Making Numbers Meaningful – improving how we communicate numbers to patients and the public

Natalie C. Benda[1], Brian Zikmund-Fisher[2], Mohit Sharma[1], Jessica S. Ancker[1]

[1]Weill Cornell Medicine, [2]University of Michigan

ABSTRACT

Numbers are a crucial piece of visual communication of health-related information. There are currently multiple resources for communicating health-related information in plain language, but an equivalent resource for numeric information is lacking. We are creating a web-based resource for providing guidance on how to visually communicate numbers related to health. Our resource was developed through a large systematic literature review under the advisement of a national expert panel on health numeracy. User testing is currently under way. This resource may be utilized by various end users including: health writers, health application developers, public health professionals, and journalists.

Keywords: Numeracy, graph literacy, patient communication, public health

1 INTRODUCTION

Patients and the public today have unprecedented access to their personal health information as well as general information about health and wellness. The "HealthEData" initiative enacted in March 2020, part of the 21st Cures Act, gives all patients secure access to and control over their electronic health data. The incidence of the COVID-19 pandemic has also made accurate, timely public health information even more essential.

To interpret and act upon numbers, people need numeracy skills. Numeracy, defined as "the ability to use, apply, interpret, and communicate mathematical information and ideas", has been found to predict health outcomes above and beyond other constructs such as literacy[1]. Over one quarter of the United States population has limited quantitative skills [2]. Low numeracy is even more prevalent than low literacy and is common even among the highly educated, though, those with low numeracy more often fall into disadvantaged groups [2, 3]. Low graph literacy, a related, yet distinct concept from numeracy, may be even more common than low numeracy, and further impacts a persons' ability to adequately interpret health information [4]. Those with lower health numeracy and graph literacy experience challenges identifying "out-of-range" values, are more likely to make medication administration errors, and make poorer health-related decisions, presumably due to their reduced understanding of numerically conveyed risks [3, 5, 6].

On a more optimistic note, several studies have demonstrated that differences in the format and visual communication of numbers impact interpretation [7]. This means that improving the communication of numbers can enhance understanding and decision-making. For example, the use of pictographs instead of numeric text (e.g. percentages and frequencies) has been shown to improve the understanding of risk, particularly for those with lower numeracy [8].

Diverse designers with varied educational backgrounds develop patient health information. Some examples include: medical writers, application developers, and a broad spectrum of healthcare professionals. These designers are not typically taught concepts related to numeracy. Multiple tools currently exist to help information designers create materials for audiences with various levels of literacy, such as the CDS's Clear Communication Index and AHRQ's Health Literacy Toolkit [9, 10]. However, no equivalent guidance exists related to communicating numbers. The goal of the "Making Numbers Meaningful" project is to synthesize existing information about the best formats for communicating health-related numbers and create a web-based decision support system to help information designers determine how to communicate numbers in the materials they produce.

2 THEORY - THE "MAKING NUMBERS MEANINGFUL PROJECT"

The Making Numbers Meaningful project includes three phases of work:

1. To integrate and organize evidence about the interpretation of numbers in health through a large, systematic literature review (ongoing).

2. To construct a Communicating Numbers Clearly system for knowledge sharing and use, which involves developing an ontology that will serve as the foundation for a public-facing website (ongoing).

3. To assess how if the Communicating Numbers Clearly helps information designers create materials that are more easily interpretable by patients and the public (future).

Our project also involves a national expert panel on health numeracy that advises in the creation of guidelines (Aim 1) and building these guidelines into a public facing website (Aim 2).

2.1 Aim 1 – Literature Review and Guidance Summarization (on-going)

To date, we have included and reviewed 356 papers that assess how different visual communication formats affect how people interpret health-related numerical information. We are currently in the process of transforming this large body of evidence into guidelines for communicating health-related numbers. Four of our team members, all experts in numeracy and visual communication, are creating guidance using a modified Grading of Recommendations, Assessment, Development and Evaluations (GRADE) approach. GRADE is a consensus rating system for systematically rating the strength of evidence for clinical guidelines that we have adapted for guidelines related to communicating health-related information [11].

2.2 Aim 2 – Ontology Development and Website Creation (on-going)

In order to organize the literature and our guidance, we also created an ontology, a standardized, computable representation of concepts. Figure 1 represents five of the high-level basic concepts in our ontology. Our guidance recognizes that the optimal visualization format for given application depends on the quantitative concept conveyed (data class, type, and format group) as well as the communication goal, in other words, what you want your audience to do with the information [12]. We also describe how our guidance may differ based on relevant audience characteristics.

We are currently developing a prototype of the Communicating Numbers Clearly public-facing website that will provide recommendations for the best visual communication formats for health-related numbers. The guidance displayed in the website will be driven by our developed ontology. Development of this website presents a nested visual communication question - how do we best convey our guidance to information designers (part 1) so that information designers may determine the way to best convey numbers to their intended audience (part 2)?

To answer the first part of this question, we are conducting a usability study described at the end of this section. To answer the second part, we will evaluate how the Communicating Numbers Clearly system impacts the how information designers create materials containing health-related numbers (see Aim 3).

To date, we have designed a prototype of the public-facing website that first asks the user three to four questions regarding the quantitative concept for their application and the communication goal for their target audience. We then present the user with a page containing series of guidance statements relevant to their chosen quantitative concepts and communication goal. Figure 2 presents an annotated example of a single
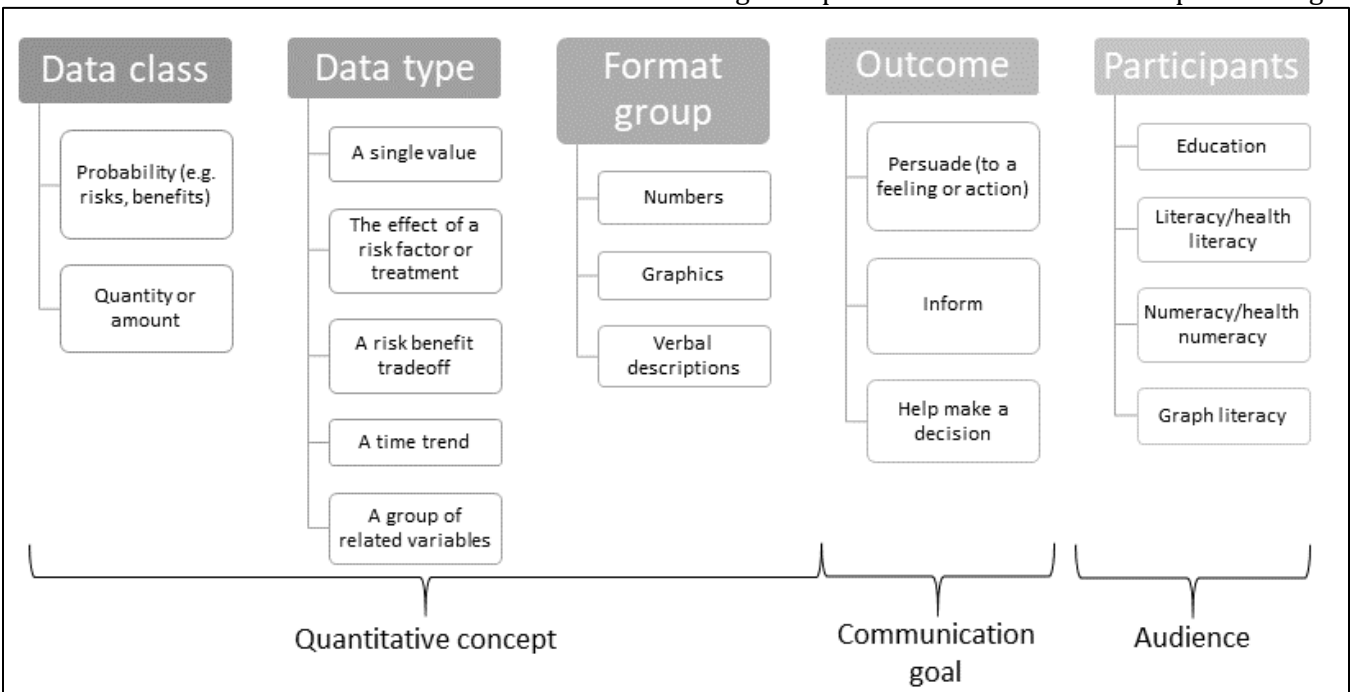

Figure 1. Depiction of high-level categories used to organize literature from a systematic review and related guidance developed by our team, together with selected concepts within each category.

piece of guidance included in the larger guidance page.

The example in Figure 2 presents guidance for a probability involving a single value where the information designer may want to persuade the audience to be more or less worried about the information communicated. We split the guidance based on the visual formats compared. The guidance page for the given quantitative concept/communication goal comparison contains multiple pieces of guidance related to comparisons such as different kinds of numbers (shown below), numbers vs. verbal probability, or numbers vs. graphics. We include illustrative examples to make the summarized guidance more quickly and easily interpretable by the user (information designer). Information related to considerations for communication based on audience characteristics, such as numeracy, is also included in the guidance summary where applicable, although no differences based on audience characteristics were found in the example shown below. The user may also see the strength of the evidence for this piece of guidance and click to link to a summary of the studies from the literature review that were used to create this piece of guidance.

We are currently conducting a usability study with representative information designers to understand if they find the current website prototype useful to their work and intuitive/easy to use. We have identified a diverse group of target end users, including: health writers, health application developers, public health professionals, and journalists who write about health-related topics. Our usability study examines the participants' current workflow for developing visual communications of numbers, assesses how our current prototype does/does not support that workflow, and evaluates how our categorization of

guidance (see Figure 1) matches with their conceptualization of numerical communication. We will utilize the results of the usability study to re-design our website to better support the needs of information designers.

2.3 Aim 3 – Evaluation of Website's Impact on Improving Numeric Information Presentation (future)

Following the usability study, we will recruit a new group of information designers to assess the effectiveness of the guidance delivered via the updated website. Information designers will be asked to use raw data sets we provide them to develop informational materials for different target audiences. Half will be introduced to the Communicating Numbers Clearly site and have it available to create their materials, the other half will not be given access to the site. Participants will include similar roles to those involved in the usability study (Aim 2).

Two groups of experts, including members of the projects' expert panel as well as patient experts (drawn from patient and family advisory councils) will complete blind evaluations of the materials developed by the information designer participants. We will then compare the ratings of the expert evaluators for materials created by those using and not using the Communicating Numbers Clearly resource. Our working hypothesis is that those using the Communicating Numbers Clearly resource will design materials that will be more highly rated by the expert evaluators. This evaluation process will also elicit feedback on the updated version of the website resource and allow us to make further improvements. The finalized website will then be hosted and available for public use.
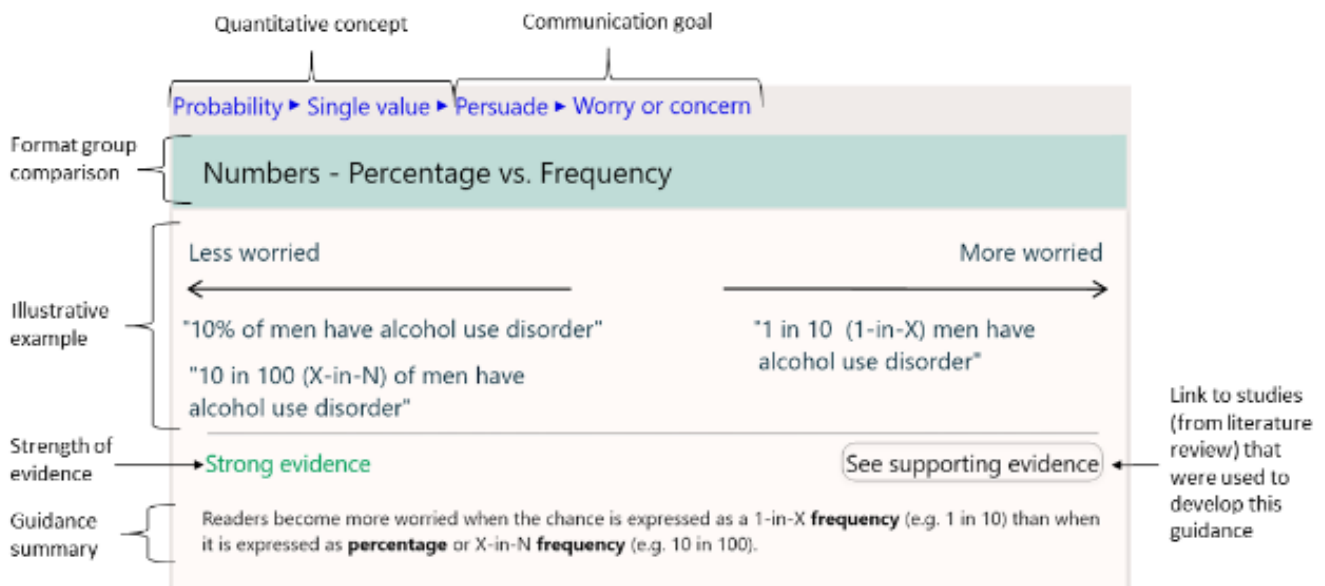

Figure 2. Annotated depiction of a single piece of guidance in the website prototype we have developed to instruct information designers in the best format for conveying health-related numbers.

3 CONCLUSION

Understanding numbers is critical piece of health and wellness. To help information designers, we are creating a consolidated resource that provides tailored guidance for communicating numbers clearly to patients and the public. The guidance system has been designed specifically for health-related numbers but may also have applications in other domains where understanding numbers is important to decision-making, such as finance or real estate.

ACKNOWLEDGEMENTS

REFERENCES

[1] M. Goodman, R. Finnegan, L. Mohadjer, T. Krenzke, and J. Hogan, "Literacy, Numeracy, and Problem Solving in Technology-rich Environments among U.S. Adults: Results from the Program for the International Assessment of Adult Competencies 2012: First Look.," National Center for Education Statistics, U.S. Department of Education, Washington, D.C., 2013.

[2] J. S. Ancker and D. Kaufman, "Rethinking health numeracy: a multidisciplinary literature review," *J Am Med Inform Assoc,* vol. 14, no. 6, pp. 713-21, Nov-Dec 2007, doi: 10.1197/jamia.M2464.

[3] V. F. Reyna, W. L. Nelson, P. K. Han, and N. F. Dieckmann, "How numeracy influences risk comprehension and medical decision making," *Psychol Bull,* vol. 135, no. 6, pp. 943-73, Nov 2009, doi: 10.1037/a0017327.

[4] M. Galesic and R. Garcia-Retamero, "Graph literacy: A cross-cultural comparison," *Medical Decision Making,* vol. 31, no. 3, pp. 444-457, 2011.

[5] E. Peters, D. Västfjäll, P. Slovic, C. Mertz, K. Mazzocco, and S. Dickert, "Numeracy and decision making," *Psychological science,* vol. 17, no. 5, pp. 407-413, 2006.

[6] H. S. Yin *et al.*, "Parents' medication administration errors: role of dosing instruments and health literacy," *Archives of pediatrics & adolescent medicine,* vol. 164, no. 2, pp. 181-186, 2010.

[7] G. Gigerenzer, W. Gaissmaier, E. Kurz-Milcke, L. M. Schwartz, and S. Woloshin, "Helping Doctors and Patients Make Sense of Health Statistics: Toward an Evidence-Based Society," *Psychological Science in the Public Interest,* vol. 8, pp. 53-96, 2007, doi: 10.1111/j.1539-6053.2008.00033.x.

[8] A. R. Tait, T. Voepel-Lewis, B. J. Zikmund-Fisher, and A. Fagerlin, "The effect of format on parents' understanding of the risks and benefits of clinical research: A comparison between text, tables, and graphics," *Journal of Health Communication,* vol. 15, pp. 487-501, 2010, doi: 10.1080/10810730.2010.492560.

[9] C. Baur and C. Prue, "The CDC Clear Communication Index is a new evidence-based tool to prepare and review health information," *Health Promotion and Practice,* vol. 15, no. 5, pp. 629-37, Sep 2014, doi: 10.1177/1524839914538969.

[10] Agency for Healthcare Research and Quality. "Health Literacy Universal Precautions Toolkit." https://meps.ahrq.gov/data_files/publications/st354/stat354.pdf (accessed 2019).

[11] G. H. Guyatt *et al.*, "GRADE: an emerging consensus on rating quality of evidence and strength of recommendations," *Bmj,* vol. 336, no. 7650, pp. 924-926, 2008.

[12] J. Ancker, Y. Senathrajah, R. Kukafka, and J. B. Starren, "Design Features of Graphs in Health Risk Communication : A Systematic Review," *Journal of the American Medical Informatics Association,* vol. 13, pp. 608-619, 2006, doi: 10.1197/jamia.M2115.Introduction.