

A Social Networking Tool for Collaborative Care for Adolescents and Young Adults with Cancer, their Caregivers and Health Care Providers



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Presenting for the Loop Team

The Team





- Adolescents and young adults with cancer (AYAC) are considered medically complex
- AYAC have high service needs and healthcare use
- During these developmental phases, AYAC are expected to assume greater responsibility for disease management to match their growing independence and autonomy in other life domains

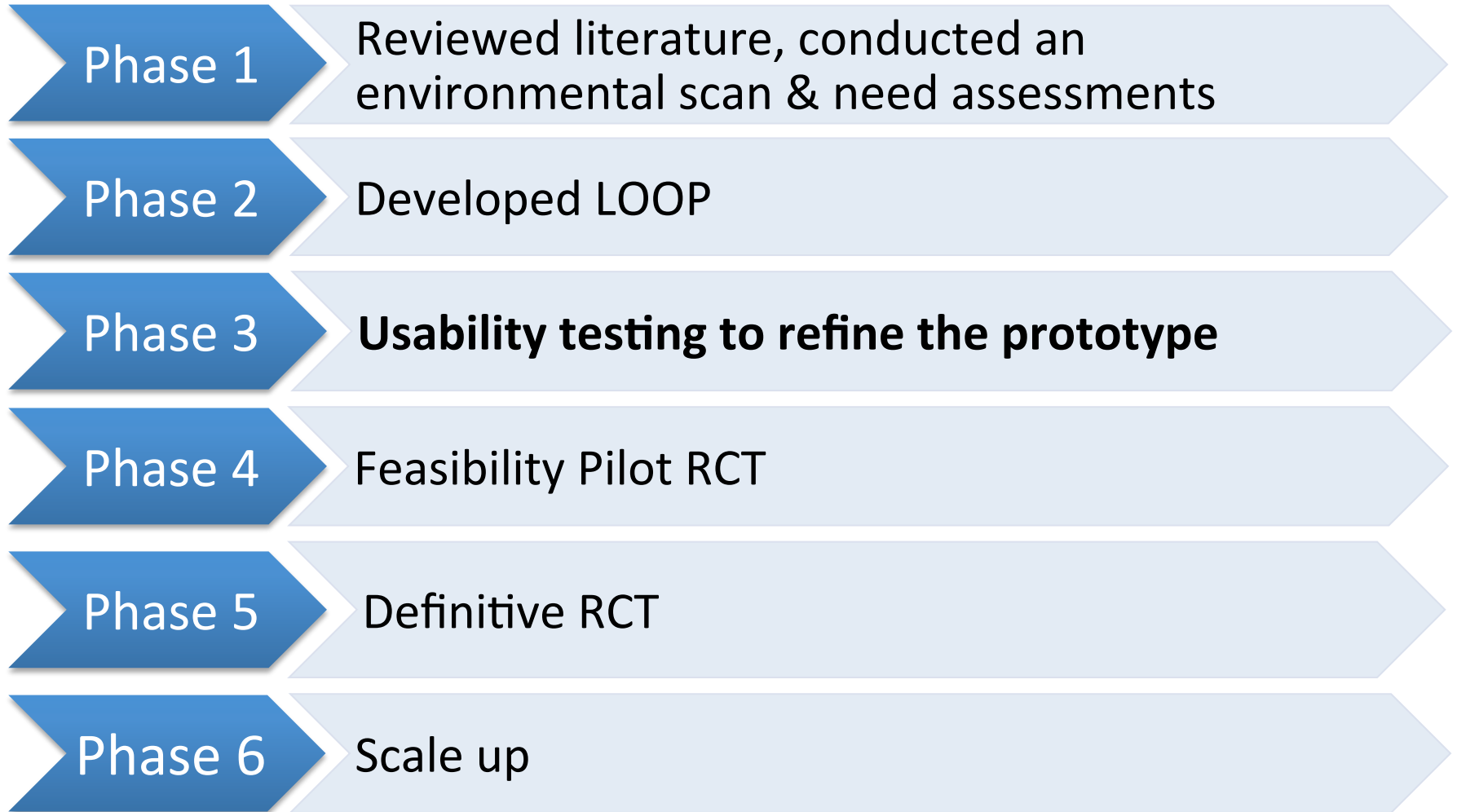
More about the Problem

- In addition, AYAC need the expertise of many healthcare professionals (HCPs) spanning different disciplines, institutions, community agencies and settings of care
- Due to this complexity, communication about plans of care and coordination among members of the care team, across hospital and community settings, is a major challenge

More about the Problem

- There is currently no organized system/tool in place for this purpose – **placing the burden of coordination on patients and their families**
- Despite the proliferation of applications, there is a paucity of user-driven, design-driven, robustly researched IT solutions in medicine
- To address these gaps, our research groups is developing and testing ***a secure, managed online communication tool centered on each patient, for the purpose of collaborative care***

User-Centred Design Approach



Sample

- AYAC were eligible if they: (a) had been diagnosed with cancer (at least 3 months from diagnosis), (b) were either actively being treated for cancer or have completed their therapy and are being followed in aftercare, and (c) were between 15 and 25 years and spoke English
- HCPs who are involved in the care of the AYAC were approached to participate

Usability Testing

- Conducted in 3 iterative cycles (High/Low fidelity)
- SickKids
 - 15 HCP (Age ranges 20-69)
 - Physicians(5), Nurses(2), NPs(7), Psychologist (1)
 - 9 patients (16.6 ± 0.65)
- Princess Margaret Hospital (PMH)
 - 1 HCP (Age range 30-39)
 - NP(1)
 - 5 patients (22.5 ± 2.5)
- All participants access to computer/Internet at home
 - adolescents & young adults reported higher levels of comfort using computers/Internet

Usability Testing

Healthcare Professionals

Workflow Integration

Transition to using system, administrative duties/responsibilities, initial communication duplication, burden of using numerous communication tools, success of tool is reliant on all members using it

Safety & Security

Visibility of messages (team vs. pt), emergency issues, shared computer use

Charting

Integration of messaging into EPC, potential legal ramifications

Portability

HCP would need smartphone/tablet version, has to be user-friendly

Usability Testing

Patients

Customization

Privacy, view, organization, backgrounds

Sharing outside of Team

Would like patient-patient interaction, share tool with friends/family

Self-Management

Communicating with team directly, have links to other social media/educational tools, helpful to connect different healthcare teams

Portability

Need to have smartphone/tablet option

Focus Group Demographics

- Purposive sample of English-speaking HCP specializing in pediatric oncology (n = 7)
- Age range 20-69 years old



■ Psychologist

■ Oncologist

■ Community Physician

■ Registered Nurse

■ Nurse Practitioner

■ Social Worker

Focus Group Results: HCP

1. Confidentiality

- Patient ability to invite anyone, age limitation for app users, saved information on portal

2. Storage

- Ability to transfer info into system, documentation, stored in medical records

3. System Usage

- Internet problems, computer literacy, sending message to wrong people

Focus Group Results: HCP

4. Workflow

- “Double the work”, time consuming, may increase anxiety for already anxious parents, too many other systems to use already

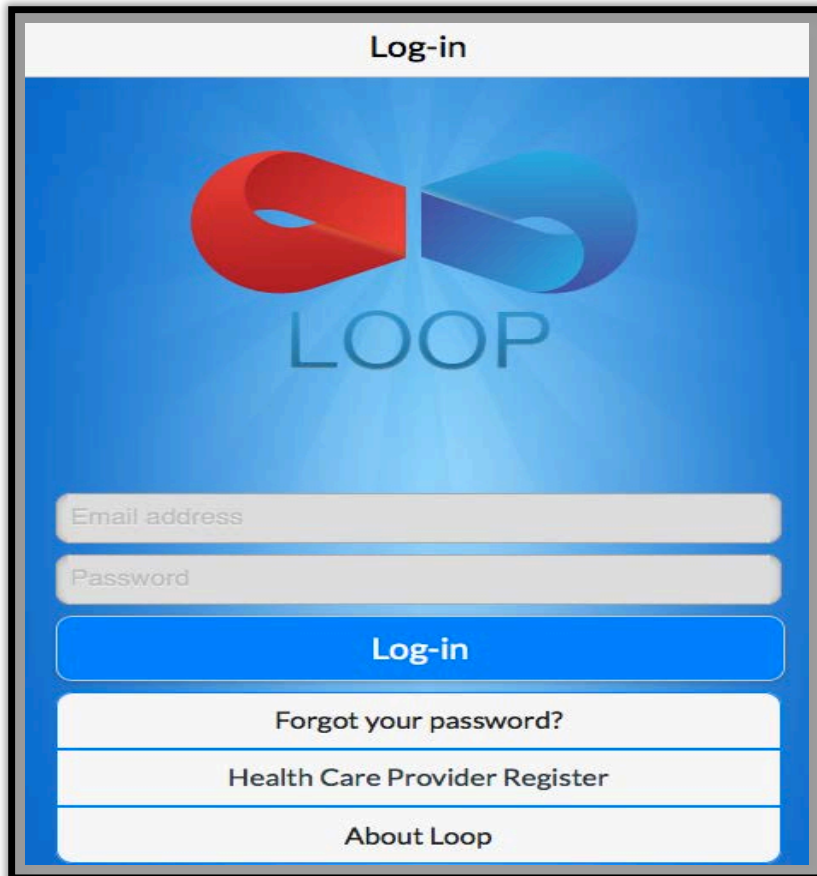
5. Communication

- Miscommunication/disagreement between HCP on team, staff on constant rotation (fellows), separated parents

Focus Group: The Vision

- *"This is a whole new way of giving care" (HCP)*
- **Allows for comprehensive care**
 - **Allows HCP to be included in one network**
- HCP liked portability of tool
- Fun way for teen to interact with HCP
- Possibly an educational tool for patients
- Everybody uses phones/social media

New Prototype



Log-in

LOOP

Email address

Password

Log-in

Forgot your password?

Health Care Provider Register

About Loop

- **Safety/Security:** Added terms/ conditions of use, auto log-out
- **Documentation:** Added exporting function
- **Portability:** Built mobile version for smartphone/tablet
- **Additional Functions/Navigation:** Hovering over commands, filtering options, patient list by frequency, “view conversation”, “back to all messages”, search bar
- **Aesthetics:** Changed fonts/ colours/layout to improve user-friendliness and satisfaction
- **System Errors:** Technical improvements

Dashboard: Other self-management tools

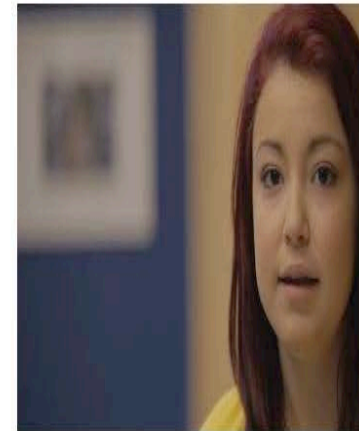


A screenshot of a website dashboard for 'Taking Charge: Cancer'. The top navigation bar is blue with the text 'TAKE CHARGE CANCER' and buttons for 'Parents' and 'Ask an Expert'. A left sidebar lists 'SESSIONS' from 1 to 11. The main content area features the title 'Taking Charge: Cancer' and a video player showing a woman's face. The background is decorated with orange and red patterns and icons.

SESSIONS

- Introduction
- 1. About Cancer
- 2. Understanding Diagnosis
- 3. Cancer medications
- 4. Cancer treatments and support therapies
- 5. The health care team
- 6. Communication
- 7. Managing your symptoms
- 8. Managing stress and emotions
- 9. Relaxation and distraction
- 10. Self-monitoring and supports
- 11. Your Lifestyle

Taking Charge: Cancer



Impact

- Potential to transform the way healthcare providers work, decrease the existing hierarchies in communication and decrease AYAC's burden in managing their disease
- Address the gap in communication across settings and disciplines, which results in poor outcomes and poor continuity of care
- With better managed and coordinated care, the frequency of preventable emergency department visits and hospitalization may be reduced
- Core platform will be easily customizable to the needs of any AYA with any complex health needs

Acknowledgements

Partner Organizations



Funding

