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

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- 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!

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”
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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