

# Self-Care Support for Patients with Gastrointestinal Cancer: iCancerHealth

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## Abstract

**Background** Patient-centered symptom assessment and management tools allow patients to perform self-assessments and engage in self-symptom management. Efficacious tools exist for reducing symptom distress; however, little is known about feature-specific use.

**Objectives** This article evaluates the feasibility of the iCancerHealth app as an adjunct to usual patient education regarding cancer symptoms and medication management.

**Methods** We conducted a single-arm, pilot study grounded in the health outcomes model. Our evaluation included (1) enrollment rates, (2) 2-month utilization rates, (3) patient acceptability, and (4) clinician satisfaction with the provider-side application. English-speaking, adult patients receiving care in the gastrointestinal oncology service of a comprehensive cancer center were invited to participate. Research coordinators enrolled consenting participants who had a personal, Internet-connected device; participants registered and used the platform to complete the baseline symptom assessment in clinic. Participants were reminded weekly to use the app and to perform a symptom report 4 to 6 weeks later.

**Results** A total of 64 patients were approached, of which 57 (89%; 95% exact confidence interval [CI], 79–96%) enrolled. About half were  $\geq 60$  years old and 40% were women. Fifty-three patients (93%; 95% exact CI, 85–99%) accessed at least one app feature, at least once, from home. The most frequently used (86%) feature was *Health Tracker* in which participants monitored and reported symptoms; followed by *My Inbox* (63%) and *My Medications* features (60%). The mean acceptability score was 24.8 (standard deviation = 4.2), indicating good acceptability. Clinicians reported that the app was most acceptable with regard to facilitating in-person interactions that occurred after app use.

**Conclusion** In a sample of adults with various stages of gastrointestinal malignancies, the iCancerHealth app was utilized at a high rate. Features that focused on symptoms and medication side effects plus communication with clinicians were used most frequently. This extends our understanding of preferences and specific feature use with patient-centered technologies.

## Keywords

- ▶ cancer
- ▶ symptoms
- ▶ mHealth
- ▶ telehealth
- ▶ communication

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## Background and Significance

Patients with cancer arrive in the therapeutic setting with varying levels of symptomatology and other types of responses to the cancer diagnosis and experience. Once treatment begins, another profile of symptoms commences as toxicities and treatment-related complications develop. These symptoms and the self-care required at home, and the related psychological, social, family, and work impact of cancer and its treatment, can be burdensome or overwhelming to many patients.<sup>1,2</sup> An exhaustive systemic review<sup>3</sup> documented cancer symptoms during active treatment as quite prevalent and severe.

Assessing and managing cancer symptoms and side effects (SX) is a major goal for both patients and oncology clinicians. Standardized assessments of SX have been developed and used widely in research studies to measure outcomes of treatments and interventions. Assessments also have been used clinically, and been found to: (1) increase the depth and breadth of discussions of SX,<sup>1</sup> and patient-reported emotional well-being<sup>4</sup>; (2) increase treatment of psychosocial issues and symptoms in patients in oncology<sup>4</sup>; and (3) reduce cancer symptom distress when combined with self-care patient education and monitoring.<sup>2</sup>

As oral chemotherapies rapidly expand in oncology practice,<sup>5</sup> an increasingly significant concern involves patient medication adherence when these oral agents are self-administered at home. Suboptimal or improper self-administration,<sup>6</sup> reduces treatment efficacy and increases toxicity<sup>7</sup> and leads to treatment delays, changes in treatment, and premature death.<sup>8</sup> Patients require systematic support for proper dosing and administration.<sup>9</sup> With new information technologies, assessments can increasingly be conducted with computerized assessment, eliminating abstraction and data entry of paper forms, increasing accuracy of reports, making summaries available to clinicians in real time, and facilitating electronic communication. An SX assessment and management tool that is patient-centered may allow patients to perform self-assessments, learn about SX management and self-administered medications, and be coached in communicating with clinicians. An intervention that combines evidence-based instructions, reminders, and monitoring tools summaries delivered to clinicians with secured messaging may be a powerful tool in the management of patients' SX concerns.

### Cancer Symptoms

Cancer symptoms not only are indications of the physiologic changes associated with disease and treatment toxicity, but also reflect linkages to patients' perceived reality, including social, psychological, and cultural factors.<sup>10</sup> With the incidence of individual and groups of cancer symptoms<sup>3</sup> and psychosocial distress<sup>11</sup> at such a high levels across various diagnoses and stages and the apparent impact of such experiences on the dimensions of quality of life, the consequences of inadequate symptom management are complex and can be overwhelming to patients and their caregivers. For example, severe mucositis or radiation-associated skin changes can put patients at risk for additional complications.<sup>12</sup> Early screening for psychosocial distress may enable clinicians to identify patients at higher risk

and intervene to prevent development of crisis events, notably in those diagnoses with the greatest symptom burden<sup>13</sup>.

Making cancer symptom issues visible and discussed in the clinic can promote partnership between clinicians and patients, validating the patients' experiences and enhancing communication and satisfaction. Rapid, predictive screening may help reduce unnecessary health care utilization costs and prolonged medical treatments, as well as enhance quality of life. The challenge of efficient, systematic, and meaningful assessment is important and in current clinical cancer settings, the American College of Surgeons Committee on Cancer has set a standard for all accredited health care institutions.<sup>14</sup> As reviewed by Mooney et al,<sup>15</sup> randomized trials provide evidence that self-monitoring of cancer symptoms and associated communication coaching result in lower symptom distress and better patient-clinician communication. When clinicians are unaware of SX, particularly treatment-related toxicities, there is danger of higher morbidity and even mortality related to unintentional overdosing.<sup>12,16</sup> Interventions to improve patient-clinician communication have been tested with positive results.<sup>1,17-20</sup>

### Medication Self-administration

Patients require systematic support for proper dosing and administration.<sup>8</sup> Systematic reviews of interventional studies for medication adherence support a standardized multi-method approach to medication management that involves tailored cognitive educational approaches<sup>21</sup> with psychosocial support strategies.<sup>22</sup> Additional use of written information and feedback and monitoring by nurses,<sup>23,24</sup> including management of SX, can provide educational reinforcement.

### Usability and Acceptability

Most people have encountered usability difficulties in their everyday lives such as trying to set the clock on the video player, ordering something online, and at self-check-outs at libraries and grocery stores. Each of these tasks requires an interaction between a human and a computer interface. If the interface is well designed, the application may be quickly embraced by the end user; however, poor design cannot only turn away potential users, but lead to measurement error and nondiffusion among target user groups. There is a well-established body of research in usability and structured software design methods,<sup>25</sup> and now it has been systematically applied to the development of patient-centered software in health care venues.<sup>26</sup> Remote utilization rates of Web-based applications have varied from 34 (consecutive clinic approaches) to 77% (self-selected volunteers) for unprompted use after enrollment in cancer symptom studies.<sup>2,27</sup> Acceptability has typically been adequate; however, the use of a variety of different measures by various investigative teams precludes comparison.

The purpose of this pilot, feasibility study was to evaluate a unique clinical deployment of a computerized patient assessment of cancer SX, targeting a customized, patient-centered intervention to coach the patient regarding communicating priority SX plus medication self-administration prompts and patient-clinician communication messaging.

## Objectives

Our three objectives were to: (1) evaluate the feasibility of iCancerHealth as an adjunct to usual patient education regarding cancer symptoms and medication management, with regard to (i) enrollment rates and (ii) utilization over a 2-month period; (2) describe patient acceptability of iCancerHealth in general and the specific features; and (3) explore clinician satisfaction with the iCancerHealth provider-side application.

## Methods

Eligible patient participants were 18 years or older and had a diagnosis of any stage malignant gastrointestinal (GI) disease, were receiving or planning treatment in the GI clinic, spoke and read English, and had Internet/cellular access via either a personal computer Web browser, iOS device (smartphone or tablet), or Android (phone only). Patients were excluded from enrollment given a documented diagnosis of a psychiatric depressive or cognitive impairment. Eligible clinician participants were nurses, physicians, or physician assistants who performed consults/exams in the GI oncology clinic.

This was a single-arm, pilot study to quantify the feasibility and acceptability of the iCancerHealth intervention. The app was provided free of charge to the investigators from the vendor, Medocity, Inc. Native apps for iOS and Android were available, plus a Web-based version for personal computer browser access.

Recruitment letters describing the elements of consent was sent to clinicians. Interested clinicians were: (1) oriented to the application (app), (2) were asked to inform eligible patients about the study during consultation, and (3) were asked to complete satisfaction survey at the end of the study. Clinicians were not compensated for participating in the study. Clinicians provided interested participants contact information to the research coordinator, who approached the potential participant and obtained written consent. All participants were provided with the opportunity to ask questions and if not comfortable to opt out. Once written consent was obtained, the research coordinator (1) helped the patient participant download the app and register an account, (2) oriented the participant to all sections of the app, and (3) collected 1st baseline (T1) SX assessment within the app. Patient participants were asked to use the app regularly for up to 6 weeks and the research staff followed up weekly in person or through a telephone call. At the 4 to 6 weeks' clinic visit, the last assessment (T2) was completed and the patient participant was given a \$50 gift card for their time and effort. Clinical characteristics including diagnosis, stage, and treatment regimen were abstracted from the patients' medical record.

For patient participants, iCancerHealth app features included real-time charting of reported symptom experiences followed by clinician-approved self-care recommendations based on the severity of symptoms. For severe symptoms, participants were instructed to contact the clinician's office right away. Education to nutrition and fluid management were included. A feature focused on medication management and adherence was provided with autoremind notifications. The

calendar feature allowed entry of appointments and other events. A community forum for peer support also was available for participants. Participants were able to send secured messages through the app to the participating clinicians. The provider side of the app provided alerts for patient participant's SX at a predetermined threshold. Clinicians were expected to respond to the alerts and read the secured messages on a daily basis. iCancerHealth was designed to be compliant with the Health Insurance Portability and Accountability Act. All messaging and data were sent through encrypted channels. A new version of the iCancerHealth app was released toward the end of the study and we marked that time point for future analyses. Modules and tabs were reorganized or renamed in the app, the three participants who were actively using versions 1 were oriented to using the new version.

Based on our previous experience with remote access to a symptom reporting and self-care instruction intervention in which 34% voluntarily (unprompted) accessed the Web-based application,<sup>28</sup> we considered use of iCancerHealth feasible if at least a 34% remote access rate was reached. The remote access rate was defined as accessing and using iCancerHealth from a nonclinic location at least once. Additionally, we considered enrollment to iCancerHealth feasible if at least 80% of the approached GI oncology patients participated.

A total of 70 patient participants were planned for this feasibility study and a 15% attrition rate was expected. With 60 evaluable patient participants and complete T1–T2 data, the 95% confidence interval (CI) was planned to be no wider than 26%.

## Outcomes

In a clinical cancer setting, all patient outcomes have been mediated by some aspect(s) of the system and/or some patient aspect(s). Modes of patient engagement with self-care, including symptom monitoring and clinician response to notices from patients about high symptom burden, are applicable to the Health Outcomes Model, explicated by Mitchell et al,<sup>29</sup> we selected outcomes that would begin to explain variables that ultimately can inform larger trials to test patient quality of life and intervention outcomes.

**Enrollment rates:** Eligible patients approached to participate in the study were tracked through a secure database that documented the number of consenting patients, reasons for refusal to participate, and attrition.

**Remote access and utilization rates:** Use was defined as accessing app and clicking in any feature at least once. Utilization was recorded electronically in the iCancerHealth app that tracked the number of times a patient clicked on a given feature (calendar, community, dashboard, health tracker, medical diary, inbox, medications, profile, nutrition, scrapbook, or settings). The rate of utilization was defined as the proportion of patients accessing and clicking on a feature in iCancerHealth at least once after the on-study demonstration. A remote access and utilization rate of at least 34% would indicate feasibility of iCancerHealth patient usage.

**Acceptability (T2):** All patient participants were presented six items on the Acceptability E-scale<sup>30</sup> plus feature-specific items at the conclusion of the T2 iCancerHealth assessment.

The items focused on how easy, how understandable, how enjoyable, how helpful, acceptable amount of time, and overall satisfaction with the app. Possible responses ranged from 1 to 5, with 1 indicating a low level of agreement regarding acceptability of the program and 5 indicating a high level. An average summed score of  $\geq 24$  is considered adequate acceptability. The Acceptability E-scale has been found to have high consistency and reliability and has been used in over 2,000 patients with cancer.<sup>1,31,32</sup>

**Clinician satisfaction (end of study):** A questionnaire adapted from the Acceptability E-scale was used to assess clinician satisfaction relevant to how easy, how understandable, acceptable amount of time, overall satisfaction, followed by whether the app identified appropriate issues, facilitated electronic interactions, facilitated in-person interactions, and symptom notifications promoted communication. Clinicians were asked to provide additional feedback with one open-ended item.

### Analysis

Descriptive statistics were used to summarize demographic and survey data. The enrollment rate and utilization rate were estimated and reported with an exact 95% CI. Additionally, the utilization of each feature was described. The total score for patients answering the Acceptability E-scale was summarized (median/range, mean/standard deviation [SD]). The number of clinicians indicating a score of at least 4 on a given Acceptability E-scale item was tabled. Because a new version of the iCancerHealth app was released during the study, all analyses were also summarized by version.

## Results

### Patient Participant Results

A total of 64 patients were approached to participate in the study of which 57 (89%; 95% exact CI, 79–95%) enrolled. Reasons given for declined participation included: too much of a time commitment ( $n = 1$ ), does not use technology to manage care ( $n = 2$ ), participant uses other technology for care ( $n = 2$ ), and unknown for 2 participants. Of the 57 patients enrolled, 43 (75%) used version one exclusively, 11 (19%) used version two exclusively, and 3 (5%) used both versions. Enrollment was halted early shortly after the release of a second version of the app because of difficulties with the provider interface.

Overall participant demographics are outlined in **Table 1**. All participants received chemotherapy (injectable, infusion, and/or oral) with 44 (77%) receiving infusion chemotherapy alone or in combination. A majority (84%) of participants indicated a preference for email as the way to receive health-related reminders. Participants were allowed to select multiple preferences and other selected methods included: 29 (51%) text message, 15 (25%) telephone, and 2 (4%) other (secure email and “I like the personal touch”).

Participant feature utilization is displayed in **Table 2**. Overall, 53 participants (93%; 95% exact CI, 83–98%) used a minimum of one feature at least once. Of those with version 1 ( $n = 43$ ), 41 (95%; 95% exact CI, 84–99%) used the app. Of those

**Table 1** Participant demographics ( $N = 57$ )

	N	%
Age group (y)		
≤ 49	9	15.79
50–59	19	33.33
≥ 60	29	50.88
Non-Hispanic <sup>a</sup>	56	98.25
Gender		
Male	33	57.89
Female	23	40.35
Race/Ethnicity		
Asian	3	5.26
Black	3	5.26
White	50	87.72
Working		
No	27	47.37
Yes	30	52.63
Married/Partnered		
No	16	28.07
Yes	40	70.18
Computer use		
Sometimes	6	10.53
Often	12	21.05
Very often	39	68.42
Smartphone use		
Never	6	10.53
Rarely	1	1.75
Sometimes	6	10.53
Often	5	8.77
Very often	39	68.42
Downloaded app		
No	27	47.37
Yes	30	52.63
Education		
9th–12th grade	5	8.77
2-y college	8	14.04
4-y college	20	35.09
Graduate degree	24	42.11

<sup>a</sup>Ethnicity not reported by one.

with version 2 ( $n = 11$ ), 10 (91%; 95% exact CI, 59–100%) used the app. Two of the three with both versions used the app. The tracking of symptoms (*Health Tracker*) and subsequent messaging from clinicians (*My Inbox*) were most accessed.

A total of 48 participants completed all of the 6 core acceptability items (easy, understandable, enjoy, helpful, amount of time, and satisfaction) to compute a total acceptability score of which the overall mean acceptability score was

**Table 2** Feature utilization: overall and by version

Feature	Overall (N = 57)		Version				
			Version 1 (N = 43)		Version 2 (N = 11)		Both (N = 3)
	N	%	N	%	N	%	N
Any use	53	93	41	95	10	91	2
Calendar	7	12	7	16	0	0	0
Community	25	44	20	47	4	36	1
Dashboard	24	42	19	44	3	27	2
Health Tracker	49	86	39	91	8	73	2
Medical Diary	18	32	15	35	3	27	0
My Inbox	36	63	31	72	5	45	0
My Medications	34	60	27	63	6	55	1
My Profile	30	53	25	58	4	36	1
Nutrition	26	46	21	49	5	45	0
Scrapbook	23	40	19	44	4	36	0
Settings	8	14	6	14	2	18	0

**Table 3** The proportion of participants indicating > 4 on each acceptability item

High acceptability	Overall <sup>a</sup>			Version					
	N respond	N ≥4	%	Version 1			Version 2		
				N respond	N ≥4	%	N respond	N ≥4	%
Easy	51	45	88	40	35	87	9	8	89
Understandable	51	48	94	40	38	95	9	8	89
Enjoy	50	29	58	39	21	54	9	7	78
Helpful	50	23	46	39	16	41	9	6	67
Amount of time	51	45	88	40	34	85	9	9	100
Satisfaction	51	34	67	40	25	62	9	7	78
Total acceptability	48	31	65	37	23	62	9	6	67

<sup>a</sup>Includes all reporting patients (version 1, version 2, both versions).

24.8 (SD = 4.2). The mean acceptability for version 1 ( $n = 37$ ) was 24.5 (SD = 4.5) and 25.5 (SD = 3.7) for version 2 ( $n = 9$ ). The proportion of participants indicating 4 or higher on each individual item of the acceptability scale is summarized in **Table 3**. **Table 4** details the additional features scored

**Table 4** The proportion of participants indicating ≥ 4 on additional features for those items answered by at least 20 participants

Item	Number answering	Score ≥4	
		N	%
Messaging	24	21	88
Doctor communication	25	23	92
Graphs	27	20	74
Resources	21	15	71
Nutrition	22	13	59

if at least 20 participants responded to the item. Communicating with the doctor and graphing of symptoms were reported as the most acceptable features.

#### Open-Ended Items

Of 57 participants, 41 provided a response regarding their favorite feature of the app. The patient–clinician communication function was favored by 10 participants, followed by the symptom tracking function ( $n = 9$ ). Five participants identified the daily medication reminder as a favorite. Suggestions from 24 participants regarding how to improve the app included: a more personalized application in which the user only tracks symptoms that were actually experienced ( $n = 5$ ). The remaining suggestions from one or two participants each focused on further tailoring and trending features, better responsive design for the smartphone user, downloading and uploading functions, and integration with personal email. For the few participants who did not use the

app remotely, reasons given were personal characteristics, not enough technology expertise ( $n = 4$ ), and feeling too sick to use ( $n = 3$ ).

### Clinician Results

Three clinicians participated, all of whom were women and at least 30 years. One was a Doctor of Medicine and the other two, advanced registered nurse practitioner and registered nurse. Each had been in oncology practice for at least 6 years. All clinicians accessed the following features at least once: community, dashboard, inbox, medication and health alerts, my inbox, my profile, and participant dashboard. Two of the three clinicians accessed: participant record, settings, and symptom management. One of the clinicians used: medical diary and participant record. All three clinicians reported that the patient participants' use of the app enhanced the subsequent in-person visits.

### Open-Ended Clinician Responses

Each clinician wrote a response with suggestions for improvement. Common to each suggestion was the difficulties caused by the version change during the study. Integration with the institutional electronic medical record was identified as essential for future use. Being able to visualize the self-care recommendation algorithm when alerted to a moderate or severe symptom was suggested.

## Discussion

In a sample of patients actively undergoing treatment for GI cancer, and who had Internet access on a personal device, we found a high percentage of remote users and adequate acceptability with the iCancerHealth app. Our criteria for patient participant success in this pilot study were met.

A previous study<sup>28</sup> of a Web-based intervention for cancer symptom and quality of life self-care in a more heterogeneous sample and without weekly prompting resulted in a much lower utilization rate (34% vs. 93% this study). Our weekly reminders appear to have had an impact on the high access rates. Ruland et al<sup>27</sup> in Norway reported a 77% unprompted access rate in a study of a Web-based program to support patients with prostate or breast cancer with symptom monitoring and self-care. That sample, recruited through advertisements in print media and one Web site, certainly was self-selected in contrast to our consecutive patient recruitment in the clinic. Similarly, in a recent pilot<sup>33</sup> of an app to monitor meals and self-care actions in participants with diabetes, 13 of 14 participants logged meal events over 30 days; it is unclear whether the participants were prompted in any way.

The tracking of symptoms (*Health Tracker*) and subsequent messaging from clinicians (*My Inbox*) were among the most highly utilized features. The value of the combined symptom reporting and communication with clinicians plus management information was evident in the acceptability scores plus the responses to open-ended queries regarding favorite feature. No other previous published study has detailed the acceptability of specific program features. How-

ever, Ruland et al<sup>34</sup> described feature usage details in which the discussion forum and messaging of nurses were most used. Messaging of clinicians was mainly automated in the iCancerHealth app because of the threshold function in which an alert to the clinician was sent for any symptom of a moderate to severe level. The community forum in our app was not used frequently and may be explained by the fact that the *community* included users outside of the clinical site and was not a secured component of the app.

Acceptability scores were higher than our preset threshold indicating adequate overall acceptability for an electronic program. The lowest scored core item was *how helpful was it to use the app/Web site*; however, only about half the participants answered this item at the last data collection time point.

All three clinicians reported high acceptability regarding how the app *facilitated in-person interactions* (telephone or in clinic) that occurred after patients used the app. Only one clinician gave high scores to the items related to *ease of use*, *identifying appropriate issues*, and *symptom notifications promoting communication*. Open-ended item reports from the clinicians indicated that "glitches" in the provider interface precluded higher ratings of the app. The request that the results of patient reports appear in the enterprise medical record is consistent with clinician feedback on recent app development for asthma symptoms.<sup>35</sup> The sponsor's decision to change the app version in the middle of the trial was unfortunate and clearly not a best practice for future testing protocols.

Our findings are limited primarily by the inclusion criterion requiring personal access to an Internet-enabled device and the racial and ethnic homogeneity of the recruited sample. By requiring a personal device, we likely excluded those who were less technology savvy. Participants may have enrolled to receive compensation for time and effort. Our findings cannot be generalized beyond this typical, urban comprehensive cancer center population.

Future researchers are encouraged to include measures of specific features used and favored by participants. The impact of systematic reminders was substantial and should be considered when mounting new changes in patient-reported outcomes. The high access rates, subsequent to telephone prompting, suggest the utilization of a Web-based program or app can be assured with such contact.

Our access rates and feature use findings are relevant to clinicians who promote Web-based monitoring of cancer symptoms, whether through an institutional vendor portal or a stand-alone system. Telephone follow-up by staff will likely enhance access rates.

## Conclusion

The findings of this pilot study suggest that prompted patients with cancer who own Internet-enabled devices are willing and able to report symptoms and communicate with clinicians regularly in between clinic visits. These most frequently used features by patient participants also were reported as most acceptable among all features. Clinicians found the communication feature acceptable as well.

## Clinical Relevance Statement

Patient–clinician communication about symptoms in between clinic visits is highly utilized and valued by patients. A systematic approach to such a mechanism may result in more engaged patients and better symptom management.

## Multiple Choice Questions

1. Web-based programs and apps for remote cancer symptom management have been tested and found to:
  - a. Reduce symptom distress.
  - b. Integrate well with enterprise medical record systems.
  - c. Interfere with patient–clinician communication.
  - d. Increase depressive symptoms.

**Correct Answer:** The correct answer is option a (As cited in the article introduction, the only correct outcomes in this list is option a).

2. Patient participants with gastrointestinal cancer favored which of the following iCancerHealth features?
  - a. Community forum.
  - b. Nutrition.
  - c. Messaging with doctor.
  - d. Calendar.

**Correct Answer:** The correct answer is option c (results in **–Table 4**; highest percent of high acceptability scores).

### Protection of Human and Animal Subjects

This study was approved as minimal risk by the Dana–Farber Cancer Institute Institutional Review Board in Boston, Massachusetts.

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Medocity, Inc. supported the first 3 months of the study through a contract to the Dana–Farber Cancer Institute.

### Conflict of Interest

None.

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