

## Reflecting on the Universal Meaning of Numbers in Health and Risk Communication

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Marilyn M. Schapira

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Numeric concepts are a universal component of the human experience, with intuitions about probability found across cultures and apparent even among young children. The field of medical decision making has long sought to elucidate how best to use words, numbers, probabilities, graphs, tables, pictures, and narratives to communicate numeric concepts to patients and laypersons. A particular challenge, and one that is the focus of the Making Numbers Meaningful (MNM) project, is the communication of risk or probabilistic information. Ouantitative risk communication often involves sharing a probabilistic estimate of an event occurrencesometimes presented with a secondary degree of uncertainty around the estimate. The source of these estimates can be from expert opinion, prior experience, or scientific studies, each with their own strengths and limitations. As in all biologic processes in the natural world, uncertainty in outcomes in health are inevitable.

The MNM project has the ambitious goal of synthesizing a large body of research and creating evidence-based practice guidance on how best to communicate probabilistic information in the health care context. The series of MNM articles published in this issue of MDM Policy & Practice report the results of a rigorous systematic review of this literature. The project also introduces a novel conceptual model as an organizing framework for this evidence. The systematic review includes 316 experimental or quasi-experimental studies that compare strategies of communicating health-related probabilistic data to patients or lay persons. The authors summarized this body of work guided by their conceptual framework and using a series of evidence tables and practice guideline statements. This provides a resource for those seeking to

use evidence-based risk communication strategies in the development of decision support tools, educational interventions, or shared decision-making discussions.

As the results of the MNM project become disseminated and integrated into clinical practice, it is important to reflect on the populations represented in this systematic review. Study participant factors such as primary language, culture, socioeconomic background, and literacy may affect the interpretation and salience of different data presentation formats. Studies across diverse populations can help us to understand this variation. For example, in a study that explored the meaning of numbers in health among a Mexican American population using focus groups conducted in both English and Spanish, a major theme to emerge was the desire of people to find meaning in numbers. One Spanish-speaking participant stated (presented in the English translation), "So with numbers, we should understand more than anything that

Division of General Internal Medicine, Department of Medicine, Perelman School of Medicine, University of Pennsylvania and the Center for Health Equity Research & Promotion, Philadelphia Veterans Affairs Medical Center, Philadelphia, PA, USA (MMS). The author declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: I was an editor for the MNM papers series. The author received no financial support for the research, authorship, and/or publication of this article.

## **Corresponding Author**

Marilyn M. Schapira, Division of General Internal Medicine, Department of Medicine, Perelman School of Medicine, University of Pennsylvania and the Center for Health Equity Research & Promotion, Philadelphia Veterans Affairs Medical Center, 1316 Blockley Hall, 423 Guardian Dr, Philadelphia, PA 19104-6021, USA; (mschap@pennmedicine.upenn.edu). each number has its own meaning, when we can understand the meaning of a number, we can understand the degree of illness." Although participants found numbers helpful in conceptualizing their health, they also expressed that using a number to convey that they are at risk of poor health can lead to fear. Of note, the MNM project did not require that studies be conducted or published in English and translated 4 of the studies included in the systematic review.

The 316 articles reviewed for the MNM project included samples that were diverse in the setting from which participants were recruited and the country in which the study took place. Some studies recruited participants from patient populations that were actively engaged in medical care. Others recruited participants who were not necessarily engaged in medical care including from graduate and undergraduate universities, jury pools, public settings, or using online survey panels and crowd-sourcing platforms. An important question to address is the degree that findings across these settings and contextual situations are generalizable. A person engaged in cancer treatment, for example, may find a given risk information format more salient than a healthy person considering a hypothetical or future health condition. As the quotation from a focus group cited above illustrates, numbers can provide an emotional impact on how persons relate to their health, and the context and setting remain critical to consider in using numbers to communicate risk.

The MNM samples were also diverse in geographic location and cultural backgrounds, including studies based in Australia, Canada, China, Denmark, Germany, Japan, the Netherlands, Singapore, the United States, and the United Kingdom. Although the MNM systematic review did not compare findings across these countries, individual studies in the review focused on minority groups within a country, including American Indian or Alaskan Natives in the United States<sup>4</sup> and Polishspeaking immigrants in the United Kingdom.<sup>5</sup> Others focused on cross-cultural differences in risk communication, such as persons living in Spain and Germany.<sup>6</sup> This geographic diversity enriches the scope of evidence included in the MNM project. However, there remain regions of the world, languages, and cultures that are underrepresented in this body of work. Future studies are needed to elucidate how language, culture, and background can affect how to make numbers most meaningful in the context of health. Individual-level factors including race, ethnicity, gender, education, literacy, and socioeconomic status may also affect the way individuals respond to risk communication. However, as these

factors were inconsistently reported across the studies in the MNM project, the investigators were unable to conduct analyses of the impact of participant-level factors on their findings.

The conceptual model of the MNM project may be helpful in designing future studies that are cross-cultural and include diverse populations. An interesting insight from the MNM project is that the strength of the evidence for a given risk communication format varies with the task asked of the participant and the outcome of interest. When considering if evidence is generalizable or specific to certain populations, we may find that the answer depends on the outcome of interest. For example, the MNM review identifies a gap in studies that examine the outcomes of trust and behavioral change. Given the complexity of these constructs, it is particularly important that investigators are intentional about the samples they use and interpretation of findings when evaluating these outcomes.

Several recommendations can address the issues raised above. First, investigators should use available standard reporting procedures for participant factors including race and ethnicity, gender, nativity, primary language, socioeconomic status or neighborhood deprivation index, health care access, and insurance type. In the United States, the National Academies of Science, Engineering, and Medicine issued a recent report titled Rethinking Race and Ethnicity in Biomedical Research (2024), with new guidance on how to define, categorize, and report race, ethnicity, and ancestry. <sup>7,8</sup> Categories and reporting may differ across countries and regions in ways that best represent their populations, but following reporting guidelines will make it easier to compare populations across studies. Second, to understand which findings are generalizable and which are specific to certain populations, studies should be designed with more deliberatively considered samples and powered analyses to make comparisons between groups as well as make efforts to replicate studies across contexts. Third, evaluating how the evidence for practice guidelines in risk communication generalizes to broader populations may require additional methods and study designs including qualitative inquiry.

The MNM project has collected and abstracted data on a diverse group of research studies evaluating the use of numbers in the context of health communication. Importantly, the authors of the MNM project have made public both the data collection forms and the data abstracted—both of which are available on the project Web site, https://osf.io/rvxf2/. These data and the conceptual framework, methods, and findings of the MNM

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project provide rich opportunities for further research. As we continue to advance this area of research and practice, we should keep in mind the powerful and personal impact that numbers can have and the challenge of creating evidence-based practice guidelines applicable across populations and settings given the complexity and nuances of risk communication in medical decision making.

## **ORCID iD**

Marilyn M. Schapira (b) https://orcid.org/0000-0002-3775-9462

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