Promoting and Evaluating Plain Language in a Website/App for Cancer Clinical Trials

Regina Carlisle, RN, Chesley Cheatham, M.Ed., MCHES, Melissa O'Grady, MLIS, Paula Schultz, RN, CNRN
University Hospitals Seidman Cancer Center Office of Patient and Public Education - Cleveland, Ohio

Background

Searching for cancer clinical trials can be confusing and difficult for patients and caregivers. Medical jargon used in clinical trial titles and descriptions can make it hard to figure out what a trial is studying.

In early 2014, the University Hospitals Seidman Cancer Center (UHSCC) launched a website/app for searching their clinical trials database. The UHSCC Office of Patient and Public Education was asked to make edits for the website/app based on health literacy principles.

Objectives

- To make the clinical trials search process simpler and more user friendly through the use of plain language and health literacy principles

- To promote patient and provider discussions about clinical trials

Approach

- Create plain language titles and "Purpose of this Study" descriptions for over 140 cancer trials

- Suggest changes to improve website's layout

- Collaborate with pharmacy for accurate wording of cancer treatments

- Create a patient User Guide and flyers to promote website/app

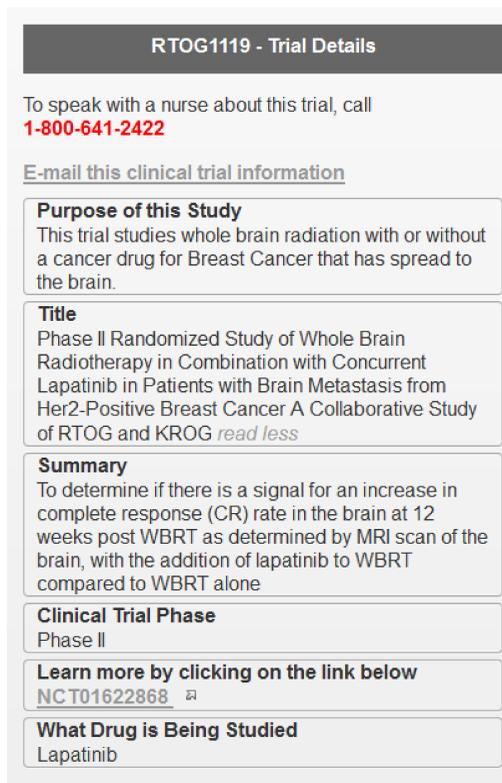## Examples from the Website/App Search Results
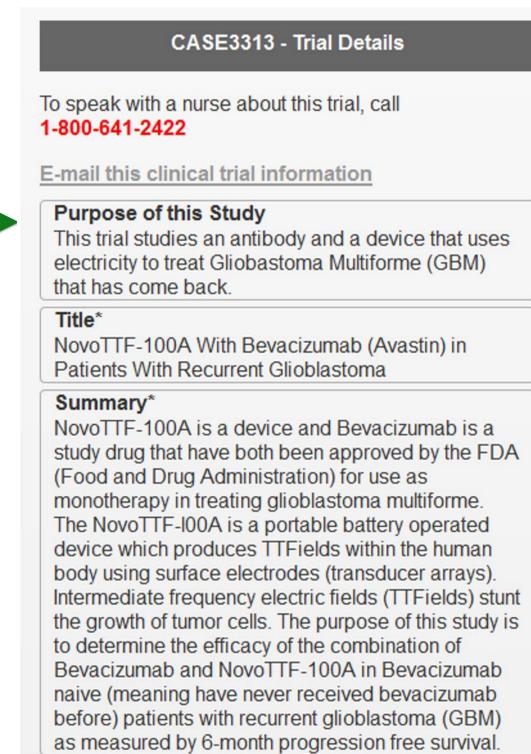

Website: uhseidman.org/clinicaltrials

First trial **has not** been edited for health literacy

Remaining trials have plain language titles created by the health literacy team

Plain language **Purpose of this Study** statement added to the Trials Details page.

Outcomes/Impact

- User testing of 217 volunteers

  - Given screen shot of trials details page; asked to answer three to five comprehension questions

  - Questions falling below 80% correct answer rate were reviewed by health literacy team

  - 83% of questions answered correctly

  - Incorrect answers were to the 1st question: "What is being studied?" Some said "cancer" instead of the treatment(s) listed in the purpose statement

  - Revealed other areas for change such as listing Stage IV as stage 4

- After introduction of promotional flyers and User Guide, hits to the website/app increased by 48% in one month compared to hits 6 months before

Implications for Practice

- Improving the readability of clinical trials descriptions is a first step in making them more accessible to patients and caregivers.

- User testing is critical to the editing process.

- Future direction:

  - Continue to edit trials as they open

  - Embed readability survey and feedback tab on website/app

  - Identify new ways to promote the site to patients and improve its overall layout