Rally Internship Summer 2021

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Internship Roadmap Streamlining CT.gov Lit. Review **Inclusivity Assessment** Studies to Rally Wrap - up Accessibility Work User Profile Prototype **Inclusivity Assessment** Continued

Lit. Review: Patient Engagement & Recruitment

- Patient Engagement in Research
 - "Nothing about me, without me."
 - What is meaningful patient engagement?



- 86% of studies don't meet recruitment goals (Huang, et al., 2018)
- Unique patient recruitment methods
 - Ethical concerns
- Challenges



Accessibility



- □ WCAG3
 - Perceivable, operable, understandable, robust
 - Guidelines and conformance levels
- Think about who, why, and how?
- ☐ Is there a methodology for testing compliance to WCAG?
 - How have diverse individuals been involved in the development process?

Accessibility



- □ No defined methodology
 - Online evaluation websites, internal reviews, and accessibility experts
- ☐ Met with Dr. Elaine Short
 - Get in there with your hammer and wrench, and break things."
- \Box Accessibility widgets \rightarrow \$\$

Defining Inclusivity

- □ What is "inclusivity"?
 - Equal accessibility for marginalized groups
 - Physical disability and/or mental disability
 - Gender nonconforming individuals
 - POC & BIPOC
 - ESL & language barriers
 - Unique family structure
- ☐ Ties in with accessibility (WCAG)
- □ Why is this important?



Inclusivity Assessment



- ☐ Is this site built to support a wide range of audiences?
 - Assessing patient engagement
 - Meaningful inclusivity
 - Engagement throughout the design process
 - No single solution

Some Best Practices for Meaningful Inclusivity



Caregiver Participation

Are registered caregivers able to navigate patient portals and/or research platforms on behalf of their patients?



Are a diverse set of patients represented in the images displayed on site?



Implication-Free Language

Is all the content on site presented free from stereotypes? Are surveys phrased with implication-free language?



Language Complexity

Is all the language on site phrased in a non-advanced way (a reasonable reading level)?



Collect *Necessary* Info

When requesting for specific demographic / personal info, are we certain these are necessary pieces of info to ask for?



Different Languages

Can the site be presented in languages other than English?



Measuring Inclusivity

- Patient Engagement In Research Scale
- Questionnaire-style assessment
 - Sliding scale option
 - Yes / No option
 - Inclusivity score/rating or grade
- Looking at PEIRS
 - Measuring patient engagement
 - Likert rating scale

Another direction...

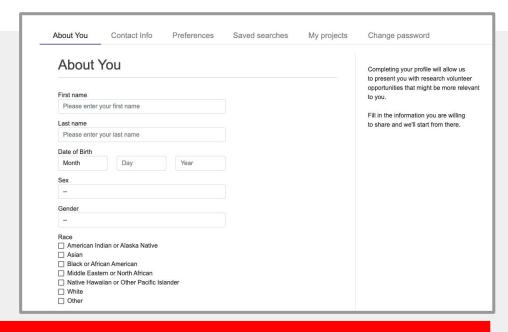


- ☐ Including RSVP for Health
 - Matching algorithms Alvin Roth market design
 - Patients in RSVP for Health → studies in Rally website!
- "Studies like this" feature
 - Developing user profile + study criteria
 - What information should we ask the users?

User Profile Prototype

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- Candidate additions to user profile
 - Informed by United Against Racism initiative/proposal and Ryan's work
- Develop a working prototype of the user profile on Rally
 - Learn to use Angular framework
 - Use existing Rally code on Github



User Profile

- ✓ Age
- ✓ Race
- ✓ Ethnicity
- ✓ Primary language
- ✓ Geographic location
- ✓ Motives
- ✓ Study Includes
- ✓ Areas of Interest
- ✓ Travel

w/ list of additional questions

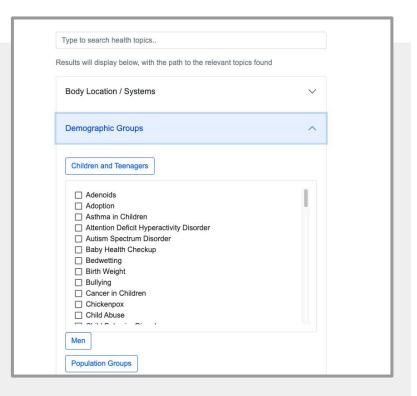
Areas of Interest



- □ Accordion / tree structure
- Search functionality
 - Breadcrumbs
 - Supercategories / categories / topics



- ✓ User experience + testing
- ✓ Working with Bootstrap, JSON, Angular pipes, etc
- **✓** Bugs :(



Streamlining CT.gov Studies to Rally

- ☐ Incorporate data elements to transfer to Rally
 - NCT number, primary study contact name, eligibility criteria, etc.
- □ CT.gov APIs
 - Identifying fields to query
 - NCTId, CentralContactName, EligibilityCriteria
- □ Using Node.js to query CT.gov
- □ End goal: CT.gov studies appearing on Rally

NIH) U.S. National Library of Medicine

Clinical Trials.gov

Wrap-Up



- Learned more about accessibility + inclusivity in web design
- Exposure to technical projects (Angular, Node.js)
- Practiced navigating academic research
- Made amazing mentors!

Thanks!

Any questions?

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