comprehensive literature review to understand how health-related stigma has been measured. Fifty-one studies were identified that included some measure of stigma (excluding mental health articles) and he identified two common themes in the items: the effect of the health condition on the individual and community and the effect of the health condition on public health programs and intervention. He also found commonalities in the impact of the stigma on participation, self-efficacy, shame, guilt, fear, attitudes, and stereotyping. He recommends including a comprehensive mixed methods assessment of the individual, media, education system, and legislation, and suggests several best example measures included in Table 1. Of note, the UNAIDS protocol for the identification and discrimination against people living with HIV is unique in its assessment of institutional attitudes. It is a

checklist of possible discriminatory acts and it “documents actual, verified instances of discrimination” (Van Brakel, 2006).

Though older, Westbrook, Legge, and Pennay (1993) present an interesting study assessing the attitudes of health care providers in six ethnic communities in Australia towards people living with one of 20 disabilities and compared these attitudes to those over the past 20 years. This five-point social distancing scale asked respondents to rate each health condition (from Asthma to mental retardation to AIDS) on the following scale: “(1) No acceptance (people would prefer a person with this disability to be kept in an institution or out of sight); (2) Low acceptance (people would try and avoid a person with this disability); (3) Moderate acceptance (a person with this disability would be acceptable as a fellow worker); (4) High acceptance (a person with this disability would be acceptable as a friend) and (5) Full acceptance (people would accept a person with this disability marrying into their immediate family)” (Westbrook et al, 1993 pp 617) . This measure allowed them to compare results from four other data collection periods in the past 20 years and to compare across groups- in this case ethnic groups. It was a simple scale with explicit instructions and response rates between 40-65%.

### *Social Representations/Constructions Framework*

Grounded in social psychology, the framework of social representations focuses on understanding the “*interactive and dynamic relationships* between social knowledge, common identities, and social practices” (Howarth, 2006 pp 8). Long used to try to explain societal processes- racism, war, policy making- this framework has recently been applied to health-related phenomena. In this framework, the social being (how one exists and functions in the larger social environment, while accounting for myriad contextual factors) is the central unit of analysis- not the individual which distinguishes this framework from all others in this paper. Accordingly, representations form through interaction, are grounded in our traditions and ideologies, and occur primarily in a specific context. If social representations are dynamic, interactive and context-dependent, it may be hard to measure them in a systematic, reproducible, and ultimately valuable way.

An analysis by Mayor, Eicher, Bangerter, Gilles, Cèlemence, and Green (2013) provide methods to help understand dynamic social representations, in this case about sudden disease outbreaks (the H1N1 pandemic) over time. They narrowed their investigation to analyzing changes in mentions of collectives (“large institutionalized groups; for example corporations, nations, or professions or social categories like gays or intravenous drug users” Mayor, et al, 2013 pp 1012), the themes associated with those collectives, and the roles attributed to the collectives among Swiss people. At three data collection waves, Mayor et al (2013) conducted semi structured interviews. Questions focused on the emergence or origin of the virus of H1N1 virus, emotion/worry about H1N1, consequences of H1N1 (to self and state), trustworthiness of the official explanations of origin of H1N1, protective measures, knowledge of other emerging diseases, and responsibility for combating H1N1. They also analyzed media coverage over the same timeframe. Within interviews they counted the frequencies of mentions of collectives and used qualitative thematic analysis to analyze the roles attributed the collective (note: they a priori determined the roles as hero, villain, and victim). They used this qualitative data to identify collectives and then analyzed the mainstream media coverage of those collectives during the concurrent data collection timeframe. The repeated measures design allowed the investigators to describe several shifts in the beliefs and attitudes held by Swiss people in regards to H1N1 pandemic.

A second study by Moriera et al (2015) aimed to describe the content and structure of social representations of teenagers and their impact on the teens’ quality of life. It used the Central Nucleus Theory, which structurally organizes social representations around a central core (most frequent and important constructs) and various peripheral and contrasting zones. The investigators used the Evocation of Words data collection technique, in which they asked teens to recall the first 4 words that came to mind after hearing the phrase “quality of life”. Data were reduced and organized structurally

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using a Four House chart and the core nucleus was found to be healthy eating, physical activity, money, and sex. Winskell, Hill and Obyerodhyamo (2011) analyzed HIV-related scripts (obtained from an African scriptwriting contest) to examine cross-national variation in HIV stigma. Using descriptive analyses, thematic data analyses, and a narrative analysis focusing on plot summary and key words they found representations of HIV genre narratives, othering, expressions of personal blame and shame, and tone of narratives. Interestingly, these representations were able to be compared across country and related to prevalence of disease.

The methods used to understand social representations vary considerably and are unique from measures to analyze attitudes, beliefs, and behaviors using other frameworks. The three theories discussed here are representative of measures used in other literature and offer new options for the Committee to consider. The structural focus of social representations is a strength of these measures and would complement a multifactorial evaluation plan.

## Conclusions and Implications

There are varied perspectives and frameworks in which to consider measuring the attitudes beliefs and behaviors related to physical health and illness. The Committee will need to determine first if they want to measure the attitudes, beliefs, and behaviors of people considering their own health or in considering the health of others. If the former, the Health Belief Model, the Common Sense Model of Illness and Self-Regulation Theory are excellent frameworks in which to situate measurement selection. Within this literature, there are a number of validated quantitative scales, both generic and disease specific, on which to base the decision.

However, if the latter is determined to the Committee's primary focus, several of the frameworks described above can help to inform selection of measures. The Theory of Reasoned Action is a nice bridge framework between the individual's perspectives towards their own health, to that of others. Stigmatizing or social distancing, though a negative frame, does help us to understand the negative consequences of attitudes and beliefs. Finally, social representations can help us to situate attitudes, beliefs and behaviors in their own dynamic context, thus facilitating analysis of potential ways to intervene to change these factors. Overall, the evidence reviewed suggests using multiple measures, with multiple units of analyses to best answer this question. Individual interviews with or without vignettes and scales can be used, similar to Siminoff et al's (2004) strategy. An indicator checklist of actual discriminatory behavior, similar to one used in the UNAID's protocol to identify discrimination, can help to measure institutional-level attitudes, beliefs, and behaviors.

Other decisions that will aid in measurement strategy selection include determining whether attitudes and beliefs are dynamic or static, when they should be measured, and how new the phenomena is that needs to be measured. If this phenomena is new, than social representations might be the best framework from which to organize a measurement strategy. Novel measures of social representations such as evocation of words, discourse analysis, and script analysis can also be used to better understand the dynamic context in which these attitudes, beliefs, and behaviors occur. However, these strategies require resources including having access to, and critically, an ability to analyze and reduce, all necessary source documents (legal codes, media samples, scripts, diaries, transcripts). This will be the most challenging part of devising a comprehensive measurement strategy.

In summary, by reviewing these various measurement methods, I hope that the committee will be able to develop a measurement strategy to help inform the development of efficacious messaging to improve social acceptance of people living with mental and substance use disorders.

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<b>Table 1: Measures of attitudes, beliefs and behaviors related to physical health and illness described in articles</b>				
<b>Citation</b>	<b>Measure (s) Name</b>	<b>Health Conditions</b>	<b>General Themes (subscales)</b>	<b>Items</b>
<b>Health Belief Model</b>				
Tovar, Yayens, Clark, and Nguyen (2010)	Health Beliefs Related to Cardiovascular Disease Scale	Cardiovascular disease but tested in those with diabetes	Perceived Susceptibility and perceived benefits of diet and exercise	25
<b>Jones, Smith &amp; Llewellyn, 2013</b>				
Aiken, et al 1994	Health Belief Model Scale	Health beliefs related to mammography screening	Perceived severity, perceived susceptibility, perceived benefits, perceived barriers	17
Bertakis, 1985	Standardized Compliance Questionnaire (adapted)	Health beliefs for adherence to antibiotic therapy for otitis media	Perceived susceptibility, perceived severity and costs and benefits of antibiotic treatment	15
Carmel, Shani & Rosenberg, 1996	No name given; adapted from Jenkins & Zyzanski	Health beliefs for skin cancer protective behaviors	Perceived severity, perceived susceptibility and perceived benefits	3
Olsen, et al, 2012	Functional Outcomes of Sleep Questionnaire and Self-Efficacy Measure for Sleep Apnea	Health beliefs for CPAP adherence	Perceived severity, perceived benefits, perceived barriers and self-efficacy,	30 & 26
Rees, 1986	No name given	Health beliefs for adherence to alcoholism treatment	Perceived susceptibility and perceived severity	7
<b>Common Sense Model of Illness and Self-Regulation Theory</b>				
Maas, Tall, van der Linden & Boonen (2009)	Illness Cognition Questionnaire	Generic	Helplessness, Acceptance , Disease Benefits	18
	Illness Perception Questionnaire	Generic and several chronic disease adaptations	Identify, cause, timeline, consequences, control-cure	38
	Illness Perception Questionnaire-revised	Generic and several chronic disease adaptations	Identity, consequences, time, illness coherence, motional dimensions, psychological attributions, risk factors, immunity, accidents/chance, personal control, treatment control	70
	Implicit Models of Illness Questionnaire	Generic	Seriousness, personal responsibility, controllability, changeability	24
	Meaning of Illness Questionnaire	Generic	Impact on activities of daily living, type of stress, degree of stress, positive attitude, expectancy/recurrence	30
Johansson, AC, Axelsson, M, Berndtsson, I & Brink, E; 2014	Qualitative Study Grounded Theory	Colorectal Cancer	Describe an ordinary day: think about disease today; think about treatment received?	N/A
<b>Theory of Reasoned Action</b>				
Siminoff, Burant & Younger (2004)	Public Attitudes and Beliefs about organ procurement	Organ Procurement	Attitudes toward organ donation and transplantation, trust in the health care system, understanding of brain death, personal definitions of death, willingness to donate	~10

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Friedman & Shepeard (2007)	Qualitative Focus groups on knowledge, attitudes and beliefs on HPV	HPV	General STD attitudes, knowledge and information sources, and more specific questions about HPV knowledge, attitudes, and communication preferences	N/A
<b>Stigmatizing and Social Distancing Framework</b>				
<b>Van Brackel, 2006</b>				
Weiss, Doongaji, Siddhartha, Wypij, Pathare, Bhatawdekar, et al (1992)	Explanatory Model Interview Catalogue	Generic measure of attitudes and perceptions of various health conditions	Perceived cause, timeline, treatment, general health beliefs	N/A
UNAIDS, 2000	Protocol on identifying discrimination against people living with HIV	Discriminatory or stigmatizing practices	Institutional discrimination in the law, internal regulations and procedures of organizations, occurring in practice in which there is no written basis	37
Berger, Ferrans & Lashley, 2001	HIV Stigma Scale	Perceived or felt stigma	Personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes toward people with HIV	40
Westbrook et al., 1993	Social Distancing Scale	Attitudes of individuals with various health conditions	Acceptability	20
<b>Social Representations/Constructions Framework</b>				
Mayor, Eicher, Bangerter, Gilles, Cèlemence, and Green (2013)	Social representations of H1N1 pandemic Mixed methods with individual interviews and concurrent media analysis repeated over three waves	H1N1 Virus	Identity of H1N1 virus, emotion/worry about H1N1, consequences of H1N1, trustworthiness of the official explanations of origin of H1N1, protective measures, knowledge of other emerging diseases, and responsibility for combating H1N1	N/A
Moreira, et al (2015)	Social representations of adolescent quality of life	Quality of life/health	Evocation of Words with data being reduced using a Four House Chart	N/A
Winskell, Hill, & Obyerodhyambo (2011)	Social representations of HIV Stigma	HIV	Script analysis from script wiring contest.	N/A

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