# Engaging a Diverse Patient and Care Partner Council to Refine Dementia Care Digital Tools

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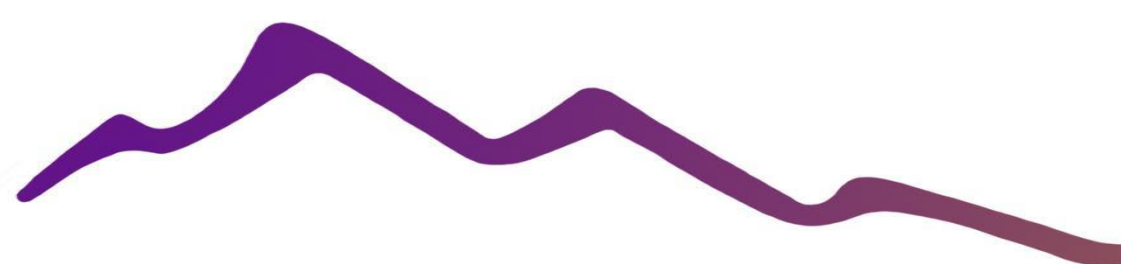
BACKGROUND

- There is a need to reduce disparities in the care of persons with dementia and their family care partners (i.e., dementia dyads).
- The use of clinical digital tools may improve communication but may also be limited by digital health equity issues.
- Engagement with dementia dyads as stakeholders can help prioritize and refine digital tools for testing in real-world studies.

OBJECTIVE

To promote communication between dementia dyads and clinical teams, we engaged stakeholders to identify priorities and refinements to digital tools.

We describe pragmatic methods for implementing Participatory Action Research (PAR) methods.

METHODS

Setting/Population: We convened 18 individuals of diverse background to form the "Memory Research Partners in Caring and Technology" including:
- Three dementia dyads
- Two additional family care partners
- 10 community members with experience as patient partners.

The council met six times over seven months (two in person, four virtually).
Partners were compensated for their time and expertise.

Recruitment:
- Collaboration with an existing patient research council
- Clinicians from dementia clinical settings
- Community partners

Pragmatic Stakeholder Engagement Methods:
- Presentations by and discussions with expert guest speakers
- Participatory methods such as a World Café
- Small group discussions using Google Jamboards at virtual meetings
- Mailing preparatory educational materials
- Phone contact with partners between meetings to gather additional input

Analysis:
We used rapid qualitative analysis methods to identify, share, and clarify findings from previous meetings.

Fig 1. Memory Tech Council Members

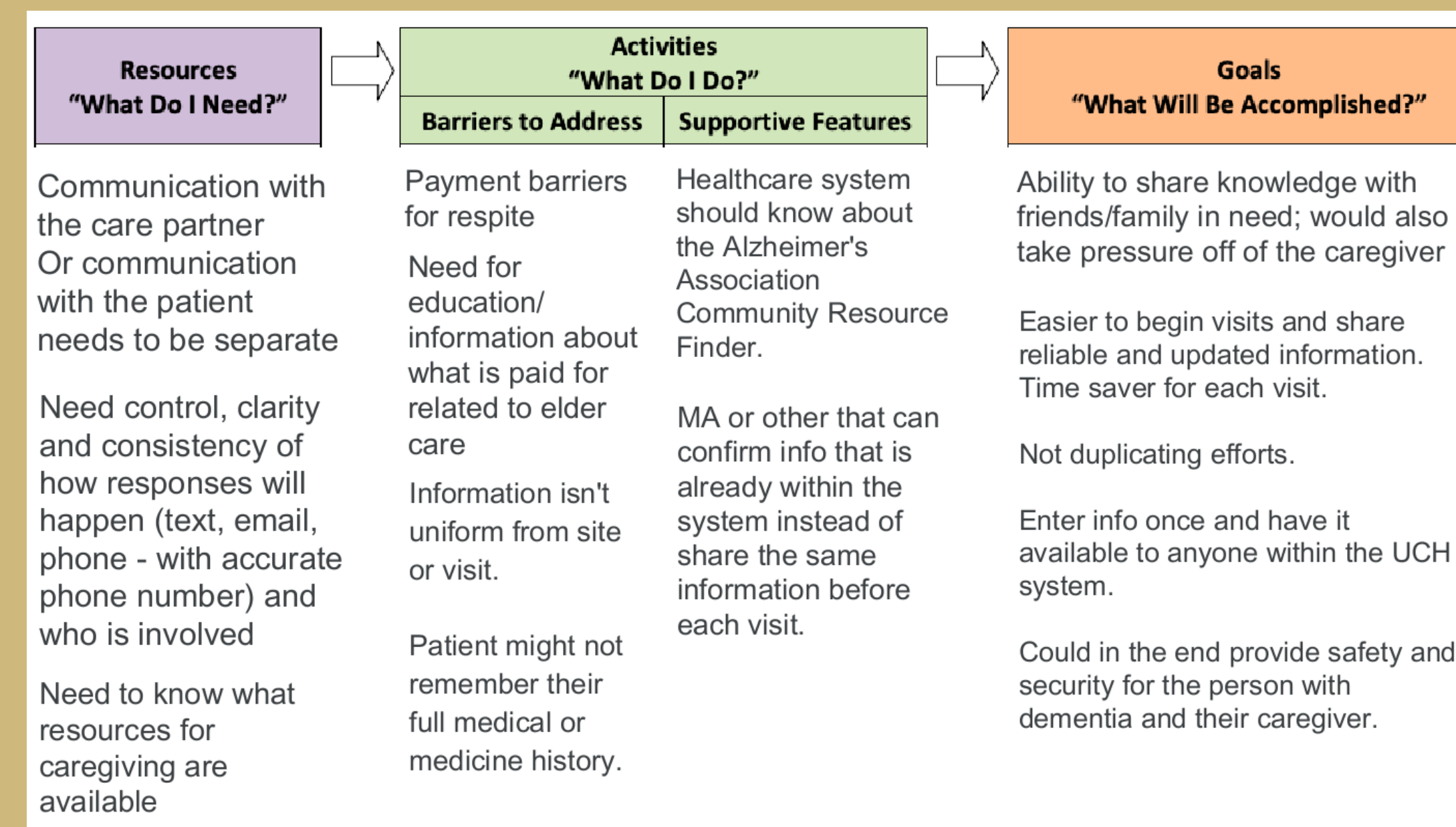Memory Research Partners Caring through Technology Council

2021-2022

RESULTS

Fig 1. Calendar of Events

Sept 2021	"What it means to be a research partner" Speaker: Dr. Holden: "Dementia Vs. Normal Aging" World Café Activity: Use of patient portals for dementia dyads
Oct 2021	"Patient Portal Utilization and Features" Speaker: Dr. Portz: "Using the Patient Portal." Jamboard Activity: Portal features & building trust with providers
Nov 2021	"Understanding Facilitators and Barriers to Using Digital Tools" Speaker: Alzheimer's Association Community Partners Jamboard Activities: Logic models and OurNotes
Dec 2022	"How to use My Health Connection and OurNotes" Speaker: Epic Team Member: Matt Andazola
Feb 2022	"Digital Health Equity" Project Review: Current Progress and Future Steps Discussion: What does digital health equity mean to you?
Mar 2022	"Digital Health Equity and Digital Tools for Dementia Dyads" Discussion: Digital Health Equity Recap and Additional Thoughts Poster Board Activity: Refining Digital Tools for Dementia Dyads

Fig 2. Research Partner Description of Communication Needs

Fig 3. Example Google Jam-Board Activity

Resources "What Do I Need?"	Activities "What Do I Do?"		Goals "What Will Be Accomplished?"
	Barriers to Address	Supportive Features	
Communication with the care partner Or communication with the patient needs to be separate	Payment barriers for respite	Healthcare system should know about the Alzheimer's Association Community Resource Finder.	Ability to share knowledge with friends/family in need; would also take pressure off of the caregiver
Need control, clarity and consistency of how responses will happen (text, email, phone - with accurate phone number) and who is involved	Need for education/ information about what is paid for related to elder care	MA or other that can confirm info that is already within the system instead of share the same information before each visit.	Easier to begin visits and share reliable and updated information. Time saver for each visit. Not duplicating efforts.
Need to know what resources for caregiving are available	Information isn't uniform from site or visit. Patient might not remember their full medical or medicine history.		Enter info once and have it available to anyone within the UCH system. Could in the end provide safety and security for the person with dementia and their caregiver.

CONCLUSIONS

1) The collaboration with research partners provided rich insight on user experiences with existing systems of care and digital tools.

2) Findings will inform future aims of this project towards improving dementia care coordination using digital tools.

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