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Principles of Health Literacy and Numeracy in Returning Trial Results to Participants

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Additional Disclaimer

- I am here today representing the work done on return of results by the MRCT Center at Harvard working group, which I co-chaired.
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Health Literacy Overview

- Health Literacy is not the same as ability to read.
- US: “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”¹
- Even those with adequate health literacy can struggle to understand health information, and appreciate clear communication.
- The complexity of the healthcare system can challenge everyone!

1. U.S. Department of Health and Human Services (HHS). Healthy People 2010. Washington, DC: U.S. Government Printing Office. 2000.

Health Literacy Overview

- Application of “universal health literacy precautions” may facilitate understanding.
- Input of patients/participants is critical:
 - Development of the content
 - Comprehension testing of the summary
- Less can often be more. Additional links/information may be offered to participants who would like additional detail.



Health Literacy Principles (Implementation)

- Plain language
- Use active voice and short sentences
- Formatting to aid comprehension:
 - Headlines to organize information
 - Presentation of “big picture” before the details
 - Descriptive headers and subheadings
 - Limited use of tables and charts
 - Adequate “white space”; 12+ point font
 - Avoidance of text in “all caps”



Evaluation – CDC Clear Communication Index

- Consider use of the CDC Clear Communication Index to evaluate materials:

www.cdc.gov/ccindex

- The CDC Clear Communication Index is a research-based tool to help you develop and assess public communication materials.
- The Index has 4 introductory questions and 20 scored items drawn from scientific literature in communication and related disciplines.
- The items represent the most important characteristics that enhance and aid people's understanding of information.



Evaluation – CDC Clear Communication Index

- Introductory questions assess primary audience; health literacy skills of audience; primary communication objective, and the main message.
- Four evaluation sections include:
 - Core Items (Main Message, Call to Action, Language, and Information Design)
 - Behavioral Recommendations
 - Numbers
 - Risk
- Output is a numerical score.



Numeracy

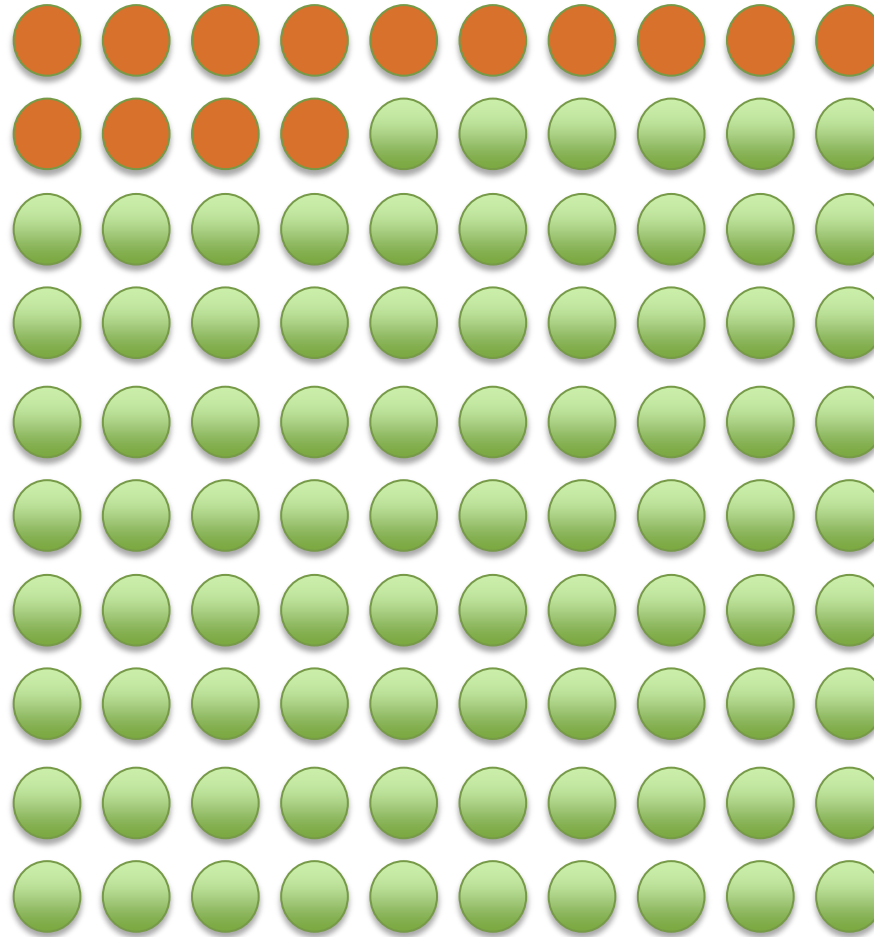
- The ability to use basic probability and mathematical concepts to explain mathematical and statistical terms.
- Numeracy principles in health literacy focus on simple explanations, instead of using complex fractions, percentages or statistical terms.
- Consider when to include numbers—don't ignore them!
 - Give people the information they need to make their own choices.
 - Providing necessary numbers can increase comprehension.

Numeracy

- Less is more – how critical are the numbers?
 - Omitting unrelated numbers can lead to improved comprehension and higher quality choices.
 - The depth of necessary data may differ. For example, a cancer patient choosing a treatment type will need data regarding effectiveness and survival rates, where a patient wanting to learn how to use an inhaler does not need data on asthma prevalence.
- Summary: “Give the right tool at the right time”.



Numeracy Example



14%

Or

About 1 in 7

Cultural Literacy

- Numerous studies have highlighted the under-representation of racial and ethnic minorities in clinical trials. Cultural literacy may foster clinical trial participation, and encourage clear communication of results.
- Translate documents if trial participants exceed a certain percentage (e.g. 10%) at a specific trial location. A native speaker should review. Be consistent with the languages used in informed consent documents.



Cultural Literacy

- Certain anatomical and medical terms may need further definition in another language.
- In Spanish, “*Once*” means 11.
- Consider training investigators in cultural sensitivity.
 - Sensitize investigators that culture may have an impact on how participants choose to receive summaries – for instance, they may prefer to have family members present.



Teach Back

- Consider the use of “teach back” to confirm comprehension of participants.



Thank You

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