



SCOPE: Examining Technology-Enhanced Collaborative Care Management of Depression in the Cancer Setting

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Collaborative care management is an evidence-based approach to integrated psychosocial care for patients with comorbid cancer and depression. Prior work highlights challenges in patient-provider collaboration in navigating parallel cancer care and psychosocial care journeys of these patients. We design and deploy *SCOPE*, a platform for technology-enhanced collaborative care combining a patient-facing mobile app with a provider-facing registry. We examine *SCOPE* through a total of 45 interviews with patients and providers conducted in *SCOPE*'s 15 months of design and development and 24 months of *SCOPE*'s deployment for actual care in 6 cancer clinics. We find that: (1) *SCOPE* supported patient engagement in its underlying collaborative care and behavioral activation interventions, (2) patient-generated data in *SCOPE* improved patient-provider collaboration between and within in-person sessions, (3) *SCOPE* supported providers in delivering care and improved care team collaboration, (4) experience with *SCOPE* created evolving expectations for collaboration around data, and (5) *SCOPE*'s deployment in actual care surfaced important implementation barriers. We discuss the implications of our findings in terms of designing for engagement with behavioral health interventions, negotiating patient data sharing and provider responsiveness, supporting personalized self-tracking goals in evidence-based interventions, exploring the role of digital health navigators in technology-enhanced care, and the need for flexibility in aligning technology-supported interventions to patient needs.

CCS Concepts: • Human-centered computing → Human computer interaction (HCI); Interactive systems and tools; Empirical studies in HCI.

Additional Key Words and Phrases: Technology-Enhanced Collaborative Care Management, Behavioral Activation, Cancer, Depression, Clinical Deployment

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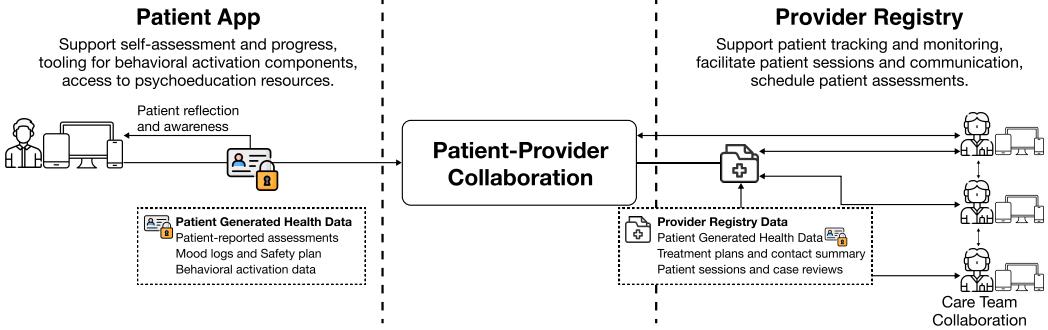


Fig. 1. *SCOPE* is designed to support collaborative care management and behavioral activation. Patient-provider collaboration is supported around patient-generated health data in the patient app, also visible in the provider registry. Care team collaboration is supported around data captured in the registry.

1 Introduction

Worldwide incidence of cancer is expected to exceed 28 million people in 2040 [113]. Depression is a common challenge during and after cancer treatment, with rates as high as 24% [65, 90]. 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 [52, 90, 108]. Challenges in treating depression among cancer patients include: (1) a lack of specialized training among oncology providers to detect and diagnose depression [76, 86, 115]; (2) a lack of standard processes for psychosocial follow-up and treatment adjustments [127]; and (3) inadequate availability of behavioral health providers [33, 60, 94, 118].

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 [4, 59, 119, 121]. It is a population-based and measurement-based approach to integrated psychosocial care [37], 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 [31, 32], including in cancer patients [53, 55]. 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 vicious cycle wherein reduction of meaningful and pleasant activity exacerbates depression.

Although collaborative care has been found effective for patients with cancer and depression [39], 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) [112]. 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 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 2 reviews related work and background, including background in collaborative care management and behavioral activation as *SCOPE*'s underlying evidence-based interventions. Section 3 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 reports findings in terms of the above-noted themes identified in analysis, Section 5 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 6 shares limitations to consider in interpreting our findings, and Section 7 briefly concludes.

2 Related Work and Background

We 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. We then provide background in two evidence-based interventions that drive the design of *SCOPE*: Collaborative Care Management and Behavioral Activation.

2.1 HCI and CSCW Research in Health

HCI and CSCW researchers have long pursued research in health [13, 40], including self-care technologies (e.g., [19, 21, 80]), clinical and hospital settings (e.g., [7, 84, 116]), experiences of people with chronic conditions (e.g., [17, 22]) and of caregivers (e.g., [12, 62]), women's health (e.g., [34, 63, 67]), online health communities (e.g., [45, 83, 104]), clinician-facing AI (e.g., [16, 126]), and patient-provider collaboration (e.g., [6, 24, 85]). Within HCI and CSCW research, mental health and well-being is an important and growing area [97]. Researchers have studied depression among older adults (e.g., [124, 125]), stigma around mental health (e.g., [20]), opportunities for improving peer support (e.g., [82]), mental health management through social and collaborative lenses (e.g., [18, 68, 78]), and when depression occurs as a comorbidity (e.g., [47]). 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 [97].

Our 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 [112]. 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. We build 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.

We further draw 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 [23, 111], challenge power relations [1], provide new opportunities for collaboration [79], facilitate sharing patient experiences [107], improve patient awareness [14], motivate patients [98], help recognize and solve condition-related challenges [91], support treatment adjustments [23], and facilitate shared decision-making [77]. Researchers have examined patient-provider collaboration around patient-generated data through stage-based models of personal informatics [35, 71], through models emphasizing patient-generated data as boundary negotiating artifacts [24, 69], and through models emphasizing multiple evolving goals for patient-generated data [98, 100, 101]. Much of our 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.

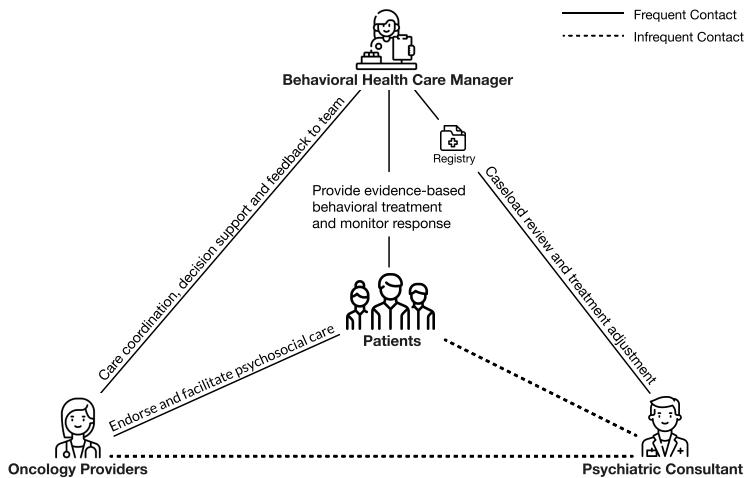


Fig. 2. Collaborative Care Management is an evidence-based and patient-centered approach to integrating psychosocial care with cancer care (i.e., a team of providers collaborating to improve patient health outcomes).

2.2 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 [4, 119, 121], including for depression in cancer patients [72]. 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 [5].

In a cancer setting, collaborative care integrates psychosocial care with cancer care (Figure 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 [25, 29] and collaborative care can leverage existing staffing [26]. Care managers further provide patient education, monitor patient-reported outcomes, help with systematic patient outreach, and assist with care coordination [29, 48]. Clinical practice guidelines for depression in the cancer setting have promoted collaborative care [37, 38] and the American Psychosocial Oncology Society has identified collaborative care as the most prioritized model for integrated psychosocial oncology care [89].

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 [112]; (2) poor inter-professional communication pathways and attitudes [102, 122], (3) low fidelity to collaborative care principles [5], and (4) dropout from depression treatment [114]. Technology has the potential to help address these challenges [9, 92, 112] 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 [42–44, 66, 95, 109]. 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 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 [27, 31, 32, 75], including in cancer patients [53, 55, 110]. 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) [61]. 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 [30]. Reasons for failures of behavioral activation in the cancer setting include inability to understand and adopt strategies, behavioral nonadherence, and ineffective contingency management [56, 96, 112].

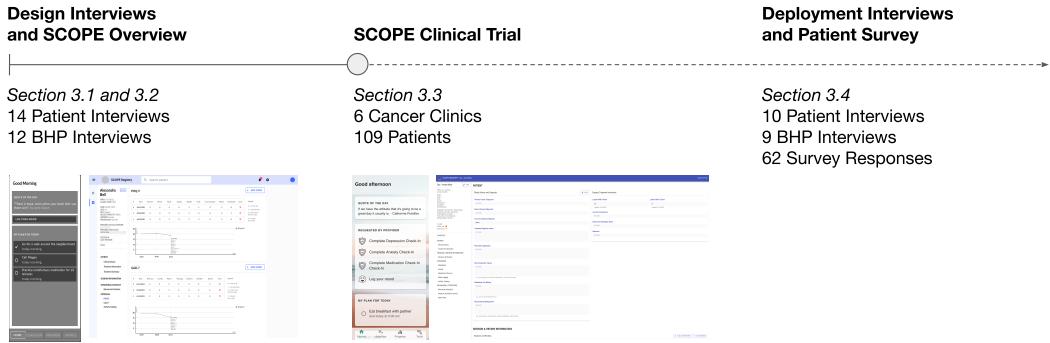
Behavioral activation is a time-efficient approach [41] that does not require complicated skills from providers or patients, making it an accessible treatment option [27]. It has further shown effective in primary and general care settings due to its flexible and modular delivery [120]. Recommended in practice guidelines for patients with cancer and depression [3], behavioral activation is associated with engagement in active coping, decreased suicidal ideation, increased hopefulness, improved quality of life [54, 55, 74], improved treatment and medical outcomes [53, 54], and completing a higher proportion of scheduled activities [96].

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) [8]. 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.

3 Designing and Deploying *SCOPE*

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. [112]. 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.



(a) Timeline of our research in design and deployment of *SCOPE*. Section 3.1 presents 26 design interviews conducted in approximately 15 months of iterative design, and Section 3.2 presents the resulting design of *SCOPE*. Section 3.3 describes a trial deploying *SCOPE* for actual care in 6 cancer clinics for 24+ months. Within the context of that clinical trial, Section 3.4 presents an additional 19 deployment interviews.

14 Patient Design Interviews

ID	Self-Reported Race & Ethnicity	Age	Sex
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

12 Provider Design Interviews

ID	Number of Interviews
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

10 Patient Deployment Interviews

ID	Self-Reported Race & Ethnicity	Age	Sex
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

9 Provider Deployment Interviews

ID	Number of Interviews
BHP2	2 Deployment Interviews
BHP4	2 Deployment Interviews
BHP8	2 Deployment Interviews
BHP10	1 Deployment Interview
BHP11	1 Deployment Interview
BHP12	1 Deployment Interview

(c) Summary of Provider Participants, 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).

(b) Summary of Patient Participants, including 14 design interviews and 10 deployment interviews.

Fig. 3. An overview of our process and data in research with *SCOPE*: (a) the timeline of design and deployment, (b) a summary of patient interview participants, and (c) a summary of provider interview participants.

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 3a overviews our additional research activities, including 45 interviews conducted throughout *SCOPE*'s design and deployment. Section 3.1 first introduces 26 design interviews conducted during our iterative design process, and Section 3.2 then presents the resulting design of *SCOPE*. Section 3.3 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 3.4 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 3.5 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 [49, 50].

3.1 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 ≥ 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 [117]. Participants are summarized in Table 3b (i.e., 14 patient interviews) and Table 3c (i.e., 12 behavioral health provider 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 [57]. 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 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 4a 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 4b shows elements of an early design used in these provider interviews.

(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 for recording notes about a patient session, including tracking relevant components of behavioral activation.

Fig. 4. Early mockups of *SCOPE*, iteratively designed and used for feedback in Section 3.1's design interviews.

System Usability Scale data collecting during design indicated participants found the design "Excellent" or "Good" [70]. 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.

3.2 *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

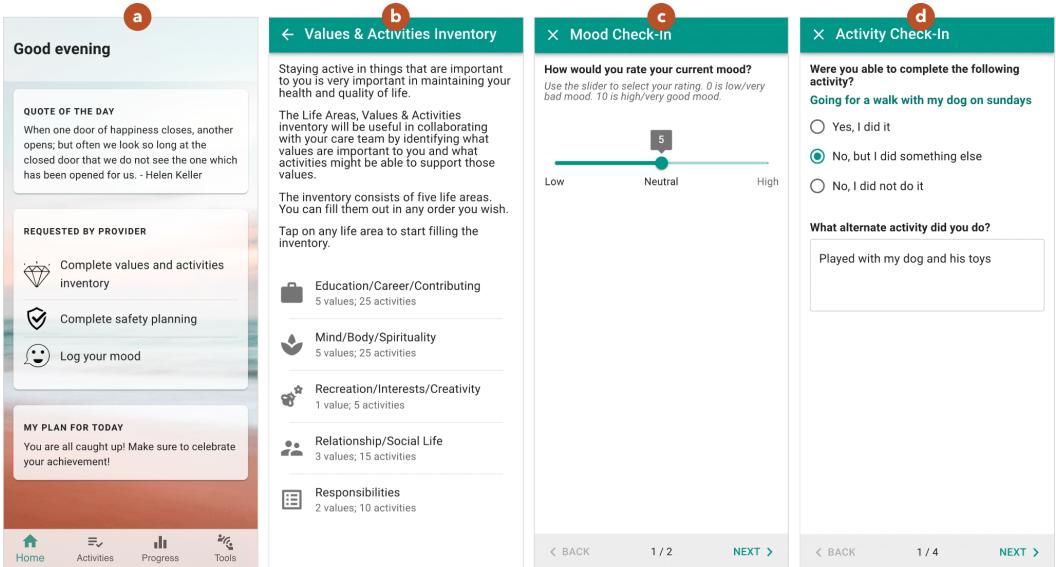


Fig. 5. The patient-facing SCOPE app supports core components of behavioral activation while sharing patient-generated data with the provider-facing SCOPE registry. This includes (a) provider-assigned and patient-scheduled action items, (b) a values and activities inventory, (c) mood logging, and (d) activity logging.

messaging channel beyond those already available). Available design and development resources also required prioritization of capabilities (e.g., an early determination *SCOPE* would not integrate with electronic health records). This section describes the deployed system. We also note *SCOPE*'s design was largely stable throughout deployment, but Section 5 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 5. A *Home* page (Figure 5a) includes an inspirational quote, tasks requested by the provider, and scheduled activities. In the *Values & Activities Inventory* (Figure 5b), 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. Mood logging (Figure 5c) asks patients to rate their mood on a scale of 0 (Low) to 10 (High). They are then able to enter any relevant notes. Selecting a scheduled activity allows marking its completion (Figure 5d). 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. 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. A landing page (Figure 6a)

a Caseload Overview

SCOPE REGISTRY

Caseload for All Social Workers in All Clinics

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

b Patient Detail

SCOPE REGISTRY / Valerie Kim

Valerie Kim EDIT

PATIENT

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 Latest GAD: 13

Updated: 08/06/2024 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

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- Activity Tracking
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- Behavioral Activation
- Values & Activities Inventory
- Safety Plan

Fig. 6. 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.

displays a patient caseload overview. Selecting a patient opens a detail page with multiple sections (Figure 6b), 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* (Figure 6d) includes information about a patient's cancer and mental health diagnoses and treatment. *Session & Review Information* (Figure 6e) displays a table of patient sessions and case review discussions. *Progress* (Figure 6f) displays patient-generated data, such as depression assessments (PHQ-9 [51]), anxiety assessments (GAD-7 [36]), 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 6g) 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. 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 until they complete the assignment.

3.3 SCOPE Clinical Trial

SCOPE is currently deployed in a pragmatic randomized controlled trial [11, 28] 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 ≥ 10 , and with at least one endorsed cardinal symptom (i.e., depressed mood or anhedonia). As in Section 3.1, these are conservative criteria for clinically significant moderate to severe depression in cancer patients [117]. 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*.

3.4 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 3b (i.e., 10 patient interviews) and Table 3c (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 [104]) and additional challenges of comorbid depression (e.g., as in [112]).

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.

3.5 Data Analysis and Reporting

We analyzed 45 interview transcripts, comprising 26 design interviews and 19 deployment interviews. We used combined deductive and inductive coding [15]. 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 [112]

and reflecting scenarios in Section 3.1. 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 Figure 3, 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^{Des}*, *BHP1^{Des}*) versus a deployment interview (e.g., *Pt15^{Dep}*, *BHP2^{Dep}*), 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 3.3'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 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 4.1 presents patient experiences directly engaging with *SCOPE*'s interventions, Section 4.2 presents patient and provider experiences with *SCOPE* improving collaboration between and within sessions, and Section 4.3 presents provider experiences with *SCOPE* supporting structure and collaboration within the care team. Section 4.4 then describes how patient and provider experiences with patient-generated data in *SCOPE* created evolving expectations for collaboration around that data. Finally, Section 4.5 shares insights into implementation barriers that surfaced through design and deployment of *SCOPE* for actual care in 6 cancer clinics for 24 months.

4.1 SCOPE Supported 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^{Des} 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^{Des}*) and help them understand impacts of “*all the stuff that [they're] dealing with*” (*Pt9^{Des}*). *Pt9^{Des}* explained they could see using the values and activities inventory as a planning tool for understanding “*success*” in different areas of life, and *Pt10^{Des}* similarly described it could help

provide “*direction*” and “*clarity*” for them and their providers. Consistent with goals of *SCOPE*’s behavioral activation intervention, *Pt8^{Des}* 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^{Dep}* explained that tracked values helped them realize they “*have some areas where I [they] don’t really have a lot of things*”, and *Pt18^{Dep}* described it helping them reflect on how their “*values have changed*” and whether they “*want to change anything*.” *Pt18^{Dep}* 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 ***SCOPE Supported 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 [112].

4.2.1 ***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^{Dep}*

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^{Dep}* shared that their provider would use data to provide “*encouragement*” and remind them they were not doing as bad as they felt. *Pt22^{Dep}* 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^{Dep}* 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^{Dep}* explained it felt “*like an extension of the therapeutic alliance*”.

4.2.2 ***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^{Dep}* 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^{Dep}* 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^{Dep} 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^{Dep} shared that SCOPE “was a wonderful conversation starter” which allowed sessions to focus on reflections around patient activities, mood, or assessments.

4.2.3 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^{Dep}

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^{Des} 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^{Des} 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^{Des}, “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^{Dep} 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^{Dep} 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^{Dep} 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^{Dep} 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^{Dep} 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^{Dep} 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 [87]. Patients further described *SCOPE*’s historical data as helpful for motivation and review in the context of memory issues. For example, *Pt21^{Dep}* 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.

4.3 *SCOPE* Supported 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.

4.3.1 Structure Improved Patient Sessions and Care Team Caseload Reviews. As introduced in Section 2.2, 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^{Des}*) in an electronic health record, “*hunting and pecking to find information*” (*BHP2^{Des}*) in a prior Excel-based registry, or not capturing information necessary for effective caseload review (*BHP6^{Des}*). Providers frequently adjust patient treatment plans, and *BHP1^{Des}* 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^{Dep}* 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 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^{Dep}* 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^{Dep}* 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 3.3’s trial, and that they felt the clinic had become a “*stronger program*” and “*much better clinic overall*” because of *SCOPE*.

4.3.2 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^{Dep}* 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^{Dep}* 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^{Dep}* 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^{Dep}* 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^{Dep} 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^{Dep}* similarly explained they became “*more comfortable*” and “*confident*” with asking psychiatrists more “*clinical questions*”.

4.4 Evolving Expectations Around Patient-Generated Data in *SCOPE*

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.

4.4.1 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^{Dep}* 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^{Des}*), to daily (*Pt6^{Des}*), to a few times a week (*Pt9^{Des}*). 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^{Des}*). If a depression assessment was severe, some patients wanted *SCOPE* to “*alert the care team right away*” (*Pt12^{Des}*) with a “*red flag*” (*Pt6^{Des}*) so providers could respond “*aggressively*” (*Pt14^{Des}*). *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^{Dep}* 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^{Dep}*, *Pt22^{Dep}*, *Pt24^{Dep}*). Peer social support can be invaluable in navigating cancer and depression [58, 104], so this suggests future exploration of how data in platforms like *SCOPE* could support such opportunities (e.g., while preserving patient privacy).

4.4.2 Providers Seeking Additional Registry Capabilities Around Patient-Generated 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^{Des}*

Providers described wanting to use data to reach out to patients who might be having a hard time. For example, *BHP7^{Des}* 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^{Des}* described wanting to reach out with a “*small cheerleading note*” or a “*note of encouragement*”.

As noted in Section 3.2, *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^{Dep}* 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^{Dep}* 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^{Des}* 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^{Des}* 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^{Dep}* 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^{Dep}* 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.

4.5 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.

4.5.1 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^{Des}* 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^{Des}* 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^{Dep}* 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^{Dep}* 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^{Dep}* 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^{Dep}* 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”.

4.5.2 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^{Des}* 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^{Des}*). 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^{Des}*). 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^{Des}*).

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^{Dep}*). Patients also suggested it would have been easier to understand *SCOPE* if it included "*a tutorial that was available anytime in the app*" (*Pt23^{Dep}*) or a "*visual walkthrough*" (*Pt18^{Dep}*). *Pt23^{Dep}* 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^{Des}* 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^{Dep}* 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^{Dep}* 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^{Dep}* 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.*"

4.5.3 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 3.2). Several providers described additional work associated with *SCOPE*, including duplicated data entry between *SCOPE* and the electronic health record. *BHP8^{Dep}* 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^{Dep}* 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^{Des}*). Some providers noted information they put in the registry "*might not be something that [they] necessarily want the patient to read*" (*BHP4^{Des}*, *BHP5^{Des}*) and shared concerns that electronic health record notes could be "*demanded in court*" (*BHP2^{Des}*).

5 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'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.

5.1 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 [2, 73, 97, 105]. 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 [106]. 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.

5.2 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 4.4.1). 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 4.4.2, visible as “New” flags in Figure 6).

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 [123], balancing tensions among control, visibility, sharing, and accountability is important to preserving trust in patient-provider relationships [103]. 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 [88], as with provider concerns for integration with electronic health records in Section 4.5.3). 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 [24, 69]).

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 4.4.2). Such capabilities could further support connectedness (e.g., as in Section 4.2.1) 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).

5.3 Supporting 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 [24]. 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 4.1, Section 4.2, Section 4.3). 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 [35, 64, 93, 98, 99, 101]. Considering such techniques in the context of evidence-based interventions introduces an additional need to ensure flexible tracking preserves components of an intervention. Section 5.1’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.

5.4 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 4.5.2). 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 [10, 81]. 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 2.2). However, these providers are themselves also highly burdened [112], 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 [46], 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).

5.5 Flexibility in Aligning Technology-Supported Interventions to Patient Needs

Although we found *SCOPE* supports patient engagement with its interventions (Section 4.1) and supports patient-provider collaboration between and within sessions (Section 4.2), 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). 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 [112] 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.

6 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.

7 Conclusion

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.

Author Contribution Statements

All authors critically reviewed the manuscript for important intellectual content. **Manuscript Preparation:** AM led, with JFo, GH, TJ, JS contributed. **Technology Design:** JS, RK led in succession, with GH, TJ, SW, AB, TL, JFa, JFo contributed. **Technology Development, Maintenance, and Iteration:** JS, AM led in succession, with JFo. **Clinical Deployment, Trial, and Implementation:** JFa led. TJ, YZ, LA, NB, AB, TL contributed. **Planning, Coordinating, and Conducting Design Interviews:** JS, RK led in succession. TJ, RK, JS, SW led and contributed to specific sessions. **Planning, Coordinating, and Conducting Deployment Interviews:** TJ led. AM, TJ, YZ led and contributed to specific sessions. **Interview Data Analysis:** JS, TJ, AM led in succession. RK, GH contributed. **Obtained Funding:** AB, TL, JFa, JFo, GH contributed.

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