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Designing for  
Communication, Collaboration, and Coordination in  
Accessibility and Health

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**Abstract**

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Communication, collaboration, and coordination are fundamental to human interaction. As computing increasingly mediates these interactions, it is essential to address the sociotechnical challenges that arise in complex settings, such as accessibility (e.g., interactions among people with and without disabilities) and health (e.g., patients with chronic conditions collaborating with providers for care). This dissertation focuses on the design, implementation, and examination of two systems: (1) *Jod*, an accessible videoconferencing platform tailored to facilitate communication in mixed hearing groups, and (2) *SCOPE*, a technology-enhanced platform for collaborative care management for patients with cancer and depression. Grounded in the design and domain theories that informed the development of these feature-rich platforms, this work critically examines these systems through a sociotechnical lens. The complexities of settings like accessibility and health reveal a range of needs for communication, collaboration, and coordination, motivating sociotechnical systems that can adapt according to evolving social dynamics.

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## Glossary

DHH: d/Deaf or hard of hearing.

MIXED HEARING GROUP: Group comprising DHH and hearing individuals.

SPEECHREADING: Communication method that relies on visual and contextual cues to observe the movements of the speaker's lips to support communication.

SIGN LANGUAGES: Full-fledged languages that rely on communicating information through hand shapes, body movements, and facial expressions.

SIGNERS: People who communicate using sign language.

SIGN LANGUAGE INTERPRETERS: Person trained in translating between a spoken and a signed language.

JOD: Videoconferencing platform for mixed hearing groups. *Jod* is a Hindi word, pronounced as *j-o-rr-h*, which means 'link'.

COLLABORATIVE CARE MANAGEMENT: An effective and evidence-based approach to integrated psychosocial care with cancer care.

BEHAVIORAL ACTIVATION: An evidence-based psychosocial intervention that focuses on engagement in valued activities and overcoming avoidance behaviors.

SCOPE: Supporting Collaborative Care to Optimize Psychosocial Engagement, a technology-enhanced collaborative care system for cancer and depression setting.

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---

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## Dedication

*To Angoori Mittal (Amma),  
for traveling in the heat of Delhi to provide comfort and to instill a sense of wonder in me.*

# Chapter 1

## Introduction

Communication, collaboration, and coordination are fundamental to social interaction [63, 202]. When properly supported, they can lead to personal and institutional success [28]. *Communication* involves exchanging information, ideas, thoughts, feelings, and messages between individuals or groups. It can be verbal (e.g., spoken, written) [118, 142, 161], non-verbal (e.g., body language, facial expressions, gestures) [7, 146], or visual (e.g., images, tables, graphs) [68, 127] as well as synchronous (e.g., information exchange in real-time) [82, 140] or asynchronous (e.g., information exchange at different times) [96, 106]. Effective communication can support *collaboration*, which involves individuals or groups communicating and working together to complete a shared task or achieve a shared goal [56, 159, 221]. Collaboration assumes dynamic interaction and shared decision making, with success criteria including open communication, knowledge sharing, and appropriate participation and contribution of all individuals [48, 144, 166, 189]. *Coordination*, a subset of collaboration, involves organizing and managing independent or interdependent activities to support collaboration [154, 160]. Although subtly distinct, these concepts are deeply interwoven because effective communication supports collaboration and effective coordination helps structure collaborative work [77, 120, 121, 216].

This dissertation contributes to the broad design space of communication, collaboration, and coordination systems through multiple empirical observations of technology-mediated group work in complex settings of *accessibility* (e.g., interactions among people with and without disabilities) and *health* (e.g., patients with chronic conditions collaborating with providers for care, providers collaborating with other providers in a care team).

The accessibility setting in this dissertation explores the design space to facilitate remote communication and collaboration in groups of mixed hearing individuals (i.e., individuals

who are d/Deaf or hard of hearing (DHH) and those with no hearing impairment) through videoconferencing. Although the adoption of videoconferencing platforms increased during the COVID-19 pandemic, current platforms impose significant accessibility barriers for 430 million DHH people worldwide [149]. They offer limited layout options and automatically resize and distribute video tiles of call participants on multiple pages, posing obstacles to visual communication [108, 168]. For DHH people who can employ multiple communication methods (e.g., sign language, speechreading), these limited customization capabilities prevent them from personalizing their view of other DHH individuals, active speakers, and sign language interpreters [101, 108, 168, 204]. Further, many DHH individuals can feel uncomfortable attracting other people’s attention in multi-participant conversations and so find it challenging to interject in ongoing conversations [168]. Finally, in mixed hearing settings, participants may face challenges in remembering appropriate communication accommodations, such as hearing people forgetting to speak slowly or turning on their video when conversing with DHH participants [125].

The health setting in this dissertation explores the design space of technology-enhanced collaborative care management of comorbid cancer and depression (i.e., where behavioral health providers deliver treatments, coordinate psychosocial care, monitor outcomes, and adjust treatment with the input of psychiatric consultants and a patient’s cancer care team). Collaborative care in this context coordinates cancer treatment with treatment of other symptoms (e.g., anxiety, low mood, loss of interest, low energy, poor concentration). The worldwide incidence of cancer is expected to exceed 28 million people in 2040 [195]. Depression, a common challenge during and after cancer treatment that affects up to 24% of cancer patients [104, 158], can arise due to psychological reactions to phases of the cancer journey, social factors, physical side effects, and neuropsychiatric effects of certain cancers and their treatments [76, 158, 187]. Prior work found that patients struggle to navigate physical cancer care and psychosocial care journeys in parallel and highlighted opportunities for technology support that focuses on overcoming challenges that now exist between patient-provider sessions [194]. For example, the burdens of cancer and its care (e.g., physical, cognitive, emotional, financial) can limit a person’s capacity to engage in behavioral health treatment. Similarly, a lack of accessible documentation of a treatment plan can cause patients to become uncertain or forgetful about the next steps or to personally assume the burdens of between-session coordination work, and it can cause

providers to struggle to remember what a patient has been asked to do.

Informed by prior work in technology-mediated communication, collaboration, and coordination, this dissertation explores two specific domains.

1. **Accessibility:** The design, implementation, and evaluation of *Jod*, a videoconferencing platform to facilitate communication and collaboration in mixed hearing groups, with features such as customizable visual layout, preset feedback messages and accessibility indicators, among others.
2. **Health:** The design, implementation, and evaluation of *SCOPE*, a platform for collaborative care management of depressed cancer patients, which combines a patient-facing mobile app with a provider-facing registry.

## 1.1 Thesis Statement

This dissertation demonstrates the following thesis:

*The complexities of settings like accessibility and health reveal a range of needs for communication, collaboration, and coordination, motivating sociotechnical systems that can adapt according to evolving social dynamics.*

To support this thesis statement, I compare and contrast empirical observations from my research work around *Jod* (i.e., an accessibility setting of mixed ability communication, collaboration, and coordination) and *SCOPE* (i.e., a health setting of patient-provider and provider-provider communication, collaboration, and coordination). I employ a *human-centered design process* that ranges from identifying needs to designing and evaluating both systems in real-world contexts. I show that in settings like accessibility and health, sociotechnical systems can support communication, collaboration, and coordination by adapting according to evolving social dynamics, including by: (1) supporting the agency of multiple stakeholders (e.g., people tailoring tools to their own needs), (2) negotiating social behaviors that are inherent to these interactions, and (3) supporting adaptability that surfaces from new needs and evolving expectations (e.g., arising from the relaxation of prior technical constraints).

I intentionally include “sociotechnical” in the thesis statement because, in both accessibility

and health settings, I observe that the support for evolving dynamics can include that: (1) people adapt to their social contexts, (2) technology supports people in adapting, (3) people adapt technology to support their needs, or (4) technology itself requires adaptation.

## 1.2 Dissertation Overview

My dissertation contributes both major research artifacts and empirical research findings to the design space of sociotechnical systems that support communication, collaboration, and coordination [212].

[Chapter 2](#) provides relevant background and related work to identify the range of needs in the social settings I explore in accessibility and health. It first anchors the dissertation work in Ackerman’s sociotechnical gap [2]. Next, the chapter presents relevant background and related work to support the accessibility component of this dissertation (i.e., *Jod*); it discusses DHH communication methods and the affordances and limitations of current videoconferencing systems for mixed hearing groups. Finally, the chapter reviews research on collaborative care in comorbid cancer and depression settings to support the health component of the dissertation (i.e., *SCOPE*) and provides the necessary background in evidence-based interventions that drive the design of the platform.

[Chapter 3](#) presents the design, development, and evaluation of *Jod*, *a videoconferencing system that integrates multiple design recommendations from prior work to support communication in mixed hearing groups*. *Jod* lets videoconference participants customize their visual layout to more fully engage with others, guiding them in how to resize, rearrange, and add/remove video tiles of other participants. It includes a notification system with preset messages to solicit the attention of other attendees and influence speaker behavior. To balance the audio-centric design of videoconferencing platforms, *Jod* highlights the video tiles of the active signer(s) using a Wizard of Oz technique. In addition, it incorporates accessibility indicators into participant profiles to help participants identify and gauge the real-time needs of others in the videoconference meeting and to support the recall of appropriate communication accommodations.

The chapter then describes the study I designed to evaluate *Jod*. I conducted six *study sessions* with 34 participants (18 DHH participants, 10 hearing participants, 6 Indian Sign

Language interpreters), where each session began with a tutorial that was followed by task-based exploration, unstructured conversation, a game of charades, and a presentation with screen sharing; it concluded with a *focus group discussion*. The study design included the aforementioned varying interaction scenarios since *Jod*'s goal is to facilitate full and successful engagement of DHH participants as conversational needs evolve, and its features are designed to be general purpose and usable in real-time. *Jod* thus empowers DHH participants to be equal conversational partners in meetings that may affect or influence their career success.

The findings reveal several insights, particularly **a strong correlation between the hearing abilities of the participants and their preferred visual layout arrangements**. Notably, DHH participants made the interpreter's video tile significantly larger than the hearing participant tiles and chose to move the closed captions closer to the interpreter's video tile. They also engage in **visual layout-related rearrangements to adapt to the changing group communication context**, particularly during the game of *charades*, where they prioritized the participant whose turn it was. Such customization capabilities provide complete control over visual layouts, but also lead to additional manual labor. Thus, DHH participants desired a **balance between flexibility and automated defaults provided by the system** to reduce their labor. They also reported that **preset feedback messages improved communication between DHH signers, hearing participants, and interpreters**. The preset messages helped DHH participants interject, request attention, and influence speaker behavior, but they also raised a need for acknowledgments and prioritization of received messages based on the group communication context.

Drawing on these findings, I synthesize key takeaways and provide **guidelines and implications for designing videoconferencing platforms that better support mixed hearing communication**. I focus on visual layout customization, platform interactivity and reactivity, and d/Deaf cultural considerations. I conclude with recommendations for conducting inclusive mixed hearing studies, focusing on the importance of study protocol iterations and flexible, open-minded, and adaptable accessibility researchers.

[Chapter 4](#) presents the design, development, and evaluation of *SCOPE* (Supporting Collaborative Care to Optimize Psychosocial Engagement), a *technology-enhanced*

*collaborative care management system intended to support patients with comorbid cancer and depression and their care team. SCOPE*, informed by prior work that studies experiences and challenges in collaborative care for such patients, facilitates coordinated *collaborative care management* and *behavioral activation*, which is an evidence-based psychosocial intervention for depression. It combines: (1) a patient-facing mobile app that provides information, resources, and support for activities related to behavioral activation, with (2) a provider-facing, web-based registry that supports clinical tasks specific to collaborating providers. *SCOPE*'s key innovation is directly integrating patient-generated data into a provider registry, which we redesigned for this purpose. By doing so, *SCOPE* empowers (1) patients by supporting their communication with their providers and helping them access data that affects their quality of care and (2) clinicians by providing data and reminders that help them coordinate care with other providers and their patients and better manage the totality of cancer's affect on a patient's psychosocial health.

The chapter describes how we evaluated *SCOPE* through a total of 45 *interviews* with cancer patients and their behavioral health providers, which we conducted throughout the design and deployment of *SCOPE*. This includes 26 design interviews (i.e., 14 with patients, 12 with behavioral health providers) in approximately 15 months of design and development, then 19 deployment interviews (i.e., 10 with patients, 9 with behavioral health providers) in approximately 24 months of deployment in actual care in 6 cancer clinics.

The chapter then presents the findings, which indicate that *SCOPE* **successfully supports both patients and behavioral health providers in the goals of its underlying collaborative care and behavioral activation interventions**. Patients observed that *SCOPE* **interventions supported their engagement with providers**. Further, patient-generated data in *SCOPE* **improved (1) patient-provider collaboration between and within in-person sessions and (2) provider care team caseload reviews and knowledge-sharing among care team members**. Participant experiences with *SCOPE* expectations around patient-generated data sharing and provider responsiveness (e.g., patients seeking provider acknowledgment and support). Finally, the chapter recounts **implementation barriers** that surfaced as part of our design and deployment of *SCOPE* for actual care in 6 cancer clinics for 24+ months and discusses the implications of our findings for the design of future platforms for such technology-enhanced

collaborative care.

[Chapter 5](#) examines how *Jod* and *SCOPE* provide evidence supporting my thesis statement. Although previous chapters provide multiple empirical observations within a specific context (i.e., accessibility, health), this chapter compares and contrasts these observations between both projects. It demonstrates that a range of needs surface in these heterogeneous social settings, and empowering people to adopt and adapt capabilities according to their specific and evolving social dynamics can best support communication, collaboration, and coordination goals.

[Chapter 6](#) summarizes my contributions and offers future research directions for designers and developers interested in optimizing communication, collaboration, and coordination platforms for complex settings like accessibility and health.

### 1.3 Dissertation Impact

My dissertation research makes scholarly contributions to HCI, CSCW, and Accessibility literature as well as to the process of human-centered research, which includes: (1) identifying participant needs as informed by prior literature and formative interviews, (2) designing and building communication, collaboration, and coordination technology-mediated sociotechnical systems exploring complex settings in accessibility and health, (3) evaluating these systems in social settings that reflect real-world contexts (e.g., *Jod*'s study design included varied interaction scenarios in videoconferencing) and large-scale field deployments (e.g., *SCOPE*'s deployment in 6 cancer clinics), and (4) surfacing insights and design implications for future research in communication, collaboration, and coordination systems in complex settings. The codebase for both *Jod* and *SCOPE* is open-source and my research has the potential for continued real-world impact.

Hearing loss is a significant global health issue that affects millions of people worldwide: approximately 1.5 billion people globally live with some degree of hearing loss. Of these, about 430 million experience disabling hearing loss. By 2050, it is estimated that nearly 2.5 billion people worldwide (1 in 4) will live with some degree of hearing loss. Of these, at least 700 million are expected to suffer from disabling hearing loss that requires rehabilitation [69, 149]. The acceptance of videoconferencing platforms is likewise projected to grow [15]. As the world continues to embrace remote and hybrid work social interactions, the demand

for accessible and inclusive communication tools will only increase. My work in *Jod* could significantly improve the lives of individuals with hearing loss by supporting mixed hearing groups with a more accessible, inclusive, and empowering way to communicate and collaborate in remote and hybrid settings.

Similarly, my work in *SCOPE* could improve the lives of those with cancer who also experience depression. By 2050, the number of new cancer cases is projected to increase to 35.3 million globally, a 76.6% increase from 2022 [19]. Cancer patients are at increased risk of developing depression, with studies estimating that up to 24% experience clinically significant depressive symptoms [104, 158]. Depression can significantly affect cancer treatment outcomes, including treatment adherence, quality of life, and survival rates. By providing a platform that supports and optimizes collaborative care management and evidence-based psychosocial interventions, *SCOPE* could improve lives and potentially outcomes for patients with these comorbidities. *SCOPE* is currently being evaluated in a randomized controlled trial in 6 cancer clinics (292 people randomized into the study, with 146 randomized to *SCOPE*) in Washington state. The trial results will provide valuable insights into its on-the-ground effectiveness in improving patient outcomes and influence future clinical coordinated mind-body practice in collaborative care settings.

## 1.4 Authorship Statement

Although my name appears on the title page of this dissertation, the research I describe is the culmination of several years of collaboration with my advisor, Prof. James Fogarty, and many other knowledgeable collaborators. The *Jod* system and research described in [Chapter 3](#) was completed with the help of Meghna Gupta, Roshni Poddar, Tarini Naik, Seethalakshmi Kuppuraj, James Fogarty, Pratyush Kumar, and Mohit Jain. The *SCOPE* system and research described in [Chapter 4](#) was completed in collaboration with Tae Jones, Ravi Karkar, Jina Suh, Spencer Williams, Yihao Zheng, Lydia M. Andris, Nicole Bates, Amy M. Bauer, Ty W. Lostutter, Jesse R. Fann, James Fogarty, and Gary Hsieh. I appreciate their participation and contributions more than I can say.

To acknowledge the invaluable contributions of my colleagues, I use the first-person plural in [Chapter 3](#) and [Chapter 4](#). I shift to first-person language in [Chapter 5](#) and [Chapter 6](#) to discuss how I interpret and summarize the contributions of this work. I, of course, assume full responsibility for any potential errors or misstatements in this thesis.

# Chapter 2

## Background & Related Work

HCI and CSCW researchers have long pursued research in the design of communication and collaboration across different settings, including interpersonal communication [64], remote work [47, 83, 109, 148, 211], software development [20], online communities [28, 102, 103, 188], gaming [40, 62, 112], virtual agents [98], human-robot interaction [172], mixed reality [67, 87, 176], and AI-Mediated communication [64, 90, 119, 135]. My dissertation research focuses on the design of communication, collaboration, and coordination systems in accessibility (i.e., for mixed hearing groups in videoconferencing), and health (i.e., collaborative care for patients with comorbid cancer and depression).

In [Section 2.1](#), I first situate my dissertation work with a perspective anchored in Ackerman’s Sociotechnical Gap [2]. In [Section 2.2](#), I present the necessary background and related work to support my research in the social context of accessibility (i.e., *Jod*, a videoconferencing platform for mixed hearing groups). I discuss the communication methods utilized by d/Deaf or hard of hearing (DHH) people and the affordances and limitations of current videoconferencing systems for mixed hearing groups. Finally, in [Section 2.3](#), I present the necessary related work and background to support my research in the social context of health (i.e., *SCOPE*, a technology-enhanced collaborative care management platform for comorbid cancer and depression settings). I provide background in the two evidence-based interventions that drive the design of *SCOPE*: Collaborative Care Management and Behavioral Activation.

### 2.1 The Sociotechnical Gap

HCI researchers do not typically name their research problems, which is in contrast to many other areas of computer science. The result is that it is uncommon to have long-standing

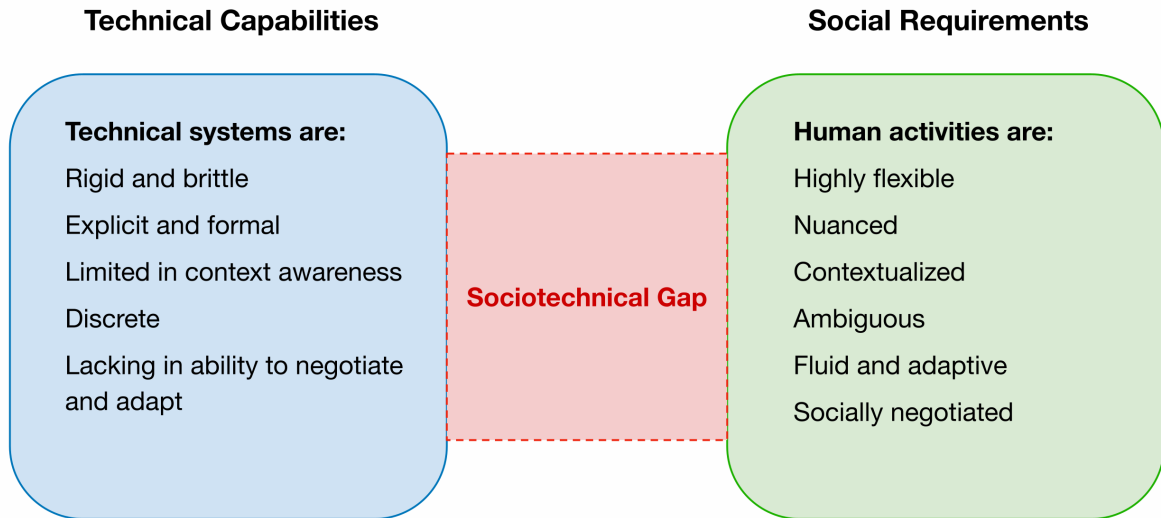


Figure 2.1: Visual representation of Ackerman’s sociotechnical gap [2]. The left side (blue) represents current technical systems, which are: rigid and brittle (i.e., follow fixed rules without flexibility), explicit and formal (i.e., require clear specification), limited in context awareness (i.e., do not understand situational factors), discrete (i.e., operate in defined states rather than continuum), and lacking in ability to negotiate and adapt. The right side (green) represents human social activities, which are: highly flexible (i.e., people adapt quickly to changing situations), nuanced (i.e., interactions have subtle distinctions and fine-grained details), contextualized (i.e., meaning depends on situation and history), ambiguous (i.e., support multiple interpretations), fluid and adaptive (i.e., constantly changing), and socially negotiated (i.e., meanings and norms are worked out through interaction). The middle section (red) is the sociotechnical gap (i.e., “the divide between what we know we must support socially and what we can support technically”).

problems with applicable names in HCI. Ackerman’s sociotechnical gap stands out as an unsolved, long-standing problem in our field [2]. The sociotechnical gap is the inherent disconnect between the complex social needs we strive to support and the limitations of current technological capabilities in communication, collaboration, and coordination systems. This gap arises because human social behaviors are nuanced, adaptable, and context-sensitive, whereas technical systems tend to be rigid, structured, and lack the flexibility to handle such complexity (illustrated in Figure 2.1). Although this gap may never be completely closed, it can be better understood and incrementally narrowed. To address the sociotechnical gap, Ackerman suggests three broad approaches, each with

distinct characteristics and purposes:

1. **Palliatives:** Consists of actionable steps or initiatives at the ideological, political, and educational levels. Ideological approaches prioritize the needs of people (e.g., through stakeholder analysis, participatory design). Political approaches include mandating trade union participation to ensure stakeholder interests are well represented and problematic impacts of a system are minimized. The educational perspective recommends training system designers and builders to understand the organizational and social impacts of their designs.
2. **First-Order Approximations:** Partial and controllable solutions that solve specific communication, collaboration, or coordination problems with known effects and trade-offs (e.g., creating systems or designs that deliberately address part of social requirements).
3. **Fundamental Lines of Inquiry:** A set of inquiries that would further communication, collaboration, and coordination systems as a science of the artificial (e.g., through examination of the platforms in real-world contexts, by exploring when a platform can safely ignore the need for nuance and context, by exploring when a platform can augment human activities).

The scope of this dissertation can be situated within the context of the sociotechnical gap as an attempt to bridge the divide between social needs for communication, collaboration, and coordination in accessibility and health relative to available technical capabilities.

## 2.2 Videoconferencing for Mixed Hearing Groups

I now present the necessary background and related work to support my research in the social context of accessibility (i.e., *Jod*, a videoconferencing platform for mixed hearing groups). *Jod* is informed by the communication challenges d/Deaf or hard of hearing (DHH) individuals face in mixed hearing groups while using videoconferencing platforms. Mixed hearing groups rely on multiple communication methods, such as sign language, speech reading (also called lipreading), gestures, body language, facial expressions, captioning, pen-paper/text-based chat, and interpreters. However, many of these may not translate well into online settings, resulting in various communication challenges. I discuss some

communication methods employed by DHH people and provide an overview of prior studies to understand the usage and challenges of these methods in current videoconferencing platforms.

### 2.2.1 Sign Language and Speechreading

*Sign languages* are the primary mode of communication in the d/Deaf community, with over 200 global variants [215]. Unlike spoken languages, sign languages rely on spatial cognition, communicating information through hand shapes, body movements, and facial expressions [23]. Each sign language has its distinct grammar and vocabulary. For instance, Indian Sign Language (ISL), the most commonly employed language by the DHH community in India [85], differs substantially from American Sign Language (ASL). Besides enabling communication, the DHH community identifies their sign language as a source of pride, thus constituting it as an essential part of their identity [110]. In the digital world, video calls enable people to interact using sign language. Prior work [108, 168, 210] has identified several challenges with it, including difficulty in reading signs due to reduced frame rates and inability to find interpreter’s video tile in large groups. Access to a human interpreter is the most reliable solution for the DHH community to interact with hearing individuals [190]. However, it is often not feasible due to the scarcity and affordability of interpreters. Additionally, Kushalnagar and Vogler [108] have discussed challenges in videoconferencing platforms, including limited and somewhat rigid support for organizing multiple visual elements (e.g. speaker video, interpreter video, captions, screen share). Through interviews and co-design sessions with d/Deaf signers and ASL interpreters, Ang et al. [168] reinforced that DHH signers and interpreters prefer having other signers in their view. Still, current videoconferencing platforms provide less flexibility in layout customizations. Interpreting linguistic information in sign language becomes more difficult as the size of video tiles decreases with the increasing number of participants. Further, keeping the view of the active speaker, interpreter’s video, and captioning text in visual proximity to each other can be challenging [101, 204]. Mack et al. [125] utilized autoethnographic methods to reflect on their virtual work experience in a mixed-ability team and reported being unable to see participants who employed sign language and giving more visual space to the shared screen, resulted in losing sight of the speaker or interpreter. Ang et al. [168] recommend adding the flexibility to rearrange and resize video tiles and the ability to group and pin together video tiles. To reduce the burden on DHH people when

consuming information from multiple sources, the option to overlay semi-transparent video over shared workspace has also been suggested [136].

DHH individuals also communicate through *speechreading*, a technique that relies on visual and contextual cues to observe the movements of the speaker’s lips to support communication. However, prior studies have shown that DHH individuals often find speechreading challenging in videoconferencing, especially when the speaker’s face is less visible, there is a lack of eye contact, or background lighting is insufficient [89, 108, 204]. A participatory design study by Kim et al. addressed these issues by providing a zoomed-in portion of the speaker close to their regular video tile, and in case of screen share, suggested that passive participants in the call be removed from the visual layout to reduce distractions [101].

### 2.2.2 Captioning in Videoconferencing

Due to speechreading challenges in video-mediated communication, DHH individuals often rely on captions, often against their preference [101]. Videoconferencing platforms leverage automatic speech recognition (ASR) for live captions and transcriptions, which can benefit DHH people when human interpreters and captioners are unavailable. As ASR output can be erroneous, specifically for non-native English speakers, DHH people face challenges with it [94]. Seita et al. conducted a remote study with DHH and hearing participant pairs to derive designs that let hearing people identify errors in ASR output and correct them [180]. Apart from fixing ASR-related errors, McDonnell et al. found that in small-group conversations involving mixed hearing identities, DHH participants suggested speaker identification and warnings for overlapping speakers be built into the videoconferencing system [130], and Seita et al. found that DHH participants were more satisfied with communication wherein hearing individuals maintained neither a high nor a low speech rate [179]. As part of exploring future captioning designs with DHH participants, prior work discussed features like color coding speakers, having the ability to keep captions close to the active speaker, using visual or haptic means to get people’s attention and notify hearing individuals to change their behavior [168, 180].

### 2.2.3 Audio-Centric Videoconferencing Designs

Given the audio-centric nature of videoconferencing designs, hearing people can gauge a listener’s understanding by receiving verbal backchannel feedback [168]. *Backchannels* are

verbal or non-verbal feedback given while someone is talking to show interest or attention. However, consuming backchannel feedback by DHH participants, like head nods and other non-verbal cues, is challenging and physically tiring due to the need to constantly pay attention to everyone’s video tiles, as videoconferencing platforms highlight active speakers solely based on audio. This also results in DHH person’s video tile never getting displayed or highlighted because their interpreter speaks for them [204]. Although an interpreter is essential to facilitate conversation between DHH and hearing participants, it not only can create frequent conversational lags that discouraged DHH people’s participation, but it also can complicate efforts for the participants to identify deaf signers [210]. To address that, Kushalnagar and Vogler suggest that videoconferencing organizers should avoid making assumptions and ask DHH participants about their preferred accommodations, captioning, and interpreter preferences [108]. Other prior works [108, 210] suggest having procedures and guidelines to manage turn-taking, having instructions on how to make meetings accessible, asking speakers to identify themselves, reminding participants to sit in well-lit areas, and requesting that they wear headphones with a microphone to improve audio and automated speech recognition quality.

All these prior studies utilize methods like participatory design, co-design, interviews, and autoethnography to identify communication challenges in mixed hearing groups and suggest design recommendations. This dissertation research builds upon these recommendations to design and develop a videoconferencing platform called *Jod* and to evaluate it by simulating real-world contexts where an interplay of social, environmental, and technological factors exists simultaneously.

### **2.3 Collaborative Care for Comorbid Cancer and Depression**

I now present the necessary related work and background to support my research in the social context of health (i.e., *SCOPE*, a technology-enhanced collaborative care management platform for comorbid cancer and depression settings). I first review work from the HCI and CSCW communities focusing on collaborative care within comorbid cancer and depression settings and on patient-provider collaboration around patient-generated data. I then provide background in two evidence-based interventions that drive the design of *SCOPE*: Collaborative Care Management and Behavioral Activation.

### 2.3.1 HCI and CSCW Research in Health

HCI and CSCW researchers have long pursued research in health [21, 57], including self-care technologies (e.g., [29, 32, 143]), clinical and hospital settings (e.g., [11, 151, 203]), experiences of people with chronic conditions (e.g., [26, 33]) and of caregivers (e.g., [18, 95]), women’s health (e.g., [49, 97, 107]), online health communities (e.g., [65, 150, 183]), clinician-facing AI (e.g., [25, 219]), and patient-provider collaboration (e.g., [10, 35, 152]). Within HCI and CSCW research, mental health and well-being is an important and growing area [170]. Researchers have studied depression among older adults (e.g., [217, 218]), stigma around mental health (e.g., [31]), opportunities for improving peer support (e.g., [147]), mental health management through social and collaborative lenses (e.g., [27, 111, 139]), and when depression occurs as a comorbidity (e.g., [70]). As part of surveying HCI and CSCW research in mental health and well-being, Sanchez et al. highlight a relative lack of research examining deployed clinical interventions [170].

This dissertation research presents insights gained through design and clinical deployment of *SCOPE* as a platform for technology-enhanced collaborative care for patients with comorbid cancer and depression. We draw upon Suh et al.’s examination of breakdowns and opportunities in collaborative care for patients with cancer and depression [194]. Their parallel journeys framework highlights challenges as patients navigate both a cancer care journey and a psychosocial care journey, and they identify opportunities for technology support focused on breakdowns between patient-provider sessions. For example, the burdens of cancer and its care (e.g., physical, cognitive, emotional, financial) can limit patient capacity for engaging in behavioral health treatment. Similarly, a lack of accessible documentation of a treatment plan can leave patients unsure or forgetful of what they are supposed to do, can leave providers struggling to remember what a patient has been asked to do, and can create burdens as patients are tasked with between-session coordination work. This dissertation research builds upon these prior insights with new patient and provider design interviews in our design and development of *SCOPE*, through 24 months of the deployment of *SCOPE* in actual patient care, and through patient and provider deployment interviews.

This dissertation further draws upon prior research in patient-provider collaboration around patient-generated data. Prior work has found collaboration around patient-

generated data can improve transparency of patient concerns [34, 193], challenge power relations [1], provide new opportunities for collaboration [141], facilitate sharing patient experiences [186], improve patient awareness [22], motivate patients [173], help recognize and solve condition-related challenges [162], support treatment adjustments [34], and facilitate shared decision-making [134]. Researchers have examined patient-provider collaboration around patient-generated data through stage-based models of personal informatics [50, 116], through models emphasizing patient-generated data as boundary negotiating artifacts [35, 113], and through models emphasizing multiple evolving goals for patient-generated data [173, 175, 177]. Much of the examination of *SCOPE* considers the role of patient-generated data and how patients and providers use and collaborate around that data to navigate complexities of patient parallel journeys in their psychosocial and cancer care.

### 2.3.2 Background on Collaborative Care Management

*SCOPE* is designed to support an evidence-based approach to integrated care known as Collaborative Care Management (also *collaborative care*). Multiple trials have demonstrated collaborative care to be effective [6, 207, 209], including for depression in cancer patients [117]. Core components include: (1) team-driven care provided by primary medical providers, a care manager (e.g., social worker, nurse, psychologist) who coordinates care and delivers brief behavioral interventions, and a consulting psychiatrist; (2) population-focused care responsible for a defined population of patients; (3) measurement-guided care using validated patient-reported outcome measures to guide shared clinical decision-making; and (4) evidence-based care using proven patient-centered treatments [8].

In a cancer setting, collaborative care integrates psychosocial care with cancer care (Figure 2.2). Collaborative care uses evidence-based behavioral strategies (e.g., behavioral activation, further introduced next) and validated patient-reported outcome measures. A behavioral health care manager works closely with both oncology providers and an on-site or remote consulting psychiatrist. Care managers are thus primary providers of psychosocial services and interventions [36, 41] and collaborative care can leverage existing staffing [37]. Care managers further provide patient education, monitor patient-reported outcomes, help with systematic patient outreach, and assist with care coordination [41, 71]. Clinical practice guidelines for depression in the cancer setting have promoted collaborative

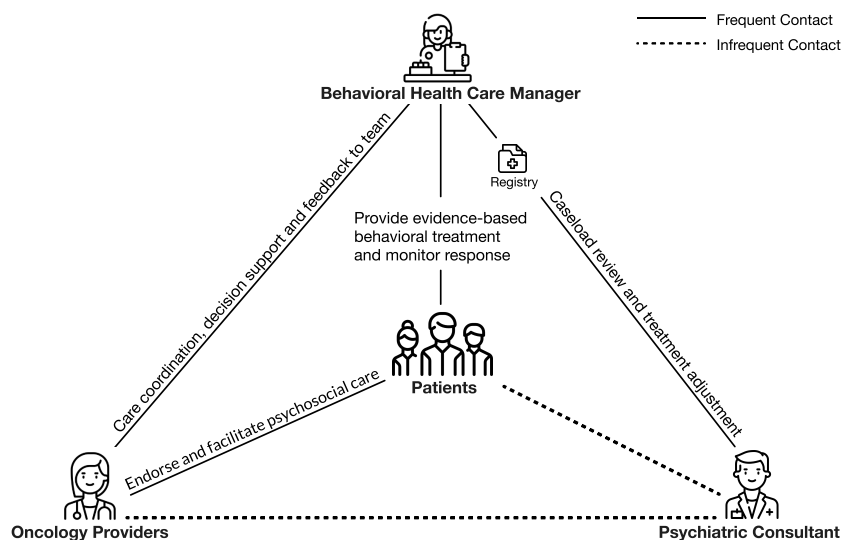


Figure 2.2: Collaborative Care Management is an evidence-based and patient-centered approach to integrating psychosocial care with cancer care. Its core components include: (1) team-driven care provided by primary medical providers, a care manager (e.g., social worker, nurse, psychologist) who coordinates care and delivers brief behavioral interventions, and a consulting psychiatrist; (2) population-focused care responsible for a defined population of patients; (3) measurement-guided care using validated patient-reported outcome measures to guide shared clinical decision-making; and (4) evidence-based care using proven patient-centered treatments.

care [53, 54] and the American Psychosocial Oncology Society has identified collaborative care as the most prioritized model for integrated psychosocial oncology care [157].

Successful implementation of collaborative care in a cancer setting requires overcoming several challenges: (1) barriers and burdens of cancer leading to missing information about patient symptoms and treatment, preventing timely adjustments [194]; (2) poor inter-professional communication pathways and attitudes [181, 213], (3) low fidelity to collaborative care principles [8], and (4) dropout from depression treatment [200]. Technology has the potential to help address these challenges [13, 163, 194] and to increase accessibility of psychosocial care. Prior studies have used electronic health records, telephone, video, and the web to facilitate delivery in primary care and cancer care settings [59, 60, 61, 105, 167, 191]. Informed by core principles of collaborative care, *SCOPE* builds on prior examinations of technology-enhanced support with a focus on challenges of a

cancer setting and the integration of patient-generated data directly into a provider registry.

### 2.3.3 Background on Behavioral Activation

Behavioral health care managers are trained to deliver evidence-based psychosocial treatments (e.g., problem-solving therapy, cognitive behavioral therapy, mindfulness therapy). *SCOPE* includes support for behavioral activation, a core component of collaborative care that has been shown to be effective for treating depression [38, 43, 45, 128], including in cancer patients [78, 80, 192]. A form of behavioral psychotherapy, behavioral activation focuses on goal-setting and problem-solving to enhance functioning and engagement in valued activities (e.g., walking to support physical health, calling friends to support important relationships) and to overcome avoidance behaviors (e.g., social withdrawal) [93]. Dimidjian et al. define behavioral activation as an approach to (1) grow engagement in activities associated with happiness or contentment, (2) reduce engagement in activities that increase risk for depression, and (3) solve problems that limit access to reward or the ability to reduce avoidance behaviors [42]. Reasons for failures of behavioral activation in the cancer setting include inability to understand and adopt strategies, behavioral nonadherence, and ineffective contingency management [81, 169, 194].

Behavioral activation is a time-efficient approach [58] that does not require complicated skills from providers or patients, making it an accessible treatment option [38]. It has further shown effective in primary and general care settings due to its flexible and modular delivery [208]. Recommended in practice guidelines for patients with cancer and depression [5], behavioral activation is associated with engagement in active coping, decreased suicidal ideation, increased hopefulness, improved quality of life [79, 80, 123], improved treatment and medical outcomes [78, 79], and completing a higher proportion of scheduled activities [169].

Clinical guidelines for behavioral activation outline delivery of several patient skills (e.g., self-monitoring of activities, mood tracking, activity scheduling, activity structuring, problem-solving) [12]. Treatment is conducted collaboratively, with providers educating patients about the relationship between values, activities, and mood. Providers then guide patients to assess personal values and set individualized goals. Patients schedule pleasant activities, track the association between mood and activities within these values and goals, and are encouraged to employ problem-solving when barriers or avoidance behaviors

interfere with scheduled activities. *SCOPE* aims to support patients in these activities while also sharing resulting patient-generated data with their provider, thus supporting patient-provider collaboration in the intervention.

## Chapter 3

### Jod: Accessible Videoconferencing for Mixed Hearing Groups

Broad adoption of videoconferencing platforms has surged in recent years, primarily due to the COVID-19 pandemic. The prevalence of popular videoconferencing platforms (e.g., Zoom, Microsoft Teams, Google Meet) was 21 times higher in the first half of 2020 compared to the first half of 2019 [30], and their usage is projected to grow in the coming decade [15]. Studies by the Pew Research Center have found that these platforms are used for many purposes, such as remote work, maintaining social connections, and telehealth, among many others [9]. With the increase in adoption and use, videoconferencing platforms also aim to provide more inclusive support through features related to accessibility needs (e.g., live captions and transcriptions, support for screen readers, and multi-pinning and multi-spotlighting to support visual layout customization [196, 222]). Particularly relevant to the d/Deaf or hard of hearing (DHH) population, Microsoft Teams and Zoom introduced sign language interpretation views [171, 199]. These views prioritize sign language speakers (hereafter called signers) and interpreters by maintaining a fixed view of their video tiles.

Despite these efforts, videoconferencing platforms present significant accessibility barriers for the DHH community [4, 108, 125, 168, 204], estimated to comprise over 430 million people worldwide [149]. Prior research in HCI and accessibility has examined the usage of videoconferencing platforms by DHH individuals [108, 168] and identified three main challenges. First, current videoconferencing platforms offer limited default layouts for the participants to choose from and tend to automatically resize and distribute video thumbnails over multiple pages, posing obstacles for visual communication [108, 168]. Such limited layout customization capabilities prevent DHH individuals from personalizing their view of other DHH individuals, active speakers, and interpreters [101, 108, 168, 204].

Second, DHH individuals often feel uncomfortable getting attention of other participants, as they find it challenging to interject an ongoing conversation (i.e., including with the interpreter’s help) [168]. Additionally, in mixed hearing videoconferencing settings, hearing and DHH individuals face challenges in remembering appropriate communication accommodations, such as hearing individuals forgetting to speak slowly or turning on their video when conversing with DHH individuals [125]. Third, the audio-centric designs of current videoconferencing platforms do not support highlighting the video tiles of signing participants [204]; instead, the interpreter who voices them gets the focus in visual layouts. Therefore, current videoconferencing platforms fail to provide personalized visual layout arrangements, support DHH participants in interjecting, and help attendees remember appropriate accommodations for others.

Prior research [101, 168, 180] has primarily employed participatory design methods such as co-design workshops to explore potential design solutions to address these challenges. Design recommendations include options for resizing and reordering video frames, grouping videos, offering visual and haptic feedback to request attention, and prioritizing frames of active speakers [101, 168, 180]. However, a limited understanding remains of how these solutions would translate into action in real-world mixed hearing videoconferencing settings. To examine this, we designed and developed *Jod*, a videoconferencing platform to facilitate communication in mixed hearing groups. *Jod* is a Hindi word, pronounced as *j-o-rr-h*, that means ‘link’ and emphasizes the system’s goal to connect individuals. *Jod* provides participants with an enhanced option to customize their visual layout, supporting them to resize, rearrange, and add/remove video tiles of other participants. It also includes a notification system with preset messages to get attention of other attendees and influence speaker behavior. To balance the audio-centric design of videoconferencing platforms, *Jod* highlights the video tiles of active signer(s) through a Wizard of Oz technique [44]. Furthermore, it incorporates accessibility indicators into participant profiles to help gauge and identify the needs of fellow participants and support the recall of appropriate communication accommodations.

To understand behaviors and perceptions when navigating mixed hearing ability conversations using *Jod*, we conducted six study sessions with 34 participants, including 18 DHH participants, 10 hearing participants, and 6 Indian Sign Language (ISL) interpreters



Figure 3.1: Snapshots from study sessions (a) a camera shot of *Jod* showcasing its interface during a video call, (b) a d/Deaf or hard of hearing participant actively signing while interacting with *Jod*, and (c) mixed-hearing focus group discussion with interpreter.

(Figure 3.1). Each session consisted of a tutorial, followed by task-based exploration, unstructured conversation, a game of charades, a presentation with screen sharing, and concluded with a focus group discussion. To supplement our qualitative analysis, we also collected system-wide telemetry data. Participants engaged in 485 visual layout-related arrangements and sent 40 preset messages throughout the study. Our findings unveiled several insights, particularly a strong correlation between hearing abilities of participants and their preferred visual layout arrangements. Notably, the DHH participants made the interpreter’s video tile significantly larger than the hearing participants and chose to move the closed captions closer to the interpreter’s video tile. Interestingly, participants also engaged in visual layout-related rearrangements to adapt to the changing group communication context, particularly during the game of *charades* where they prioritized the participant whose turn it was. Though such customization capabilities provided complete control over visual layouts, it also led to additional manual labor. Thus, our participants desired a balance between flexibility and system-provided automated defaults to reduce their labor. Participants further reported improved communication between DHH signers, hearing participants, and interpreters through preset feedback messages. Though the preset messages helped in interjecting, requesting attention, and influencing speaker behavior, these features also raised a need for acknowledgments and prioritization of received messages based on the group communication context. Drawing on these findings, we synthesize key takeaways and provide guidelines for designing videoconferencing platforms to support mixed hearing communication better, focusing on visual layout customization, interactivity and reactivity of the platform, and cultural considerations. We conclude with

recommendations for conducting inclusive mixed hearing studies.

The presentation of our research in *Jod*, contributes the following:

- The design and development of *Jod*, a videoconferencing platform integrating recommendations from prior work to facilitate communication in mixed hearing groups, that supports its participants in customizing their visual layout to more fully engage with others, guiding them in how to resize, rearrange, and add/remove video tiles of other participant. It includes a notification system with preset messages to solicit the attention of other attendees and influence speaker behavior. To balance the audio-centric design of videoconferencing platforms, *Jod* highlights the video tiles of active signer(s) using a Wizard of Oz technique. Further, it incorporates accessibility indicators into participant profiles to help participants identify and gauge the real-time needs of others in the videoconference meeting and support the recall of appropriate communication accommodations.
- Findings from 6 study sessions with 34 participants, including 18 DHH participants, 10 hearing participants, and 6 ISL interpreters, examining how *Jod*'s features interact with each other and the emergent behaviors and perceptions of participants. Sessions include a set of varying interaction scenarios because *Jod*'s designs are intended to be general purpose, consisting of a tutorial, followed by task-based exploration, unstructured conversation, a game of charades, a presentation with screen sharing, and concluded with a focus group discussion.
- Guidelines for designing accessible videoconferencing platforms, including the need (1) for balance, to provide customization with automated support, (2) to overlay context-aware notifications with means for acknowledgment, and (3) to further explore features adhering to Deaf cultural practices.
- Recommendations for conducting inclusive mixed hearing studies, including the (1) importance of iterating over the study protocol, (2) the need for accessibility researchers to be more flexible, open, and adaptable to quick iterations, and (3) to establish effective communication protocols around when, how, and where to lead focus groups in mixed hearing settings.

[Section 3.1](#) describes the design and implementation of *Jod*. [Section 3.2](#) describes the study design for evaluation of *Jod*. [Section 3.3](#) reports findings in terms of layout flexibility in videoconferencing, connections through notifications in mixed hearing groups, need for flexibility but with automated support to reduce labor, and varying cultural and communication norms and mismatched expectations in mixed hearing settings. [Section 3.4](#) discusses implications of our findings for the design of accessible videoconferencing platforms to support mixed hearing. [Section 3.5](#) shares limitations to consider in interpreting our findings, and in [Section 3.6](#), I situate *Jod* within the context of Ackerman’s sociotechnical gap (as discussed in [Section 2.1](#)).

The *Jod* system and research described in this chapter were started during an internship at Microsoft Research and completed at the University of Washington. This work was completed in collaboration with Meghna Gupta, Roshni Poddar, Tarini Naik, Seethalakshmi Kuppuraj, James Fogarty, Pratyush Kumar, and Mohit Jain. My contributions included: designing, developing, and maintaining the system; designing the study protocol; supporting the conduct of study sessions; analyzing quantitative and qualitative data; and leading the manuscript preparation that resulted in a publication at the ACM SIGACCESS Conference on Computers and Accessibility 2023 (ASSETS ’23) [138].

### 3.1 Designing and Implementing Jod

*Jod*’s features were iteratively designed using a combination of findings from prior work (summarized in [Table 3.1](#)) and feedback received from the participants in the first study session we conducted. It additionally implements many common features of current videoconferencing platforms (e.g., chat, automated speech recognition for live captions and transcriptions, emoji-based reactions, mute, video on/off indicators, and highlighting video tile of active speakers). [Figure 3.2](#) shows a screenshot of a video call on *Jod* with six active participants (3 DHH, 1 interpreter, 2 hearing individuals). The top panel contains gesture and call control bars. The right panel lets individuals switch between People, Chat, and Transcription tabs. The remaining visual space is used for rendering video tiles and the captions box.

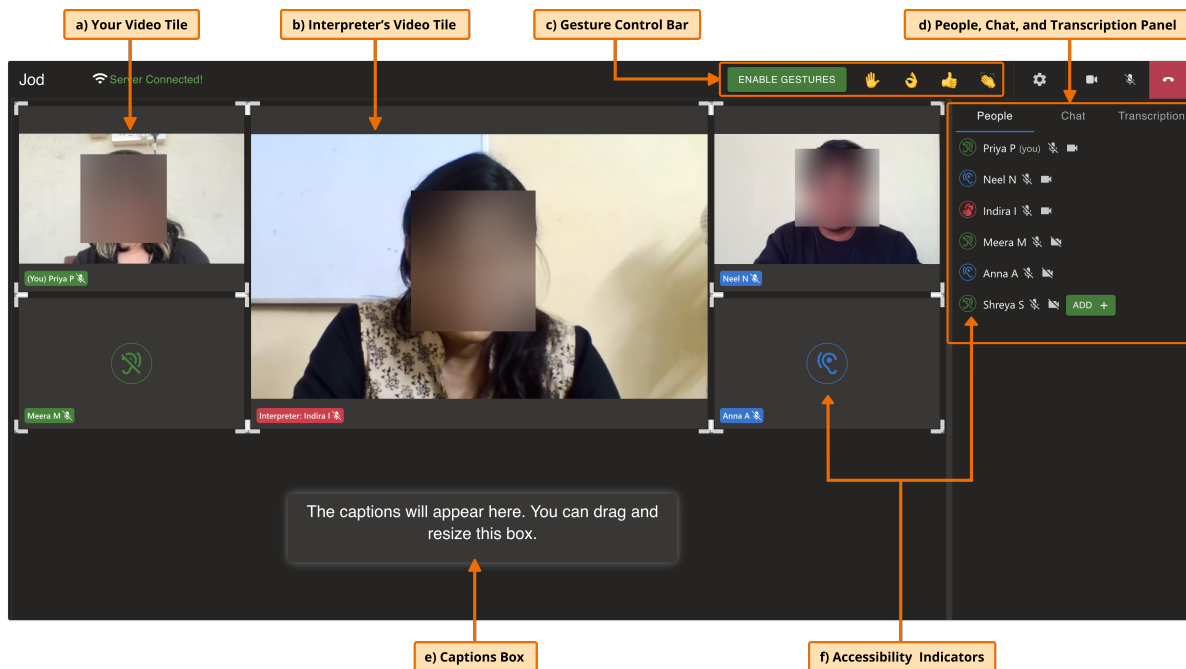


Figure 3.2: Interface of *Jod* with six participants on a simulated video call. The participants include three DHH individuals, two hearing individuals, and one interpreter. From the left: *Jod*'s include: (a) your video tile, (b) the interpreter's video tile, (c) the gesture control bar, (d) the people, chat, and transcription panel, (e) the captions box, and (f) accessibility indicators. Participant names are pseudonyms.

### 3.1.1 Design of *Jod*

We now describe the design of *Jod*'s key features: (1) Customizable Visual Layout, (2) Preset Feedback Messages, (3) Active Signer Identification, (4) Accessibility Indicators, (5) Enhanced Transcription, and (6) Gesture Recognition.

#### Customizable Visual Layout

Multiple studies on challenges in videoconferencing for DHH [101, 108, 168, 204] have identified that current platforms offer limited layout customization. They provide default layouts to choose from and automatically resize and rearrange video tiles. In screen sharing mode, these platforms automatically move all video tiles to different parts (e.g., top, bottom, right) of the screen, with minimal flexibility. The rigidity of such layouts poses a variety of challenges for DHH participants. *Jod* provides participants customizability so they can reorganize their visual layout to suit their personal preferences. All video tiles

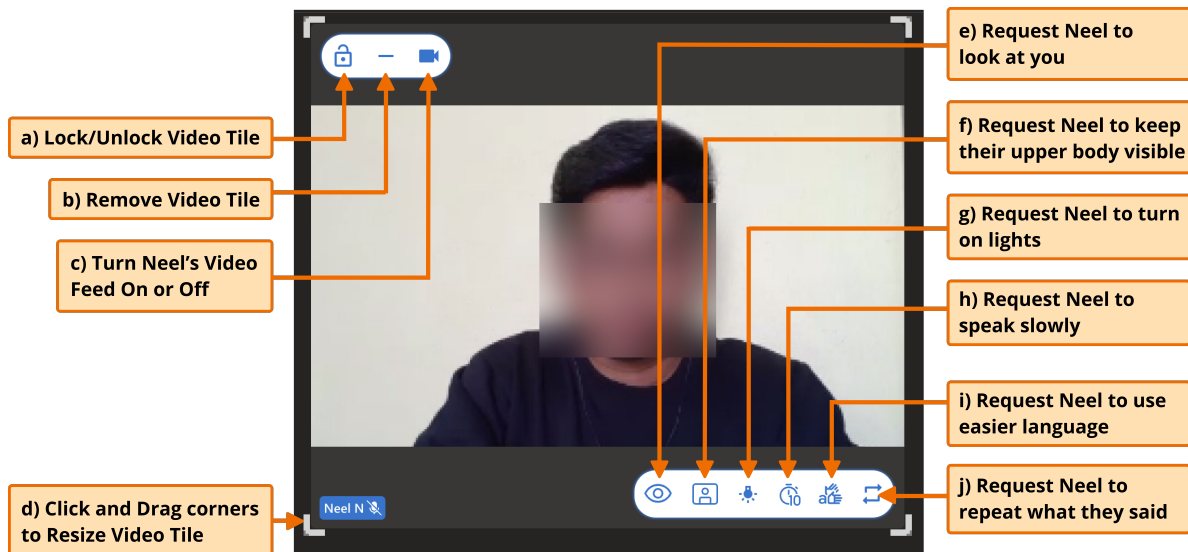


Figure 3.3: The hover state of a video tile on *Jod* supports its *Customizable Visual Layout* and *Preset Feedback Messages* feature. Counterclockwise from the left, the icons on the video tile support: a) locking/unlocking the video tile in visual layout, b) removing video tile from the layout, c) turning participant’s video ON or OFF, d) clicking and dragging corners of the tile to support resizing video tile, e) requesting participant to look at you, f) requesting participant to keep their upper body visible, g) requesting participant to turn on lights, h) requesting participant to speak slowly, i) requesting participant to use easier language, and j) requesting participant to repeat what they said.

(i.e., including the tile of the participant), captions box, and screen share, can be resized, added or removed, and moved anywhere in the visual layout. To resize a video tile, you can click and drag the white handles on its corners (Figure 3.3); to change position of a tile, they click anywhere on the video tile (except the corners) and drag it to the preferred location. Call attendees can also fix the position and size of any video tile(s). To do so, they hover over the tile, and three icon buttons appear in the top-left corner (Figure 3.3). The first button provides a locking feature (same as pinning) that disables resizing and fixes the position of the tile. You can unlock the video tile by clicking again on the same button to allow resizing and repositioning. To reduce visual clutter, participants can either click the second button to remove the video tile from their layout, or the third button to turn off the video stream. To add a removed video tile back to their screen, participants can click the “Add +” button in the People tab (Figure 3.2).

### Preset Feedback Messages

The audio-centric nature of videoconferencing platforms makes it difficult for d/Deaf signers and interpreters to grab attention of other signers. In physical settings, there are Deaf cultural practices, like banging on a desk or flashing lights on and off, to get attention; however, such practices do not translate well to online settings [168]. Studies [94, 179] have also discussed frustrations among DHH signers with speaking behaviors of hearing participants, such as speaking too fast or at a low volume. It can also get difficult for DHH signers or speechreaders to consume information or lip read when backgrounds on a video call are cluttered or not well-lit [108, 204]. Further, when a hearing person wants to interrupt speakers during a call, they can simply unmute and speak up, but DHH participants face discomfort and feel they are interrupting or slowing down the ongoing conversation if they ask questions [168]. To overcome these barriers, there have been design suggestions for building notification systems that can influence behavior or speakers [168, 180]. In *Jod*, on hovering over the video tile of a participant, six icon buttons appear in the bottom-right corner of the tile (Figure 3.3). These buttons can be clicked to send preset feedback messages, such as “Please look at me”, “Please keep your upper body visible”, “Please turn on some lights”, “Please speak slower”, “Please use easier language”, and “Please repeat what you said”. The messages appear as toast elements in the interface of the recipient participant. To ensure that the receiver pays attention, these notifications do not auto-dismiss but must be clicked to close.

### Active Signer Identification

Videoconferencing platforms (e.g., Zoom, Microsoft Teams) have speaking indicators to highlight the active speaker (e.g., a bright border around the video tile of the active speaker appears). This feature does not translate appropriately for d/Deaf signers because the video tile of the interpreter—who ‘voices’ them—gets highlighted. Ang and Liu et al.[168] found that hearing participants tend to engage more with the voice and the person in the video tile whose border gets highlighted in the layout, that is, the interpreter, not the d/Deaf signer. Furthermore, hearing people find it hard to identify d/Deaf signers from the voice of the interpreter [210]. In contrast, the d/Deaf signers feel that because interpreters speak on their behalf and voice their thoughts, their video tile never gets highlighted on these platforms [204]. We utilized a Wizard of Oz method to study this feature in *Jod*. A researcher joined the study sessions (described in Section 3.2) as “Admin”, a special

participant type, and operated an admin panel to indicate when Deaf participants would start or stop signing with a toggle button. For other participants on the call, a blue border around the video tile of the signer would appear, similar to how the video tile of speaking participants were highlighted.

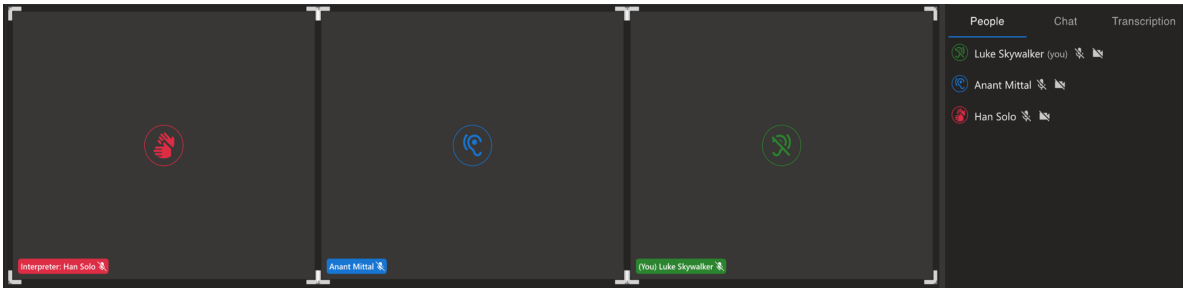


Figure 3.4: Accessibility indicators on *Jod* supports its participants in understanding the accessibility needs of other participants on the call. The red signing icon and red color highlight in the name label are for interpreters, the blue icon and blue highlight in the name label are for hearing individuals, and the green icon and color highlight are for DHH individuals. The same icons, in the corresponding colors, are also repeated in the People panel next to each participant’s name.

### Accessibility Indicators

In mixed ability groups, people may need indicators to understand the accessibility needs of another person. In online or remote group settings, call participants often find it difficult to remember the appropriate accommodations for accessibility (e.g., remembering to speak slowly) [125]. *Jod* supports its participants in gauging the accessibility needs of others with explicit indicators. Participants can share their abilities and accessibility needs by selecting a participant type (e.g., Deaf, Hearing, Interpreter) which are indicated in the interface through different colors, icons, and, for interpreters, an explicit “Interpreter” label (Figure 3.4).

### Enhanced Transcription

DHH individuals often encounter situations where they lack a complete conversational context. Currently, transcriptions and captions in videoconferencing platforms only contain automated speech recognition output. To provide call participants with a holistic view of the conversation, *Jod* enhances audio transcriptions and captions to include preset feedback

messages, emoji reactions, and information when a DHH signer starts or stops signing (Figure 3.5). Transcription text also displays the accessibility needs of each participants through the accessibility indicator feature of *Jod*.

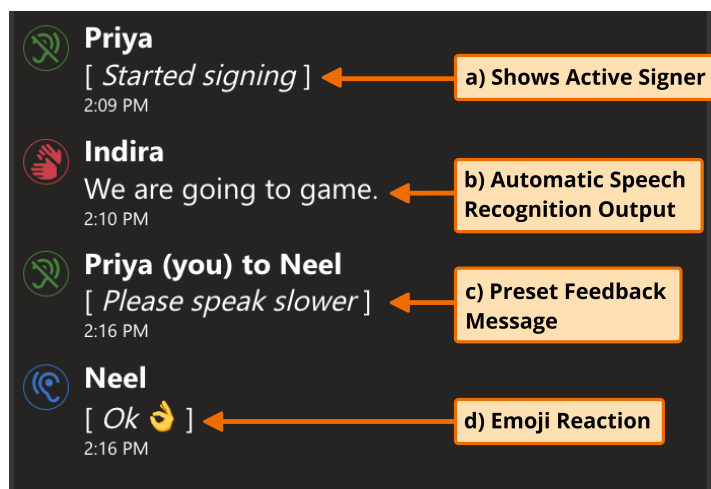


Figure 3.5: The transcription panel on *Jod* includes: a) information on when a DHH signer starts or stops signing b) automatic speech recognition output c) preset feedback messages that the participant sent or received, and d) emoji reactions. Each piece of information is displayed with a timestamp, the sender’s name, and, in the case of preset feedback messages, also the recipient’s name.

### Gesture Recognition

Hearing people can gauge if others are listening and following their conversations in online settings because of their ability to receive verbal backchannel feedback along with non-verbal cues. To increase the ways participants can provide feedback while being on mute, we added four emoji-based gestures: clap, hand raise, okay, and thumbs-up. Participants can enable this feature by clicking on “Enable Gestures” in the gesture control bar (Figure 3.2). When a gesture is recognized, a circular progress bar gets rendered around that emoji. Once the circular progress bar is completed (in  $\approx 1$  sec), the emoji is sent to everyone on the call. To reduce false positives, the person must hold their gesture for a few seconds. Emojis can also be sent by directly clicking one of the four emoji buttons. Some videoconferencing platforms have a similar gesture recognition feature, however, no prior work exists on how people utilize them in mixed hearing conversations, and observe how such background communication interplays with signing.

Table 3.1: *Jod's* features and the addressed accessibility barriers from related work.

<i>Jod's Features</i>	<i>Addressed Accessibility Barriers</i>
<p><b>Customizable Visual Layout.</b> Supports participants in customizing their visual layout by resizing, rearranging, and removing video tiles. They can also reposition and resize the captions box.</p>	<p>Speechreading is challenging due to lack of eye contact and because speaker's gestures and facial expressions can get inaccessible [101]. Suggested Design Direction: Ability to zoom in on the speaker and remove passive participants [101].</p> <p>DHH individuals need to rely on captions when speechreading becomes difficult [101]. Suggested Design Direction: Keep captions near the speaker [101].</p> <p>Vide Conferencing platforms offer limited support to customize visual elements but the needs of DHH participants to rearrange and resize the elements on their screen are unique [108].</p> <p>Maneuvering multiple sources of information during video conferencing (e.g., slides or screen share, signing interpreter, speaker video) [136]. Suggested Design Direction: Semi-transparent video which can be overlaid over a shared screen [136].</p>
<p><b>Preset Feedback Messages.</b> Participants can request others to look at them, keep their upper body visible, sit in well-lit areas, speak slower, use easier language, and repeat themselves.</p> <p><b>Accessibility Indicators.</b> Help gauge accommodations and preferences in mixed hearing settings.</p>	<p>Poor lighting and busy visual backgrounds can make it hard for DHH attendees to speechread or follow signing [108, 204].</p> <p>Bad camera adjustments can be perceived as a lack of engagement [108]</p> <p>Behavior of hearing participants may negatively affect the experience of DHH participants (e.g., speaking at a low volume or speaking too fast) [94, 178, 179]. Suggested Design Direction: Notification systems to influence behavior or hearing participants [180].</p>
<p><b>Active Signer Identification.</b> Focus on DHH individuals who are signing instead of interpreters who are voicing for them.</p>	<p>Difficulty in speaker identification [101, 108, 168, 210] and DHH signer identification through the voice of the interpreter [210]. Suggested Design Direction: Dedicated location for essential elements such as speaker and captions [101].</p>
<p><b>Enhanced Transcriptions.</b> Ensure all call attendees have a shared conversational context through ASR outputs of past conversations, emojis, and start-stopped signing tags.</p>	<p>If a speaker speaks too fast, captions may disappear faster than someone's reading speed [108].</p> <p>DHH participants may miss content and lose conversation context if they look away from their screen and miss reading captions [108].</p>

### 3.1.2 Implementation Details

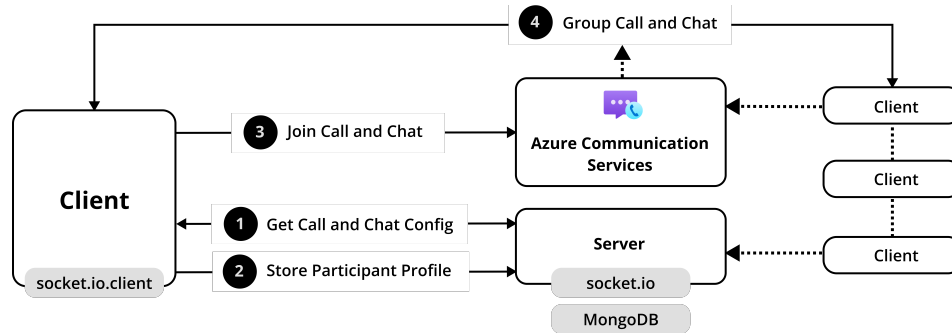


Figure 3.6: System Architecture of *Jod* showing the flow of data between the clients, Azure Communication Services, and the server during a group video call in a browser. A request is sent to the server to 1) get call and chat config, 2) prompt the participant to fill in profile details, which are stored in a MongoDB database, 3) send a request to Azure Communication Services to join the video call, and finally, 4) get authenticated and join the group call and chat.

Figure 3.6 provides a high-level overview of *Jod*'s architecture. *Jod* is developed to be accessible through a web browser and built on top of Microsoft Azure Communication Services (ACS) and Socket.IO to enable group calling and group chat. The client-facing component of the application is built with React, and the server is developed over Node.js and Express.js. To join a group video call, the participant first opens *Jod* in a web browser. A request is sent to the server (1) to get a list of possible sessions the participant can join. Each session holds unique configuration identifiers that ACS needs for group call and chat functionality. (2) The participant is then prompted to fill profile details (e.g., full name, session name, participant type), and this information, along with the unique socket identifier of the client, is stored in a MongoDB database. (3) Using unique identifiers, the client sends ACS a request to join the group call and chat. Finally, ACS (4) authenticates the participant's request, adds them to the group call, and starts sending call- and chat-related information to the client. *Jod*'s *preset feedback messages* feature is powered by Socket.IO for client-to-client communication. Sign detection is a complex problem [23]; due to lack of off-the-shelf AI models that could detect signing with high accuracy, we resorted to a Wizard of Oz method for *Jod*'s *active signer identification* feature. *Jod*'s *enhanced transcription* feature and *live captions* leverages ACS in-built automated speech recognition pipeline for English. The *accessibility indicator* icons for each participant type are from

the Material UI library. For the *gesture recognition* feature, we built an AI pipeline to run within the client’s browser. The pipeline is built with Google’s MediaPipe Holistic model for tracking a person’s hands and runs a post-processing function to further classify each gesture. The colors in *Jod* are accessible, according to the Web Content Accessibility Guidelines. *Jod* collects telemetry that contains visual layout events that are logged when participants alter their layout arrangement by dragging, resizing, removing, or adding any video tile. Each visual layout event contains an array of length equivalent to the total number of participants in the call. Each object in the array has the format ‘{i: string, x: number, y: number, w: number, h: number}’ where ‘i’ is the unique key corresponding to a call participant, (x, y) are the coordinates of the top-left corner of that participant’s video tile with (0, 0) being the top-left corner of the screen, and (w, h) are the width and height of the video tile. The extensive log data supports recreating a participant’s visual layout including the location, arrangement, and size of each video tile. Additionally, *Jod* logs preset messages, gestures, chat messages, and click-based emoji reactions.

## 3.2 Study Design

We conducted six study sessions (S1-S6) involving 34 participants (detailed in [Table 3.2](#)) to investigate the behaviors and perceptions of people navigating mixed hearing conversations on *Jod*. Out of the six sessions, four were conducted in person, while two were conducted remotely. Our study was approved by our Institutional Review Board (IRB) and took place between Nov-Dec 2022.

### 3.2.1 Participant Recruitment

Out of the total 34 participants (13 Female, 21 Male), 18 were Deaf or hard-of-hearing (DHH), 6 were sign language interpreters, and 10 were hearing individuals. Demographic information and session details are listed in [Table 3.2](#). All hearing participants were recruited through our personal and professional networks. For the remote sessions, interpreters were recruited through our professional network and DHH individuals from the National Institute of Speech & Hearing (NISH), an institute for the education and rehabilitation of individuals with speech-language and hearing impairments. For in-person sessions, DHH individuals and interpreters were recruited through our partner organization, WinVinaya Foundation, a nonprofit organization and skills training center for persons with disabilities in Bengaluru, India.

Table 3.2: Detailed demographics of 34 participants (18 DHH, 6 sign language interpreters, 10 hearing) from our six study sessions.

	<i>ID</i>	<i>Age</i>	<i>Sex</i>	<i>Hearing Loss / Role</i>	<i>ISL Proficiency</i>
<b>Session 1 (S1)</b>	P01	22	M	Profound	Intermediate
	P02	25	M	Profound	Intermediate
	P03	22	M	Profound	Intermediate
	P04	26	M	Interpreter (7 years)	Expert
	P05	29	F	Interpreter (7 years)	Expert
	<i>ID</i>	<i>Age</i>	<i>Sex</i>	<i>Hearing Loss / Role</i>	<i>ISL Proficiency</i>
<b>Session 2 (S2)</b>	P06	30	M	Moderate	Intermediate
	P07	28	M	Mild	Intermediate
	P08	25	F	Profound	Expert
	P09	22	M	None	None
	P10	42	F	None	Novice
	P11	35	F	Interpreter (15 yrs)	Expert
	<i>ID</i>	<i>Age</i>	<i>Sex</i>	<i>Hearing Loss / Role</i>	<i>ISL Proficiency</i>
<b>Session 3 (S3)</b>	P12	23	F	Profound	Expert
	P13	22	F	Mild	Intermediate
	P14	22	F	Profound	Expert
	P15	24	M	None	None
	P16	25	M	None	None
	P17	34	M	Interpreter (7 yrs)	Expert
	P18	29	M	Interpreter (6 yrs)	Expert
	<i>ID</i>	<i>Age</i>	<i>Sex</i>	<i>Hearing Loss / Role</i>	<i>ISL Proficiency</i>
<b>Session 4 (S4)</b>	P19	28	M	Moderate	Expert
	P20	22	F	Profound	Intermediate
	P21	25	M	Moderate	Intermediate
	P22	35	M	None	None
	P23	24	F	None	None
	P11	35	F	Interpreter (15 yrs)	Expert
	<i>ID</i>	<i>Age</i>	<i>Sex</i>	<i>Hearing Loss / Role</i>	<i>ISL Proficiency</i>
<b>Session 5 (S5)</b>	P24	24	F	Mild	Novice
	P25	25	M	Mild	Novice
	P26	21	F	Profound	Novice
	P27	22	M	None	None
	P28	24	F	None	None
	P11	35	F	Interpreter (15 yrs)	Expert
	<i>ID</i>	<i>Age</i>	<i>Sex</i>	<i>Hearing Loss / Role</i>	<i>ISL Proficiency</i>
<b>Session 6 (S6)</b>	P29	24	M	Moderate	Intermediate
	P30	22	M	Mild	Intermediate
	P31	23	M	Profound	Expert
	P32	24	M	None	None
	P33	25	F	None	None
	P34	26	M	Interpreter (3 yrs)	Expert

We compensated DHH participants with an INR 750 gift voucher upon completion of the study session. Interpreters were compensated with INR 2500 per session, calculated per the standard cost of interpreting services in India. All our participants had prior experience with video calling applications (e.g., Zoom, Microsoft Teams, Google Meet, Google Duo, WhatsApp). For 2 DHH participants and 7 hearing individuals, this was their first time video conferencing in a mixed hearing group setting. 17 out of 18 participants identified as Deaf and 1 participant was hard of hearing. Indian sign language was the primary mode of communication for the Deaf participants. 10 out of 18 could speechread in regional languages and (e.g., Hindi, Telugu, Malayalam). 3 of these 10 participants were beginner-level speechreaders in English.

### 3.2.2 Study Setup

Each study session was approximately 2.5 hours long and involved 3 DHH signers, 1 or 2 interpreters, 2 hearing individuals, and 2 hearing researchers. While one researcher moderated the call, the other acted as a wizard who was not visible to the participants on *Jod*. We began our sessions by sharing a tutorial of *Jod* followed by task-based explorations, unstructured conversations, games, and a presentation round with screen share. We concluded with a focus group discussion. The study protocol remained consistent for both remote and in-person sessions.

#### In-person Sessions

We conducted in-person sessions because of two reasons – (1) to ensure DHH participants were comfortable and familiar with the study space, and (2) to adjust to any unanticipated system breakdowns and quickly iterate over the study protocol if needed [126]. We conducted four sessions in-person at the nonprofit organization (S2, S4, S5, and S6). In a large open space, we positioned three tables with two chairs at each table and assigned specific seats to each participant to minimize echo and interference. To maintain the ecological validity of our study and to prevent direct communication, we ensured there was no sound or visual bleed between participants outside of *Jod*. Hearing participants were seated farther apart, and moderators were seated next to Deaf participants. We provided participants with laptops and earphones. We also provided notebooks and pens to all participants for note-taking and drawing. We had one interpreter per in-person session; to avoid interpreter fatigue, we took necessary breaks based on the recommended guidelines

followed at the nonprofit organization. Researchers moderating were also present in-person and helped answer any participant questions during the sessions.

### Remote Sessions

We conducted two remote sessions (S1 and S3). All participants joined the sessions from their homes on their personal laptops. The initial introductions, *Jod* onboarding, and focus group discussions were conducted on Zoom. The remaining study-related parts took place on *Jod*. Two interpreters took turns interpreting and switched every 20 to 30 minutes.

### 3.2.3 Procedure

Each session began with introductions and an overview of the research study. The moderators explained how the data would be collected and asked for verbal consent. Throughout the study, the interpreters and Deaf participants communicated in ISL, while the moderators, hearing participants, and interpreters communicated in English. Communication between DHH participants and others was facilitated by interpreters. Sessions consisted of the following six key components, listed chronologically:

#### Jod Onboarding (~10 mins)

To provide consistent training to all participants, we played a ~5 minute video tutorial on YouTube. The tutorial showed one of the researchers using *Jod* and introducing its key features; it included a voice-over and closed captions. An ISL interpreter was additionally present to facilitate communication.

#### Round 1: Task-based Feature Exploration (~30 minutes)

After watching the video tutorial, participants were given an opportunity to ask clarifying questions. Once all participants were ready, they joined the call using *Jod*. After successfully joining the call, both researchers (moderator and wizard) also joined the call. The goal of this round was to familiarize participants with the system and let them interact with its features. To facilitate this, the moderator prompted participants by assigning 10 tasks, one after another. Participants were asked to send a “like” reaction after completing each task so that moderators knew when to proceed to the next one. [Table 3.3](#) describes the 10 tasks but examples included “*Make participant X’s video tile bigger,*” “*Inform me (the researcher) to turn ON background lights,*” and “*Perform raise hand gesture.*”. At the end of

this activity, participants were given 5 minutes to freely explore the system and capture a screenshot of their preferred video-tile layout arrangement.

Table 3.3: We asked participants to explore *Jod*'s system features with 10 task prompts in Round 1: Task-based Feature Exploration.

<i>Task Description</i>	
1	Make a participant's video tile larger or smaller.
2	Move another participant's video tile anywhere on the screen.
3	Remove a participant's video. Add it back by clicking on the Add button in the participant list on the right side.
4	You can also lock a participant's video. If you lock someone's tile, you cannot move them around or resize it.
5	Can you ask me (the researcher) to turn ON my lights?
6	Can you try requesting Participant X to speak slowly?
7	Try clicking on notifications and see what happens.
8	Try gestures like raising your hand, clapping, ok, and thumbs-up. You can also click on the icons on the top right to communicate these reactions.
9	Can you try sending a message on the chat?
10	Can you try resizing and moving the closed captions box?

### **Round 2: Unstructured Conversation (~15-20 minutes)**

To encourage free-form conversations between DHH and hearing participants, the moderator initiated a casual conversation on food preferences. It further progressed to include topics like social celebrations, cities, and occupations.

### **Round 3: Game of Charades (~15-20 minutes)**

During the first in-person session (S2), we observed a lack of direct communication between DHH and hearing participants. To bridge this gap and initiate intermingling across the two groups, we added a modified version of the game of charades to the last three in-person sessions. The moderator divided participants into two teams based on hearing abilities, DHH and hearing, then provided a movie title that one team had to act out, and the other team had to guess. For example, a hearing person would enact to the DHH team, whereas a DHH person would enact to the hearing team. To ensure fair play, the participants were not allowed to sign alphabets or numbers and instead were encouraged to act out movie scenes.

They typed their guesses in the chat tab.

#### **Round 4: Screen Share Presentation (~7-8 minutes)**

To capture participant behaviors on customizable video tile arrangements, the moderator started screen sharing to give a 5-minute talk. She shared slides about an app for sign language speakers and learners. In the end, all participants were asked to capture a screenshot of their video tile arrangements while viewing the shared screen.

#### **Focus Group Discussion (~60-90 minutes)**

After completing the preceding rounds, the researchers conducted a focus group discussion (FGD) with all participants to capture their general perceptions of *Jod* and gather detailed feedback on key features. In-person FGD participants gathered around in a circle. Interpreters had a dual role — as study participants and interpreters. For remote interpreters, FGDs were held on Zoom. Each FGD started with open-ended questions on the overall experience of using *Jod*. We then delved deeper into interactions and experiences with specific features, what participants liked or disliked, and suggestions for additional features in future iterations.

We included a set of varying interaction scenarios because *Jod*'s features are intended to be general purpose, and we wanted to examine their interaction leading to emergent behaviors across scenarios. Screen sharing and non-screen sharing scenarios have been highlighted in prior work [101, 168]. We introduced charades because it requires social interaction that helps establish comfort levels among participants, similar to the Twenty Questions game utilized by McDonnell et al. [131].

### **3.2.4 Data Analysis**

We analyzed the qualitative data, which consisted of ~7 hours of audio recordings from five focus group discussions (S2, S3, S4, S5, S6), researchers' detailed handwritten notes, participants' screenshots of *Jod*, participants' notes, and pictures clicked at the in-person study site. Audio recordings were anonymized and transcribed soon after the sessions were conducted. Focus group discussion data were analyzed using reflexive thematic analysis, as described by [24]. The field data were read several times by the two research team members to identify the initial set of codes. Multiple rounds of open coding were conducted, and codes were rigorously discussed between the researchers for prioritization and grouping into

themes. After a final set of themes was resolved, transcripts were reviewed for relevant participant quotes. Consistent with [Table 3.2](#), the remainder of the chapter refers to participants with their ID and a subscript indication of their ability or role (e.g.,  $P01_{DHH}$  for DHH,  $P04_I$  for interpreter,  $P09_H$  for hearing). For quantitative analysis, we relied on telemetry data from all the rounds except the task-based feature exploration round. S1 was a design feedback session. There was telemetry data loss during S2 and S3. We utilized data from S4, S5, and S6 in-person sessions for the layout-related telemetry analysis. We intend findings from the qualitative data to be our primary focus and consider telemetry data only as a valuable supplement to our qualitative analysis. To understand the relationship between participant abilities and how they interacted with the available screen real estate, we grouped all active participants in the call based on their ability and calculated the average video tile size. For each participant, we extracted the layouts they interacted with for the longest duration per minute and calculated the average video tile size across round(s).

### 3.3 Findings

Participants engaged with the *Jod* system for  $\sim 10$  hours across the six study sessions. Participants rearranged their visual layout 485 times, sent 40 preset feedback messages, and conveyed 30 emojis via gestures. Below, we discuss our key findings, focusing on flexibility and diverse choices of visual layouts across the different participant groups, notifications sent through preset feedback messages to influence behavior of other participants, and cultural nuances and mismatched expectations in mixed hearing settings.

#### 3.3.1 Leveraging Layout Flexibility in Videoconferencing

*Jod* offers its participants complete control over their visual layout (e.g., video tiles of participants, captions). Our participants leveraged this flexibility to tailor the platform to their hearing ability and the continuously changing group communication context. We also describe how participants navigated the multiplicity of assistive features during the study and the constant trade-offs between human labor and system efficiency.

##### Agency to Customize Layout

In the task-based feature exploration round, we asked participants to explore the system and organize their visual layouts per their preference. In response, they actively interacted

with the customizable elements and rearranged the video tiles of everyone, including their own. For DHH participants, we observed that the interpreter was a priority and essential to their communication on the platform; as  $P19_{DHH}$  mentioned, “*I really like the option that I can resize the interpreter and see it clearly,*” and  $P29_{DHH}$  described his layout choice:

“I first chose the interpreter and made their tile bigger because the speaking people are not my priority...the interpreter is my priority. Being deaf, I want the interpreter screen to be big.” –  $P29_{DHH}$

Personal priorities were reflected in the layout arrangements (Figure 3.7) across participants. On comparing the sizes of the video tiles, DHH participants accorded to other individuals on the conference call; we found that they allocated maximal visual space to the interpreter (Figure 3.7c - 3.7f and Figure 3.8a). For DHH participants, a Kruskal-Wallis test revealed a significant effect of *participant ability* on average video tile size ( $\chi^2_3 = 24.99, p < 0.0001$ ). A pairwise comparison using Wilcoxon rank sum test with Bonferroni correction showed significant differences between the video tile size of the interpreter and (1) DHH participants ( $Z = -3.64, p < 0.01$ ), (2) hearing individuals ( $Z = -3.68, p < 0.01$ ), and (3) their self-video tile ( $Z = 3.74, p < 0.01$ ).

Similarly, in the screen share presentation round, the interpreter’s video tile remained significantly different except relative to the screen share video tile (Figure 3.7i - 3.7k and Figure 3.8b). This suggests that DHH participants gave equal importance to the interpreter and the screen share. The ability of the participant had a significant impact on the video tile area of the interpreter ( $F_{1,13} = 5.1473, p \approx 0.04$ ). Comparing the size of the interpreter’s video tile between DHH and hearing participants, we found that the interpreter tile in the visual layouts of DHH participants ( $59.7 \pm 22.2$ ) significantly exceeded the size the hearing participants gave to the interpreter ( $33.7 \pm 20.9$ ), with  $t = -2.3, p \approx 0.04$ . This was also true in the screen share presentation round.

In addition to allotting prominent visual space to the interpreter, DHH participants discussed their layout choices for organizing other DHH and hearing participants. Although some preferred to keep all participants on the screen, with hearing participants occupying minimal visual space, others chose to remove hearing participants entirely to free up visual space. For instance,

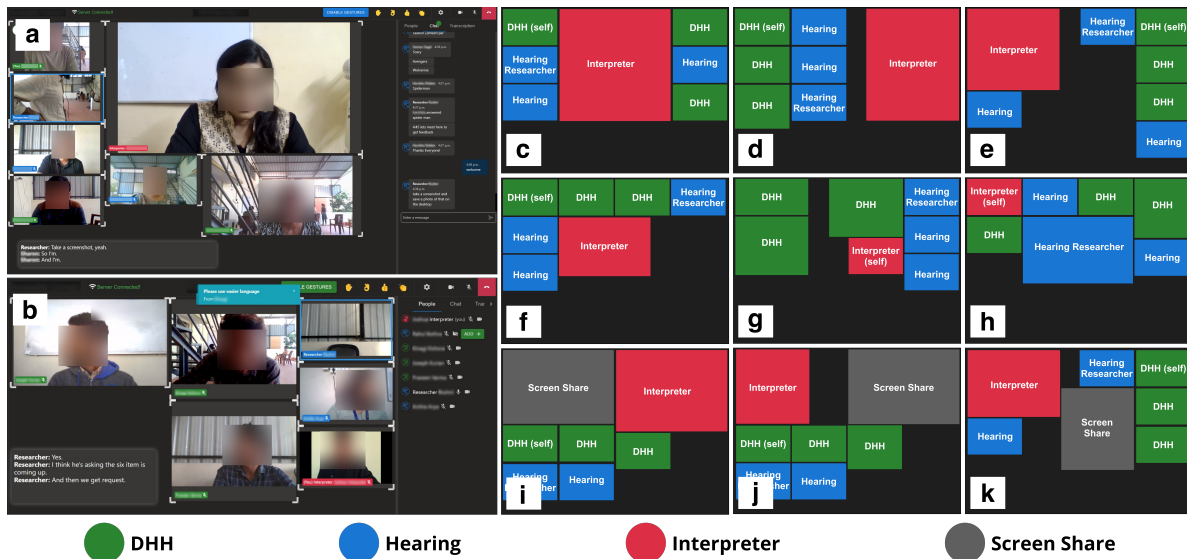
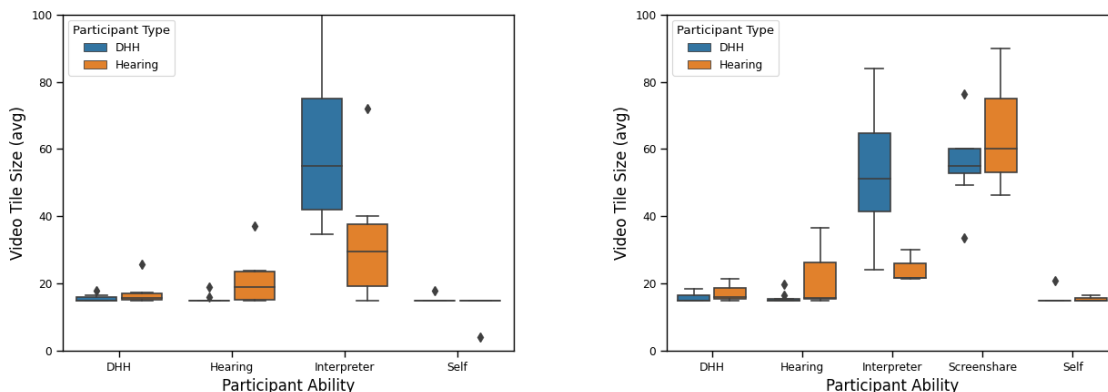


Figure 3.7: Screenshots of *Jod* from study sessions and visual layout abstractions generated using telemetry: (a) layout of a DHH participant where video tile of the interpreter is largest, (b) interpreter’s layout with DHH participant video tiles larger than others and one hearing participant’s video tile removed, (c) to (f) are examples of other arrangements DHH participants created keeping the interpreter’s video tile largest, (g) interpreter’s layout where DHH participant video tiles were enlarged, (h) interpreter’s layout where hearing researcher’s video tile was enlarged, and (i) to (k) are examples of arrangements DHH participants created when screen sharing was active, with interpreter’s video tile and screen share competing for visual space. Additionally, in (d), we see grouping based on hearing abilities, where the participant arranged DHH and hearing individuals in two vertical columns. Similar vertical or horizontal grouping based on hearing abilities also exists in (e), (f), (g), (i), (j), and (k).

“I would only want to see the deaf participants... so I can have all the deaf participants and the speaker (interpreter) on the screen. This allows me to manage the screen so the interpreter and the deaf participant are side-by-side.” –  $P13_{DHH}$ .

Similarly, we found that interpreters resized the video tiles of DHH participants and the researcher conducting the study session, making them bigger than the other video tiles (Figure 3.7g, 3.7h). This behavior was motivated by the need to follow the DHH signers and their facial expressions, as  $P34_I$  noted, “My main priority was to see the deaf candidates clearly and understand what they are signing... if their tile is very small, then I would not



(a) Without Screen Share: It reinforces that DHH participants made the interpreter’s video the largest. Compared to the interpreter video tiles in hearing participant layouts, DHH participants made the interpreter’s video significantly larger.

(b) With Screen Share: DHH participants enlarged the interpreter and screen share tiles in screen share rounds by similar amounts. In contrast to DHH, hearing participants only enlarged the screen share tiles.

Figure 3.8: Two bar plots comparing the video tile sizes (average) of other participant types in DHH and hearing participant visual layouts during a call on *Jod*. The x-axis represents participant abilities: DHH, hearing, interpreter, and self. The y-axis represents the average video tile size. The blue color represents DHH individuals, and yellow is for hearing individuals.

*be able to understand their signs properly.*” All but one interpreter kept all the hearing participants on the screen; *P18<sub>I</sub>* surrounded their video tile with DHH participants and removed all other hearing participants except the hearing researcher. Another interpreter, *P11<sub>I</sub>*, kept the “*deaf participants on the top... to see all their reactions.*”

In addition to rearranging video tiles, participants actively interacted with other customizable visual elements, such as closed captions and the screen share tile. DHH and hearing participants interacted and reorganized the captions (Figure 3.7a). For instance, *P33<sub>H</sub>*, a hearing participant, described her arrangement of the captions and the video tiles of the interpreter to grasp the ongoing interpretation better:

“I arranged it like... I had all the hearing people (on the left side), deaf people (in the center), and the interpreter (on the right side), and the captions below that. I made the captions and interpreter larger so that I can keep up with the

interpreting and make sense of how the words are being interpreted.” – *P33<sub>H</sub>*

This flexibility to reorganize multiple visual elements augmented the communication abilities of the participants and facilitated comprehension. Most participants felt agency and control to align the *Jod* platform to their personal preferences. As *P12<sub>DHH</sub>* shared, “*It was very independent. I could resize whoever I want. Like the hearing people, I could move them aside... put them below the deaf people. It was very good overall.*”

### **Adapting to Dynamic Group Communication Context**

Besides aligning *Jod* according to their hearing abilities, participants did on-the-fly visual rearrangements to keep pace with the continuously changing group communication context. Dynamic rearrangements also supported participants in keeping their video layout organized and helped them prioritize the active speaker or signer. For instance, the ease of dynamic rearrangement helped a hearing participant prioritize different players responsible for acting during the game of charades:

“My usual goal was to keep as few tiles as possible on the screen. I would usually just have the researcher’s tile who was speaking... on the right side. On the left side, I would have the interpreter’s tile just out of curiosity to see how the interpretation was going on. And closed captions running at the bottom. While playing charades, whoever was doing sign gestures, I would just add their tile.” – *P32<sub>H</sub>*

In addition, *Jod* conveyed if someone started signing by highlighting their video tile and adding the “*started signing*” message in both the closed caption and transcription. *P11<sub>I</sub>*, who had been interpreting for 15 years, shared that it helped her track the signer(s) since it is challenging to keep track of who is signing on video calls. It also helped her envision future notification modalities to help with attending to the active signer.

“Let’s say in a group of 30 hearing and 2 DHH folks, it is hard to keep track when someone starts signing... but as it appears [in the] captions box, I can keep track. There should be a way to notify the interpreter that someone started signing to focus on their video tile.” – *P11<sub>I</sub>*

*P32<sub>H</sub>*, a hearing participant, recalled that he preferred a minimum number of video tiles

in his layout, he had the researcher (who was the active speaker), the interpreter’s video tile, and the close captions running in the bottom. However, during charades, the “started signing” message helped him identify whose video tile to bring back to the visual layout. Other participants also described dynamically adding and increasing the visual space of the active speaker’s video tile. For instance,  $P25_{DHH}$ , who would usually remove the hearing participants from her video layout, said,

“If they were speaking or asking some question, I would bring them to the screen – otherwise, I would just remove them from my screen.” –  $P25_{DHH}$

While having the active hearing participant on screen was not a necessity for most DHH participants, they engaged in such usage patterns when provided with an accessible option to do so.

### Offering Flexibility through Multiplicity

*Jod* also offered flexibility to its participants through the multiplicity of various videoconferencing features. Participants can understand the context of ongoing conversations by following the interpreter and reading the automated speech recognition output, either in closed captions or transcriptions. We found that while conversing with hearing individuals, DHH participants (like  $P29_{DHH}$ ) simultaneously referred to video tile of the interpreter and the transcriptions/captions. Transcriptions were preferred to catch up on conversations, while real-time captions were leveraged to verify if anything was missed by the interpreter or lost in translation. As  $P19_{DHH}$  explained, “*Both are useful and [I] used both. Because cc (closed captions) happens in real time... if I have forgotten something, I could go up and see it in the transcript*”. Captions also served as a fallback mechanism for DHH participants to continue conversations when the interpreter was unavailable; as  $P13_{DHH}$  noted, “*If there was an internet lag and the interpreter froze, I could look at captions*”. Interestingly, a hearing participant,  $P32_H$  also referred to the transcriptions when he “*missed something in the captions*” (e.g., when someone sent a reaction that he missed because it went away too fast).

In addition, participants could communicate emoji reactions (like thumbs-up) either via signing (through *Jod*’s gesture recognition feature) or by clicking on the emoji icons. In the study sessions with telemetry data for emoji reactions (i.e., S3–S6), people sent a total of 72

emoji reactions, of which 30 were through AI gesture recognition and 42 were click-based. DHH and hearing participants felt that gesture recognition took too long to send a reaction: *“It wasn’t super useful for me, partly because it took like 4s to detect. So, keeping my hand raised in the air for 4 seconds? It’s easier for me to just click that button.”* – P32<sub>DHH</sub>. Participants also brought up instances when there were false positives; as P28<sub>H</sub> mentioned, *“when I was holding my pen up... it recognized it as a thumbs-up gesture.”*

We find that flexibility through multiplicity gave participants more than one option to choose and helped them adapt to the changing needs of mixed hearing group conversations (e.g., partial unavailability of interpreters).

### 3.3.2 Connections through Notifications in Mixed Hearing Settings

*Jod* introduces a novel way to disseminate notifications (i.e., through Preset Feedback Messages), in mixed hearing conversations. We detail how these notifications helped connect the DHH, hearing, and interpreters. Though they generally enhanced communication among participants, they were occasionally found to be obtrusive and to leave the sender in limbo due to a lack of acknowledgment of receipt mechanisms.

#### Connecting DHH, Hearing, and Interpreter

When asked about using feedback messages, participants recounted being able to connect with others of different hearing abilities without interrupting the ongoing conversation. Prior studies highlighted that DHH participants seek minimal clarifications to avoid interrupting the conversation [168]. However, *Jod* supported DHH participants in overcoming this. As P12<sub>DHH</sub> said, *“This is much better because it does not distract other people – I could just directly send them the feedback – can you please repeat – so that was really good, actually, very different.”* Moreover, these notification mechanisms helped DHH participants connect with interpreters in multiple ways, from flagging their attention to requesting better background lighting. For instance, P19<sub>DHH</sub> noted, *“One issue we always have is the issue of getting the interpreter’s attention or getting another deaf person’s attention in sessions when there are deaf on the call.”* To this, P11<sub>I</sub> added,

“...therefore, they (DHH) always flash on the camera. If some person is talking and they want that person’s attention, they do <flashing>. However, if I specifically want P19<sub>DHH</sub>’s attention when there are 50 people, I would

repeatedly do <flashing> and his sign name. If he sees me, he'll say *P11\_I*. So that's how we would get each other's attention." – *P11\_I*

However, with *Jod*, *P29\_DHH* instead chose to send the “*Please look at me*” feedback message to capture the interpreter's attention.

In addition to augmenting the communication between DHH participants and interpreters, these feedback messages also helped the DHH and hearing participants converse directly. *P22\_H*, who had never previously conversed with DHH individuals, shared how preset messages helped him directly converse with a DHH participant:

“Another interesting feature I realized initially – the way I arranged my screen, I removed my tile. I was like why should I see my own tile. Instead, I will make everyone else bigger. I think someone sent me a message saying to be more visible. I realized that I should put my video tile back so that I can reorient.”  
– *P22\_H*

He further described it as a “*new kind of experience*” and agreed with others that it made things easier by removing interpreters from the loop for these conversations.

### **Capturing Attention and Acknowledging Notification Messages**

While these notification mechanisms aided in capturing attention, several participants highlighted two major shortcomings: its obtrusive design and lack of acknowledgment of receipt mechanisms. When asked about their experience with feedback messages, participants reported the notification messages often overlapped with the video tiles, which felt visually “*distracting*.” For instance, *P33\_H* shared,

“The way it was coming, it was actually coming in the middle of the screen, and a lot of notifications were coming together. So that was a bit distracting from what was going on. So maybe if it comes on the side or in the chat, then that would be better... because I was missing what people were signing/speaking on the screen. There were a lot of notifications, and unless I went and clicked on them, it did not disappear.” – *P33\_H*

Participants must click on notification messages to dismiss them and clear their screens. Additionally, such visual distractions were particularly challenging for interpreters, requiring

them to pause their signing, possibly resulting in information gaps momentarily. As  $P11_I$  mentioned, *“I think [P25<sub>DHH</sub>] sent ‘turn your lights on’ to me thrice by mistake, and that remained on my screen... So I had to put my sign down to disable all those three notifications. I had to manually click on the notifications to disable it.”* As a result, multiple notifications hampered the ongoing interpretation, causing the interpreter to miss the signing.

Participants also highlighted the lack of acknowledgment or receipt mechanisms for these notifications. This resulted in participants being unsure about whether the receiver received their sent feedback message, as  $P12_{DHH}$  mentioned

“When we click – can you please repeat – to send it to the interpreter, there is no feedback feature to know if the interpreter has actually received that message... The message has been sent to the interpreter, but how does the sender know that the interpreter has received that message?” –  $P12_{DHH}$

To overcome this, one DHH participant manually clarified his confusion and *“asked [P11<sub>I</sub>] if she got a notification, and she said yes.”*

In addition to manual interventions seeking acknowledgment of notification receipt, participants suggested their desire for automated ways to acknowledge notifications. For instance,  $P28_H$  suggested, *“I would want it to be acknowledged. If I am on the receiver’s end, then I would want to acknowledge it – am I in a position to do that? Have I made that change? Can I not make the change? Will I make it later?”* This demonstrates that acknowledgment extends beyond mere confirmation; it is equally important for the receiver to inform the sender if, how, and when they will respond to the request. However,  $P11_I$ , an interpreter, expressed reservations about this suggestion: *“That might be challenging from an interpreter’s perspective because while they are interpreting, they might not be able to provide an acknowledgment by clicking – so we might just have to do a sign and say yes or okay.”* As a result, it might be useful to explore non-click-based acknowledgment mechanisms.

### **Supporting Additional Preset Messages**

Our participants were inspired by preset messages and made creative suggestions to support mixed-ability conversations. For example,  $P07_{DHH}$  requested “please mute/unmute yourself”

because, “for the hard of hearing, some of them rely on voice. Also, if there’s a lot of background noise, they can request to disable it.” Other participants discussed the utility of feedback messages during communication breakdowns (e.g., preset messages could inform participants that their “internet is bad” or “screen is frozen.”). For internet issues at the interpreter’s end, such feedback messages could be beneficial in alerting everyone and preventing information gaps. *P08<sub>DHH</sub>* added,

“If, for example, the internet is slow and someone is signing – you are in a very odd position. (laughs). Is there a way to message, "Sorry I’ll join back" or something like that instead of just freezing their video.” – *P08<sub>DHH</sub>*

Apart from suggestions about different preset messages, one participant commented on the design of feedback notifications, reflecting on their earlier interaction during the charades round. She noted that most participants would speak/sign “repeat” while guessing during charades instead of using the “please repeat yourself” preset message. She added,

“Why is it easier to say it and have it interpreted than to just use that button? The point of the button was to reduce the labor of that action...you need a much larger or bolder notification that does not look like other notifications to ask you to repeat yourselves.” – *P28<sub>H</sub>*

This indicates the need to consider communicating different preset messages using different form factors. For example, a bolder notification might be helpful if the message is essential and requires urgent attention.

### **3.3.3 Flexibility with Automated Support to Reduce Labor**

Study participants appreciated the flexibility offered by *Jod*. However, our participants realized they had to labor extra to align the platform with their communication needs. We now detail how participants envisioned complementing flexibility with automated support from the platform to enhance their experience.

#### **Customized Templates to Reduce Labor**

We observed that the flexibility to reorganize the visual layout per specific needs enhanced communication experience for the participants. Yet, a few participants found it challenging to navigate through this flexibility to create the best layout for themselves. For instance,

*P28<sub>H</sub>* complained, “*The chat is one thing, the on-screen captions is another, and the interpreter’s video is another. So currently, it’s like... it’s the labor of the hard-of-hearing participant, that they have to maneuver everything out – how do I see everything together? It should be on the part of the technologists to provide all these together easily.*” Other participants also noted the labor required, especially for repetitive tasks. For instance, *P13<sub>DHH</sub>* mentioned, “*I shouldn’t have to go and remove individual participants... we can have one option where I can click to show only deaf participants... we could just click that.*” Automating such repeated tasks, including adding or removing participants based on hearing ability, would help to reduce human labor.

In addition, *P23<sub>H</sub>* suggested adding a feature to revert the rearranged layout to the default one automatically:

“With respect to the resizing that we do in the starting – if there was an option to revert to the original layout, like default mode because what happened with me, accidentally, I think, I increased someone’s screen, I mean, someone’s window and the button for the window disappeared somewhere, and I just couldn’t go back – the resizing, the white corner, yeah, it accidentally went to someplace. So it would be really nice to have that kind of an option.” – *P23<sub>H</sub>*

Participants suggested providing custom layout templates to reduce their initial effort in reorganizing the default layout. *P27<sub>H</sub>* said, “*With respect to the maneuvering, maybe you can have a bunch of templates instead of leaving everything to the user? They can pick, they don’t have to do everything, but they can if they want to.*” To decide on the custom templates, a hearing participant, *P28<sub>H</sub>*, suggested basing it on focus group discussions and usage patterns of *Jod*:

“...hearing all of these conversations, it would be so nice to have an optional template for the interpreter, an optional template for DHH participants that takes into account all these different perspectives and comes up with the best possible layout. For example, now we know that the interpreter needs to see the hard of hearing participants – there should be a template that reduces the labor of the interpreter. Similarly for DHH participants, if you constantly keep hearing that there is no point in seeing the hearing participants – then there could be a

template that could cater to that.” – *P28<sub>H</sub>*

Such templates could replicate the most frequent layout of each participant group, and platforms could offer flexibility as an additional feature. In addition to providing custom video tile arrangements, it is essential to consider for each custom template the placement and size of widgets (e.g., chat windows, closed captions, transcripts, reaction buttons) and how the system should react (e.g., update the size and position of other video tiles when a participant is customizing their visual layout). Participants had to manually resize those ‘other’ tiles to arrange their visual layout in *Jod* optimally. For example, *P19<sub>DHH</sub>* mentioned,

“So I just had 4 participants (on my screen), and I resized one of the video tiles... the others should get automatically resized to fit that grid. I shouldn’t have to manually increase the size of the others... it should automatically maximize others’ video tiles to reduce the blank space on the grid.” – *P19<sub>DHH</sub>*

Manually resizing was time-consuming and redundant labor, creating challenges for participants to configure their visual space optimally. Overall, we find that flexibility comes with added costs, which could be reduced by offering automated support and customized templates to participants based on their hearing abilities.

### **Automated Support for Grabbing Attention**

When designing *Jod*, we gave the shared screen a slightly larger tile size than the video tiles of participants. Still, we did not make it as prominent as current video conferencing platforms do. Though most participants navigated their way and reorganized it ([Figure 3.7i](#) - [3.7k](#)), we observed a strong desire for automated ways to prioritize the shared screen. *P07<sub>DHH</sub>* commented, “*When someone else is sharing their screen, it doesn’t pop up on my screen... It comes as a small window. That person had to inform me that he had shared the screen, and I zoomed in on that screen.*” This caused information gaps and additional labor on the participant’s end. Instead, participants wanted the shared screen to be larger than other tiles when it loaded to capture attention and then have added flexibility to resize if required.

In addition to the shared screen, some participants also expected smart behaviors from *Jod* to grab attention, especially while interrupting or asking questions. For example, *P21<sub>DHH</sub>*

said,

“If someone raises their hand – automatically they should come to the main grid. If they have a question or they have a doubt, then they can ask, so I know who is exactly asking the question or doubt.” – *P21<sub>DHH</sub>*

While common videoconferencing platforms offer these capabilities, participants complained about the constant video tile switching in these platforms, that makes it particularly challenging for DHH participants. A hearing participant, *P23<sub>H</sub>*, suggested that *“the interpreter should stay static, and maybe the others – we could have some priority order. If there is a crosstalk kind of a thing – it shouldn’t switch that much.”* Therefore, it might be beneficial to design automated mechanisms to capture attention yet avoid unnecessary switching and enable the ability to set priorities for certain participants.

Participants also suggested providing automatic focus toward other widget elements, such as the chat window, in case of new messages. Particularly, DHH participants and the interpreter complained about missing new messages unless someone explicitly informed them; as *P11<sub>I</sub>* stated, *“when they were chatting, I did not realize that they had typed in the chat unless they told me.”* This is perhaps because DHH participants and interpreters are constantly engaged in signing, making it hard for them to look away to stay updated with the chat. To mitigate this, *P22<sub>H</sub>*, a hearing participant, suggested,

“The DHH participants were doing the actions, but we were guessing in the chat. They were also pausing and looking in the chat. At some stage, these interactions have to grab your attention. The chat has to be bang in the middle. So it has to be like you know you overlay the text on the entire screen because when we were signing, they were looking at their screen... not looking at the corner. So overlay the text over the video – especially for games like charades, not always.” – *P22<sub>H</sub>*

In general, then, we find that *Jod*’s flexibility lets participants customize layouts to meet their preferences; there is an inherent need for intelligent support to achieve optimal layouts and visual spacing and to flag participant attention.

### 3.3.4 Beyond Communication: Norms and Mismatched Expectations

We now discuss the varying cultural and communication norms among DHH and hearing groups we observed in our study and how that can result in mismatched expectations in mixed hearing communication contexts.

#### Cultural and Communication Norms in Mixed Hearing Settings

During the study, we discovered that some participants—specifically, DHH participants and interpreters—relied on various cultural practices to ensure efficient communication. For instance, to capture people’s attention in a group conversation, *P11<sub>I</sub>* shared,

“If the person is talking and they (DHH) want that person’s attention, they always flash on the camera... they keep blocking [and unblocking] the camera, you notice something going black and white, they do that. However, if I specifically want [*DHH person name*]’s attention when there are 50 people (on the call), I would repeatedly do this [sign their name]. If they see me, they’ll say [sign back my name]. So that’s how we would get each other’s attention.” – *P11<sub>I</sub>*

These workarounds make communication between DHH participants and interpreters more efficient. In Deaf culture and sign language, a sign name (or a name sign) is a special sign to identify a person, and it is a common practice to employ sign names when communicating with one another. However, participants (both DHH and interpreters) were not familiar with other sign names of other participants. To navigate this, we found that interpreters relied on alternatives, such as “fingerspelling their name” or saying “S hearing person or M hearing person” to provide contextual speaker information while interpreting. However, *P24<sub>DHH</sub>* talked about the time-consuming nature of such strategies: “*Say a person is asking a question, I don’t know their sign name, and spelling their entire name is time-consuming... if we could have a number along with the names of the participants – like 1, 2, 3, 4, 5, and the name... I could just say number 1, like an ID, to save time.*” Since hearing participants often do not have sign names, designing such suggested solutions could save time and enhance communication experience for everyone.

Another key characteristic of Deaf communication is the extensive reliance on visual cues, such as facial expressions and backchanneling gestures. As *P25<sub>DHH</sub>* mentioned, “*The Deaf like to respond a lot while people are talking...they are very expressive, that’s*

*the Deaf culture. So they might give a thumbs-up while someone is speaking.*” This was not the case for hearing participants, who primarily relied on audio cues to establish conversational connections. A few DHH participants even wanted hearing participants to be more expressive, as *P30<sub>DHH</sub>* reveals:

“I want hearing people to use their expressions so that I can connect with their captions – what they are feeling and what they are trying to say. So that it can help me to understand better.” – *P30<sub>DHH</sub>*

### **Inherent Lags and Mismatched Expectations**

Despite *Jod*'s assistive capabilities, several communication gaps persist within mixed hearing group conversations. These gaps often resulted from the mismatched communication norms and expectations of different participant groups. For example, DHH participant reliance on visual cues and expressions vs hearing participant reliance on audio cues produced communication gaps: *“As a hearing person I rely on audio cues when someone starts speaking to me. I am not necessarily always looking at everyone’s video tile. So, say, when a deaf person wants my attention or when they have started signing in a charades game, I don’t realize it until unless the interpreter tells me that this person is speaking to me.”* – *P28<sub>H</sub>*. Moreover, several participants expressed frustration about the inherent gaps due to interpretation delays. Multiple delays were witnessed during the informal conversation round when hearing participants (including the researcher) or DHH participants told a joke. And the other participant group needed to wait for it to be interpreted. For example:

“Anytime you (hearing person) make a joke, we (other hearing people) will always laugh first, whereas half of the participant group (DHH people) has not yet had the joke interpreted for them. There is a lag, which kinda puts the hearing participants on the upper hand of the power dynamic because we are almost able to have different levels of conversation that might not be inclusive.”  
– *P28<sub>H</sub>*

We find similar communication lag in conversation dynamics during the game of charades, especially when the movie name was guessed first by hearing participants. Moreover, during the FGDs, we observed that except for a few DHH participants who wanted hearing participants to be more expressive, most DHH participants were content with

communicating through the interpreter. Interestingly, a few hearing participants sought a deeper connection with DHH participants, extending beyond the interpreter’s verbal communication. *P33<sub>H</sub>*, a hearing participant, even expressed uncertainty about whether what she said was being understood by DHH participants:

“I am not very confident if my words have been reached, if a deaf person has identified that ‘oh, *P33<sub>H</sub>* is speaking’, have they registered that? Do they feel that particular connection with me? Or not? Or they’re just thinking it to be a part of the talk... or just a grand continuation of what was going on.” – *P33<sub>H</sub>*

Overall, we find that the communication norms between DHH and hearing participants differed significantly, resulting in communication gaps, uncertainties, and misaligned expectations. Furthermore, these gaps were a barrier to deeper connections sought by some participants in mixed hearing videoconferencing.

## 3.4 Discussion

In examining the design and implementation of *Jod* for mixed hearing groups, we found that the flexibility and multiplicity that *Jod* offered supported participants in customizing their interface to meet their personal preferences and continuously changing group communication context. Notifications tailored to mixed hearing ability conversations helped different participant groups to better communicate with each other. Building upon [Section 3.3](#)’s reporting of mixed hearing group experiences with *Jod*, we now discuss several implications for future accessibility research in videoconferencing platforms. We discuss the need (1) for balance, to provide customization with automated support, (2) to overlay context-aware notifications with means for acknowledgment, and (3) to further explore features adhering to cultural practices. We further provide recommendations for conducting mixed hearing studies. Below we discuss them in detail.

### 3.4.1 Flexibility vs System-Provided Defaults

Prior work has identified layout-related challenges faced by DHH people in videoconferencing platforms [[101](#), [108](#), [168](#), [204](#)], including the inability to keep other signers in view, difficulty in consuming information when the video tile of signer is small, and the inability to reduce visual clutter while consuming information from multiple sources. In our sessions, we observed participants actively customize *Jod*’s visual layout

to create diverse layout arrangements (e.g., enlarging video tiles of the interpreter, removing hearing participants, rearranging video tiles of DHH participants closer to each other). They updated their layout preferences multiple times as the study sessions progressed and the group communication context changed. Though such customization provides participants control of their visual environment, it can increase human labor; many participants therefore wanted responsive layouts that would automatically fill up empty screen space or a way to transition back to the default layout. Some DHH participants felt the burden of individually removing or resizing video tile of each participant. We witnessed this constant tension between the need for complete flexibility versus the support they expected from the platform.

### **Design Recommendations**

To reduce human labor and increase platform support, we recommend adding options for quick layout modifications (e.g., one-click actions to add or remove video tiles based on hearing ability, a back button to revert any layout changes), similar to hiding non-video participants option that Zoom offers [198]. Additionally, we recommend having optional video layout templates to choose from based on group context, substantiating Ang and Lee et al.'s suggestion for customizable layout templates [168]. These predefined templates need to be dynamic and should account for several attributes of the ongoing mixed hearing group conversation (e.g., group and individual accessibility needs, number of signers with active videos, presence or absence of interpreters) to suggest layouts that are contextual and useful. Though the interpreter was available in our study, we observed DHH participants relying on captions and transcriptions for multiple use cases, such as to verify interpreters' voicing or when the interpreter's video got stuck due to low internet bandwidth. Thus, these layout templates must also accommodate appropriate placement for captions and transcriptions. Finally, future research should study this amalgamation of flexibility with templates, particularly automated ways to optimize screen real estate while supporting call participants in creating their preferred layout.

#### **3.4.2 Context-Aware Notifications**

In *Jod*, participants used preset messages to influence behavior of other participants. Prior work have studied the designs of notification systems for DHH individuals to grab attention of others and provide feedback [168, 180]. Our findings offer critical insights into the future

designs for notifications and delivery mechanisms. We observed the disruptive nature of alerts that participants speculated in a prior work [131]. We implemented a click-to-dismiss interaction to ensure that notifications were dismissed only after the receiver had seen them. However, while signing, interpreters stand slightly away from their videoconferencing setup to ensure their upper body, hands, and head are visible in the video. This made it difficult for them to dismiss notifications quickly, thus cluttering their visual layout with messages. Similarly, hearing participants felt that notifications were distracting and they felt interrupted. Furthermore, *Jod*'s design did not inform the sender if, how, and when the recipient of their message will respond to their request, leading them to send more notifications and further causing interruptions for the recipient.

### **Design Recommendations**

In future designs, researchers could explore making notifications less distracting. Further designs can be explored on how recipients could acknowledge them and how this information gets relayed to the sender. Our findings suggest that notifications are not equally urgent and may have an underlying priority based on the group communication context. For example, requesting active speakers to repeat what they said is more critical than asking passive participants to adjust their upper body. The priority of a message can be represented through visual design concepts like high-contrast colors and larger font sizes. The system could filter the repeats to not overwhelm the recipient with the same notification. Besides person driven notifications, we could have system notifications to support mixed hearing groups. For example, intermittently losing an interpreter's audio or video introduces information gaps in a mixed hearing ability conversation. Thus, similar to network connection notifications like poor connectivity, the interpreter's absence can be communicated at a system level. Similarly, informing participants that they are out-of-frame can also be the responsibility of the system. Computer vision algorithms to detect if someone's upper body and hands are not visible or if they are sitting in poor lighting can support that. On the recipient's end, there should be multiple ways to acknowledge the received message (e.g., "I will do it", "I cannot do it"). To support participants in interacting with notifications while they are signing or interpreting, additional modalities (e.g., swipe right/down gestures) can be studied further.

### 3.4.3 Integrating Deaf Cultural Norms

A sign name (or a name sign) is a unique sign used to identify a person, and it is an integral part of Deaf culture [132]. As the hearing participants and researchers did not have sign names, DHH participants and the interpreter shared their struggle in referring them using fingerspelling [23], leading to increased labor and further information gaps. Furthermore, not knowing each other's sign names could also lead to a disconnect with the DHH individuals on the call. A DHH participant suggested adding numeric identifiers for each hearing individual in the platform to ease the action of referring them.

#### Design Recommendations

To be more inclusive, some videoconferencing platforms now have an option for participants to add and share their pronouns as part of their identity [197]. Similarly, videoconferencing platforms could allow adding sign names to participant profiles through short self-recorded videos. Future explorations would need to distill how this integration works for hearing participants because typically, sign names are given to hearing individuals by another person from the Deaf community [16, 137]. We believe this could be a small step towards introducing a rich part of Deaf culture to videoconferencing platforms. The profiles on the videoconferencing platform could further ask participants to add their accessibility needs and preferred communication methods. As discussed previously, these details could help the system increase its awareness and provide contextual support.

### 3.4.4 Towards Conducting Inclusive Mixed Hearing Studies

With the emergence of research surrounding video-mediated communication within mixed hearing groups [100, 124, 125, 131, 179], several studies have outlined considerations for designing and facilitating inclusive studies [126, 168, 180]. Some recommendations proposed by studies employing participatory design to explore the future of videoconferencing include DHH representation within research team [130, 168], developing communication norms [126, 168], and use of appropriate phrasings [168]. Mack et al. discussed that academic papers often omit access accommodations and the labor put into making research methods accessible in accessibility studies [125]. Based on our experience in examining *Jod*, we now reflect and highlight several considerations and discuss implications for future research.

While conducting our study, we realized the “messiness” of our method and the importance

of iterating over the study protocol. In the initial sessions (S2 and S3), we primarily relied on a researcher-facilitated informal conversation to encourage interactions among DHH and hearing participants. Though our participants were engaged, the conversations remained organized, researcher-driven, and lacked intermingling between the two groups. In the fourth study session, we introduced a *Charades* play round to improve this. In addition to facilitating cross-communication, *Charades* enhanced the overall experience and made the study much more enjoyable for our participants. Based on our learnings, we encourage accessibility researchers to be more flexible, open, and adaptable to quick iterations. Future studies could also explore novel, creative methods similar to *Charades* that could facilitate better intermingling and comfort and create a playful experience in mixed hearing studies. Such methods could particularly benefit studies involving system exploration, as they would facilitate closer to the natural, real-world interactions among both DHH and hearing groups.

Prior studies in HCI and Accessibility have also highlighted the need to consider the accessibility of the full-method pipeline, from selecting a research method to analyzing the data [126]. In our study, the in-person sessions were conducted in the workplace of our DHH participants. We opted to conduct focus group discussions (FGDs) instead of semi-structured interviews for two main reasons: (1) to encourage participants, both DHH and hearing, to express their individual and collective viewpoints and engage in group discussions, and (2) to mitigate the burden of interpretation and minimize transcription expenses. We observed a clear distinction between the remote and in-person FGDs. The FGDs conducted in person, where participants and researchers were in close physical proximity to each other, proved to be more engaging and interactive, as opposed to the FGDs conducted over Zoom. However, given the structured nature of remote FGDs and the advanced capabilities of Zoom, the transcription was straightforward, unlike that for the in-person FGDs, which posed difficulties due to lack of established communication norms. E.g., speaker identification posed a significant challenge during the transcription of in-person FGDs, as the interpreter failed to indicate the corresponding DHH participant while interpreting, leading to information gaps in our audio recordings. To address this issue, we relied on our handwritten notes to map the participant quotes with the respective speakers. We argue in-depth discussions are necessary to establish effective communication protocols, specifically around *when*, *how*, and *where* to lead focus groups in mixed hearing settings.

Lastly, as most of our hearing participants had limited experience interacting with DHH individuals, they were unsure of how to communicate with the DHH participants through the interpreter. For example, one hearing participant asked whether to direct her gaze toward the DHH signer or the interpreter. In alignment with prior recommendations [168], we encourage establishing clear communication protocols for both DHH and hearing participants.

### 3.5 Limitations

The *Jod* system and study design have several limitations. First, our findings focused on medium-sized mixed hearing groups and may not generalize to large group settings. Second, some of *Jod*'s design choices may not scale well to large groups of people. For instance, the participants anticipated the effort it would take to manually resize and remove or add video tiles if more people were on the call. Third, a critical use case for videoconferencing platforms is to present information through screen sharing, and the type of shared content varies. Though we explored a screen sharing experience during the study session, it was limited since DHH participants did not experience the complexities that arise with sharing multimedia presentations. For example, the DHH participants did not experience the challenges of following a speaker while viewing a shared screen, which is a common scenario in group meetings. Future work should explore how DHH participants interact with shared content in group settings, such as following a speaker while viewing a shared screen. Fourth, as the DHH participants and interpreters were recruited from the same partner organization for some sessions, our observations and findings could have been influenced by the comfort of participants already knowing each other. Each session also had the same ratio of DHH to the interpreter to hearing participants, which is possibly different in different settings in real-world group conversation. Finally, though our study design was motivated by real-world situations, the limited time people spent on *Jod* was insufficient to recreate diverse group contexts that could have led to communication challenges. For example, though the DHH participants favored *Jod*'s *accessibility indicators* feature, given they might have known each other would have made the feature less valuable during the study. Our work can inform future research on conducting large-scale longitudinal studies and exploring different group compositions across session activities.

### 3.6 Sociotechnical Gap in Jod

*Jod* can be situated within the context of Ackerman’s sociotechnical gap (discussed in [Section 2.1](#)) as a deliberate attempt to bridge the divide between social requirements (i.e., what we know we must support socially) and technical capabilities in videoconferencing systems for mixed hearing groups. *Jod* employed palliatives at ideological and educational levels. Stakeholders participated in the entire research lifecycle of *Jod* (e.g., people who are d/Deaf or hard of hearing (DHH), hearing individuals, sign language interpreters). The research team was interdisciplinary with an appropriate balance of expertise and educational background (e.g., HCI researchers with expertise in accessibility, staff of an organization with significant experience working with DHH individuals). *Jod* is a feature-rich system with several partial solutions (i.e., wide range of functionalities and capabilities that cater to diverse but specific needs and contexts). *Jod* is also an artifact that advanced the science of the artificial through its examination as a communication, collaboration, and coordination platform in real-world contexts of mixed hearing groups.

It addressed several characteristics of the sociotechnical gap:

- *Flexibility and Nuance.* *Jod* provided more flexibility in communication by offering customizable visual layouts, preset feedback messages, and enhanced transcriptions. This aligns with Ackerman’s observation that human activity is nuanced and contextualized, while technical systems are often rigid. By supporting people to resize, reorganize, and add / remove video tiles, *Jod* empowered participants to adapt their visual layout based on their specific needs and changing communication contexts.
- *Multiple Communication Methods.* Videoconferencing for mixed hearing groups requires supporting diverse communication methods simultaneously. By integrating various communication methods such as sign language, speech, enhanced captions, and gestures, *Jod* supported the diverse and fluid nature of human interaction that Ackerman highlights as challenging for technical systems. For example, *Jod* also highlights the video tiles of active signers to balance the audio-centric design of current videoconferencing platforms.
- *Contextual Awareness.* *Jod* incorporates features such as accessibility indicators and active signer identification, attempting to provide more contextual information that is

crucial in mixed hearing interactions but often challenging to capture technically. This aligns with Ackerman’s observation that technical systems struggle to incorporate the contextual knowledge that humans employ effortlessly.

Despite its efforts, *Jod* still faced challenges that exemplified the sociotechnical gap:

- *Balancing Flexibility and Automation.* *Jod* provided customization capabilities that gave participants control over visual layouts, which led to additional manual labor. The participants desired a balance between customization and automated support, highlighting the difficulty in creating systems that are flexible and efficient.
- *Missing Nuance in Notifications.* The study revealed issues with the notification system, such as their disruptive nature and the lack of nuanced feedback mechanisms for the interpreter, reflecting the gap between social activity in a mixed hearing setting and technical implementations.
- *Cultural and Communication Norms.* The study observed varying norms between DHH and hearing groups, leading to mismatched expectations, an example of the sociotechnical gap where technical systems struggle to accommodate diverse social contexts.

As Ackerman indicated, the sociotechnical gap did not completely close, but *Jod* demonstrated how we can better understand and incrementally narrow this gap by carefully considering social requirements in mixed hearing settings.

### 3.7 Chapter Summary

We designed and developed *Jod*, a videoconferencing platform integrating design recommendations from prior work to facilitate remote communication in mixed hearing groups (e.g., supporting participants in customizing their visual layout, providing a notification system for soliciting attention of other attendees and influencing speaker behavior, balancing audio-centric designs of videoconferencing platforms through highlighting video tiles of active signer(s), incorporating accessibility indicators into participant profiles).

We examined how *Jod* supports communication, collaboration, and coordination in

mixed hearing groups through 6 study sessions with 34 participants, including 18 DHH participants, 10 hearing participants, and 6 Indian Sign Language interpreters.

We found a strong correlation between the hearing abilities of the participants and their preferred visual layout arrangements. The DHH participants made the interpreter's video tile significantly larger than the hearing participants and chose to move the closed captions closer to the interpreter's video tile. Participants also engaged in visual layout-related rearrangements to adapt to the changing group communication context. Participants further reported improved communication between DHH signers, hearing participants, and interpreters through preset feedback messages.

We then discussed implication of our findings in terms of designing for balance between flexibility and system-provided automated defaults, the need for acknowledgments and prioritization of received messages based on the group communication context, and exploring designs adhering to Deaf cultural practices. We also provided recommendations for conducting inclusive mixed hearing studies, including the importance of iterating on the study protocol and the need for accessibility researchers to be more flexible, open, and adaptable to quick iterations. Our findings therefore both inform the design of future platforms for mixed hearing communication, collaboration, and coordination and suggest future opportunities for related HCI and CSCW research.

## Chapter 4

### SCOPE: Technology-Enhanced Collaborative Care of Depression and Cancer

Worldwide incidence of cancer is expected to exceed 28 million people in 2040 [195]. Depression is a common challenge during and after cancer treatment, with rates as high as 24% [104, 158]. Depression can arise due to reactions to phases of the cancer journey, social factors, physical side effects, and neuropsychiatric effects of certain cancers and their treatments [76, 158, 187]. Challenges in treating depression among cancer patients include: (1) a lack of specialized training among oncology providers to detect and diagnose depression [129, 153, 201]; (2) a lack of standard processes for psychosocial follow-up and treatment adjustments [220]; and (3) inadequate availability of behavioral health providers [46, 91, 165, 206].

*Collaborative Care Management* (known as *collaborative care*) is an evidence-based system of care that has led to sustained improvement in depression symptoms in patients with cancer and other medical conditions [6, 88, 207, 209]. It is a population-based and measurement-based approach to integrated psychosocial care [53], where behavioral health care managers who are clinicians (e.g., social workers) deliver behavioral treatments, coordinate psychosocial care, monitor outcomes, and adjust treatment with input of a psychiatric consultant and a patient's cancer care team. Collaborative care coordinates cancer treatment with treatment of other symptoms (e.g., anxiety, low mood, loss of interest, low energy, poor concentration). *Behavioral Activation* is a core psychosocial component of collaborative care, effective for treating depression [43, 45], including in cancer patients [78, 80]. Behavioral activation promotes engagement in valued activities (e.g., walking to support physical health, calling friends to support relationships) and reducing maladaptive behaviors (e.g., social withdrawal, avoidance) as part of interrupting a

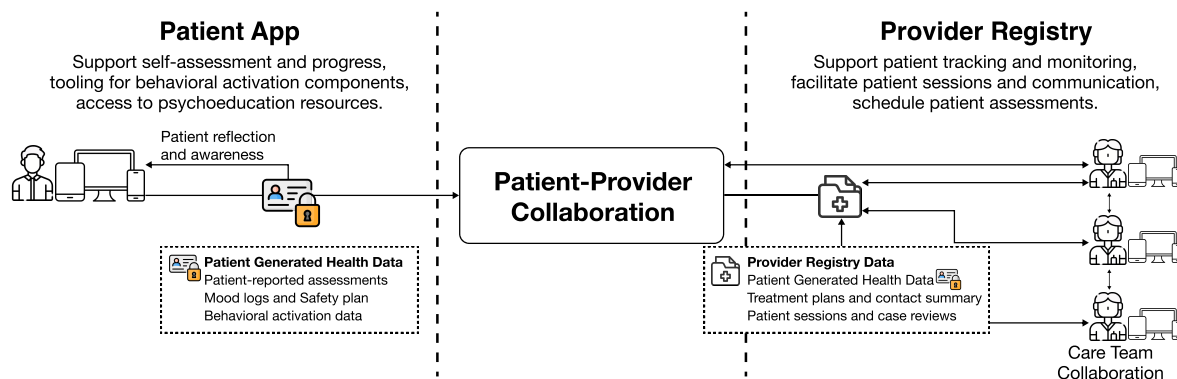


Figure 4.1: *SCOPE* is designed to support collaborative care management and behavioral activation. It combines a patient-facing mobile app and a provider-facing web-based registry. The patient app supports self-assessment, progress tracking, behavioral activation, and provides access to psychoeducation resources. Patient-generated health data, such as assessments, mood logs, safety plans, and behavioral activation data which support reflection and awareness, are also visible in the provider registry to support patient-provider collaboration. The provider registry supports patient tracking and monitoring, facilitates patient sessions and communication, and enables scheduling patient assessments. Care team collaboration and coordination are supported in collecting, organizing, and reviewing data on a population of patients in the registry.

vicious cycle wherein reduction of meaningful and pleasant activity exacerbates depression.

Although collaborative care has been found effective for patients with cancer and depression [55], important challenges remain. Suh et al. studied experiences and breakdowns in collaborative care for patients with cancer and depression through contextual inquiries with behavioral health providers and interviews with patients and other stakeholders (i.e., oncologists, psychiatrists, behavioral health providers) [194]. They found patients with cancer and depression struggle to navigate cancer and psychosocial care journeys, introduced the parallel journeys framework for characterizing challenges of patients and their care teams, and highlighted opportunities for technology support focused on breakdowns between patient-provider sessions. Informed by Suh et al.'s analyses of breakdowns and opportunities, we design and deploy *SCOPE* (Supporting Collaborative Care to Optimize Psychosocial Engagement). Illustrated in Figure 4.1, *SCOPE* combines: (1) a *patient-facing mobile app* providing information, resources, and support for activities related to behavioral activation, with (2) a *provider-facing web-based registry* supporting clinical tasks among collaborating

providers (e.g., collecting, organizing, reviewing data about a population of patients). A key innovation in *SCOPE* is direct integration of patient-generated data into the provider registry (e.g., validated depression assessments, behavioral activation activity data, mood logs).

This presentation of our research in *SCOPE* contributes the following:

- We report data collection through a total of 45 interviews with cancer patients and their behavioral health providers, conducted throughout design and deployment of *SCOPE*. This includes 26 design interviews (i.e., 14 with patients, 12 with behavioral health providers) in approximately 15 months of design and development, then 19 deployment interviews (i.e., 10 with patients, 9 with behavioral health providers) in approximately 24 months of deployment in actual care in 6 cancer clinics.
- We report findings that *SCOPE* supports both patients and behavioral health providers in the goals of its underlying collaborative care and behavioral activation interventions, starting with patients describing that *SCOPE* supported their engagement with its interventions.
- We report findings that patient-generated data in *SCOPE* supports improved patient-provider collaboration between and within in-person sessions, with patients and providers describing that patient-generated data: (1) helped patients feel connected to their provider, (2) decreased time spent recalling relevant information within in-person sessions, and (3) improved shared decision-making between patients and providers.
- We report findings that *SCOPE* supports providers, with providers describing that structure and collaboration supported by *SCOPE* improved: (1) patient sessions and care team caseload reviews, and (2) knowledge-sharing between care team members.
- We report findings that participant experiences with *SCOPE* created evolving expectations around patient-generated data: (1) patients described seeking additional provider recognition and support, and (2) providers described seeking additional registry capabilities.
- We share insights into implementation barriers that surfaced as part of our design

and deployment of *SCOPE* for actual care in 6 cancer clinics for 24+ months: (1) challenges in determining if *SCOPE* is appropriate for a patient, (2) challenges of providing patients justification for using *SCOPE*, and (3) challenges in integrating with existing tools.

- We discuss implications of our findings in terms of: (1) designing for engagement with a behavioral health intervention, (2) the importance of negotiating patient data sharing and provider responsiveness, (3) opportunities for supporting personalized self-tracking goals in evidence-based interventions, (4) opportunities for exploring the role of digital health navigators in technology-enhanced care, and (5) the need for flexibility in aligning technology-supported interventions to patient needs.

[Section 4.1](#) describes data collection throughout design and deployment of *SCOPE*, including design interviews, an overview of the resulting design, the clinical trial in which *SCOPE* is deployed, deployment interviews, and our analysis of data collected in a total of 45 interviews. [Section 4.2](#) reports findings in terms of the above-noted themes identified in analysis, [Section 4.3](#) discusses implications of our findings for the design of future platforms for technology-enhanced care and future opportunities for related HCI and CSCW research. [Section 4.4](#) shares limitations to consider in interpreting our findings, and in [Section 4.5](#), I situate *SCOPE* within the context of Ackerman’s sociotechnical gap (as discussed in [Section 2.1](#)).

The *SCOPE* system and research described in this chapter was completed in collaboration with Tae Jones, Ravi Karkar, Jina Suh, Spencer Williams, Yihao Zheng, Lydia M. Andris, Nicole Bates, Amy M. Bauer, Ty W. Lostutter, Jesse R. Fann, James Fogarty, and Gary Hsieh. I contributed to: developing and maintaining the system, along with others; conducting participant interviews as part of a team; collaboratively analyzing qualitative data; and leading the manuscript preparation that resulted in a publication at the ACM SIGCHI Conference on Computer-Supported Cooperative Work & Social Computing 2025 (CSCW ’25) [138]. This research has also to date resulted in a workshop publication I led at ACM CHI Conference on Human Factors in Computing Systems (CHI ’23) Workshop on Bridging HCI and Implementation Science and a American Psychosocial Oncology Society 2023 (APOS ’23) poster led by our clinical collaborators.

## 4.1 Designing and Deploying *SCOPE*

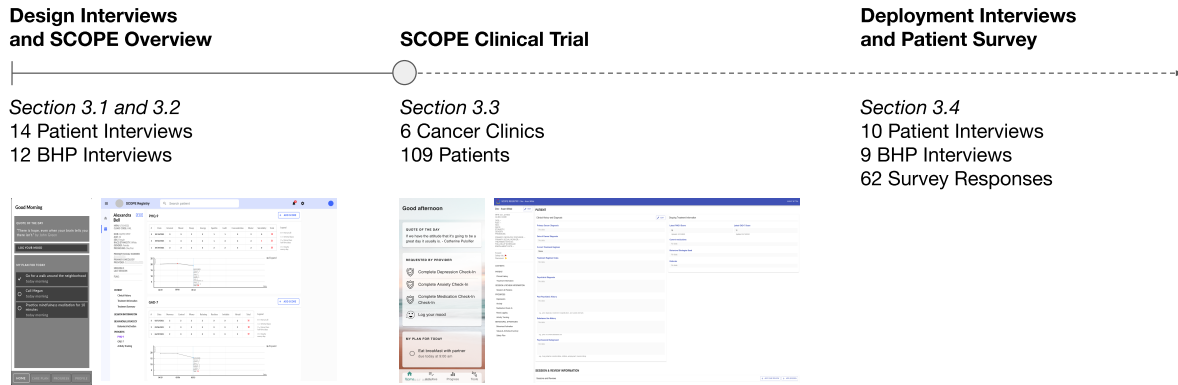


Figure 4.2: Timeline of our research in the design and deployment of *SCOPE*. Section 4.1.1 presents 26 design interviews conducted in approximately 15 months of iterative design, and Section 4.1.2 presents the resulting design of *SCOPE*. Section 4.1.3 describes a trial deploying *SCOPE* for actual care in 6 cancer clinics for 24+ months. Within the context of that clinical trial, Section 4.1.4 presents an additional 19 deployment interviews.

Our design and deployment of *SCOPE* as a platform for technology-enhanced collaborative care includes research goals of examining how a multi-stakeholder platform around patient-generated data can support core components of both collaborative care and behavioral activation.

*SCOPE* is further informed by needs and opportunities identified by Suh et al. [194]. They studied breakdowns in collaborative care for patients with cancer and depression through contextual inquiries with behavioral health providers and interviews with patients and other stakeholders (i.e., oncologists, psychiatrists, behavioral health providers). They characterized challenges of patients and care teams in navigating parallel patient cancer and psychosocial care journeys, highlighting opportunities for technology support in breakdowns between patient-provider sessions: (1) providing tools for self-assessment, (2) providing tools for population-based patient monitoring, (3) providing access to evidence-based psychosocial interventions, (4) documenting shared understanding between patients and providers, (5) supporting timely and appropriate communication, and (6) improving access to online and community resources.

Table 4.1: An overview of patient participant data in research with SCOPE, including 14 design interviews and 10 deployment interviews.

	<i>ID</i>	<i>Self-Reported Race &amp; Ethnicity</i>	<i>Age</i>	<i>Sex</i>
<b>14 Patient Design Interviews</b>	Pt1	White / Not Hispanic	77	Female
	Pt2	White / Not Hispanic	21	Male
	Pt3	White / Not Hispanic	66	Female
	Pt4	Multiracial / Not Hispanic	56	Female
	Pt5	White / Not Hispanic	51	Female
	Pt6	White / Not Hispanic	72	Male
	Pt7	Black / Not Hispanic	60	Female
	Pt8	White / Not Hispanic	61	Female
	Pt9	White / Not Hispanic	59	Female
	Pt10	Black / Not Hispanic	62	Male
	Pt11	American Indian / Not Hispanic	78	Female
	Pt12	White / Hispanic	31	Female
	Pt13	Multiracial / Not Hispanic	54	Female
	Pt14	White / Not Hispanic	66	Male
	<i>ID</i>	<i>Self-Reported Race &amp; Ethnicity</i>	<i>Age</i>	<i>Sex</i>
<b>10 Patient Deployment Interviews</b>	Pt15	White / Not Hispanic	43	Female
	Pt16	White / Not Hispanic	79	Female
	Pt17	White / Not Hispanic	63	Female
	Pt18	Black / Not Hispanic	28	Female
	Pt19	White / Not Hispanic	75	Female
	Pt20	White / Not Hispanic	48	Female
	Pt21	White / Not Hispanic	65	Female
	Pt22	White / Not Hispanic	66	Male
	Pt23	White / Not Hispanic	47	Female
	Pt24	White / Not Hispanic	63	Female

We build upon these results while conducting new iterative design research and examining patient and behavioral health provider experiences with the deployed *SCOPE* system.

[Figure 4.2](#) overviews our additional research activities, including 45 interviews conducted throughout *SCOPE*'s design and deployment. [Section 4.1.1](#) first introduces 26 design

Table 4.2: An overview of provider participant data in research with *SCOPE*, including 12 design interviews and 9 deployment interviews. Some providers participated in multiple rounds of interviews (e.g., because some clinics had very few behavioral health providers).

	<i>ID</i>	<i>Number of Interviews</i>
<b>12 Provider Design Interviews</b>	BHP1	2 Design Interviews
	BHP2	1 Design Interview
	BHP3	1 Design Interview
	BHP4	2 Design Interviews
	BHP5	2 Design Interviews
	BHP6	1 Design Interview
	BHP7	1 Design Interview
	BHP8	1 Design Interview
	BHP9	1 Design Interview
	<i>ID</i>	<i>Number of Interviews</i>
<b>9 Provider Deployment Interviews</b>	BHP2	2 Deployment Interviews
	BHP4	2 Deployment Interviews
	BHP8	2 Deployment Interviews
	BHP10	1 Deployment Interview
	BHP11	1 Deployment Interview
	BHP12	1 Deployment Interview

interviews conducted during our iterative design process, and [Section 4.1.2](#) then presents the resulting design of *SCOPE*. [Section 4.1.3](#) describes our deployment of *SCOPE* in 6 cancer clinics for 24+ months as part of an ongoing clinical trial. Within that deployment and clinical trial, [Section 4.1.4](#) reports an additional 19 patient and behavioral health provider interviews together with 62 patient survey responses, all based in experiences with the deployment of *SCOPE* in actual care. Finally, [Section 4.1.5](#) describes analysis of resulting data throughout the design and deployment of *SCOPE* and provides clarity in how the remainder of this paper reports data from these stages of design and deployment.

Participants were recruited from the 6 cancer clinics participating in the associated clinical trial. Study procedures were approved by our Institutional Review Board. All sessions were

conducted and recorded over Zoom and transcribed using Otter.ai. Additional study data was collected and managed using REDCap electronic data capture tools [72, 73].

#### 4.1.1 Design Interviews

We conducted 26 design interviews (i.e., 14 with patients, 12 with behavioral health providers) over 15 months, in parallel to iterative design and development of *SCOPE*. Design interviews gathered feedback, guidance, and reactions to: (1) a patient mobile app providing information, resources, and support for behavioral activation activities, (2) a web-based registry supporting clinical tasks of collaborating providers (e.g., collecting, organizing, reviewing data about a population of patients), and (3) direct integration of patient-generated health data into the provider registry (e.g., validated depression and anxiety assessments, mood logs, behavioral activation related activity data).

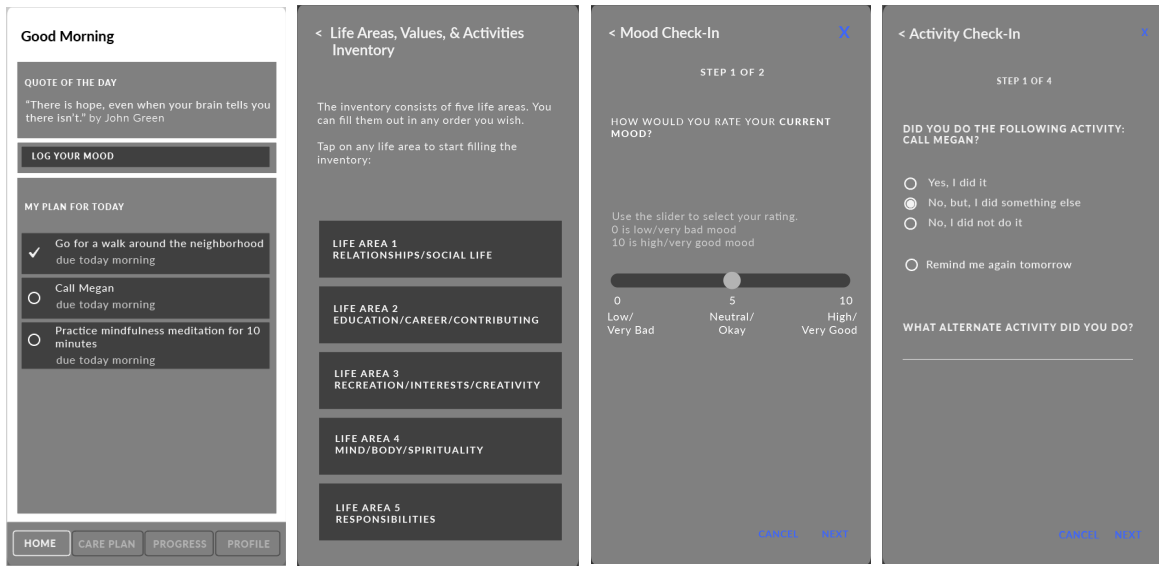
#### Participants

We recruited cancer patients who were at least 18 years old, with PHQ-9  $\geq 10$ , with at least one endorsed cardinal symptom (i.e., depressed mood or anhedonia). These are conservative criteria for clinically significant moderate to severe depression in cancer patients [205]. Participants are summarized in Table 4.1 (i.e., 14 patient design interviews) and Table 4.2 (i.e., 12 behavioral health provider design interviews). Some behavioral health providers participated in multiple rounds of design interviews (e.g., because some clinics had very few behavioral health providers). To ensure participant anonymity, we intentionally do not further characterize providers (e.g., do not report specific clinics from which they were recruited).

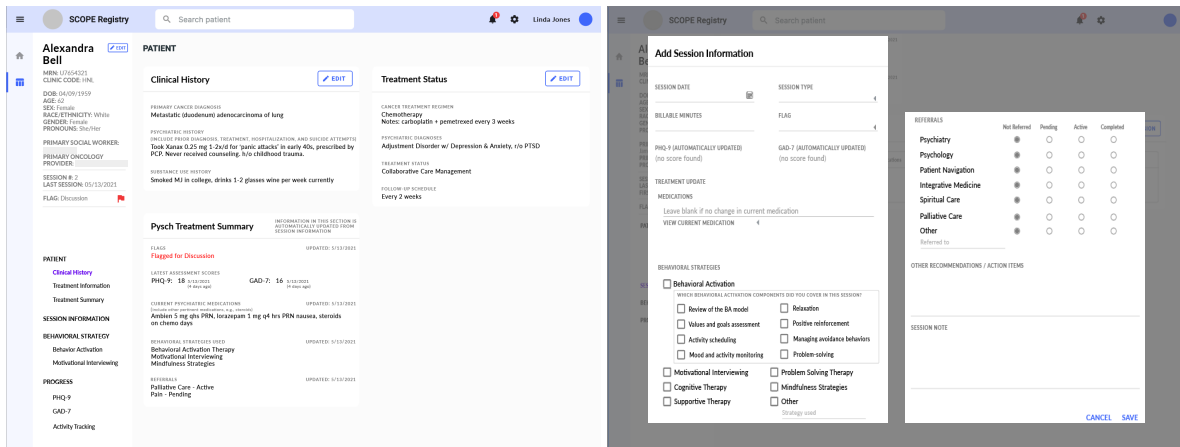
#### Procedure

We conducted three rounds of design interviews, iterating on the design and prototype between each. Participants in each round were introduced to the then-current design, using it as a technology probe [84]. Patient participants also received a brief introduction to behavioral activation. Participants were prompted via open-ended questions regarding aspects of the design they liked, perceived challenges, and desired design changes. Interviews lasted 60 to 90 minutes. Participants were offered a gift card for their time, although many provider participants were unable or unwilling to accept direct compensation.

Scenarios explored with patients included mood logging, identifying personal values as part



(a) Early mockups of the *SCOPE* patient app, showing support for viewing provider-assigned and patient-scheduled action items, a values and activities inventory, mood logging, and activity logging.



(b) Early mockups of the *SCOPE* provider registry, showing support for viewing patient treatment status and recording notes about a patient session, including tracking relevant components of behavioral activation.

Figure 4.3: Early mockups of *SCOPE*, iteratively designed and used for feedback in Section 4.1.1's design interviews.

of a values inventory, adding and scheduling specific activities corresponding to personal values, logging activities, completing a remote assessment assigned by their behavioral

health provider, and examining their activity and assessment history. [Figure 4.3a](#) shows elements of an early design used in patient interviews. Scenarios explored with behavioral health providers included reviewing an overview of the patient population, creating a new record about a patient, adding information about a patient session, examining patient-submitted assessment data, reviewing patient progress, preparing for a case review with a patient’s care team, and presenting a patient’s information during a case review. [Figure 4.3b](#) shows elements of an early design used in these provider interviews.

System Usability Scale data collecting during design indicated participants found the design “Excellent” or “Good” [115]. 14 patients gave the patient app an average SUS score of 84.5 ( $\sigma = 14.4$ ). 6 behavioral health providers gave the registry an average score of 89.2 ( $\sigma = 6.6$ ). The remainder of the paper focuses on more nuanced insights surfaced through qualitative data and analyses.

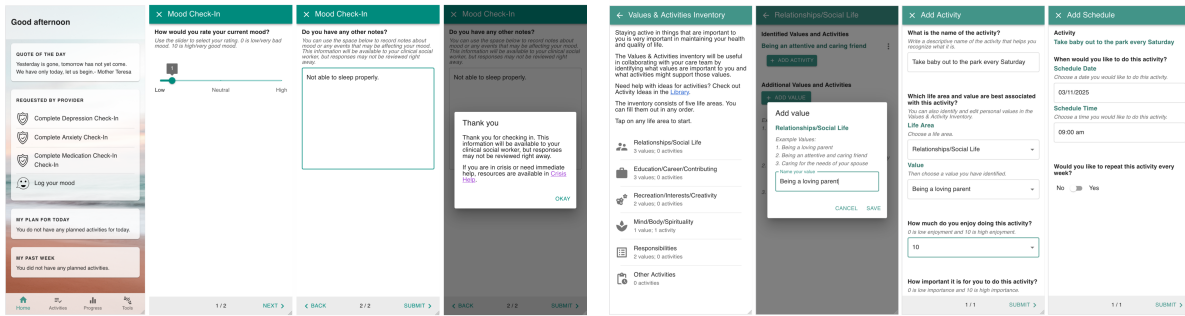
#### 4.1.2 *SCOPE* Overview

*SCOPE* was therefore informed by a focus on its underlying evidence-based interventions of collaborative care management and behavioral activation, by feedback from patients and providers across sites where *SCOPE* would be deployed, and by expertise of medical collaborators in our research team. Patient and provider feedback had important impact (e.g., early proposals for messaging were removed in part because provider participants expressed concern about another messaging channel beyond those already available). The available design and development resources also required the prioritization of capabilities (e.g., an early determination *SCOPE* would not integrate with electronic health records). This section describes the deployed system, and the features are summarized in [Table 4.3](#). We also note that *SCOPE*’s design was largely stable throughout the deployment, but [Section 4.3](#) will discuss key adaptations.

#### **Patient-Facing App**

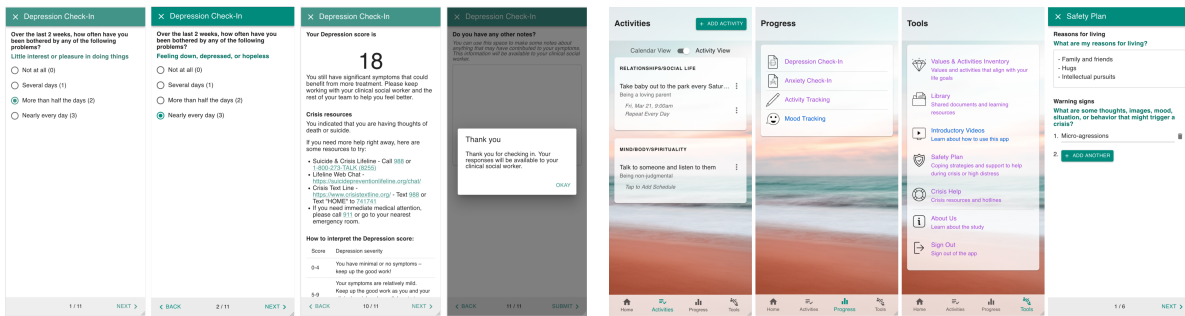
The patient app facilitates behavioral activation activities, remote self-assessments, and access to resources, with several capabilities illustrated in [Figure 4.4](#).

A *Home* page ([Figure 4.4a](#)) includes an inspirational quote, tasks requested by the provider, and scheduled activities for the day. Providers could request patients fill in a values and activities inventory, a safety plan, or depression and anxiety assessments. Mood logging asks



(a) Home page includes an inspirational quote, tasks requested by the provider, and scheduled activities for the day. Patients can log their mood multiple times in a day by rating it on a scale of 0 to 10 and then entering any relevant notes.

(b) Patients can identify values associated with specific life areas (e.g., Relationships/Social Life, Education, Mind), can identify activities corresponding to those values, and can schedule planned activities.



(c) When patients complete their depression assessment, they see their final score, including a table that helps them interpret their score (e.g., encourage them if their score is low, or if the patient responds positively to the suicidality question, the app displays the crisis resources).

(d) Activities page shows scheduled activities with support for logging and editing existing activity schedules. Progress page supports review of previously-tracked data. Tools page provides access to library of shared documents, learning resources, crisis resources, and a personalized safety plan.

Figure 4.4: The patient-facing SCOPE app supports core components of behavioral activation while sharing patient-generated data with the provider-facing SCOPE registry. This includes (a) provider-assigned and patient-scheduled action items, (b) a values and activities inventory, (c) completing depression and anxiety assessments, and (d) activity logging.

patients to rate their mood on a scale of 0 (Low) to 10 (High). They are then able to enter any relevant notes.

In the *Values & Activities Inventory* (Figure 4.4b), a patient can identify values associated with specific life areas (e.g., Education/Career/Contributing, Mind/Body/Spirituality), can

identify activities corresponding to those values, and can schedule planned activities.

Selecting a scheduled activity allows three options for marking its completion. If the patient marks the activity as ‘Yes, I did it’, they are asked to rate their accomplishment and pleasure in performing it. If the patient marks the activity as ‘Yes, but I did something else’, they are asked to provide the alternative activity they performed. If they answer ‘No, I didn’t do it’, they are prompted to reflect on barriers to doing that activity.

When a patient completes their depression or anxiety assessment (Figure 4.4c), they can see their final score, including a table that helps interpret the score (e.g., encouragement if a score is low, crisis resources for any patient responds positively to the suicidality question).

Patient data generated in these interactions is also immediately available via the provider registry (e.g., values and activities, mood and activity logs).

Additional capabilities are accessed via the bottom application bar (Figure 4.4d). An *Activities* page displays scheduled activities with support for logging, scheduling of new activities, and editing of existing activity schedules. A *Progress* page supports review of previously-tracked data for depression, anxiety, mood, and activities. A *Tools* page provides access to the values and activities inventory, a library of shared documents and learning resources, a personalized safety plan, and crisis resources. The library contains forms and worksheets identical to those in the provider-facing registry. When a patient accesses their safety plan, they answer a series of prompts (e.g., reasons for living, warning signs, coping strategies, social distractions and support, professional support, attributes of a safe environment), and responses are again immediately available via the provider registry.

### **Provider-Facing Registry**

The provider registry facilitates population-level patient monitoring and management with integrated support for behavioral activation.

The landing page (Figure 4.5a) displays a patient caseload overview, designed to view a population of patients and identify those who need attention or those who have not seen providers recently. The table provides summary information, such as the first and last session, the last case review, and the total number of sessions. It tracks patient-level flags (e.g., safety risk, need discussion) and when follow-up is due, provides patient outcome

**a Caseload Overview**

SCOPE REGISTRY

Caseload for **All Social Workers** in **All Clinics**

Flags	Tx Status	Name	Clinic Code
New	CoCM	Valerie Kim	GU
	CoCM	Thomas Cook	Melanoma/Renal
	CoCM	Connie Hayes	Immunotherapy
	CoCM RP	Samantha Harris	GI – Pancreatic
	CoCM RP	David Logan	Sarcoma
	CoCM RP	Elizabeth Morrow	HEME – Sickle Cell
New	CoCM RP	Jesse Dev	HNL
	D/C	Brandi Brown	Melanoma/Renal
	Other	Faith Kelley	Endocrine
	Other	Gregory Estrada	GI – Pancreatic
	Other	Robert Barnes	GU

**b Patient Detail**

SCOPE REGISTRY / Valerie Kim

**Valerie Kim** [EDIT]

MRN: 358560  
CLINIC CODE: GU  
DOB: 10/11/1943  
AGE: 81  
SEX: Female  
RACE: White  
ETHNICITY: Not Hispanic or Latino/Latina/Latinx  
GENDER: Female  
PRONOUNS: She/Her  
PRIMARY ONCOLOGY PROVIDER: Gloria Smith  
PRIMARY SOCIAL WORKER: Sandra Jones  
TREATMENT STATUS: CoCM  
FOLLOW-UP SCHEDULE: 1-week follow-up  
ENROLLMENT DATE: 01/01/2022

SESSION #1: 2  
FIRST SESSION: 07/24/2024  
LAST SESSION: 10/08/2024

FLAGS:  
Safety risk: 🚩  
Discussion: 🗨️

**PATIENT** [EDIT]

**Clinical History and Diagnosis** [EDIT]

**Primary Cancer Diagnosis**  
Bladder Cancer

**Date of Cancer Diagnosis**  
2005

**Current Treatment Regimen**  
Chemotherapy  
Radiation

**Treatment Regimen Notes**  
Has ongoing nausea and fatigue. Treatment is scheduled to be completed in early November.

**Ongoing Treatment Information**

**Latest PHQ-9 Score** 17 (Updated: 08/06/2024) | **Latest GAD** 13 (Updated: 0)

**Current medications**  
Escitalopram 10 mg po qam (Updated: 10/08/2024)

**Behavioral Strategies Used**  
Behavioral Activation  
Motivational Interviewing  
Cognitive Therapy (Updated: 10/08/2024)

**Referrals**  
Integrative Medicine - Pending (Updated: 10/08/2024)

**Psychiatric Diagnosis**  
Major Depressive Disorder

**Past Psychiatric History**  
History of depression and anxiety in 40's after divorce, treated with nortriptyline and counseling.  
e.g., prior diagnosis, treatment, hospitalization, and suicide attempts

**Substance Use History**  
No alcohol or drug use.  
e.g., prior or current substance use

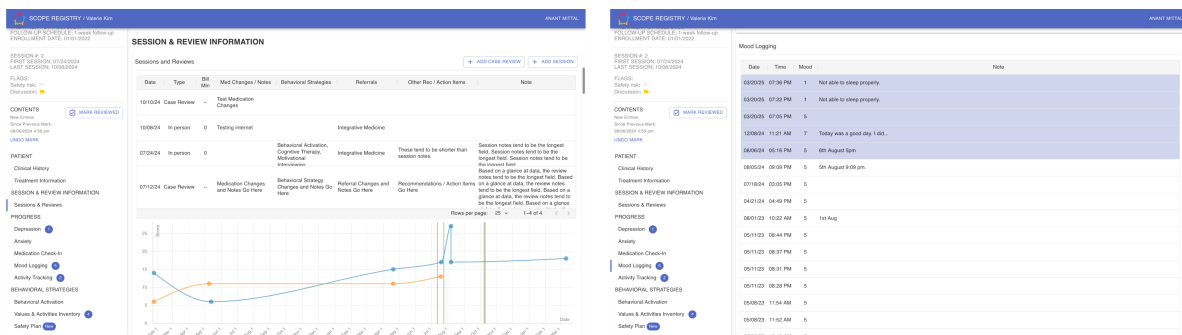
**Psychosocial Background**  
Married, 1 son age 5.  
e.g., living situation, marital status, children, employment, trauma history

**c Table of Contents**

- CONTENTS [MARK REVIEWED]
- New Entries Since Previous Mark: 08/19/2024 4:16 pm
- UNDO MARK
- PATIENT** [d]
- Clinical History
- Treatment Information
- SESSION & REVIEW INFORMATION** [e]
- Sessions & Reviews
- PROGRESS** [f]
- Depression 1
- Anxiety
- Medication Check-In
- Mood Logging 2
- Activity Tracking
- BEHAVIORAL STRATEGIES** [g]
- Behavioral Activation
- Values & Activities Inventory
- Safety Plan

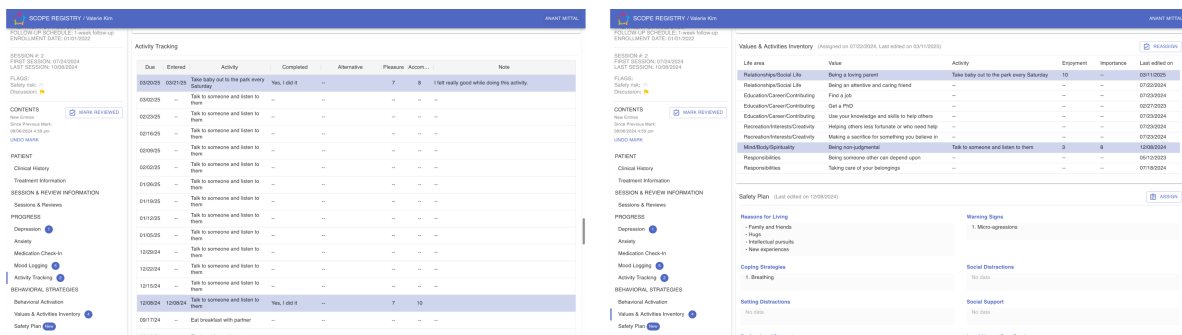
Figure 4.5: The provider-facing *SCOPE* registry supports collaborative care management and behavioral activation through: (a) a caseload overview summarizing all patients, with (b) details about each patient organized (c) according to the underlying interventions. Patient-generated data from the *SCOPE* app is visible in the provider registry. Providers can also (d) enter patient history, (e) add session and case review notes, (f) monitor patient progress, and (g) review behavioral strategies and resources. All pictured data is artificial.

assessment results (e.g., PHQ-9, GAD-7), when assessments were last administered, and changes in outcomes to help identify patients who have not improved and may need attention. The caseload table is an entry point to individual patient overviews. Selecting a patient opens a detail page with multiple sections (Figure 4.5b), including a patient profile and clinical history, session and case review information, assessment results and progress, behavioral treatment strategies, and flags for safety risks and discussion in case review meetings. *Patient* includes information about a patient's cancer and mental health diagnoses and treatment.



(a) Providers can track patient session details and case review notes with consulting psychiatrists.

(b) Behavioral health providers can monitor patient-generated mood logs between sessions.



(c) Viewing patient progress on scheduled activities can support behavioral health providers in improving health outcomes.

(d) Patient-generated values and activities can support providers in making treatment adjustments and shared decision-making with patients.

Figure 4.6: The provider-facing *SCOPE* registry supports core components of collaborative care management. This includes (a) tracking patient sessions and case review discussions, (b) monitoring patient-generated mood logs, (c) tracking patient activities between sessions, and (d) patient's values and activities inventory.

The *Session & Review Information* (Figure 4.6a) displays a table of patient sessions and case review discussions. Providers can add a session to track session type, its duration, medications, behavioral strategies used, referrals made during the session and their status, recommendations, action items, and session notes. They can add case reviews to track any changes to medications or behavioral strategies, referrals, recommendations, action items, and review notes with the consulting psychiatrist.

*Progress* (Figure 4.6b, and Figure 4.6c) displays patient-generated data, such as depression

assessments (PHQ-9 [75]), anxiety assessments (GAD-7 [52]), mood logging, and activity tracking. Based on patient needs, providers can assign assessments for specific frequencies and days of the week, which then appear in the patient app.

*Behavioral Strategies* (Figure 4.6d) includes information about behavioral activation treatments, a patient's values and activities inventory (i.e., values, activities, enjoyment and importance ratings of each activity) and a patient's safety plan. The behavioral activation panel lists relevant forms and worksheets providers can review with patients. The same resources are also available on the patient-facing app for access at any time. A provider can assign or re-assign a patient the values and activities inventory or the safety plan, which adds a prompt in the patient's app to complete the assignment.

Table 4.3: *SCOPE*'s features were informed by a focus on its underlying evidence-based interventions of collaborative care management and behavioral activation, by feedback from patients and providers across sites where *SCOPE* would be deployed, and by expertise of medical collaborators in our research team.

---

***Patient-Facing App***

---

Completing depression and anxiety assessments  
 Logging mood data  
 Scheduling an activity  
 Viewing and managing scheduled activities  
 Logging scheduled activity data  
 Viewing shared documents and learning resources  
 Completing values and activities inventory  
 Viewing depression and anxiety assessments  
 Viewing logged activity data  
 Viewing logged mood data  
 Completing safety plan  
 Viewing crisis help resources  
 Sending patient data to care team

---

***Provider-Facing Registry***

---

Assigning assessments to patients  
 Assigning values inventory  
 Assigning safety plan  
 Accessing behavioral activation resources  
 Viewing and editing patient history and information  
 Viewing and editing session information  
 Viewing completed behavioral activation components  
 Viewing patient progress on depression and anxiety  
 Viewing patient progress on mood  
 Viewing patient progress on scheduled activities  
 View patient values and activities inventory  
 View patient safety plan  
 Flagging patients for safety or discussion  
 Viewing and interacting with the list of patients in the caseload table  
 Viewing and editing caseload review information

### 4.1.3 *SCOPE* Clinical Trial

*SCOPE* is currently deployed in a pragmatic randomized controlled trial [17, 39] to compare effectiveness of usual collaborative care versus technology-enhanced collaborative care with *SCOPE*. This deployment includes 6 cancer clinics within 2 regional cancer centers in Washington, USA. This subsection briefly summarizes trial participation because the clinical trial shaped which patients encountered *SCOPE*. The next subsection then details our data collection through deployment interviews and surveys.

#### Participants

Patients in the 6 participating clinics were eligible if receiving active cancer treatment, at least 18 years old, with PHQ-9  $\geq 10$ , and with at least one endorsed cardinal symptom (i.e., depressed mood or anhedonia). As in Section 4.1.1, these are conservative criteria for clinically significant moderate to severe depression in cancer patients [205]. Patients were excluded if they were engaged in or needed immediate specialty mental health care (e.g., for bipolar disorder or schizophrenia), or were unable to read and speak English. Patients were identified via screening procedures at each center and by referral. Patients who met study inclusion criteria were informed about the study. Patients who declined study participation received usual care.

As of June 2024, 109 patients were enrolled in this trial and then randomized to technology-enhanced collaborative care with *SCOPE*.

### 4.1.4 Deployment Interviews and Patient Survey

We conducted 19 deployment interviews (i.e., 10 with patients, 9 with behavioral health providers) over approximately 24 months, all with participants who had substantial experience with *SCOPE* in actual care as part of the clinical trial. We supplemented this with a patient survey sent to each patient after 6 months of enrollment in the clinical trial.

#### Participants

We recruited from clinical trial participants randomized to *SCOPE*. *Pt15* was interviewed 4 months after deployment began, and all other patient participants were interviewed 6 months after randomization. Providers were interviewed after at least 5 months of experience using *SCOPE*. Providers who participated in multiple interviews had at least 11 months of experience between those interviews. Participants are summarized in Table 4.1

(i.e., 10 patient interviews) and Table 4.2 (i.e., 9 provider interviews). As part of ensuring participant anonymity, we intentionally do not further characterize providers. Patients were emailed the survey 6 months after randomization. As of June 2024, we received 62 survey responses. We consider this an appropriately strong level of participant engagement, accounting for the burdens of participating in research amidst navigating cancer and cancer treatment (e.g., as in [183]) and additional challenges of comorbid depression (e.g., as in [194]).

### Interview Procedure

Patient and behavioral health provider interviews explored: (1) *implementation of SCOPE* (e.g., how did patients learn about the study, experiences being introduced to and onboarded with *SCOPE*); (2) *collaboration* around *SCOPE* (e.g., how patients experienced *SCOPE* in the context of their care team, how behavioral health providers felt their interactions with patients changed with the introduction of *SCOPE*); (3) *usability of SCOPE*; and (4) *motivation* for using *SCOPE*. Participants were asked to detail experiences using *SCOPE*, how it compared to prior experiences receiving or giving care, and issues they encountered. Interviews lasted 45 to 60 minutes. Participants were offered a gift card for their time, although most provider participants were unable or unwilling to accept direct compensation.

### Survey Procedure

The patient survey contained open-ended questions (e.g., how did *SCOPE* impact their provider relationship, what did they find most helpful about *SCOPE*), quantitative scales related to *SCOPE* and the larger clinical trial, and questions about specific *SCOPE* features.

#### 4.1.5 Data Analysis and Reporting

We analyzed 45 interview transcripts, comprising 26 design interviews and 19 deployment interviews. We used combined deductive and inductive coding [24]. Deductive codes were developed separately for design interviews and deployment interviews. For design interviews, deductive codes characterized common tasks and objectives, guided by the parallel journeys framework [194] and reflecting scenarios in Section 4.1.1. For deployment interviews, deductive codes related to major topics explored in the interviews (i.e., implementation, collaboration, usability, motivation). Initial deductive codes were reviewed and agreed

upon before coding began. Inductive codes were subsequently developed throughout coding. These were related to desires and experiences of multiple participants spanning design and deployment interviews. As new inductive codes were developed, previously-coded transcripts were revisited for consistency of code application.

Themes were iteratively developed through collaborative review and discussion of codes among 6 authors. After all data was coded, a final set of themes was resolved, and transcripts were reviewed for relevant participant quotes. Surveys were reviewed as supplemental data to consider the perspective of patients who did not participate in interviews. The first and second authors reviewed survey responses for consistency with themes developed from analysis of interview data.

Consistent with [Table 4.1](#) and [4.2](#), the remainder of this paper refers to patient interview participants as *Pt1* through *Pt24* and to behavioral health provider participants as *BHP1* to *BHP12*. We annotate quotes with a superscript indication of a design interview (e.g., *Pt1<sup>Des</sup>*, *BHP1<sup>Des</sup>*) versus a deployment interview (e.g., *Pt15<sup>Dep</sup>*, *BHP2<sup>Dep</sup>*), in part to support interpretation of participant perspectives (e.g., *design interviews* were based in patient and provider understanding of challenges of comorbid cancer and depression, in prior experience with care and with other technologies, were often structured around scenarios explored with the in-progress design; *deployment interviews* were additionally based in understanding gained through long-term use of *SCOPE* in actual care, were less structured and more guided by experiences that participants most wanted to emphasize). We further note randomization in [Section 4.1.3](#)'s trial occurred at the level of individual patients. Providers therefore had experience delivering collaborative care to different patients with and without *SCOPE*'s technology support. Providers sometimes made this contrast explicit, but it was often implicit in deployment interview discussions of experiences with *SCOPE*.

## 4.2 Findings

We now present findings organized by identified themes. We first present patient and provider participant perceptions of experiences with *SCOPE* in terms of its underlying interventions: [Section 4.2.1](#) presents patient experiences directly engaging with *SCOPE*'s interventions, [Section 4.2.2](#) presents patient and provider experiences with *SCOPE* improving collaboration between and within sessions, and [Section 4.2.3](#) presents provider experiences with *SCOPE* supporting structure and collaboration within the care team.

Section 4.2.4 then describes how patient and provider experiences with patient-generated data in *SCOPE* created evolving expectations for collaboration around that data. Finally, Section 4.2.5 shares insights into implementation barriers that surfaced through design and deployment of *SCOPE* for actual care in 6 cancer clinics for 24 months.

#### 4.2.1 Patient Engagement with its Underlying Interventions

*SCOPE* included support for patients to enter symptom assessments, safety plans, mood logs, and behavioral activation components like values, activities, schedules, and logs. It further supported patient review of previously-entered data. This was suggested by patients in design interviews, and then discussed by patients who had been using the deployed app in their care.

*Pt7<sup>Des</sup>* shared this could help them be more transparent with themselves: *“If I’m honest about using that, there would be less places that I could hide, you know, hide information from myself or from [providers] that could affect my treatment, my care, my well being ... And the app would definitely give information so that ... I would be stepping out of isolation.”* Patients said data would be *“informative”* (*Pt11<sup>Des</sup>*) and help them understand impacts of *“all the stuff that [they’re] dealing with”* (*Pt9<sup>Des</sup>*). *Pt9<sup>Des</sup>* explained they could see using the values and activities inventory as a planning tool for understanding *“success”* in different areas of life, and *Pt10<sup>Des</sup>* similarly described it could help provide *“direction”* and *“clarity”* for them and their providers. Consistent with goals of *SCOPE*’s behavioral activation intervention, *Pt8<sup>Des</sup>* described how data could help avoid a vicious cycle: *“For having actual data for perspective versus the mind that can lie to you at times, over mood especially”*.

Patients who used *SCOPE* then reported similar expectations, experiences, and support for self-awareness in the interventions. *Pt20<sup>Dep</sup>* explained that tracked values helped them realize they *“have some areas where I [they] don’t really have a lot of things”*, and *Pt18<sup>Dep</sup>* described it helping them reflect on how their *“values have changed”* and whether they *“want to change anything.”* *Pt18<sup>Dep</sup>* further recalled they had felt they were not doing enough for their family and health, that *“everything was horrible”*, but then *“after setting up the values and setting up the activities, I kind of felt like, oh, well, I am taking care of things at home, I am doing the best that I can. And so I feel like... doing that a little by itself helped a lot.”*

#### 4.2.2 Patient and Provider Collaboration Between and Within Sessions

*SCOPE* was designed around patient-generated data as a form of patient-provider communication *between* in-person sessions. Participants discussed three key ways data improved collaboration, including *between* and *within* in-person sessions. Prior work in turn notes patient-provider collaboration and rapport is critical to the interventions *SCOPE* is designed to support [194].

##### SCOPE Helped Patients Feel Connected to their Provider

Patients described *SCOPE* as improving communication with and connection to their behavioral health providers:

“I didn’t really talk with her...my counselor outside of [sessions]. But then, when the app and the study got started, I felt like she reached out to me more. And she would have at least some idea of what was going on based off the stuff that I put in there. And she was like, well, you kind of said this was going on. And so that was useful ... I feel like we actually talked more after we started using the app.” – *Pt18<sup>Dep</sup>*

Communication is pivotal for establishing and maintaining a collaborative patient-provider relationship. Patients shared that *SCOPE* fostered interconnectedness and helped facilitate productive and meaningful communication, which they believed resulted in a more productive relationship. *Pt18<sup>Dep</sup>* shared that their provider would use data to provide “*encouragement*” and remind them they were not doing as bad as they felt. *Pt22<sup>Dep</sup>* said their provider made them feel relaxed, which helped them share more: “*So after I got onto the app, I started sharing thoughts and feelings and my mood levels. I think because she got to see right what I was doing on SCOPE... [it] helped me relax more and share my feelings more.*” *SCOPE* was designed for data to make patient activities visible between sessions, and patients described that provider access to real-time data helped them stay connected outside sessions. *Pt23<sup>Dep</sup>* recalled, “*if something happens, something critical happens or something upsetting whatever it is, I’m not going to wait two weeks until I talk to my [provider]*” and that *SCOPE* “*was a way to almost connect real-time with the [care] team*”. Providers also shared that mood logging became a way for patients to talk to them, as *BHP8<sup>Dep</sup>* explained it felt “*like an extension of the therapeutic alliance*”.

### **Patient-Generated Data Decreased Session Time Spent Recalling Information**

Patients and providers described that *SCOPE* created more efficient and effective in-person sessions, as patients no longer needed to use time to remember what they had experienced between sessions.

For example, *BHP4<sup>Dep</sup>* remarked on “*patients that totally engaged with the app, and so they would write almost every day, do a mood log, and write about what they did that day. So I got a lot of information. And so instead of spending a lot of our time together kind of gathering that information, we could start our session with me knowing, ‘I noticed that you did these activities and...noted that your mood improved. You know what, how do you feel about that?’*” Patient *Pt23<sup>Dep</sup>* similarly shared that when “*you’re starting your every appointment, you’re basically starting cold, like, how are you today? Or the social worker [BHP] might say, Okay... let’s talk about this, or it [is] kind of a slow start, for lack of a better way to put it.*” With *SCOPE*, Patient *Pt23<sup>Dep</sup>* instead felt their provider did not have to ask questions because they were “*starting from an actual base of what I had been doing this last week or two*” and this “*moved things along faster.*” Providers further explained they often have time to review a patient’s information only in the 30 minutes before an appointment, and that patient data therefore helped providers to quickly move sessions toward relevant goals. *BHP11<sup>Dep</sup>* shared that *SCOPE* “*was a wonderful conversation starter*” which allowed sessions to focus on reflections around patient activities, mood, or assessments.

### **Patient-Generated Data Improved Patient-Provider Shared Decision-Making.**

*SCOPE* data supported providers in engaging with patients regarding interventions, new strategies, and other decisions aimed at improving health outcomes.

“Having that continuum of data and numbers to quantify things has helped to figure out what’s working and what’s not for the patient to be able to problem solve.” – *BHP2<sup>Dep</sup>*

Providers appreciated the registry’s visualizations of assessments and mood, wanting to share these with patients during sessions to show progress, celebrate small wins, and validate patient feelings. *BHP1<sup>Des</sup>* explained: “*It would be possible to share with them, ‘You’re still really feeling like you’re not feeling yourself, but look at where you’ve come*

from;’ it kind of helps using that to help them reflect.” Several providers wanted to use data as evidence to challenge patient beliefs and perceptions. *BHP9<sup>Des</sup>* shared, “If they’re telling me something, and the numbers say something different, right? They may say, I don’t feel... like I’m making any progress. And then you can show that actually... scores are showing that there’s even a small amount of improvement.”

In design and then deployment, providers described that detailed data can help detect issues, problem-solve, and modify treatment. Per *BHP4<sup>Des</sup>*, “We meet to look at what worked well, what didn’t work. What kind of adjustments we need to make...are there barriers getting in the way? Do they need some motivational interviewing or something else?” Treatment data can also be examined relative to assessments for consulting psychiatrists to adjust treatment recommendations. *BHP10<sup>Dep</sup>* shared: “I like the graphical representations. I like the ability to see concurrent GAD-7 and PHQ-9 scores. So, like on a certain date, what’s happening? I like the ability to be able to...correlate those dates with ‘Okay, well, what changed? Did we recommend that increase? Are you doing more behavioral activation?’...and I like the granularity.” Contrasting to their experiences without *SCOPE*, *BHP2<sup>Dep</sup>* shared that they often utilized *SCOPE*’s patient-generated data as a “jumping point to modify the treatment” and that *SCOPE* provided “more focus and formality, and maybe accountability”. *BHP11<sup>Dep</sup>* similarly explained that patients who were not using *SCOPE* often experienced “a lot of back and forth...where I would one week recommend doing this, and they would let me know whether or not it was helpful, and then the next week we would try something else to see if it was helpful”. *BHP11<sup>Dep</sup>* said *SCOPE* enabled them to “see kind of the activity that they [patients] were doing through the app” and felt this “sped up or helped ... identify useful interventions more efficiently.”

Patients discussed *SCOPE* creating rapport with their care team, which created an environment where they could naturally discuss progress in their treatment and health goals. *Pt23<sup>Dep</sup>* shared their provider would use data to ask if they are “feeling better or worse”, or if they should “change this medication”, and they would then discuss it “together and come to a decision.” *Pt20<sup>Dep</sup>* similarly explained that values generation initiated conversations with their provider about what was important to them: “I did talk with [my provider] about what I liked about [SCOPE], like having that values assessment in there and then... the discussion from there would lead to... what is important and how to support those things,

*and what I can sort of let go of and what I need to focus on.”*

Many patients self-described experiencing cancer-related “chemo brain”, cognitive dysfunction, or cognitive impairment, which we note is consistent with cancer settings [155]. Patients further described *SCOPE*’s historical data as helpful for motivation and review in the context of memory issues. For example, *Pt21<sup>Dep</sup>* explained they liked *“being able to record my thoughts and experiences and feelings and tracking those so I could go back and have a record and discuss those with [the provider]”* and that the app was *“really good historically, for, you know, one day goes by, and you forget what you felt like the day before”*. *SCOPE*’s data thus also supported patient-provider collaboration by capturing between-session experiences that patients may have forgotten or otherwise been unable to recall during a session.

### **4.2.3 Structure and Collaboration within the Care Team**

In addition to supporting patient-provider collaborations, providers further discussed how *SCOPE* supported delivering care. Providers shared that the registry provided structure that helped improve sessions (e.g., by surfacing potentially-relevant components of behavioral activation) and caseload reviews (e.g., by surfacing relevant patient data). Providers also shared that knowledge-sharing between care team members was improved because *SCOPE* provided opportunities to use patient-generated data to ask questions and seek advice from other providers.

#### **Structure Improved Patient Sessions and Care Team Caseload Reviews.**

As introduced in [Section 2.3.2](#), collaborative care emphasizes a behavioral health care manager as provider of behavioral interventions. Collaborative care includes regularly scheduled caseload reviews between behavioral health care managers and a consulting psychiatrist.

As part of explicit support for behavioral health care manager delivery of behavioral activation, the *SCOPE* registry outlines core components of behavioral activation and presents patient-generated data according to goals of the intervention. Providers described prior tools as lacking such structure, leading to prior experiences using an *“blank notes section”* (*BHP3<sup>Des</sup>*) in an electronic health record, *“hunting and pecking to find information”* (*BHP2<sup>Des</sup>*) in a prior Excel-based registry, or not capturing information

necessary for effective caseload review (*BHP6<sup>Des</sup>*). Providers frequently adjust patient treatment plans, and *BHP1<sup>Des</sup>* described that *SCOPE*'s included library of behavioral activation resources and tracking of specific behavioral activation components could be used to “*fall back on*” and could help remind providers of strategies they “*have not inquired about*”.

Based on their experience using *SCOPE* in care, *BHP2<sup>Dep</sup>* described it helping structure sessions and care to be more effective, saying “*The positives... it’s like a new language. So having a new language on what behavioral activation is, and how you track it, your mood with it.*” They further detailed this as benefiting both patients and providers, saying “*For some of the patients, that seems to be really clicking well and spurring them on to continue to do the behavioral activation. So I think having the tracking and the scales of the mood is a different language tool than us just sitting in the counseling room chatting.*” and “*I think for me, as the counselor, it has helped my structure of my counseling with having the library having the PHQ and the gap and seeing the progress and having the the measurements, that’s what it is having the measurements visually, so that I can be tracking more over the continuum of how they’re doing.*”

Providers similarly described structure of the *SCOPE* registry as improving caseload reviews with psychiatrists. *BHP10<sup>Dep</sup>* explained “*So I like that we can be looking at the registry together; we can quickly at a glance see what’s a patient’s oncologic situation. We have a list of medications they’ve been on; we can review PHQ-9 scores, GAD-7 scores, mood logs, activities together; and then we can really readily access what the [patient told] them in [the] last session [and] what [the provider] recommended at the last case review. So I think that is actually a more effective way to collaborate.*”

Finally, providers described feeling structure provided by *SCOPE* improved care even for patients who were not using *SCOPE*. *BHP2<sup>Dep</sup>* explained that *SCOPE* helped them become a “*better clinician*” because “*rather than talking in general broad strokes about behavioral activation, [SCOPE] made it very applicable...before that my use of behavioral activation was more general*”, that *SCOPE* introduced “*formality and accountability*”, that this carried over to being more specific in “*applying the behavioral activation with the non-tech arm*” of Section [Section 4.1.3](#)'s trial, and that they felt the clinic had become a “*stronger program*” and “*much better clinic overall*” because of *SCOPE*.

### **Improved Knowledge-Sharing between Care Team Members.**

Providers described that *SCOPE* created opportunities for sharing knowledge and experiences with other providers which they would not have sought on their own. *BHP4<sup>Dep</sup>* shared that other providers approached them about a few patients who “*are the most active of anybody’s*”, asking how she motivates them to engage with care via *SCOPE*. As more providers were added to the study, *BHP4<sup>Dep</sup>* explained that having *SCOPE* as a shared resource created an environment of collaboration amongst the team that did not previously exist, which led providers seeking advice from each other, and that it has “*been really helpful*” having other providers as a resource when trying to find alternative methods for her patients. *BHP2<sup>Dep</sup>* also shared that providers “*go to each other a lot more*” for “*case review type of questions*” and to ask “*here’s the context, what would you do in this situation?*” For providers already using coworkers as a resource, *SCOPE* created a space for recording unscheduled meetings or knowledge gathering. *BHP8<sup>Dep</sup>* shared, “*It’s nice to have [the registry] formalized because if we have a verbal conversation, it’s like nice to have a place where we can then kind of write it down.*” *SCOPE*’s visibility of patient-generated data and provider notes thus supported the care team in asking questions, seeking advice, comparing strategies, and commiserating on difficult situations.

*BHP4<sup>Dep</sup>* also described that better communication with the psychiatrist on patient treatments has improved their relationship with other senior or experienced providers, noting that “*providers are lot more willing to listen to our recommendations when we kind of say... [Psychiatrist] and [Psychiatrist] and are behind it.*” *BHP2<sup>Dep</sup>* similarly explained they became “*more comfortable*” and “*confident*” with asking psychiatrists more “*clinical questions*”.

#### **4.2.4 Evolving Expectations Around Patient-Generated Data**

Where previous subsections have emphasized how *SCOPE* data and structure supported its underlying interventions, participant experiences also created evolving expectations around *SCOPE* data. Patients discussed seeking additional provider recognition and support, and providers discussed seeking additional registry capabilities around patient-generated data.

##### **Patients Seeking Provider Recognition and Support**

Patients described that *SCOPE*’s provider access to patient-generated data created new patient expectations for recognition and support. For example, *Pt20<sup>Dep</sup>* wanted their

provider to encourage them around big life moments, like *“if I have a surgery coming up”*.

In design interviews, patients expressed widely varying expectations of a timeframe for provider engagement with data: from *“as soon as it’s available”* (Pt12<sup>Des</sup>), to daily (Pt6<sup>Des</sup>), to a few times a week (Pt9<sup>Des</sup>). Several patients shared that expectations varied depending on symptom severity. They wanted providers to reach out immediately if assessment scores were bad, if suicidality was detected, or for consecutive logs of bad mood or severe symptoms: *“If I was in some kind of an acute or crisis mode, I would assume they’re going to be checking more frequently. If things are cruising along, maybe they’re not going to need to access that data”* (Pt8<sup>Des</sup>). If a depression assessment was severe, some patients wanted *SCOPE* to *“alert the care team right away”* (Pt12<sup>Des</sup>) with a *“red flag”* (Pt6<sup>Des</sup>) so providers could respond *“aggressively”* (Pt14<sup>Des</sup>). *SCOPE*’s resulting design includes automatic flagging of patients based on assessments (i.e., high scores, indications of suicidality).

In deployment interviews, patients expressed uncertainty around when other forms of patient-generated data would be reviewed. For example, Pt16<sup>Dep</sup> shared a concern they did not *“know where this [data] is going and who’s reading it at [what] time”*. After several months of deployment, providers shared that patients were using a freeform text field in *SCOPE*’s mood logging to communicate with providers. Although intended as a journal which could be periodically reviewed, some patients were using it as a messaging feature where they expected immediate review and response. This created safety concerns, and we revised the design to be clear that submitted data will be available to providers but may not be immediately reviewed.

Although *SCOPE* was designed for patient-provider collaboration in a clinical setting and did not intend any functionality for peer support, patients in deployment interviews asked if there were ways to connect with other patients who would be willing to talk and share experiences (Pt16<sup>Dep</sup>, Pt22<sup>Dep</sup>, Pt24<sup>Dep</sup>). Peer social support can be invaluable in navigating cancer and depression [86, 183], so this suggests future exploration of how data in platforms like *SCOPE* could support such opportunities (e.g., while preserving patient privacy).

### Providers Seeking Additional Registry Capabilities Around Data

Consistent with patient expressions of a desire for recognition and support, design interviews with providers also surfaced goals for ensuring patients feel acknowledged:

“I think one thing that it seems like will be important is for people to feel like I’m actually paying attention to the stuff that they’re doing...that’s going to be one of the key features of this for us is being able to act more in real time.” – *BHP5<sup>Des</sup>*

Providers described wanting to use data to reach out to patients who might be having a hard time. For example, *BHP7<sup>Des</sup>* said “*I can see if there’s really drastic things and I had safety concerns. I could see kind of ad hoc adding an appointment or just a casual phone call or something like that to check in.*” If a patient was improving, *BHP5<sup>Des</sup>* described wanting to reach out with a “*small cheerleading note*” or a “*note of encouragement*”.

As noted in [Section 4.1.2](#), *SCOPE* intentionally does not include messaging. Existing clinical systems already support patient-provider messaging, and providers in design interviews expressed concerns about monitoring another messaging channel (e.g., for associated burden, for patient safety if messages were not reviewed). In later deployment interviews, providers have described challenges with existing messaging (e.g., it can be cumbersome to switch out of *SCOPE* for connecting with patients, available messaging systems lack the relevant context of patient-generated data in the *SCOPE* registry). Providers have described an opportunity to acknowledge patient data and to provide support via lightweight capabilities within *SCOPE*. *BHP8<sup>Dep</sup>* suggested they “*didn’t even need to type something in*” and patients would “*feel good*” if it was made known that their provider has reviewed their data. For highly-active patients, *BHP4<sup>Dep</sup>* wanted to let them know that “*I am reading this, I am noticing, I think you’re doing great. I appreciate that you’re trying to do behavior activation,...[and] honestly trying to use this to feel better, and it’s working.*” Provider concerns about another open-ended messaging channel remain consistent with design interviews, but the structure provided by patient-generated data within *SCOPE* has suggested other opportunities for lightweight and one-way messaging.

As providers have gained experience with *SCOPE*, they have also expressed a desire for additional capabilities in supporting a population of patients. Design interview feedback

often focused on capabilities for distilling insights in support of adjusting treatment and improving shared decision-making with individual patients. For example, *BHP5<sup>Des</sup>* requested registry capabilities for sorting, color coding, and filtering as part of “*trying to suss out [a] pattern*” so they could show a patient which particular activities “*seem[ed] to be high pleasure and/or low pleasure activities.*” *BHP8<sup>Des</sup>* similarly anticipated working to determine how to make data actionable: “*It’s just going to be a clinician learning curve for me to figure out. Well, on October 4, they recorded you know, this thing on the GAD-7 and this other thing on the PHQ-9, and now I have mood ratings on that same day. So now I’ve got to kind of figure out, what does all of this mean, right? It’s going to be a learning curve. [...] What do I do with information that comes in?*” Distinct from such capabilities focused on in-depth understanding of a single patient, deployment interviews have included additional feedback seeking population-level capabilities to support monitoring multiple patients. For example, *BHP2<sup>Dep</sup>* requested automated analyses “*[like in] FitBit, you can get just those quick little snapshots...I don’t know how you could do it with such a big registry with everybody there.*” *BHP12<sup>Dep</sup>* requested “*I so wish the registry would tell me when someone inputs something in because I just don’t have time to be proactive.*” Such requests highlight different tasks: providers may access the registry for detailed review of a specific patient (e.g., immediately before a session), but may also access the registry seeking a higher-level check-in on their patients.

#### 4.2.5 Implementation Barriers Identified in Design and Deployment

*SCOPE*’s deployment in actual care for 24+ months in 6 cancer clinics has also surfaced insights into its implementation in those clinics. These include considerations for *who* is the focus of the intervention as well as *when* and *how* the intervention is introduced to patients, together with challenges of integrating with existing provider tools.

##### Determining If *SCOPE* Is Appropriate for a Patient

Although *SCOPE* was designed with a focus on behavioral activation as a flexible and time-effective intervention, patients explained that the complexity of cancer may mean there are situations where the design may not be appropriate. *Pt1<sup>Des</sup>* said the app would not appeal when experiencing severe depression: “*I’ve even been hospitalized. And this would not be attractive. But since I am healthy now, this is appealing to me. But when I was at my most depressed, it would not have been.*” *Pt4<sup>Des</sup>* described wanting to use the app

after chemotherapy: *“Maybe when chemo is over, and you’re just trying to heal...Because I remember like, after right after surgery..., no matter how hard I try, but maybe this can help. I don’t know, because I never tried anything like this. You know, it’s like, you’re just in this disease mode.”*

Providers also described feeling *SCOPE* was more or less appropriate for specific patients. *BHP4<sup>Dep</sup>* said appropriateness can depend on a patient’s situation: *“I have had a really hard time...not because of the app or the registry, but because of where my patients are. My patients are really ill. They’ve been in and out of the hospital. They’ve had some cognitive changes, and they just weren’t getting on it...I think it has to do with their lives. And then I’ve got one that is so fully engaged...I don’t have to do much. She just kind of does that; she loves it. She writes notes, like when she does a PHQ. She tells you kind of how she’s feeling...she doesn’t need much direction.”* *BHP11<sup>Dep</sup>* shared they felt patient motivation for using *SCOPE* was low *“if they just had a lot on their plate, like if they were coming to a lot of appointments, if they were struggling with a lot of stuff, even outside of [the cancer clinic]...I think they just didn’t prioritize it.”* *BHP12<sup>Dep</sup>* recalled referring a patient who was experiencing homelessness and was a recovering addict, feeling *“it was a justice thing”* that *SCOPE* should not be *“only for folks who are...upper middle class”*, but with hindsight felt the app was not focused on that patient’s most urgent needs. *BHP12<sup>Dep</sup>* also described that *SCOPE* might not be appropriate for patients with advanced cancer, as conversations are then around *“hospice”* and *“death with dignity as an option”*.

### **Patients Need Justification for Using SCOPE**

Patient interest and motivation for using *SCOPE* varied. Some saw clear value in understanding the association between mood and activity, and *Pt5<sup>Des</sup>* said *“If my doctor said, ‘you know, I think this is what you need,’ I would certainly give it my best shot.”* Others were not interested, were hesitant, or felt the app and its underlying intervention entailed too much work: *“It is making me feel [...] that here’s yet another task that I have to do and I’m tired”* (*Pt10<sup>Des</sup>*). Patients often described their care in terms of relationship to the provider, and patient willingness to use *SCOPE* depended on a clear justification, need, and commitment from their provider. Some patients were unsure how *SCOPE* would help their depression and how providers would use the data to improve their symptoms: *“Who is accessing this information...my care teams...? ...how are they going to use it to help*

me? (Pt7<sup>Des</sup>). Patients thus wanted assurance the care team would be leveraging *SCOPE* in their treatment: “*It’s going to have to be something that my care team is familiar with. Otherwise, you know, the data capture and the usefulness in face-to-face interaction with your team is going to be limited if they’re not willing to buy into this tool*” (Pt8<sup>Des</sup>).

Patients sought guidance and initial support from providers for incorporating *SCOPE* into their care: “*I [would have] appreciate[d] it step by step, someone sort of holding my hand and leading me through [the app] once*” (Pt16<sup>Dep</sup>). Patients also suggested it would have been easier to understand *SCOPE* if it included “*a tutorial that was available anytime in the app*” (Pt23<sup>Dep</sup>) or a “*visual walkthrough*” (Pt18<sup>Dep</sup>). Pt23<sup>Dep</sup> further suggested, “*it may have been a good idea to sit down and maybe have a session with someone like [the researchers].*” Providers described that patients often need guidance with the value and activities inventory. BHP5<sup>Des</sup> explained her standard practice with a paper version of the inventory is to start the exercise together: “*I’ll often do like one part of it with them just to kind of give them..an idea of..its purpose and how to do it, and then they’ll usually take it home and fill out the rest of it.*” BHP10<sup>Dep</sup> further explained that, in her prior experience, patients “*sometimes mistake activities for values and vice versa*” and that *SCOPE*’s version, although readily available, lacks “*enough direction for them to understand*” such distinctions in the intervention.

Providers described trying to walk patients through the app, but also how this became a logistical challenge. BHP4<sup>Dep</sup> explained “*We keep trying to meet face to face so I can kind of show her. And yeah, like, I can’t explain it on the phone. And she’s 70 something and she’s like we just can’t work out a time when because I’m only in the ... clinic one day [per week]. Yeah, that never seems to work for her.*” Some providers also felt unequipped to help patients with the app. BHP2<sup>Dep</sup> said “*I also feel that I don’t know the app inside and out. So I stumble a bit in trying to teach them. So even the times that we tried to do it together, I’ve pulled out the paper instructions of how to do that. I’ve given them a copy of it. But I don’t know that that’s very helpful. That might be just be too much.*”

### **Challenges of Integration with Existing Tools**

Project resources and timeline led to an early determination that *SCOPE* would not integrate with electronic health records (Section 4.1.2). Several providers described additional work associated with *SCOPE*, including duplicated data entry between *SCOPE*

and the electronic health record. *BHP8<sup>Dep</sup>* explained “*I have to enter in all of the patient’s information, which was pretty easy. It was well organized and made sense [but] it’s kind of a repeat of what we see in [the electronic health record]...I’m not sure why I was putting that information in again.*” A lack of integration also meant data was accessed separately, and *BHP8<sup>Dep</sup>* described potential benefits of integrated data: “*I can see other people’s inputs. It’s not just me ... so I can integrate. So a lot of the things that I do, I can see the psychiatry note, I can see palliative care notes, I can see whether the patient’s dose has been reduced on their medications, I can see what side effects they’re experiencing, like I can really get the whole patient.*”

Although integration with the electronic health record was desired, providers also described challenges in how this should be approached. Some wanted data pulled from the electronic health record into the registry, but not the other way around. One benefit of a separate system was the ability to keep provider notes separate from what patients can access: “*In [the electronic health record], we’re sharing all of our notes with our patients. And so I’m more inclined to write less there and write more in this*” (*BHP1<sup>Des</sup>*). Some providers noted information they put in the registry “*might not be something that [they] necessarily want the patient to read*” (*BHP4<sup>Des</sup>, BHP5<sup>Des</sup>*) and shared concerns that electronic health record notes could be “*demanded in court*” (*BHP2<sup>Des</sup>*).

## 4.3 Discussion

Prior sections have provided key context for our research in *SCOPE*, have detailed our process of designing and deploying *SCOPE* for actual care in 6 cancer clinics for 24 months, and have presented our data collection, analysis, and findings from 45 patient and provider interviews throughout design and deployment. Building upon [Section 4.2](#)’s reporting of patient and provider experiences with *SCOPE*, we now discuss several implications for future research in technology-enhanced care and patient-provider collaboration around patient-generated data.

### 4.3.1 Designing for Engagement with a Behavioral Health Intervention

*SCOPE*’s values and activities inventory design is based on a commonly-used behavioral activation worksheet, which providers use to structure a patient process of identifying personal values, determining activities aligned with those values, and scheduling those

activities. Patient engagement with this process is considered a core component of behavioral activation. Our initial design used this sequential process of identifying values, identifying activities, and scheduling activities. Design interviews found this appropriate, but feedback in the deployment described it as a barrier (i.e., patients wanted an ability to directly schedule activities without first identifying underlying values). We deployed an adaptation to relax the sequence of this process (i.e., making value identification optional in creating and scheduling activities, supporting later identification of values and their association with existing activities).

In deploying this adaptation, we found it necessary to navigate a tension in conceptualizing desired engagement. The adapted design removed a barrier to patient engagement with *SCOPE* and with activities, and patients and providers appreciated the adaptation because it decreased the steps required to schedule an activity. However, the new design also seemed to effectively allow some patients to circumvent the intended reflection on values (i.e., a core component of behavioral activation). We navigated this tension by providing multiple points of entry to engagement with values (e.g., via the original inventory process, when scheduling a new activity, when editing an existing activity). A provider who sees a patient is not engaging with values can then decide when and how to raise this component of the intervention with the patient (i.e., our design solution leverages the role of the provider in the long-term collaboration).

Our experience complements prior work highlighting challenges in combining human-centered design practices with evidence-based interventions, including challenges of integrating multiple perspectives in multi-disciplinary teams and tensions between patient experience and medical knowledge of intervention design [3, 122, 170, 184]. Slovak and Munson's recent framework argues for a form of design brief they call an *intervention implementation*, illustrating an intervention system together with sociotechnical components addressing specific implementation barriers [185]. Our identification and adaptation according to the specific details of this barrier in *SCOPE* contributes such a design brief, and we expect future research will need to continue exploring design tensions around ease of use versus desired engagement with components of evidence-based interventions.

### 4.3.2 Negotiating Patient Data Sharing and Provider Responsiveness

Interviews found varying and evolving expectations for provider responsiveness in reviewing patient-generated data in *SCOPE*. Patients raised concerns about knowing data is being received, wanted provider recognition and support, and wanted to know data is used in their care. Providers wanted to acknowledge and support patients, but also raised concerns about keeping pace with data. As part of negotiating this design challenge, we deployed two design adaptations. We first revised the patient app to be clear that data will be available but may not be immediately reviewed (e.g., [Section 4.2.4](#)). We then also enhanced the registry’s caseload overview with flags highlighting patients that have entered new data since a provider last marked them as reviewed (e.g., motivated in [Section 4.2.4](#), visible as “New” flags in [Figure 4.5](#)).

Our findings highlight a need to establish appropriate expectations for data sharing and provider responsiveness as part of introducing patient-generated data into a patient-provider relationship, including a process for adjusting expectations as appropriate. Consistent with explorations of patient and provider expectations [214], balancing tensions among control, visibility, sharing, and accountability is important to preserving trust in patient-provider relationships [182]. Shared decisions should be documented and respected by collaborative systems, but such negotiation can also conflict with organizational needs for standards (e.g., to meet legal and regulatory requirements [156], as with provider concerns for integration with electronic health records in [Section 4.2.5](#)). Additional research should continue examining individual, interpersonal, and organizational needs for sharing and engagement with patient-generated data in real-world clinical settings (e.g., through a lens of patient-generated data as boundary negotiating artifacts in patient-provider collaborations [35, 113]).

For example, additional research should explore how structure provided by patient-generated data can support lightweight messaging (e.g., as suggested by providers in [Section 4.2.4](#)). Such capabilities could further support connectedness (e.g., as in [Section 4.2.2](#)) and could allow providers to share reminders, inspiration, and positive reinforcement. However, care must be taken that patients may come to expect such messages and then be discouraged by their absence (e.g., if a provider is unavailable, if a provider does not use such messaging). Research could also explore automation (e.g., automated or semi-automated provider

acknowledgments), but this will bring its own challenges and concerns (e.g., if a patient feels an acknowledgment is not genuine, if automation undermines provider engagement with data).

### 4.3.3 Personalized Self-Tracking Goals in Evidence-Based Interventions

Goal alignment and shared understanding of how data will inform care is critical in patient-provider collaborations with patient-generated data [35]. *SCOPE* was intentionally designed around patient-generated data toward its underlying goals for collaborative care and behavioral activation, and the design succeeded in these goals (e.g., as in [Section 4.2.1](#), [Section 4.2.2](#), and [Section 4.2.3](#)). However, patients also described desiring other self-tracking capabilities, including symptoms related to their cancer journey (e.g., pain, headaches, tinnitus, nausea), cancer treatment (e.g., the starting day of a chemotherapy cycle), other emotions (e.g., gratitude), and other activities (e.g., sleep, social activities). Patients further described desiring flexibility in the form of tracking, such as describing mood with a single word (e.g., “*impatient*”, “*irritable*”) or an emoji.

Such requests surface an opportunity to consider personalized self-tracking goals in the context of evidence-based interventions. Recent personal informatics research has explored goals people bring to self-tracking and flexible tools that support individuals in configuring personalized tracking routines [50, 99, 164, 173, 174, 177]. Considering such techniques in the context of evidence-based interventions introduces an additional need to ensure flexible tracking preserves components of an intervention. [Section 4.3.1](#)’s adaptation of the design of activity tracking can be seen as an example of this (i.e., we relaxed the structure of the values and activities inventory to support patient goals of scheduling and tracking activities without requiring they complete the behavioral activation inventory process). Other possibilities could include designs with both fixed support for core tracking required by interventions and configurable personalized tracking for additional personalized goals. Additional research should explore this intersection from both directions: how techniques for configuring personalized tracking routines can integrate with evidence-based approaches, and how designs based in evidence-based approaches can support more flexibility and personalized goals for patient-generated data.

#### 4.3.4 Opportunities for Navigators in Technology-Enhanced Care

For a collaboration platform like *SCOPE* to succeed, both patients and providers must be able to use their respective platform components effectively. As part of ensuring appropriate usability, our design and development was iterative and incorporated feedback from multiple experts and stakeholders. Our deployment also prepared and distributed printable guides, conducted live and recorded training sessions with providers, and prepared patient videos showing how to use the app.

Despite strong usability and these additional implementation supports, some patients experienced challenges with understanding and using the app (e.g., as in [Section 4.2.5](#)). Some part of this may be due to participant demographics (e.g., often self-described as experiencing “chemo brain”) or to the high burdens of comorbid cancer and depression. But we also observed that many patients have few resources for technology help-seeking (e.g., may not have access to a person able to answer technology questions). Patients would sometimes seek technology assistance from providers, but providers were not always available or familiar with details of the patient app. To address this, we designated a member of the research team to provide technology walkthroughs and troubleshoot technology issues with participants.

This detail of our implementation is important in the context of the field’s growing interest in *digital health navigators*, an emerging role focused on supporting digital inclusion and the role of technology in improving patient outcomes, patient experience, and total health care costs [[14](#), [145](#)]. We note collaborative care management is itself motivated in part by the scarcity of psychiatry resources, hence the behavioral health care manager serves as primary provider of psychosocial care ([Section 2.3.2](#)). However, these providers are themselves also highly burdened [[194](#)], so answering patient questions about details of an app may not be the best use of that provider’s time (i.e., neither with that patient nor with an overall population). HCI and CSCW research often comes with strong traditions of “walk up and use” experiences [[66](#)], but multi-disciplinary research in such challenging settings also requires consideration of approaches like digital health navigators. We in turn believe there are important opportunities to explore how to design technology and technology-enhanced care with more explicit consideration of potential roles for digital health navigators (e.g., in facilitating per-patient technology customization that may

otherwise be infeasible).

### 4.3.5 Flexibility in Aligning Technology-Supported Interventions

Although we found *SCOPE* supports patient engagement with its interventions (Section 4.2.1) and supports patient-provider collaboration between and within sessions (Section 4.2.2), patients and providers also described contexts where *SCOPE* may not fit a patient's needs, where a patient may be unlikely to engage with *SCOPE*, or where *SCOPE* may otherwise not be appropriate. This highlights the continuing need for research examining factors that facilitate or impede care for different patient populations, but also serves as a reminder that behavioral health providers are trained in multiple interventions (Section 2.3.3). Providers traditionally adapt and choose among available interventions and low-technology support (e.g., available worksheets) to align to their understanding of a patient's needs and context. As technology-enhanced approaches are increasingly deployed, it is important to preserve provider ability to align care to patient needs and context. *SCOPE* was designed with a focus on behavioral activation, motivated in part by Suh et al.'s [194] identification of amplified challenges for rural populations (i.e., who experience greater difficulties accessing in-person care, thus amplifying opportunities for technology-based support). Patients for whom behavioral activation was not a good fit may have still benefited from other elements of the collaborative care intervention, but likely found many elements of the *SCOPE* app did not align to their needs. Additional research should explore how platforms like *SCOPE* might be extended to support components of multiple underlying interventions and how patients, providers, and organizations can align such flexible platforms to their complex needs and context.

## 4.4 Limitations

Our findings should be interpreted in the context of several limitations. Although drawn from 2 different regional cancer centers, all 6 participating clinics are in a single geographical region within Washington, USA. *SCOPE* was designed for patients comfortable reading and speaking English, and this was among the criteria for participation in the surrounding clinical trial. Although patient age was not a recruitment criterion, the demographics of cancer (i.e., more common among older adults) mean that participants are older than in many HCI and CSCW studies. We also expect patients who are less comfortable with technology would have been less likely to participate. We recruited across

all forms of cancer in participating clinics, and our research was not designed to account for potential differences or opportunities for more specialized support (e.g., in different types of cancer care journeys). Additional research should continue to explore commonalities and potential differences with additional patient populations.

Our deployment and ability to examine patient and provider experiences with *SCOPE* in actual long-term patient care was possible only through organizational support for the surrounding clinical trial. Patient participants used *SCOPE* as part of their actual care, and provider participants similarly used *SCOPE* as part of their clinical work. However, both patients and providers had consented to participate in the research. Experiences with a technology like *SCOPE* might be different or require additional considerations outside the context of a research trial (e.g., might include patients or providers who are more or less motivated, might require new approaches to implementation). We have noted *SCOPE* did not integrate with the existing electronic health record, and that providers offered feedback on challenges and nuances in such an integration. *SCOPE* also focused on behavioral activation as its primary underlying psychosocial intervention, but providers will have continued to use techniques from other interventions. Additional research will therefore continue to be needed as systems like *SCOPE* become more capable and more integrated.

## 4.5 Sociotechnical Gap in *SCOPE*

*SCOPE* can be situated within the context of Ackerman’s sociotechnical gap (discussed in [Section 2.1](#)) as a deliberate attempt to bridge the divide between social requirements and technical capabilities in collaborative care management for cancer patients with depression. *SCOPE* employed palliatives at ideological and educational levels. Stakeholders participated in the entire research lifecycle of *SCOPE* (e.g., cancer patients with depression, their care team comprising behavioral health care managers and psychiatrists). The research team was interdisciplinary with an appropriate balance of expertise and educational background (e.g., clinical researchers, HCI researchers with expertise in health systems). *SCOPE* combines a patient-facing app with a provider-facing registry, having several partial solutions (i.e., wide range of functionalities and capabilities that cater to diverse needs but specific contexts of patients and providers). Rather than trying to automate all aspects of health care delivery, *SCOPE* focused on specific collaboration challenges (i.e., provided a patient-facing mobile app that supports behavioral activation

while sharing patient-generated data with providers, a provider-facing registry that integrated this data for care coordination). *SCOPE* also advanced the science of the artificial through its examination as a technology-enhanced collaborative care platform in 6 cancer clinics.

It addressed several characteristics of the sociotechnical gap:

- *Flexibility and Nuance.* *SCOPE* supported the highly flexible, nuanced, and contextualized nature of patient activity between provider sessions in cancer and depression settings. This aligns with Ackerman’s observation that human activity is nuanced and contextualized, while technical systems are often rigid. It integrates patient-generated data into the care process, supporting more contextualized and personalized care.
- *Supporting Multiple Stakeholders with Differing Goals.* The collaborative care setting involves patients, behavioral health providers, psychiatrists, and oncology teams with potentially different priorities and perspectives. *SCOPE* addressed social requirements identified in collaborative care, such as improving patient-provider collaboration, supporting the communication and coordination of the care team, and enhancing patient participation in its interventions. *SCOPE* supported the diverse and fluid nature of human interaction that Ackerman highlights as challenging for technical systems.
- *Contextual Awareness.* The patient data generated between sessions became visible in the provider registry and provided more contextual information that was valuable for shared decision making in in-person sessions, but had previously been difficult to capture. This aligns with Ackerman’s observation that technical systems struggle to incorporate the contextual knowledge that humans employ effortlessly.

Despite its efforts, *SCOPE*’s examination surfaced challenges that exemplified the sociotechnical gap:

- *Evolving Expectations.* As people interacted with *SCOPE*, their expectations for collaboration around data evolved, demonstrating the dynamic nature of social requirements that technical systems can struggle to anticipate and accommodate.

- *Implementation Barriers.* The deployment of *SCOPE* in actual care settings uncovered implementation barriers, such as challenges in determining when *SCOPE* is appropriate for a patient and in integrating it with existing provider tools. These barriers illustrate the gap between idealized technical design and the complexities of real-world healthcare settings.
- *Flexibility in Interventions.* The need for flexibility in aligning technology-supported interventions (e.g., behavioral activation) to patient needs highlights the ongoing challenge of creating systems that can adapt to the nuanced requirements of individual patients. This is precisely the kind of flexibility that Ackerman argues is difficult to achieve technically.

As Ackerman indicated, the sociotechnical gap did not completely close, but *SCOPE* demonstrated how we could better understand and incrementally narrow this gap by carefully considering social requirements in collaborative care for treating depression in cancer settings.

## 4.6 Chapter Summary

We designed and developed *SCOPE* (Supporting Collaborative Care to Optimize Psychosocial Engagement), combining: (1) *a patient-facing mobile app* providing information, resources, and support for activities related to behavioral activation, with (2) *a provider-facing web-based registry* supporting clinical tasks among collaborating providers (e.g., collecting, organizing, reviewing data about a population of patients). A key innovation in *SCOPE* is the direct integration of patient-generated data into the provider registry (e.g., validated depression assessments, behavioral activation activity data, mood logs).

We examined how *SCOPE* supports collaborative care through 45 interviews with cancer patients with depression and their behavioral health providers. This included 26 design interviews (i.e., 14 with patients, 12 with behavioral health providers) over approximately 15 months of design and development, then 19 deployment interviews (i.e., 10 with patients, 9 with behavioral health providers) over approximately 24 months of deployment in 6 cancer clinics.

We found *SCOPE* supported the goals of its underlying interventions: (1) patients described that *SCOPE* supported their engagement with the interventions; (2) patients and providers described that patient-generated data in *SCOPE* supported improved collaboration between and within sessions through improved feelings of connection, through more efficient and effective in-person sessions, and through the use of patient-generated data for improved shared decision-making; (3) providers described that *SCOPE* supported structure and collaboration within the care team, which improved patient-provider sessions, care team caseload reviews, and care team knowledge-sharing. We further found (4) participant experiences with *SCOPE* created evolving expectations around patient-generated data, with patients seeking additional provider recognition and support and providers seeking additional registry capabilities around patient-generated data. Finally, we shared (5) insights into implementation barriers that surfaced as part of deployment of *SCOPE* for actual care, including challenges in determining if *SCOPE* is appropriate for a patient, of providing patients justification for using *SCOPE*, and in integrating with existing tools.

We then discussed implications of our findings in terms of challenges of designing for engagement with behavioral health interventions, the importance of negotiating patient data sharing and provider responsiveness, opportunities for supporting personalized self-tracking goals in evidence-based interventions, opportunities for exploring the role of digital health navigators in technology-enhanced care, and the need for flexibility in aligning technology-supported interventions to patient needs. Our findings therefore both inform the design of future platforms for technology-enhanced care and suggest future opportunities for related HCI and CSCW research.

## Chapter 5

### Agency, Negotiation, and Adaptation in Sociotechnical Systems

The previous chapters provide empirical observations based on our findings from *Jod* and *SCOPE*. In reflecting across them, I reviewed the data and iteratively reanalyzed them together with a focus on the sociotechnical gap (i.e., first understanding the gap that exists through characterization of social requirements and needs, uncovering common and emerging themes across *Jod* and *SCOPE* and how they supported nuanced and context-sensitive social activities, developing insights into how and where the gap persisted). Here, I compare and contrast several observations and reflections as part of demonstrating my thesis statement:

*The complexities of settings like accessibility and health reveal a range of needs for communication, collaboration, and coordination, motivating sociotechnical systems that can adapt according to evolving social dynamics.*

I contextualize my reflections on ‘evolving social dynamics’ in accessibility and health through three lenses: (1) *supporting the agency* of multiple and varied stakeholders (e.g., people tailoring tools to their own needs), (2) *negotiating social behaviors* that are inherent to these interactions (e.g., the impact of tools in supporting or limiting these negotiations), and (3) *supporting adaptability* that surfaces from new needs and evolving expectations (e.g., tensions arising from the relaxation of prior technical constraints). I include “sociotechnical” in the thesis statement because, in both accessibility and health settings, I observe that to support evolving dynamics: (1) people adapt to their social contexts, (2) technology supports people in adapting, (3) people adapt technology to support their needs, or (4) technology itself requires adaptation.

My first lens, *agency*, refers to the ability of individuals to act independently and make decisions in their own best interests. Agency in sociotechnical systems can be supported through tools that empower people to reshape workflows, interfaces, and data flows according to their needs and priorities. My second lens, *negotiating social behaviors*, is supported by the concept of *social translucence*, which aims to support coherent behavior by making participants and their activities visible to one another [51]. Social translucence can be characterized by three key principles, namely, *visibility* (i.e., making information visible within the sociotechnical system), *awareness* (i.e., making people aware of other’s actions), and *accountability* (i.e., helping people feel responsible for their actions). Sociotechnical systems can help people negotiate social behaviors, such as turn-taking, attention management, and power imbalances. My third lens, *supporting adaptability*, refers to sociotechnical systems that can adapt to new needs and evolving expectations that may arise from incorporating new design interventions into a technical system or from the relaxation of prior technical constraints.

In [Section 5.1](#) and [Section 5.2](#), I resurface observations from *Jod* and *SCOPE* to build context towards my thesis statement through the above-noted lenses. In both sections, I characterize the range of needs and contextual challenges in their respective settings, then how platform designs aim to support those needs, and then tensions and evolving expectations that arise with these platforms. [Section 5.3](#) next connects [Section 5.1](#) and [Section 5.2](#) and presents them together. In [Section 5.4](#), I synthesize my reflections across *Jod* and *SCOPE*. [Section 5.5](#) then briefly concludes by discussing my reflections in terms of the sociotechnical gap.

## 5.1 Accessibility in Mixed Hearing: Observations from Jod

In [Section 5.1.1](#), I characterize the range of needs and contextual challenges for accessibility in mixed hearing groups to support first half of my thesis statement that “*complexities of settings like accessibility reveal a range of needs for communication and collaboration.*” [Section 5.1.2](#) and [Section 5.1.3](#) will then support the second half of my thesis statement that “*sociotechnical systems that can adapt according to evolving social dynamics*” can support communication, collaboration, and coordination goals in mixed hearing group setting in videoconferencing.

### 5.1.1 Characterizing the Range of Needs and Contextual Challenges

I characterize the range of needs and contextual challenges for accessible videoconferencing in mixed hearing groups from related work (Section 2.2), from my observations in conducting studies to evaluate *Jod* (Section 3.2), and from my reflections in findings and discussion (Section 3.3 and Section 3.4).

#### *Audio-Centric Designs*

Mainstream videoconferencing platforms prioritize audio-centric designs, where the “active speaker” is determined by voice input. Such designs marginalizes DHH participants who rely on visual communication modalities like sign language and lipreading.

#### *Visual Layout Rigidity*

Videoconferencing platforms offer limited default layouts to choose from and tend to automatically resize and distribute video thumbnails over multiple pages. This design choice poses obstacles for visual communication. *Jod* addressed these challenges by offering customizable layouts to personalize their view of other participants, active speakers, and sign language interpreters.

#### *Attention Asymmetry and Turn-Taking Challenges*

Mixed hearing groups may often have systemic power imbalances in turn-taking. Hearing participants often dominate conversational flow through auditory backchannels (e.g., verbal affirmations), while DHH participants may feel uncomfortable to interject without culturally appropriate visual and audio cues (e.g., flashing lights).

#### *Cultural Misalignment in Accessibility Norms*

Videoconferencing platforms may often treat accessibility as a checklist of features (e.g., captions) rather than a cultural practice. As a consequence, their designs can overlook or misrepresent cultural needs of DHH participants. *Jod*'s study sessions surfaced such misalignments:

1. *Spatial Norms*. Hearing participants often forget to maintain upper-body visibility for lipreading, requiring DHH participants to send repetitive reminders.
2. *Identity Markers*. The lack of sign name integration requires DHH participants and interpreters to fingerspell names, a laborious process that demeans Deaf cultural

identify and introduces interpretation lags.

3. *Expressive Communication.* Hearing participants often forget to use facial expressions and body language to convey emotions, causing DHH participants to miss important emotional cues. In contrast, hearing participants are often uncertain of whether DHH participants understood them due to a lack of non-verbal affirmations.

### 5.1.2 Designing for Agency and Social Negotiation in *Jod*

*Jod*'s design supported participants in reconfiguring their social environment through: customizable visual layouts, preset feedback messages, and explicit accessibility indicators. These features shifted power dynamics by centering the needs of DHH participants and supporting all participants in addressing the range of needs in mixed hearing groups.

#### *Supporting Agency through Customizable Visual Layouts*

*Jod*'s customizable visual layout's use of a drag-and-drop interface helped participants resize and cluster video tiles. Participants appreciated the ability to customize their view, which helped them focus on the most relevant information and reduced cognitive load from concurrently tracking multiple visual channels (e.g., signing, captions, facial expressions). For example:

1. *DHH Configurations.* Participants created "signing zones" (illustrated in [Figure 3.7](#)) by grouping interpreters and DHH participants. They positioned captions beneath the video tile of the interpreter and ensured that this tile got the maximum visual space.
2. *Hearing Adaptations.* Some hearing participants adopted minimalist views (e.g., only active speaker and interpreter) but engaged more with DHH participants when layouts made their presence visually salient through preset feedback messages (e.g., a DHH participant requesting that the hearing participant look at them) or enhanced transcription (e.g., active signing indication).

#### *Supporting Negotiation through Preset Feedback Messages*

*Jod*'s preset feedback messages supported participants with social negotiations by helping them make their own needs visible so other participants could become aware of them. These messages also served as *social scripts* (i.e., a set of expected behaviors and interactions that people follow in a particular social situation) [[74](#), [133](#)] that supported participants in both:

1. *Norm Education.* Messages codified accessibility expectations, reducing the need for DHH participants to repeatedly educate hearing participants about their needs. For example, DHH participants sent the “Please look at me” message to assert their conversational agency and request visual attention from hearing participants.
2. *Needs Assertion.* Notifications like “Please speak slower” empowered DHH participants to assert their needs without the help of intermediaries. This reduced the interpretation lag that is common in mixed hearing groups and encouraged hearing participants to adapt their speech patterns after receiving feedback.

#### *Accessibility Indicators as Accountability Markers*

Explicit labels (e.g., Deaf, Interpreter) functioned as accountability markers, embedding accessibility into the interaction grammar of mixed hearing groups. These labels helped participants remember needed accommodations, fostering collective responsibility for accessibility.

#### *Flexibility and Transparency through Multiplicity*

*Jod* supported its participants with flexibility and transparency by using a multiplicity of designs (e.g., accessibility indicators were visible in profiles, captions, transcriptions, video tiles; preset feedback messages were visible in the layout through toast elements, captions, transcriptions; captions could be resized and dragged anywhere). For example, multiple design elements supported DHH participants in simultaneously referring to the video tile and the transcriptions/captions if the interpreter was unavailable or if lags occurred due to internet connectivity issues. Multiple design options also empowered them to verify whether the interpreter missed any information or lost critical information in translation when communicating with hearing participants.

### **5.1.3 Tensions and Evolving Expectations**

I now present my reflections on participant experiences around tensions and their evolving expectations for accessible video conferencing. The design of *Jod* aimed to narrow the sociotechnical gap, but through a real-world examination I observed that characteristics of the sociotechnical gap in a mixed hearing setting were further revealed through improved understanding. In addition, as people adapted to the new technical capabilities of *Jod*, new characteristics of the sociotechnical gap also began to evolve and emerge.

### *Labor of Customization vs. Automation*

Although *Jod*'s flexibility empowered its participants, the study sessions highlighted tensions between customization (flexibility) and automation (efficiency). For example, participants expressed frustration at the cognitive load of constantly reconfiguring layouts to accommodate changing conversational dynamics.

1. *DHH Labor*. Participants requested one-click templates to reduce labor (e.g., to show only DHH participants, hide hearing participants, revert to a default layout).
2. *Platform Responsibility*. Participants wanted the platform to automatically adjust layouts based on conversational dynamics (e.g., wanting a hand-raising participant to come to the main layout, system-wide notifications if the interpreter was unavailable).

### *Notification Overload and Prioritization*

During the study sessions, DHH participants sent “Please look at me” and “Please repeat yourself” notifications to reclaim conversational agency. However, this reactive approach perpetuated what participants described as the *burden of interruption* (i.e., the need for DHH participants to constantly ask for attention rather than participating organically). Preset messages supported participants in negotiating social needs but introduced new frictions:

1. *Interruption Cascade*. Hearing participants received an average of 3–5 simultaneous messages during fast-paced discussions, overwhelming their attention. For interpreters, who typically sit or stand a few feet away from their videoconferencing setup, these interruptions caused them to stop interpreting to dismiss messages, leading to communication gaps.
2. *Feedback Loop*. DHH participants expressed frustration when their messages were not acknowledged. They wanted feedback on the effectiveness of their messages (e.g., knowing if the hearing participant understood the message), underscoring the need for read receipts or prioritization flags to bridge this acknowledgment gap.
3. *Message Prioritization*. All participants desired nuanced prioritization mechanisms to manage notification overload (e.g., urgent vs. non-urgent).

## 5.2 Collaborative Care in Cancer and Depression: Observations from SCOPE

In [Section 5.2.1](#), I characterize the range of needs and contextual challenges for technology-enhanced care to support first half of my thesis statement that “*complexities of settings like health reveal a range of needs for communication and collaboration.*” [Section 5.2.2](#) and [Section 5.2.3](#) will then support the second half of my thesis statement that “*sociotechnical systems that can adapt according to evolving social dynamics*” can support communication, collaboration, and coordination goals for cancer and depression setting in health.

### 5.2.1 Characterizing the Range of Needs and Contextual Challenges

Cancer care and depression care represent intersecting but often misaligned social systems. Patients navigate parallel journeys: one focused on cancer treatment (e.g., surgery, chemotherapy, and radiation protocols governed by oncology teams) and another on psychosocial care (e.g., behavioral activation therapy, mood tracking, and safety planning led by behavioral health providers). This duality creates tension and reveals critical needs in collaborative care management when these domains intersect. I characterize the range of needs and contextual challenges from related work ([Section 2.3](#)), from my observations in *SCOPE*’s design, deployment, and evaluation ([Section 4.1](#), [Section 4.2](#), and [Section 4.3](#)).

#### *Fragmented Communication Architectures*

Oncologists and behavioral health teams (i.e., social workers, psychiatrists) operate in silos, with asynchronous data flows that exacerbate care delays and can lead to inconsistent follow-up and delayed treatment adjustments.

1. *Temporal Misalignment.* Depression symptom escalation can often go unnoticed between oncology visits. Patients may struggle to recall and communicate their mental health status during oncology appointments, leading to under-reporting and delayed intervention.
2. *Data Fragmentation.* Patients receive care from multiple providers, leading to fragmented documentation and care plans. This fragmentation can create confusion and burdens for patients and providers, who must navigate multiple care plans and treatment recommendations. For example, behavioral health plans may exist outside of EHRs, which burdens patients with the task of coordinating and relaying

information between providers.

#### *Rigid Patient Tools and Passive Patient Roles*

Behavioral activation and other therapy tools are often paper-based and do not support flexibility in tracking personal data. Patients can also often feel disconnected from care decisions due to limited access to their own health data and unclear documentation of treatment plans. This frequently causes patients to become passive recipients, rather than active agents, in their care journey.

#### *Asymmetric Patient-Provider Collaboration*

Many patients can struggle to articulate psychosocial needs during brief clinical interactions in therapy sessions, and behavioral health providers can lack visibility into the between-session experiences of their patients. Patient-generated data (e.g., mood logs, activity tracking) rarely integrates with provider workflows, limiting shared decision-making. During oncology treatment, psychosocial care can take a backseat, resulting in situations where patients may not see their behavioral health provider for weeks.

#### *Behavioral Activation Barriers*

Depression can reduce a patient's capacity to engage in value-based activities, creating cycles of disengagement, especially when experiencing cancer-related "chemo brain," cognitive dysfunction, or cognitive impairment.

### **5.2.2 Designing for Agency and Social Negotiation in *SCOPE***

*SCOPE*'s design empowered patients and providers to bridge the gap between cancer and depression care through: structured data sharing, behavioral activation tools, and a patient-facing mobile app. Patient data was directly available in the registry, supporting visibility and shared decision-making. These features shifted power dynamics by highlighting patient needs and supporting both patients and providers in addressing the range of needs in collaborative care management of depression in the cancer setting.

#### *Supporting Patient Agency in Care*

Several patients noted that data generated by the *SCOPE* app helped them become aware that they were doing more activities than they initially thought during depressive episodes. For some, having agency in tracking values they cared about helped them identify life areas

where values and activities were misaligned, prompting reflection on whether they wanted to make changes. This empowered patients to take more active role in their care.

*Flexibility in Aligning Intervention through Multiplicity.*

The patient app provided multiple entry points to engage in SCOPE's underlying behavioral health interventions. The app also supports multiple approaches to scheduling activities.

*Patient-Provider Social Negotiations through Data Visibility and Awareness*

Patients also reported that *SCOPE* improved communication with and connection to their providers since patient activities between sessions became visible to the provider in real time. They also observed that better communication improved shared decision making with their providers. By integrating mood logs, behavioral activation data, and safety protocols that patients generated in the patient app directly into the provider registry, *SCOPE* transformed patient inputs into shared discussion points for care decisions. This integration also supported patients in articulating their psychosocial needs since they could refer to their own data during therapy sessions, reducing the burden they felt to remember their experiences between sessions.

For behavioral health providers, patient data in the *SCOPE* registry supported them in engaging with patients regarding interventions, new strategies, and other pathways aimed at improving health outcomes.

*Provider-Provider Social Negotiations*

The *SCOPE* registry provides dual-view dashboards that support providers when toggling between population-level analytics (e.g., for caseload management) and individual patient profile (e.g., for personalized care). It supported behavioral health providers when customizing how patient data was prioritized during case reviews (e.g., flagging high-risk patients for discussions with the psychiatrists, while maintaining population-level monitoring, glancing at the patient's oncologic situation, and reviewing patient assessment scores with the psychiatrists). This reduced the cognitive load on behavioral health providers of managing parallel care journeys. As more providers started using *SCOPE*, it created an environment of collaboration because it helped them easily share patient context and solicit opinions of other behavioral health providers (i.e., via registry data). Providers further shared that other senior or experienced oncologists were much more willing to listen

to their recommendations and make changes to a treatment plan based on the presented data, or that they felt more comfortable and confident when asking clinical questions to psychiatrists.

#### *Provider and Clinic Evolution through Accountability*

One behavioral health provider described how they were becoming better clinicians because *SCOPE*'s structure made behavioral activation more applicable for them. They explained that there were carryover effects even in the non-tech arm of the trial because they could take what they had learned and apply it there, improving accountability and ultimately supporting the clinic in becoming a stronger program overall.

### **5.2.3 Tensions and Evolving Expectations**

I now present my reflections on both patient and provider experiences around tensions and their evolving expectations for technology-enhanced collaborative care. The design of *SCOPE* aimed to narrow the sociotechnical gap, but through a real-world examination I observed that characteristics of the sociotechnical gap in a collaborative care setting of cancer and depression were further revealed through improved understanding. In addition, as patients and providers adapted to the new technical capabilities of *SCOPE*, new characteristics of the sociotechnical gap also began to evolve and emerge.

#### *Privacy vs. Therapeutic Transparency*

Some patients conveyed apprehensions regarding data access (e.g., at times of acute depression) and experienced discomfort in sharing their information with behavioral health providers, particularly when there was a lack of clarity on how such data would facilitate improvement of their psychosocial health.

#### *Patients Seeking Acknowledgment and Support*

Patients who engaged with the *SCOPE* app shared that they wanted their provider to engage with their generated data (e.g., provide encouragement at big life moments, support them during symptom severity). They wanted to know when their data would be assessed or reviewed. After several months of deployment in clinics, health providers shared for safety concerns that their patients were adapting *SCOPE* app's mood logging as messaging to reach out to them. We released an adaptation to the *SCOPE* app that clarified that

providers may not immediately review their data for safety concerns. Patients also wanted to connect with other patients who would be willing to talk and share their experiences.

#### *Providers Seeking Multifaceted Support*

Behavioral health providers are responsible for delivering care to a population of patients. As providers gained experience with *SCOPE*, they sought capabilities to support this population. They wanted functionality that could distill insights at a population level to aid in adjusting treatments and features that could improve decision-making with individual patients (i.e., for patients who were generating significant amounts of health data). They also wanted lightweight capabilities in *SCOPE* to acknowledge and let their patients know that they had reviewed their data. Behavioral health care providers, who are trained to deliver multiple evidence-based psychosocial treatments (e.g., problem-solving therapy, cognitive behavioral therapy, mindfulness therapy), wanted additional platform support for other low-cost, low-effort interventions in situations where behavioral activation may not be appropriate (e.g., after chemotherapy or when a patient is highly anxious).

#### *Balancing Engagement in Interventions*

*SCOPE*'s behavioral activation design is based on a paper-based worksheet; the worksheet recommendeds that patients identify their personal values and then determine activities that align with those values. The *SCOPE* app's original design constrained patients to schedule activities only after they had created values. We soon relaxed this constraint and made the values optional when scheduling activities.

#### *Intelligent Support in SCOPE App*

Patients sought provider guidance and support on how to incorporate *SCOPE* in their care. They also wanted intelligent behaviors from the app (e.g., helping them identify their values and activities, keeping them engaged during difficult episodes, supporting them with motivational messages grounded in their previously generated data).

### **5.3 Connections Across Jod and SCOPE**

The range of needs and contextual challenges in [Section 5.1.1](#) and [Section 5.2.1](#) were characterized from related work and from our observations in designing and examining *Jod* and *SCOPE*. [Section 5.1.2](#) and [Section 5.2.2](#) then described how *Jod*'s and *SCOPE*'s designs each supported stakeholders in terms of agency and social negotiation. [Section 5.1.3](#) and

Section 5.2.3 presented reflections on the participant experiences around tensions and their evolving expectations in each of *Jod* and *SCOPE*.

In this section, I connect insights from Section 5.1 and Section 5.2. Table 5.1 relates the range of needs and contextual challenges across both systems. Table 5.2 relates how *Jod* and *SCOPE* empowered its participants through agency. Table 5.3 relates how *Jod* and *SCOPE* supported its participants in negotiating social behaviors, and Table 5.4 relates participant experience around tensions and evolving expectations across both sociotechnical settings.

Table 5.1: Overview of a range of needs and contextual challenges across *Jod* and *SCOPE*.

<i>Jod</i>	<i>SCOPE</i>
<p><b>Audio-Centric Designs.</b> Active speaker is determined by voice input, marginalizing DHH participants relying on visual communication.</p> <p><b>Visual Layout Rigidity.</b> Videoconferencing platforms provide limited layouts and often auto-resize video thumbnails across pages, hindering visual communication.</p> <p><b>Attention Asymmetry and Turn-Taking Challenges.</b> Mixed hearing groups often face power imbalances in turn-taking, with hearing participants dominating through auditory backchannels, leaving DHH participants hesitant to interject.</p> <p><b>Cultural Misalignment in Accessibility Norms.</b> Platforms often treat accessibility as a checklist rather than a cultural practice, overlooking needs like upper-body visibility for lipreading and expressive body language for emotion.</p>	<p><b>Fragmented Communication Architectures.</b> Care teams often work in silos, with delayed data flows that hinder follow-up, slow treatment adjustments, and place coordination burdens on patients.</p> <p><b>Rigid Patient Tools and Passive Patient Roles.</b> Behavioral activation and other therapy tools are often paper-based and inflexible for tracking personal data. This can leave patients feeling disconnected from care decisions, reducing their active engagement.</p> <p><b>Asymmetric Patient-Provider Collaboration.</b> Patients may struggle to express psychosocial needs in therapy sessions, while providers often lack insight into their between-session experiences.</p> <p><b>Behavioral Activation Barriers.</b> Depression can reduce patient capacity to engage in value-based activities, creating cycles of disengagement, especially when experiencing cancer-related “chemo brain”, cognitive dysfunction, or cognitive impairment.</p>

Table 5.2: Overview of how *Jod*'s and *SCOPE*'s designs empowered participants through agency.

<i>Jod</i>	<i>SCOPE</i>
<p><b>Supporting Agency through Customizable Visual Layouts.</b> Participants valued layout customization, which helped them focus on key information. For example, some DHH participants grouped interpreters and other people into “signing zones”, and some hearing participants adopted minimalist views but engaged with DHH participants when layouts made their presence visually salient.</p> <p><b>Flexibility and Transparency through Multiplicity.</b> <i>Jod</i> supported participants with flexibility and transparency by using a multiplicity of designs (e.g., accessibility indicators were visible in profiles, captions, transcriptions, video tiles; preset feedback messages were visible in the layout through toast elements, captions, transcriptions).</p>	<p><b>Supporting Patient Agency in Care.</b> Data from the <i>SCOPE</i> app helped patients recognize their activity levels during depressive episodes. For some, having agency in tracking values they cared about helped in identifying life areas where they wanted to make changes, empowering them to engage more actively in their care.</p> <p><b>Flexibility in Aligning Intervention through Multiplicity.</b> The patient app provided multiple entry points to engage in <i>SCOPE</i>'s underlying behavioral health interventions. The app also supports multiple approaches to scheduling activities.</p>

Table 5.3: Overview of how *Jod*'s and *SCOPE*'s designs supported participants in negotiating social behaviors.

<i>Jod</i>	<i>SCOPE</i>
<p><b>Supporting Negotiation through Norm Education and Needs Assertion.</b> <i>Jod</i> made accessibility needs visible, with preset messages codifying expectations and reducing the need for DHH participants to repeatedly educate hearing participants. Notifications like “Please speak slower” empowered DHH participants to assert their needs independently.</p> <p><b>Accessibility Indicators as Accountability Markers.</b> Explicit labels (e.g., Deaf, Interpreter) in <i>Jod</i> functioned as accountability markers, embedding accessibility into the interaction grammar of mixed hearing groups and fostering collective responsibility for accessibility.</p>	<p><b>Patient-Provider Negotiations through Data Visibility and Awareness.</b> <i>SCOPE</i> improved patient-provider communication by making patient activities visible between sessions. This enhanced shared decision-making and helped patients articulate their psychosocial needs by referencing their own data, reducing the burden of recalling experiences.</p> <p><b>Provider-Provider Negotiations.</b> The registry supported providers to customize patient data priorities during case reviews, reducing cognitive load. As more providers joined <i>SCOPE</i>, it fostered collaboration by simplifying patient context sharing and feedback from others.</p> <p><b>Clinic Evolution through Accountability.</b> <i>SCOPE</i> supported providers in becoming better clinicians, suggesting carryover effects even in the non-tech arm of the trial, improving accountability and ultimately supporting clinic in becoming a stronger program.</p>

Table 5.4: Overview of participant experiences around tensions and their evolving expectations with *Jod* and *SCOPE*.

<i>Jod</i>	<i>SCOPE</i>
<p><b>Labor of Customization vs. Automation.</b> Participants were frustrated by the cognitive load of reconfiguring layouts for changing conversations. DHH participants requested one-click templates and automatic layout adjustments based on conversational dynamics.</p>	<p><b>Privacy vs. Therapeutic Transparency.</b> Patients expressed concerns about data access and sharing, particularly when there was a lack of clarity on how such data would facilitate improvement of their psychosocial health.</p>
<p><b>Notification Overload.</b> DHH participants used notifications to reclaim conversational agency but shared the burden of repeatedly asking for attention. During fast-paced discussions, recipients were overwhelmed, such as interpreters needing to stop signing to respond. DHH participants also felt frustrated when their messages went unacknowledged.</p>	<p><b>Patients Seeking Acknowledgment and Support.</b> Patients using the <i>SCOPE</i> app wanted providers to engage with their data, seeking encouragement during major life moments or support during severe symptoms, and clarity on when their data would be reviewed.</p>
<p><b>Notification Prioritization.</b> Participants desired nuanced prioritization mechanisms to manage notification overload (e.g., platform prioritizing what notifications were urgent vs. non-urgent).</p>	<p><b>Providers Seeking Multifaceted Support.</b> Behavioral health providers using <i>SCOPE</i> sought features to distill population-level insights for treatment adjustments and improve decision-making with individual patients. They also wanted simple tools to acknowledge reviewed data and additional support for other interventions when behavioral activation was not suitable.</p>

## 5.4 Synthesis: Sociotechnical Systems Adapting to Evolving Social Dynamics

Section 5.1 and Section 5.2 resurfaced my observations in *Jod* and *SCOPE* through the framing of three lenses. In this section, I synthesize my observations across both systems *motivating sociotechnical systems that adapt to evolving social dynamics* through the lenses of agency in Section 5.4.1, social negotiation in Section 5.4.2, and evolving expectations in Section 5.4.3.

### 5.4.1 Centering Agency through Flexibility

Technical systems can support stakeholders in tailoring tools to their personal needs. Both *Jod* and *SCOPE* prioritize customization and flexibility over rigid defaults, helping stakeholders to configure systems rather than conform to them. In *Jod*, DHH participants resized and repositioned interpreter tiles, removed non-essential video feeds, and adjusted captions to align with their communication needs. This flexibility supported DHH participants in efforts to prioritize visual communication channels (e.g., sign language interpreters) while minimizing cognitive load from audio-centric layouts. Similarly, *SCOPE*'s goal is to support patients in efforts to define personalized behavioral activation goals (e.g., scheduling value-aligned activities) and share self-tracked mood and activity data with providers. Patients tailored their engagement with the app based on their fluctuating energy levels and treatment side effects, and they reflected on generated data to support their own care.

#### Agency Implications

- *Avoid Exclusionary Defaults.* *Jod*'s relaxation of fixed layout constraints freed DHH participants from forced, suboptimal configurations (e.g., small interpreter and participant tiles). *SCOPE* avoided prescriptive activity templates, supporting patients wanting to align tasks with personal values (e.g., family time vs. physical exercise).
- *Reduce Conformity Burdens.* Systems with rigid structures that require people to adapt to majority norms (e.g., audio-centric videoconferencing) can perpetuate inequity. Customizability can support shifting some of this burden to the system itself and redress imbalances by supporting different participant abilities.

### 5.4.2 Social Negotiation through Visibility and Intervention

Sociotechnical systems can support social negotiation by making stakeholders needs visible and enabling interventions that shift/equalize group dynamics. In *Jod*, DHH participants used preset notifications (e.g., “Please speak slower,” “Please repeat yourself”) to influence the behavior of hearing participants, thus disrupt the default privileges of audio-centric communication. In *SCOPE*, patients and providers leveraged patient-generated data to support and advocate for treatment adjustments during sessions and case review meetings, elevating patient perspectives in shared decision making. *SCOPE* also supported social negotiation between behavioral health providers and other providers, helping all team clinicians advocate for their own perspectives on patient treatment and resolve clinical questions. Due to visibility and awareness of participant needs in *Jod* and notifications from preset messages, it became possible for DHH and hearing participants to negotiate about accountability and shared responsibility for accessibility measures.

#### Social Negotiation Implications:

- *Interruption Trade-offs.* *Jod*’s notifications risked overburdening interpreters and other participants if they went unacknowledged, highlighting the need for shared clarity.
- *Excess Data Burden.* Patient requests for data acknowledgment clashed with provider workload limitations, necessitating transparent guidelines on response time and appropriate support in tools for providers to process and analyze the patient data.

### 5.4.3 Adaptability to New Needs and Evolving Expectations

Despite our best design efforts, both *Jod* and *SCOPE* faced challenges due to new needs and evolving expectations. As people interacted with the systems, their expectations for communication, collaboration, and coordination evolved and matured, demonstrating the dynamic nature of social requirements in technical systems. Both these system characterize the sociotechnical gap through a need to solve for:

- *Balancing flexibility and automation.* Participants desired a balance between customization and automated support, highlighting the difficulty in creating systems that are both flexible and efficient.
- *Notification design.* The study revealed issues with the notifications system, such

as its disruptive nature and the lack of feedback mechanisms for the interpreter, reflecting the gap between social activity in mixed hearing settings and technical implementations.

- *Cultural and communication norms.* The study observed varying norms among DHH and hearing groups, leading to mismatched expectations, a classic example of the sociotechnical gap where technical systems struggle to accommodate diverse social contexts.
- *Implementation barriers.* The deployment of *SCOPE* in actual care settings uncovered implementation barriers, such as challenges in determining when in the cancer care journey *SCOPE* would be appropriate for a patient and how to integrate it with existing provider tools.
- *Flexibility in interventions.* The need for flexibility in choosing which technology-supported interventions (e.g., behavioral activation) best align with patient needs highlights the ongoing challenge of creating systems that can be adapted to the nuanced requirements of individual patients.

These observations and reflections suggest that sociotechnical systems must be designed to support dynamic adjustments as social or environmental conditions shift.

## 5.5 Chapter Summary

[Figure 5.1](#) reflects on my overall dissertation through the lens of the sociotechnical gap. First, my dissertation work was informed by the existing sociotechnical gap in the complex settings that I explored in accessibility and health. With an understanding of the gap guided by established frameworks and design recommendations from relevant contexts (e.g., d/Deaf culture, communication challenges in mixed hearing groups as described in [Section 2.2](#); the parallel journey framework, patient-provider collaboration around patient-generated data as described in [Section 2.3](#)), the technical design of *Jod* and *SCOPE* aimed at narrowing the sociotechnical gap (illustrated in [Figure 5.1a](#)). Our examination of these systems in real world environments found that we succeeded in bridging elements of the gap through new capabilities in the system (e.g., both *Jod* and *SCOPE* empowering participants through agency and negotiation of social behaviors, as

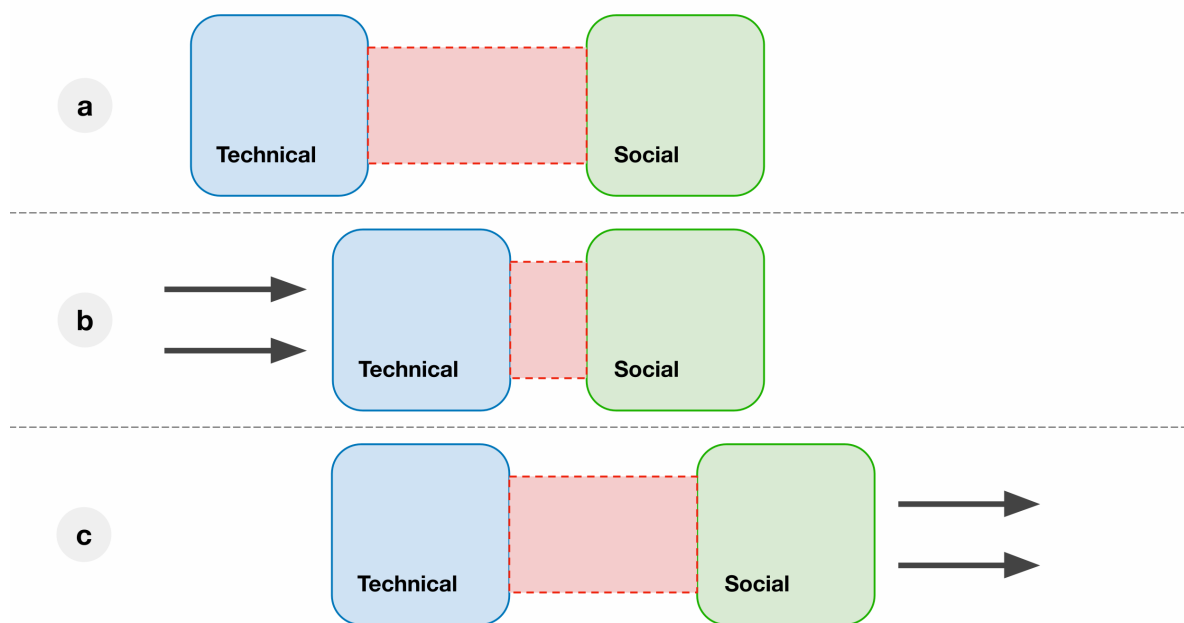


Figure 5.1: The sociotechnical gap in the context of this dissertation research: (a) My work was informed by the existing sociotechnical gap in the complex settings I explored in accessibility and health. With an understanding of the gap guided by established frameworks and design recommendations from relevant contexts, the technical design of *Jod* and *SCOPE* aimed to narrow the gap. (b) Through real world examination we found that we succeeded in bridging several elements of the gap. (c) At the same, the characteristics of the sociotechnical gap were further revealed through improved understanding. As people adapted to both systems, new characteristics of the sociotechnical gap also began to evolve and emerge.

illustrated in [Figure 5.1b](#)). At the same time, I also observed the gap expanding. On one hand, characteristics of the sociotechnical gap were further revealed through improved understanding. On the other hand, as people adapted to both systems, new characteristics of the sociotechnical gap also began to evolve and emerge (illustrated in [Figure 5.1c](#)).

This chapter compared and contrasted empirical observations from *Jod* and *SCOPE* to demonstrate my thesis statement:

*The complexities of settings like accessibility and health reveal a range of needs for communication, collaboration, and coordination, motivating sociotechnical systems that can adapt according to evolving social dynamics.*

I contextualized the evolving social dynamics of my work in accessibility and health through the lenses of (1) supporting the *agency* of multiple stakeholders (e.g., people tailoring tools to their own needs), (2) *negotiating* social behaviors that are inherent to these interactions (e.g., tools supporting or limiting social translucence), and (3) *supporting adaptability* that surfaces from new needs and evolving expectations (e.g., tensions arising from the relaxation of prior technical constraints).

I show that in settings such as accessibility and health, sociotechnical systems that can adapt according to these evolving social dynamics can support communication, collaboration, and coordination.

# Chapter 6

## Conclusion and Future Research Directions

[Section 6.1](#) summarizes the contributions in this dissertation. [Section 6.2](#) offers future research directions for designers and builders interested in optimizing communication, collaboration, and coordination platforms for complex settings, and [Section 6.3](#) briefly concludes.

### 6.1 Review of Thesis Contributions

My dissertation contributed both artifacts and empirical research findings in the design space of sociotechnical systems that support communication, collaboration, and coordination.

I first provided relevant background and related work to identify the range of needs in social settings in accessibility and health. To support the accessibility component of this dissertation, I first discussed DHH communication methods and the affordances and limitations of current videoconferencing systems for mixed hearing groups ([Section 2.2](#)). I then presented research on collaborative care within comorbid cancer and depression settings to support the health component of the dissertation. I provided the necessary background in evidence-based interventions that drove *SCOPE* platform design ([Section 2.3](#)).

I then presented the design, development, and evaluation of *Jod*, a videoconferencing system that integrated multiple design recommendations from prior work to support communication in mixed hearing groups. *Jod* supported videoconference participants to customize their visual layout to more fully engage with others, guiding them in how to resize, rearrange, and add/remove video tiles of other participants. It included a notification system with preset messages to solicit the attention of other attendees and influence speaker behavior. To

balance the audio-centric design of videoconferencing platforms, *Jod* highlighted the video tiles of active signer(s). Further, it incorporated accessibility indicators into profiles to help participants identify and gauge the real-time needs of others in the videoconference meeting and to support the recall of appropriate communication accommodations (Section 3.1).

I then described the study to evaluate *Jod*, detailing six study sessions with 34 participants (18 DHH participants, 10 hearing participants, 6 Indian Sign Language interpreters), where each session began with a tutorial that was followed by task-based exploration, unstructured conversation, a game of charades, a presentation with screen sharing, and concluding with a focus group discussion (Section 3.2).

The findings revealed several insights, particularly a strong correlation between the hearing abilities of participants and their preferred visual layout arrangements. Notably, DHH participants made the interpreter's video tile significantly larger than the tiles of hearing participants and moved the closed captions closer to the interpreter's video tile. They also engaged in visual layout-related rearrangements to adapt to the changing group communication context, particularly during the game of charades, where they prioritized the participant whose turn it was. Such customization capabilities provided complete control over visual layouts but also led to additional manual labor. Thus, DHH participants desired a balance between flexibility and system-provided automated defaults to reduce such labor. They further reported that preset feedback messages improved communication between DHH signers, hearing people, and interpreters. The preset messages helped DHH participants interject, request attention, and influence speaker behavior, but they also raised a need for acknowledgments and prioritization of received messages based on the group communication context (Section 3.3). Drawing on these findings, I synthesized key takeaways and provided guidelines and implications for designing videoconferencing platforms that better support mixed hearing communication. I focused on visual layout customization, platform interactivity and reactivity, and d/Deaf cultural considerations. I concluded with recommendations for conducting inclusive mixed hearing studies, emphasizing the importance of study protocol iterations and the need for flexible, open-minded, and adaptable accessibility researchers (Section 3.4).

I then presented the design, development, and evaluation of *SCOPE* (Supporting Collaborative Care to Optimize Psychosocial Engagement), a technology-enhanced

collaborative care management platform intended to support patients with comorbid cancer and depression and their providers. *SCOPE* combined: (1) a patient-facing mobile app that provided information, resources, and support for activities related to behavioral activation, with (2) a provider-facing, web-based registry that supported clinical tasks specific to collaborating providers. *SCOPE*'s key innovation was directly integrating patient-generated data (i.e., associated with its behavioral activation intervention) into a provider registry, which we redesigned for this purpose (Section 4.1).

I described how we evaluated *SCOPE* through a total of 45 interviews with cancer patients and their behavioral health providers, which we conducted throughout the design and deployment of *SCOPE*. This included 26 design interviews (i.e., 14 with patients, 12 with behavioral health providers) over approximately 15 months of design and development (Section 4.1.1), followed by 19 deployment interviews (i.e., 10 with patients, 9 with behavioral health providers) over approximately 24+ months of deployment in actual care across 6 cancer clinics (Section 4.1.4).

I then presented the findings, which indicated that *SCOPE* successfully supported both patients and behavioral health providers in achieving the goals of its underlying collaborative care and behavioral activation interventions. Patients observed that *SCOPE* interventions supported their engagement with clinicians. Further, patient-generated data in *SCOPE* improved (1) patient-provider collaboration between and within in-person sessions and (2) provider care team caseload reviews and knowledge-sharing among care team members. Participant experiences with *SCOPE* created evolving expectations around patient-generated data sharing and provider responsiveness (Section 4.2.1, Section 4.2.2, Section 4.2.3, and Section 4.2.4). Finally, the chapter recounted implementation barriers that surfaced during the design and deployment of *SCOPE* for actual care in six cancer clinics over 24+ months (Section 4.2.5) and discussed implications of our findings for the design of future platforms for such technology-enhanced collaborative care (Section 4.3).

Together, this research demonstrated my thesis:

*The complexities of settings like accessibility and health reveal a range of needs for communication, collaboration, and coordination, motivating sociotechnical systems that can adapt according to evolving social dynamics.*

I discussed how my research shows that in settings like accessibility and health, sociotechnical systems can support communication, collaboration, and coordination by adapting according to evolving social dynamics, including by: (1) supporting the agency of multiple stakeholders (e.g., can people tailor tools to their own needs), (2) negotiating social behaviors that are inherent to these interactions (e.g., do the tools support or limit social translucence), and (3) supporting adaptability that surfaces from new needs and evolving expectations (e.g., arising from the relaxation of prior technical constraints) (Chapter 5).

## 6.2 Future Research Directions

The exploration of *Jod* and *SCOPE* in this dissertation advances our understanding of sociotechnical systems in accessibility and health. These systems address critical gaps in mixed hearing communication and in collaborative care in comorbid cancer and depression. They also surface new questions and opportunities for future research. Section 6.2.1 first situates *Jod* and *SCOPE* within the Model of Coordinated Action [114], a framework for understanding complex collaborative environments, then suggests future research directions by reflecting on the specific characteristics of the framework dimensions that *Jod* and *SCOPE* did or did not support. I next further outline three broad research directions: (1) advancing adaptive sociotechnical systems (Section 6.2.2), (2) exploring human-AI collaboration (Section 6.2.3), and (3) expanding longitudinal accessibility and health research ecosystems (Section 6.2.4).

### 6.2.1 The Model of Coordinated Action

Researchers have developed conceptual frameworks to categorize, understand, and examine collaborative settings. Johansen’s time-space matrix classifies systems based on space (e.g., co-located, remote) and time (e.g., synchronous, asynchronous) [92]. Frameworks like the Model of Coordinated Action address more complex collaborative scenarios and environments, moving beyond traditional time-space matrices and providing seven dimensions falling on a continuum [114]. The framework provides a more comprehensive representation of collaborative work and a greater coverage of the social aspects of communication, collaboration, and coordination. It suggests seven dimensions that fall on a continuum: (1) *Synchronicity* that ranges from asynchronous (i.e., different-time) to synchronous (i.e., same-time) communication, (2) *Physical Distribution* that spans from co-located to geographically dispersed collaborations, (3) *Scale* that refers to the number

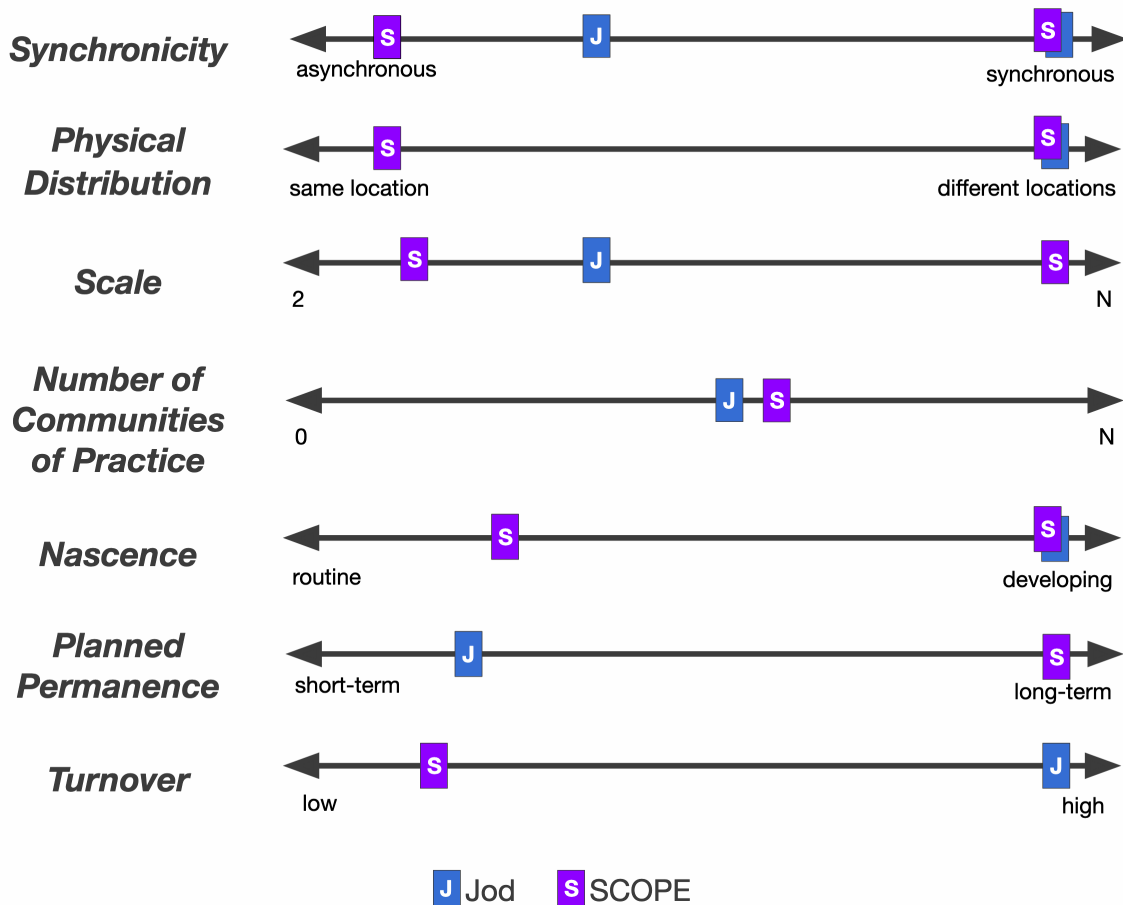


Figure 6.1: Situating *Jod* and *SCOPE* within the seven dimensions of the Model of Coordinated Action framework. The blue boxes represent *Jod*, and the purple boxes represent *SCOPE*. *Jod* is placed toward synchronous, different locations, small-to-medium scale, high NCoP, high nascence, low planned permanence, and high turnover. *SCOPE* spans asynchronous to synchronous, distributed to co-located, small to large scale, moderately high NCoP, both routine and developing nascence, long-term planned permanence, and low to potentially high turnover.

of participants involved in the collaboration, (4) *Number of Communities of Practice* that represents the diversity of professional or social groups involved, (5) *Nascence* that indicates how established (i.e., routine) or emergent (i.e., developing) the collaborative practices are, (6) *Planned Permanence* reflects the intended duration or stability of the collaboration ranging from short-term to long-term, and (7) *Turnover* that describes the rate at which

participants enter and leave the collaboration environment.

To characterize the complexity of designing communication, collaboration, and coordination systems in accessibility and health, I situate *Jod* and *SCOPE* within the seven dimensions of the model of coordinated action framework, each falling on a continuum (also illustrated in [Figure 6.1](#)) and then suggest future research directions based on this analysis.

### **Jod Within the Model of Coordinated Action Framework**

1. **Synchronicity:** *Jod* primarily operated on the synchronous end of the continuum, facilitating real-time video communication among participants. However, it also incorporated asynchronous elements such as preset feedback messages, chat-based communication, and transcriptions. This hybrid approach predominantly places *Jod* towards the synchronous end of the spectrum while acknowledging the need for asynchronous capabilities in mixed-hearing communication.

#### **Future Research Directions:**

- Investigate the optimal balance between synchronous and asynchronous features for mixed-hearing groups.
  - Explore how asynchronous communication tools could be enhanced to provide better context when participants return to synchronous interaction.
  - Study how the videoconferencing platform might dynamically adapt to varying synchronicity needs during different phases of a meeting.
2. **Physical Distribution:** *Jod* is designed for distributed collaboration, supporting participants to communicate from different locations. The platform addressed remote communication challenges for mixed-hearing groups, positioning it firmly on the different locations end of this dimension.

#### **Future Research Directions:**

- Examine how platforms could better support hybrid scenarios where some participants are co-located while others join remotely.

- Investigate bandwidth-adaptive features that maintain accessibility during network constraints.
- Research how spatial audio technologies might complement visual communication for DHH participants in distributed settings.

3. **Scale:** The research with *Jod* focused on relatively small to medium-sized groups (approximately 8 participants per session, including researchers), placing it towards the lower end of the scale dimension. Though its architecture could potentially support larger groups, its current design prioritizes intimate mixed-hearing communication environments. *Jod*'s features, such as customizable visual layouts and preset feedback messages, are optimized for these smaller-scale interactions.

**Future Research Directions:**

- Examine platform functionality and effectiveness with significantly larger groups (20+ participants in mixed hearing settings)
- Develop and evaluate adaptive layouts that automatically optimize for different group sizes, maintaining visual clarity when more participants are present while preserving DHH participant's ability to track important visual information.
- Investigate how communication dynamics and accessibility needs change as group size scales up, exploring how customization features scale and what new design considerations emerge.

4. **Number of Communities of Practice:** *Jod* is designed to support multiple communities of practice, including d/Deaf and hard of hearing signers, sign language interpreters, and hearing individuals. The diversity in participant types indicates a high number of communities of practice.

**Future Research Directions:**

- Explore how platforms could support additional communities with diverse communication needs (e.g., multilingual groups, individuals with cognitive disabilities).

- Study how the platform might adapt to participants with varying levels of sign language proficiency.
- Investigate how AI-supported intermediaries could facilitate communication across different communities of practice without disrupting natural interaction flows.

5. **Nascence:** *Jod* represented an emerging system. Its features were explored and refined based on early design feedback, and it introduced many emerging design features, indicating a high level of nascence.

**Future Research Directions:**

- Conduct longitudinal studies to understand how usage patterns and collaborative practices with videoconferencing platforms evolve.
- Investigate how groups establish communication norms and conventions when working with the platform.
- Research how emergent platform practices might influence or transfer to face-to-face interactions in mixed hearing groups.

6. **Planned Permanence:** *Jod* was studied in short-term research contexts rather than longitudinal deployments. This suggests a relatively low level of planned permanence in its current implementation, though the underlying technologies and design principles could inform more permanent solutions.

**Future Research Directions:**

- Study how platforms could support long-term professional relationships in mixed hearing organizations.
- Investigate how personal preferences, customizations, and layouts could persist across different sessions and contexts
- Determine whether the initial customization labor pays off through learned patterns and habits that reduce cognitive load in subsequent meetings.

- Research how the platform might evolve to support different stages of team development from formation to high performance.

7. **Turnover:** Although participant turnover was controlled and low within the study sessions, *Jod*'s architecture was agnostic to participant changes and could theoretically support higher turnover in real-world applications. However, it lacked explicit designs to support high turnover.

#### **Future Research Directions:**

- Develop and evaluate features that help newcomers quickly understand and adapt to ongoing conversations.
- Research how accessibility knowledge and awareness can be efficiently transferred when participants change.
- Investigate automated onboarding processes that explain accessibility requirements to new participants without disrupting the flow of meetings.

The Model of Coordinated Action framework thus provides a valuable lens for analyzing *Jod*, revealing opportunities for future research and development to support mixed hearing groups.

#### **SCOPE Within the Model of Coordinated Action Framework**

1. **Synchronicity:** *SCOPE* operated on a continuum of synchronicity. The patient app supported asynchronous data input (e.g., mood logging, activity tracking), while the provider registry supported both asynchronous review of patient data and synchronous elements during in-person sessions and case reviews. This blend of synchronous and asynchronous features places different tasks within *SCOPE* towards both ends of the synchronicity spectrum.

#### **Future Research Directions:**

- Investigate intelligent notification systems that modulate urgency based on patient data patterns.

- Develop insights for transitioning between asynchronous data collection and synchronous health interventions.
- Study how the temporal rhythms of cancer treatment could inform synchronicity requirements in collaborative care platforms.

2. **Physical Distribution:** *SCOPE* was intended for distributed collaboration, supporting patients to input data remotely and providers to access it from various locations. Simultaneously, it also supported colocated interactions during in-person sessions and case reviews. This positions *SCOPE* as highly flexible in the physical distribution dimension.

**Future Research Directions:**

- Examine how collaborative care platforms might adapt to evolving telehealth and hybrid care models.
- Investigate location-aware features that contextualize patient data based on physical environment.
- Study how to optimize collaborative interfaces for varying physical contexts (e.g., clinic, home, mobile).

3. **Scale:** *SCOPE* operated at multiple scales of collaboration. At its core, it supported small-scale interactions between individual patients and their providers. However, when embedded within larger cancer clinics, *SCOPE* scaled to support broader collaboration among numerous providers working across multiple care teams. The provider registry’s caseload overview feature demonstrates this multi-scale design, summarizing all patients while providing individual patient details.

**Future Research Directions:**

- Investigate how like *SCOPE* platforms might scale to support population-level mental health in cancer care through supporting larger networks of care providers.
- Develop mechanisms for balancing individual patient attention with increasing

provider caseloads.

- Study data-driven methods to help manage complexity at scale while preserving personalized care.

4. **Number of Communities of Practice:** *SCOPE* bridged multiple distinct communities of practice, positioning it relatively high on this dimension. It connected cancer patients with depression, behavioral health providers such as care managers and psychiatrists, and potentially other members of the cancer care team such as oncologists. Each group brought different expertise, terminology, and practices that *SCOPE* aimed to accommodate.

**Future Research Directions:**

- Explore integration pathways for additional stakeholders (family caregivers, specialists, community resources).
- Study how interfaces might adapt to different professional languages, priorities, and information needs.
- Investigate boundary objects that facilitate knowledge transfer between diverse communities of practice.

5. **Nascence:** *SCOPE* can be placed as both routine and developing on this dimension. Although its registry was built upon established collaborative care practices and existing spreadsheet approaches (routine), it also incorporated newly developed patient app components and evolving collaborative practices around patient-generated data integration (developing). Throughout its clinical trial deployment in six cancer clinics, *SCOPE*'s practices continued to evolve.

**Future Research Directions:**

- Longitudinal studies could trace how emergent practices become routinized through sustained platform support.
- Research could examine how platforms might better support practice evolution through adaptable workflows.

- Studies might identify change management approaches that help organizations transition to new collaborative care models.

6. **Planned Permanence:** *SCOPE* demonstrates long-term planned permanence, having been designed and deployed for a clinical trial in 6 cancer clinics. Its architecture anticipates long-term use in collaborative care management beyond the initial research phase, with potential for wider implementation if proven effective.

**Future Research Directions:**

- Investigate how collaborative care platforms can support different cancer journeys (e.g., from acute treatment to survivorship).
- Study data continuity needs across different permanence timeframes.
- Examine how patient-provider relationships evolve over time with sustained technology support.

7. **Turnover:** In its current implementation, *SCOPE* experienced relatively low turnover of participants. Within the clinical trial context, patients and their providers maintained consistent relationships throughout the treatment period. However, the system architecture could accommodate changes in the care team, suggesting potential for supporting higher turnover scenarios when needed.

**Future Research Directions:**

- Develop knowledge management approaches that preserve care continuity despite personnel changes.
- Study how patient-generated data might facilitate smoother provider transitions.
- Investigate onboarding frameworks that quickly integrate new care team members into established collaborative workflows.

The Model of Coordinated Action framework thus provides a valuable lens for analyzing *SCOPE*, revealing opportunities for future research and development to support technology-enhanced collaborative care systems operating within complex healthcare environments and

how they might better adapt to evolving care needs and contexts.

### **6.2.2 Advancing Adaptive Sociotechnical Systems**

My dissertation suggests several research directions toward advancing adaptive sociotechnical systems.

#### **Dynamic Adaptation in Accessibility Platforms**

*Jod*'s findings reveal tensions between individual agency and system automation in videoconferencing layouts. DHH participants valued manual control over video tiles but simultaneously desired intelligent defaults and behaviors from the platform to reduce labor. Future work could explore context-aware layout systems that dynamically adjust based on conversational patterns (e.g., prioritize interpreters during multilingual exchanges or enlarge tile of active speaker/signers during rapid-turn discussions). Such systems would need to balance control with automation, creating hybrid paradigms that respect individual preferences (i.e., to support agency) while reducing cognitive load.

Further research could also investigate how context sensing in real-time communication (e.g., gaze tracking, speech/sign recognition, semantic analysis of captions) could inform adaptive interfaces. A system might automatically cluster related elements, (e.g., positioning captions adjacent to the video tile of the interpreter or screen share), or support zooming in on a person's video tile to understand lipreading. These advancements would require addressing technical challenges in latency reduction (e.g., participants found gesture recognition in *Jod* to be slow) and privacy-preserving integration.

#### **Dynamic Adaptation in Health Systems**

*SCOPE* was designed to support breakdowns that may occur between patient-provider sessions, but the integration of patient-generated data into the provider registry demonstrated the value of bridging asynchronous and synchronous collaboration. Future work could explore adaptive systems that anticipate the needs of care. For example, for providers who manage care for a population of patients, systems could automate prioritization based on real-time patient data and flag patients who are at high-risk. Further research could also investigate how to support patient-provider sessions in their shared decision-making, treatment adjustments, and future care planning.

These adaptive sociotechnical systems could also support clinics in extending platforms

with new evidence-based interventions (e.g., cognitive behavioral therapy components) without requiring complete system overhauls. Crucially, adaptive systems must address implementation barriers identified in *SCOPE*'s deployment, such as integrating with existing EHR workflows to reduce provider burden and incorporating “digital health navigators” to assist patients with varying technological literacies.

### **6.2.3 Human-AI Collaboration**

My dissertation suggests several research directions in designing and examining human-AI collaboration features.

#### **Mediating Multimodal Communication**

*Jod*'s Wizard of Oz approach to highlighting active signers surfaces several opportunities for AI-mediated communication support. Future platforms could deploy real-time sign language recognition to automatically resize video tiles of signers or generate contextual captions that distinguish between literal signing and emotional gestures. Advances in pose estimation and hand tracking could support AI co-interpreters that supplement human interpreters during multilingual meetings. However, DHH participants emphasized cultural attachment to sign languages and such tools must support rather than replace human interpreters, requiring careful design to avoid appropriation of Deaf cultural practices. Interpreters play a critical role in knowledge sharing, and supporting all participants in mixed hearing group settings.

#### **Personalizing Evidence-Based Interventions**

In *SCOPE*, AI could support patient-provider collaboration through personalization of interventions. Future research could explore analyzing historical mood and activity logs to suggest behavioral activation tasks aligned with a patient's evolving values and capacities. For example, AI could recommend shorter, home-based activities during treatment weeks if a patient consistently logs fatigue post chemotherapy or surgery. These AI-driven methods could be refined with provider suggestions, creating a feedback loop that improves suggestions while maintaining clinical oversight.

Additionally, AI-facilitated reflection tools could help patients articulate experiences between sessions with their provider. Analysis of free-text mood entries or speech patterns from the patient app could surface unspoken concerns for provider review (e.g., financial stress affecting treatment adherence). Such systems raise ethical questions about algorithmic

transparency, necessitating participatory design with patients to define acceptable boundaries.

#### 6.2.4 Longitudinal Accessibility and Health Research Ecosystems

The complexities observed in designing and deploying sociotechnical systems like *Jod* and *SCOPE* underscore the need for future research to establish robust, longitudinal ecosystems that sustain accessibility and health interventions over time. Longitudinal studies are essential to understanding how people adapt to evolving technical capabilities, how social dynamics shift as systems mature, and how cultural or clinical contexts influence long-term engagement. In accessibility, platforms like *Jod* highlight the importance of balancing individual agency with automated support. But, longitudinal data is needed to explore how DHH and hearing participants negotiate communication norms over long-term use. For instance, while *Jod*'s customizable layouts empowered participants in short-term sessions, long-term use may reveal new challenges, such as fatigue from manual adjustments or evolving preferences for AI-driven personalization. Similarly, in health ecosystems like *SCOPE*, the integration of patient-generated data into provider registry supported collaboration, but longitudinal deployment revealed tensions in provider responsiveness and patient expectations. Future work must prioritize scalable, adaptive architectures that embed flexibility into system design—enabling features to evolve alongside the needs of the people without requiring constant re-engineering.

A key direction lies in fostering interdisciplinary research ecosystems that bridge HCI, clinical practice, and disability communities. For example, *SCOPE*'s deployment in cancer clinics demonstrated the value of co-design with providers and patients, but sustaining such collaborations requires institutional frameworks for continuous feedback, iterative refinement, shared governance, and sustained funding (e.g., *SCOPE* is supported by an NCI R01 grant). Similarly, *Jod*'s reliance on sign language interpreters underscores the need for ecosystems that integrate DHH cultural practices into platform development cycles, such as community-led feature prioritization and inclusive evaluation protocols.

Finally, longitudinal ecosystems must address ethical and infrastructural barriers to inclusivity. In health, this includes ensuring equitable access to technologies like *SCOPE* across diverse socioeconomic and cultural contexts, particularly for marginalized populations that are disproportionately affected by cancer and depression. In accessibility, it requires

rethinking platform sustainability (e.g., open source platforms that can support communities to extend and deploy tools like *Jod* while preserving cultural nuances in sign language and identity markers). Future research that can transform isolated interventions into sustainable ecosystems can support narrowing the sociotechnical gap and amplifying the impact of accessibility and health innovations.

### **6.3 Conclusion**

The sociotechnical systems explored in this dissertation illustrate the potential of human-centered design in bridging the gap between social needs and technical capabilities. By grounding system design in the lived experiences of DHH individuals, mixed hearing groups, cancer patients, and healthcare providers, this work advances our understanding of sociotechnical systems that adapt to human complexity rather than demanding conformity to rigid workflows. As computing continues to mediate critical aspects of human interaction, the lessons from this research underscore the need to build flexible systems that can learn and evolve alongside the people they serve.

By centering agency, negotiation, and adaptability, this dissertation provides insights for designing sociotechnical systems in complex settings of accessibility and health that empower individuals and groups of individuals to thrive in an increasingly interconnected yet heterogeneous world.

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