Can the Web be reimagined for the public good?

Can it be more human centric?

Less about the process than the people

**Thessis Wisperer**

**Skelleton for each chapter (What needs to be there to be just done)**

**Clear research Questions & Objectives**

**Ven Diagram of the disciplines, what I’m using from them**

**Discussion answer the issues in the literature review. Contributions linked to the lit. review. Restrict dates for literature review. Save searches and Google Scholar alerts.**

**Objective , contribution 4 sentences for each chapter.**

**METHODOLOGY DIAGRAM**

**Five main points**

Using Amazon MTurk to collect feedback on the readability of information leaflets (PILs) for clinical trials (RCTs) in the UK.

* Current issues with collecting public feedback
  + Public Involvement vs Clinical Research
  + Expenses, Equipoise and Inducement
  + Bias in Population Demographics
  + Low number of public reviewers
  + NHS proportionate approach to consent and Pragmatic Trials
* Methodology
  + Recruitment: HIT Task in Amazon MTurk, £10 for using a website to read, comment and review 3 PILs with readability issues and poor recruitment RCTs.
  + Procedure: Participants were presented a web page with the text of each PIL, the website enabled comments by selecting sections of text and clicking the “make a comment” button. After the participants gave their feedback, they were asked to assess the quality of the presented information by filling a multiple choice questionnaire, which was created based on the EQIP guidelines.
  + Analysis: Thematic and content analysis was used on the comments to identify their topics and themes. Regression models were used to identify associations between subjective perception of information quality, the unstructured feedback given the participants, their demographics and the PIL information quality.
* Results analysis
* Validation EQIP scale
  + Validation of the web tool was done by comparing the obtained feedback with the results collected in a previous face to face study.
  + The readability of the PILs was obtained by employing 3 readability metrics on the texts to select the sentences that were too hard to understand for a general audience and employing the Cloze procedure.
  + The results of the Cloze procedure were also used to determine the reading skill level of the participants as a demographic feature.
* Impact of the research

Using Amazon Mturk to assess readers’ reading skill and PIL readability

* Current approach and issues
  + PIL readability and patient comprehension before joining a RCT is not currently assessed outside high risk trials.
* Methodology
  + Identify sentences that are too hard to understand by a general audience
  + Select 3 sentences that require different levels of reading skill
  + Use Cloze procedure on the sentences, present participants with a sentence in which some words have been replaced with blank spaces and asked them to complete it.
  + Use the average number of words filled by the participants for each sentence to assess the difficulty of the document and the reading skill of the participants.
  + Use the participant submissions to find possible alternatives to jargon words.

Using Text Analysis to highlight issues in the PILs.

* Current approach and issues
  + Use of a single readability index
  + No feedback on how to improve the text
  + Focus on overall score for a large set of text
* Methodology
  + Employed the Coefficient of Variance between three commonly used readability indexes to assess each sentence readability difficulty.
  + A selection of all sentences above the average level of reading skill expected in the general population were highlighted.
  + A selection of
* Results
* Feedback and plan for improvement

Using Amazon MTurk to revise hard to understand sentences

* Current approach and issues
  + A PPI group is formed or selected and presented with a PIL draft, PPI groups commonly have less than 5 members, participants comment on the draft and propose corrections, principal investigator makes adjustments based on the feedback and submits the PIL as part of the clinical trial research ethics assessment procedure.
  + Subjective recommendations for corrections not based on experience or expertise.
  + No assessment of the participants reading skill
  + No formal record of the participant feedback, to be accessed by other researchers
  + The readability of the final version of the document is not commonly assessed
  + Small PPI groups do not give a full coverage of the PIL issues
  + PPI groups are demographically biased
  + High cost for PPI participation is a barrier for small and pragmatic trials
  + NHS proportionate approach to consent do not require low risk trials to engage in PPI
  + Severe readability issues have been found in PILs for trials with ethics approval
* Methodology
  + Objectively selected PIL sentences that were too hard to understand by a general audience, by employing the coefficient of variance between three common readability indexes.
  + Selected 3 sentences requiring different reading skill levels from each document
  + Employed Cloze procedure to assess the reading skill of each participant and the overall readability of the documents
  + Present the sentence to the participants and ask them to revise it, some groups got additional tips on how to revise the sentences
  + Employ Amazon MTurk to validate the proposed revisions by presenting the original sentence in its context and giving the participants a selection of proposals to grade as which should be selected.
* Data Analysis, Measures, Outcomes
  + Compare participant performance on the Cloze procedure and the readability score for each of the sentences and the overall score for the PILs
  + Compare the readability score of the proposals to the original sentences
  + Assess the validity of the proposals, are people with low reading skills able to revise PIL sentences? Is the crowd able to determine is a proposal is correct, complete and helpful? Can the process be automated?
  + Assess the learning and fatigue effects on participants when revising PIL sentences
  + Assess the association between sentence difficulty and time taken to revise a sentence