Co-Design Approaches Involving Older Adults
Development of a patient-centered preference tool for patients with hematologic malignancies

Amy Cole
Internship Report
Fall 2021
Lukasz M. Mazur, PhD
Daniel R. Richardson, MD
Karthik Adapa, MBBS, MPP, MPH
Amro Khasawneh, PhD
Jennifer W Bissram, UNC Health Sciences Librarian
Paul Mihas, Assistant Director of Education and Qualitative Research at the Odum Institute
Agenda

- Systematic Review
- Study Protocol
- Study Coordination
- Analysis and Reporting
Co-design approaches elicit ideas and foster a non-hierarchical environment in which concepts, tacit knowledge, and lived experiences of stakeholders, including the target population are applied to develop tools that meet the needs of the population [7,17].
Evaluate the extent to which co-design approaches engage older adults throughout the development lifecycle.

Registered with PROSPERO CRD42021240013
Methods

- Systematic Literature Search Strategy performed by UNC Health Science Librarian, Jennifer W Bissram
  - Articles published from **January 2010** to **March 2021**
  - **Keywords**: (Co-design, participatory design, user-centered design) AND (aged, older adults) AND (eHealth, mHealth) in PubMed, Scopus, and Embase.
  - Covidence
- **Quality assessment**
  - Agency for Healthcare Research and Quality (AHRQ)
Methods – Data Extraction and Synthesis

Co-Design Approaches
- Terminology & Definitions
  - Manual, binary
- Theoretical Frameworks
- Iterative Development
  - Metadata, mean

Stakeholder Involvement
- Participant Type
- Types of Involvement Processes
- Levels of Participation
- User Testing
  - Stakeholder Involvement
  - Methods – Data Extraction and Synthesis
  - Electronic Healthcare Tools
  - WHO classification of digital health interventions [19]
  - Older Adults’ Needs
    - Hermann et. al [20]
  - Metadata
  - Vaughn et. al [1]

- Metadata
  - Leinonen et. al [18]
Methods

Stakeholder Involvement

- Types of Involvement Processes
- Levels of Participation

Leinonen et. al [18]
Vaughn et. al [1]
Methods

Stakeholder Involvement

- Types of Involvement Processes
- Levels of Participation

Leinonen et al. [18]

Vaughn et al. [1]
Results
 Characteristics of Included Studies

Participants
 Age: Range (60-91) Mean (71.4)
 No. of Participants: Range (7-135) Mean (40.8)

Study Settings
 Laboratories, clinics, homes, community and senior centers, Zoom sessions

Study Locations
 Canada (1), Denmark (1), Hong Kong (1), Ireland (1), Italy (1), Netherlands (5), Sweden (3), and the United States of America (12).
Results

- Contextual Inquiry
- Participatory Design
- Product Design
- Prototype
Results

Studies classified on Vaughn’s framework

- Inform: 25
- Consult: 25
- Involve: 24
- Collaborate: 16
- Empower: 15
Results
Results

Involvement as a Process (IaaP)
Results

- **Empower (Yes)**: 5% Empower (No): 2%
  - Levels of Participation (Empower)
    - Yes (n=15): 23%
    - No (n=10): 14%
    - Other: 3%

- **Collaborate (Yes)**: 4% Collaborate (No): 4%
  - Levels of Participation (Collaborate)
    - Yes (n=16): 24%
    - No (n=9): 13%
    - Other: 4%

- **Involve (Yes)**: 4% Involve (No): 100%
  - Levels of Participation (Involve)
    - Yes (n=24): 24%
    - No (n=1): 10%
    - Other: 3%

- **Consult (Yes)**: 4% Consult (No): 24%
  - Levels of Participation (Consult)
    - Yes (n=25): 24%
    - Other: 10%
    - Other: 3%

- **Inform (Yes)**: 4% Inform (No): 24%
  - Levels of Participation (Inform)
    - Yes (n=25): 24%
    - Other: 10%
    - Other: 3%
Systematic Review Conclusion

- INVOLVEMENT OF END-USERS
- GAPS IN EVIDENCE
- FUTURE RESEARCH
Protocol Manuscript (Methods)
Phase 1 – Objective

Evaluate and compare standards on the perceived usability of the prototypes, and the cognitive workload of healthy volunteers interacting with the electronic healthcare tools.
Usability Testing Analysis Design Build Involvement as a Process (IaaP)

**Phase 1**
- Cohorts 1-3
- Healthy Volunteers
- Prototypes v1.1, v1.2, v1.3

Evaluate and compare standards

**Phase 2**
- Cohorts 4-5
- Patients/Caregivers
- Healthcare Workers
- Prototypes v2.1, v2.2

**Phase 3**
- Cohorts 6-7
- Patients/Caregivers
- Healthcare Workers
- Prototype v3.1

Evaluate and compare standards

Evaluate usability and cognitive workload
Evaluate usability, cognitive workload and performance
# Protocol Manuscript (Validated Measures)

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Patient</th>
<th>Caregiver</th>
<th>Healthcare Worker</th>
<th>Healthy Volunteer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline Participant Questionnaire</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Geriatric Assessment (Self-Reported)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geriatric Assessment-Blessed Orientation Memory Concentration (BOMC)</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Digit Span</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>eHeals</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>eHeals-Carer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PRIME</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>SEQ</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>PSSUQ</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>NASA-TLX</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Think aloud Interview</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Follow Up Interview</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Legend:**
- **X** Self-Reported Survey through REDCap
- **X** Online – virtual meeting
- **X** Human Factors Lab
Protocol to Study Coordination
Study Coordination

Develop and refine medium-fidelity prototypes

Discrete Choice Experiment

Multi-Profile Case

Best-Worse Scaling Profile Case

Best-Worse Scaling Object Case

Question 4

Choose one outcome that is the most important and one outcome that is the least important to you.

<table>
<thead>
<tr>
<th>Most Important</th>
<th>Outcome Definitions</th>
<th>Least Important</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Avoid high financial costs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Avoid long-term side effects</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Avoid hospitalizations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Avoid short-term side effects</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

hospital | 3 months
Short-term side effects | Mild
Long-term side effects | Moderate
Which drug would you prefer?
I prefer drug A

Avoid mild short-term side effects
Avoid mild long-term side effects
Have a 40% chance at complete remission
Have 12 months of event-free survival
Study Coordination
Recruit participants

Research for Me
Study Coordination
Conduct usability testing in the Human Factors Laboratory

Study Team meets volunteer in lab

1. Explain prototype testing procedures
2. Prototype testing (BWS)
3. Prototype testing (DCE)
4. Administer assessments
5. User testing session ends

Additional tools and methods:
- PSSUQ
- NASA-TLX
- Think-Aloud
- Semi-structured interview
- Audio and Screen recordings

Volunteer receives $25 gift card for participation

User testing data entered into REDCap
Study Coordination to Analysis and Reporting
### Analysis and Reporting

**Phase 1 – PSSUQ Scores**

<table>
<thead>
<tr>
<th>Prototype</th>
<th>System Usefulness (SYSUSE)</th>
<th>Information Quality (INFOQUAL)</th>
<th>Interface Quality (INTERQUAL)</th>
<th>Overall PSSUQ</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prototype</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Object Case</strong></td>
<td>n=10</td>
<td>1.57 (0.45)</td>
<td>2.35 (0.90)</td>
<td>2.05 (0.57)</td>
</tr>
<tr>
<td><strong>Profile Case</strong></td>
<td>n=5</td>
<td>1.29 (0.39)</td>
<td>1.37 (0.48)</td>
<td>1.55 (0.45)</td>
</tr>
<tr>
<td><strong>Multi-Profile Case</strong></td>
<td>n=15</td>
<td>1.38 (0.42)</td>
<td>1.70 (0.78)</td>
<td>1.72 (0.53)</td>
</tr>
</tbody>
</table>

PSSUQ Scores - Mean (SD) compared to Sauro & Lewis' benchmark scores

*Recommended means provided by Sauro and Lewis to interpret PSSUQ scores. Better performance and satisfaction are reflected in lower PSSUQ scores.*
### Analysis and Reporting

#### Phase 1 – PSSUQ Scores

<table>
<thead>
<tr>
<th>Prototype</th>
<th>System Usefulness (SYSUSE)</th>
<th>Information Quality (INFOQUAL)</th>
<th>Interface Quality (INTERQUAL)</th>
<th>Overall PSSUQ</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Object Case</strong></td>
<td>1.57 (0.45)</td>
<td>2.35 (0.90)</td>
<td>2.05 (0.57)</td>
<td>1.99 (0.24)</td>
</tr>
<tr>
<td>n=10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Profile Case</strong></td>
<td>1.29 (0.39)</td>
<td>1.37 (0.48)</td>
<td>1.55 (0.45)</td>
<td>1.40 (0.05)</td>
</tr>
<tr>
<td>n=5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Multi-Profile Case</strong></td>
<td>1.38 (0.42)</td>
<td>1.70 (0.78)</td>
<td>1.72 (0.53)</td>
<td>1.60 (0.19)</td>
</tr>
<tr>
<td>n=15</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Sauro & Lewis*\(^{23}\)  

|                         | 2.80 | 3.02 | 2.49 | 2.82 |

PSSUQ Scores - Mean (SD) compared to Sauro & Lewis’ benchmark scores

*Recommended means provided by Sauro and Lewis to interpret PSSUQ scores. Better performance and satisfaction are reflected in lower PSSUQ scores.*\(^{23}\)
Analysis and Reporting

**Phase 1 – NASA-TLX Scores**

<table>
<thead>
<tr>
<th>Prototype Case Type</th>
<th>Global</th>
<th>Mental</th>
<th>Physical</th>
<th>Temporal</th>
<th>Performance</th>
<th>Effort</th>
<th>Frustration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Object</td>
<td>10.97 (5.90)</td>
<td>46.5 (28.9)</td>
<td>1.00 (2.00)</td>
<td>7.5 (13.09)</td>
<td>40.5 (45.74)</td>
<td>24.5 (27.24)</td>
<td>10.5 (17.95)</td>
</tr>
<tr>
<td>Profile</td>
<td>16.13 (6.21)</td>
<td>58.0 (17.94)</td>
<td>2.0 (2.24)</td>
<td>31.0 (21.29)</td>
<td>50.0 (32.53)</td>
<td>37.0 (25.43)</td>
<td>49.0 (29.5)</td>
</tr>
<tr>
<td>Multi-Profile</td>
<td>11.03 (5.62)</td>
<td>48.67 (30.91)</td>
<td>0.67 (2.58)</td>
<td>6.00 (10.04)</td>
<td>41.67 (43.08)</td>
<td>26.67 (27.75)</td>
<td>9.33 (15.22)</td>
</tr>
</tbody>
</table>

*Table 4 - NASA-TLX Scores - Mean (SD) compared with optimal global scores ≥ 35 and < 55

Global Scores ≥ 55 are associated with reduced performance.22*
Analysis and Reporting

### Phase 1 – NASA-TLX Scores

<table>
<thead>
<tr>
<th>Prototype Case Type</th>
<th>Global</th>
<th>Mental (SD)</th>
<th>Physical (SD)</th>
<th>Temporal (SD)</th>
<th>Performance (SD)</th>
<th>Effort (SD)</th>
<th>Frustration (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Object n=10</td>
<td>10.97 (5.90)</td>
<td>46.5 (28.9)</td>
<td>1.00 (2.00)</td>
<td>7.5 (13.09)</td>
<td>40.5 (45.74)</td>
<td>24.5 (27.24)</td>
<td>10.5 (17.95)</td>
</tr>
<tr>
<td>Profile n=5</td>
<td>16.13 (6.21)</td>
<td>58.0 (17.94)</td>
<td>2.0 (2.24)</td>
<td>31.0 (21.29)</td>
<td>50.0 (32.53)</td>
<td>37.0 (25.43)</td>
<td>49.0 (29.5)</td>
</tr>
<tr>
<td>Multi-Profile n=15</td>
<td>11.03 (5.62)</td>
<td>48.67 (30.91)</td>
<td>0.67 (2.58)</td>
<td>6.00 (10.04)</td>
<td>41.67 (43.08)</td>
<td>26.67 (27.75)</td>
<td>9.33 (15.22)</td>
</tr>
</tbody>
</table>

Table 4 - NASA-TLX Scores - Mean (SD) compared with optimal global scores ≥ 35 and < 55

Global Scores ≥ 55 are associated with reduced performance. 22
15 Healthy Volunteers
3 Cohorts (5 volunteers/cohort)

(1) Challenges
(2) Definitions and Attribute Levels
(3) Preferred question series (BWS/DCE)
Conclusion

- Systematic review
- Protocol manuscript
- Developed and revised prototypes
- Participant recruitment
- Usability testing
- Phase 1 analysis
Thank you
References

References


References


References


