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Closing the patient-provider gap along the surgical journey one click at a time: results of a phase I pilot trial of a patient navigation tool

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Abstract

Background Patients diagnosed with complex hepato-pancreaticobiliary (HPB) conditions experience a challenging journey through the healthcare system. Patient navigation is commonly offered to patients and their caregivers throughout this process. Here, we report on the development and phase I testing of a prototype web-based dual (patient and provider) navigation application '*PatientNav*'.

Methods Evidence-based recommendations were determined through a needs assessment. The *PatientNav* app was designed to be a highly customizable tool based on the needs of the patients, the care team, and the characteristics of the institution. Our phase I pilot trial targeted adult patients who reported the capacity to use a mobile app or desktop website presenting to our HPB transplant clinic at MedStar Georgetown University Hospital/Lombardi Comprehensive Cancer Center over two months. Usability, functionality, and reliability testing were conducted by applying multiple strategies, including biometric data analysis, task completion, questionnaires, and interviews.

Results Out of 22 patients, 18 (81.8%) completed the in-app survey whose responses were included in the analysis. The usability rate of *PatientNav* among patient app users was 95.4%. Among patient app users who completed the in-app survey questionnaire, 66.6% reported that the content in the *PatientNav* app was relevant. In terms of the app's reliability, none of the patient app users reported technical issues with accessing *PatientNav* throughout the study period. To further elucidate the characteristics of individuals who exhibited high usage of the *PatientNav* assigned task functions, we divided our cohort based on the median number of tasks used ($N=75$ total tasks). The univariable comparison showed that high function users were older, with a median (IQR) age of 61.5 (57.8, 71.3) compared to 52.2 (34.5, 65.7) years among low function users. No differences were observed based on gender, racial distribution, living condition, or occupation. However, 41.7% of low function users had Medicare/Medicaid insurance, whereas all high function users had private or combined insurance.

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Conclusion Our phase I pilot study showed that *PatientNav* is a feasible, usable, and functional technological tool that enables patients with complex HPB diagnoses and their care team to interface in real-time using patient-reported outcome measures (PROMs). *PatientNav* is a reliable tool that can be used by clinical and support staff to help navigate patients through surgery and aftercare and by patients to assist in navigation and self-management.

Trial registration The trial was registered at ClinicalTrials.gov; Registration number: NCT04892927; date of registration: 5/19/2021.

Keywords Navigation, Tool, Gap, Patient-reported outcomes, Healthcare system, Electronic records

Introduction

Patients diagnosed with complex hepato-pancreaticobiliary (HPB) conditions experience a challenging journey through the healthcare system. Throughout the process, patients manage complex administrative tasks of accessing care while experiencing physical and psychosocial effects [1, 2]. Before and after surgery, patients commonly experience pain, stress, difficulty eating and sleeping, and other symptoms [3, 4]. Psychosocial concerns include financial issues, reduced quality of life, and barriers to accessing care [5–7]. Research has demonstrated a vital opportunity to improve care coordination and clinical management of patients throughout their multi-modal treatment approach [8, 9].

From the clinician perspective, care of complex HPB patients involves a high level of coordination between the different specialties providing care, such as medical and radiation oncology, interventional radiology, gastroenterology, pathology, surgery, and other ancillary services (nutrition, social work, physical therapy, and patient navigators). The process entails focusing on the proper transition of care and communication between the different personnel involved, as well as timely decision making [10–12].

Patient navigation is commonly offered to patients and their caregivers throughout this complex journey. Navigation has been shown to reduce psychosocial burdens and potentially improve efficiency and cost-effectiveness in the cancer treatment system [13–15]. However, standardizing patient navigation as a reliable tool to address their needs has yet to be fully accomplished. By enhancing real-time communication with patients and streamlining administrative transactions related to care coordination, a patient navigation app has the potential to improve care coordination and reduce the cognitive burden of cancer care providers as well [16, 17].

The standardized '*Patient Reported Outcomes Measurement and Information Set (PROMIS)*' developed by the National Institutes of Health (NIH) has introduced the value of capturing patient experience reports through researcher-developed platforms [18–20]. Several apps with a wide range of functionalities are available to patients through cancer management apps

available in the marketplace [21–24]. To our knowledge, no dual-facing navigation apps are available that integrate clinical and/or administrative information and facilitate communication between the patient, caregivers, and clinical team.

In this study, we developed and tested a prototype web-based navigation application '*PatientNav*.' The app has dual (patient and provider) features designed to be integrated with a major electronic health record (EHR) platform, Cerner Millennium, through its open developer's platform, Cerner Sandbox, using Fast Healthcare Interoperability Resources (FHIR) standards. The app enables the collection of clinical health data, patient-reported outcomes, push features for patient education, and tracking. In this paper, we report on phase I of the study, which evaluated the app in multiple domains: usability, functionality, and reliability.

Methods

Needs assessment and conceptual framework development

The *PatientNav* app was designed based on a thorough needs assessment process. Professional standards, accreditation, and standard performance measures have achieved some consensus on essential activities of navigation (Table S1) [25–27]. Essential activities identified to be targeted by our app included the coordination of services and identifying and addressing individualized patient needs along their cancer care journey.

From the patient's perspective, highly valued navigation activities included communication, defining provider care roles, providing access to information and emotional support to family/friends and caregivers (Table S2) [6, 10, 12, 28]. Navigation activities were also tailored to have value to multiple stakeholders, including payers and hospitals (Table S3) [29–34]. This value can be demonstrated by tailoring the navigation app to influence the use of services and patient experiences, potentially making it a driver of public ratings, revenue, and market positioning. The study is registered in the NIH Clinical Trials database #NCT 04892927.

PatientNav app design

Based on evidence-based recommendations determined throughout our needs assessment, the *PatientNav* app was designed to be a highly customizable tool based on the needs of the patient, the care team, and the characteristics of the institution. The development process was carried out under a multidisciplinary research and advisory team’s guidance, including technology specialists, oncologists, surgeons, patients, and nurses. The resultant decision-making process for the final app design is summarized in Table S4. The app and user-derived information are expected to improve patients’ clinical and psychosocial experiences, as well as improve efficiency and continuity of care through better outpatient clinic planning and handoffs, as well as enhanced timeliness in responding to patient concerns and tracking their recovery.

PatientNav software was designed by GMG ArcData LLC®, a software development company that provides user-centered software designs through data analytics solutions and implementation. The app enables care team members to adjust care based on patient-reported indicators such as pain, changes in wound status, and reduction in patient activity and monitor administrative indicators needed to improve efficiency and continuity of care. Through ‘task assignment,’ care

team navigators can push videos and educational material to patients who can view and complete the tasks (Fig. 1). Tasks include, but are not limited to, providing education to patients, scheduling or coordinating appointments, communicating with clinicians and coordination care planning. Patient-reported measures were incorporated into the app as tasks that can be assigned included Patient Health Questionnaire (PHQ) 2 and 9 for depression, pain assessment scale, and Surgical Recovery Scale (SRS-13 Fatigue) [35]. Educational material appropriate to each phase of care was assigned for patients to review through the *PatientNav* app. These were divided into an introduction, nutrition, surgery preparation, post-surgery care, and wound care (Table S7). The process of assigning education material was integrated into the clinic schedules during the pre-operative phase or into discharge planning in the postoperative phase. The clinical care team, including the surgeon, reviewed available educational materials and matched them appropriately to the patient’s stage in their care journey. Care team members can access a “provider platform” daily and track patient vitals, weight, task completion, image uploads, etc. The “provider platform” allows care team members to observe trends over three days with abnormal values that require immediate attention highlighted in red (Fig. 2).

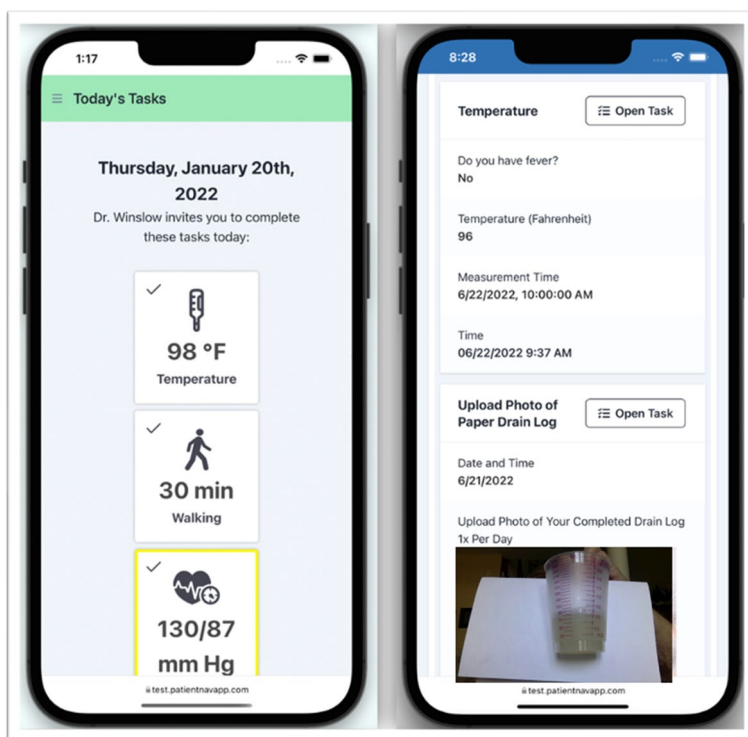


Fig. 1 *PatientNav* patient navigator platform view showing daily tasks assigned by the provider (left: vital signs and walking) and sample task completion (right: temperature and photo upload)

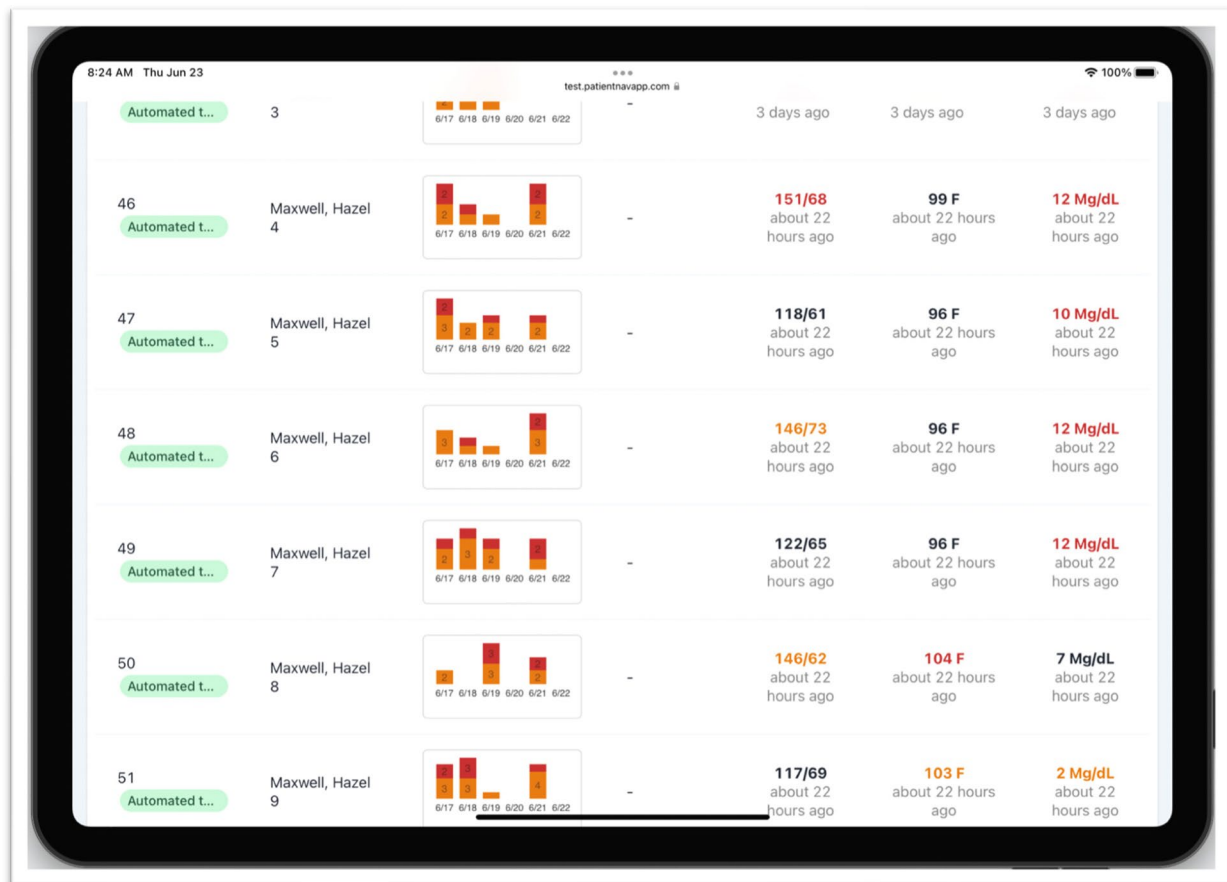


Fig. 2 PatientNav care team navigator platform view showing daily task tracking. “Maxwell, Hazel” is an alias used for demonstration that represents an individual participant

Patient population and recruitment

Our phase I pilot trial targeted individuals aged 18 years or older who reported the capacity to use a mobile app or desktop website presenting to our HPB transplant clinic at MedStar Georgetown University Hospital/Lombardi Comprehensive Cancer Center over two months. Inclusion criteria also included individuals who can read and understand English and plan to continue follow-up at our institution. The informed consent process for the study began during the initial clinic visit, where the research coordinators explained the study and addressed questions. Before downloading, participants received information about the study and the app’s functionalities. Screening for participation in the trial was extended to 26 patients by two research coordinators who were present at the time of their initial clinic visit. Individuals who agreed to participate were instructed to download the app. Informed consent documents were sent through the app, and 22 patients were eventually recruited for participation in our phase I trial (Fig. 3). One patient out of 22 did not complete any assigned tasks or participate in the

virtual interviews. The decision to distribute informed consent documentation after the app download was made to ensure participants comprehensively understood the study and their involvement before consent.

Evaluation techniques: usability, functionality, and reliability assessment

As PatientNav is a dual-facing app, we aimed to evaluate if the app is usable for both patient users and care team navigators. A third party designed and performed evaluation techniques based on validated methods to minimize designer and researcher bias [36–39]. Usability testing was conducted by applying multiple strategies, including biometric data analysis, task completion, questionnaires, and interviews. Functionality and reliability testing assessed whether the intended functions can be successfully executed through the app. Assessment techniques included basic navigation tasks, self-monitoring (vitals, drain log), self-management education, and other functions. Survey questionnaires were created based on the System Usability Scale

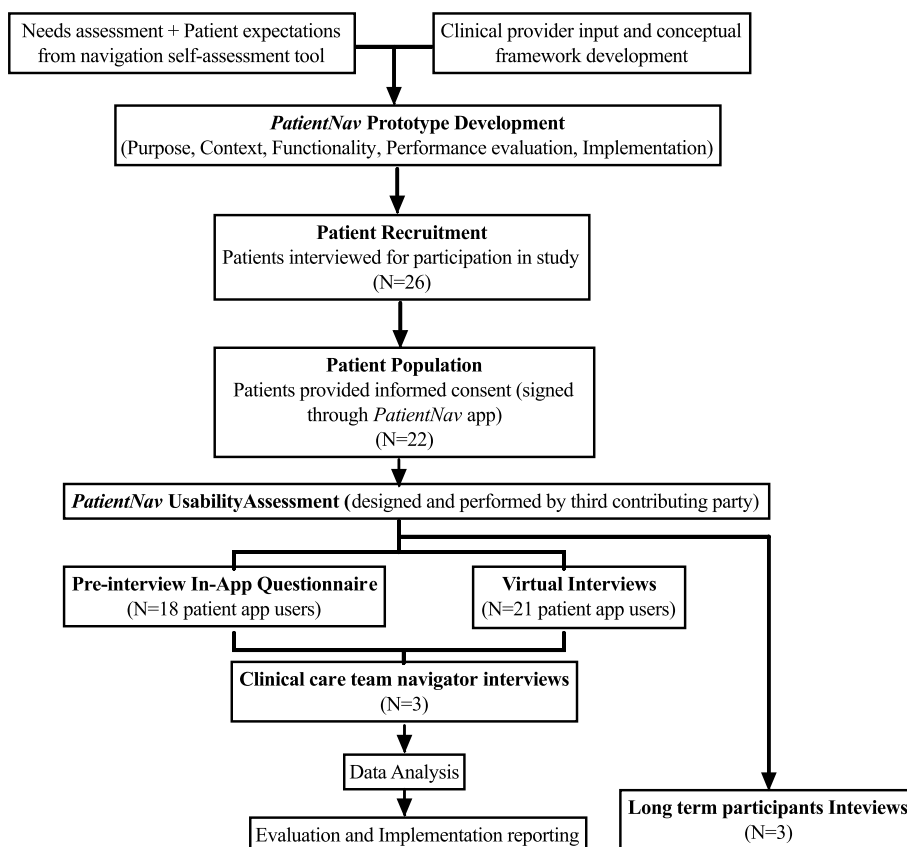


Fig. 3 Schematic diagram representing phase I pilot study timeline: *PatientNav* app development, trial design, and data analysis

(SUS), where participants were asked to score ten items with one of five responses (Table S5) [40]. These questionnaires were pushed through the app and completed by patient app users. After completion of the study, a nurse and a research coordinator carried out virtual interviews. Virtual interviews were not conducted through the *PatientNav* app, and instead, separate interviews were scheduled using video conferencing platforms or video phone calls as per participant preferences and accessibility.

Data collection and analysis

Baseline demographic and socioeconomic patient characteristics were collected from patients’ electronic medical records (EMR). Biometric data were extracted from the app (temperature, blood pressure, weight, walking input) as well as data points on logging-in attempts, use of education material, completion of assigned tasks, and in-app surveys. The extracted logged data and questionnaire responses were analyzed using descriptive statistics. Virtual interviews were transcribed verbatim and were analyzed using qualitative content analysis by two members of the research team (provider and research coordinator).

Results

Patient demographics and socioeconomic characteristics

The median age of our cohort was 59.8 years, with the majority (59.1%) being male. Ten patients (45.5%) were white, and seven (31.8%) were African American. More than half of the recruited patients were married and lived with a spouse or partner (68.2%); four individuals were single, and three (13.6%) lived alone. Most patients (68.2%) had private insurance coverage, five (22.7%) received coverage through Medicare/Medicaid programs, and two (9.1%) had combined benefits. The occupation of patient participants was diverse and included five individuals with vocational professions (one airplane pilot, two engineers, one teacher, and one nurse), four managerial or business owners, and the remainder led jobs in the technical or service industry (police officer, web design, elderly home caregiver, cashier, waitress, homemaker) (Table 1).

Clinical characteristics, services, and peri-operative management

Out of 22 patients who consented to participate in the trial, 17 (77.3%) were referred by providers within our

Table 1 Demographic and socioeconomic characteristics of the overall cohort (N=22)

	Overall Cohort; N = 22 n (%)
Age (years) ^a	59.8 (41.8, 66.9)
Gender	13 (59.1)
Race	
White	10 (45.5)
African American	7 (31.8)
Asian/ Other	5 (22.7)
Primary Language	
English	21 (95.5)
Spanish	1 (4.5)
Marital Status	
Married	15 (68.2)
Divorced/Widowed	3 (13.6)
Single	4 (18.1)
Living Condition	
Spouse/Partner	15 (68.2)
Siblings/Children	4 (18.1)
Alone	3 (13.6)
Smoking	
Never	15 (68.2)
Former/Active	7 (31.8)
Alcohol consumption	
Never	5 (22.7)
Former/Occasional	18 (77.3)
Body mass index (BMI) (kg/m²) ^a	26.6 (24.1, 29.9)
Insurance Type	
Medicare/Medicaid	5 (22.7)
Private	15 (68.2)
Combined	2 (9.1)
Occupation	
Vocational	
Airplane pilot	1 (4.5)
Engineer	2 (9.1)
Nurse	1 (4.5)
Teacher	1 (4.5)
Managerial	
Business Owner	4 (18.1)
Technical/Service Industry	
Police officer	1 (4.5)
Cashier	1 (4.5)
Waitress	1 (4.5)
Web Design	1 (4.5)
Elderly home caregiver	1 (4.5)
Homemaker	1 (4.5)
Retired/Unemployed	7 (31.8)

^a Median (Interquartile range)

institution. Fourteen patients (63.6%) were diagnosed with malignancy (pancreatic, hepatic, or biliary/gall-bladder cancer). The median time from diagnosis to the first visit at our HPB transplant clinic was 10.5 days. The median time to undergo surgery after the initial clinic visit was 33 days. Most patients underwent interventional procedures before surgery, most commonly endoscopic retrograde cholangiopancreatography (ERCP) and stent placement (59.1%). The surgical procedures performed are listed in Table S6.

The median length of stay was five (3.5, 13) days; eight (36.3%) had a complication in the perioperative period. Four patients (18.1%) were readmitted within 30 days. The median time to follow up in the clinic after discharge post-surgery was 21 days.

Usability assessment

The usability rate of *PatientNav* among patient app users was 95.4%. Out of 22 patients, 18 (81.8%) completed the in-app survey whose responses were included in the analysis. Most patient app users reported that logging into *PatientNav* was easy (83.3%), with 66.6% reporting that navigating *PatientNav* features overall was easy (33.4% reported somewhat easy) (Fig. 3).

Of 22 patient app users, 45–55% utilized educational material introducing tasks that would be assigned after surgery. A slightly higher proportion of surgery preparation education material was used, with the most viewed features being “*Are You Packed? What to Take to the Hospital*” (77.2%) and “*Tips for Family and Friends*” (63.6%). Regarding task functions, Table S7 demonstrates the total number of patients who utilized each assigned task function. The daily assigned task use rate was notably highest for weight (80.9%) and walking input (90.4%).

Usability assessment among care team navigators was also evaluated through interviews with the surgeon, staff member, and research navigator. The different care team members considered the app simple to use and “*just needed to get used to it at first like any other app; then it was straightforward.*” However, some reported that task assigning could have been more straightforward and would prefer to have a better description of the content of each task function to determine which tasks best suited the needs of each patient (Table S8).

Functionality and reliability assessment

Among patient app users who completed the in-app survey questionnaire, 66.6% reported that the content in the *PatientNav* app was relevant (Fig. 4). Validity of the app content was also highlighted through patient interviews invariably expressing the specific value of videos recorded by surgeons on steps of the surgical procedure.

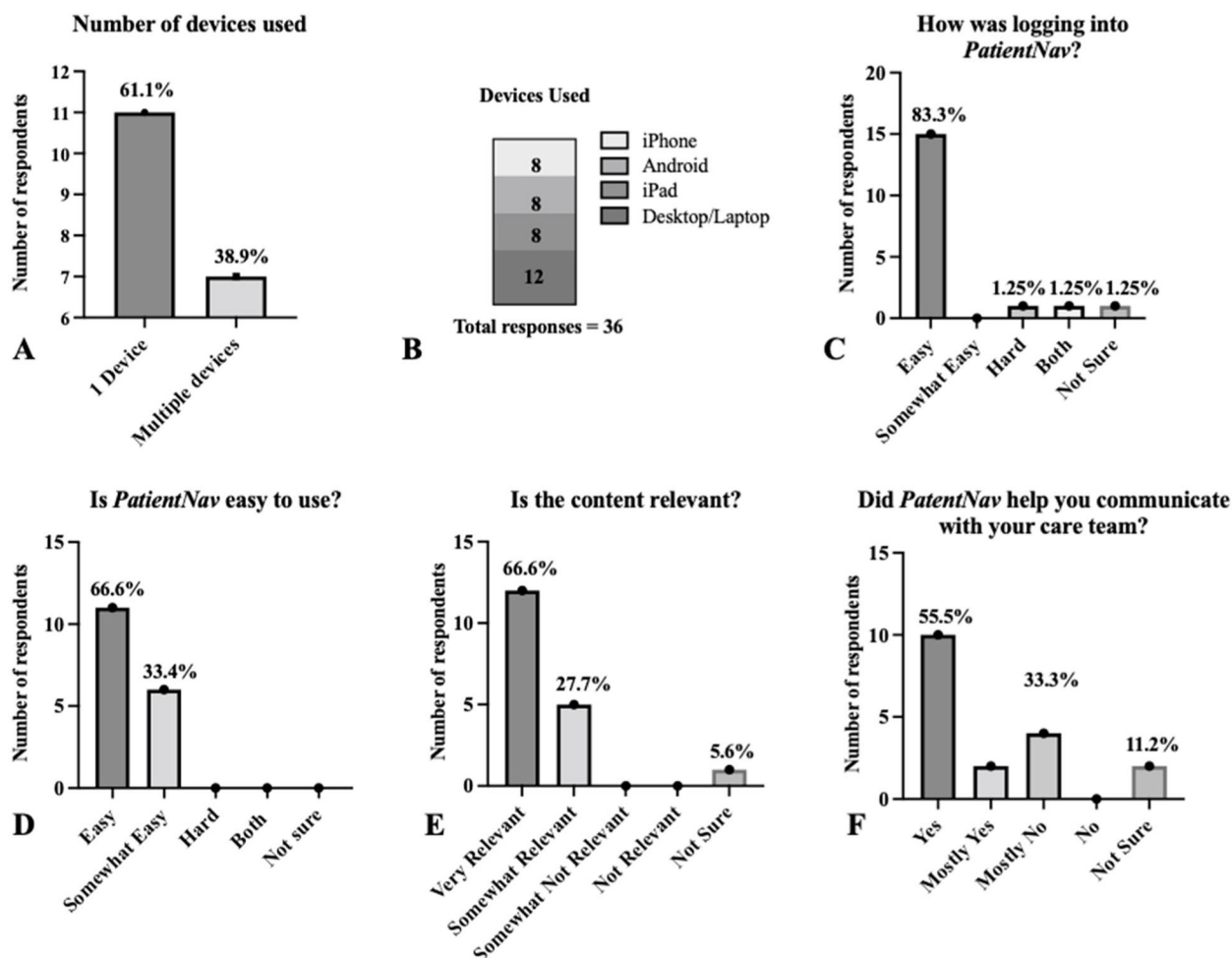


Fig. 4 Graphic representation of patient responses to the in-app survey questionnaire completed at the end of the study for usability assessment (Total responders: 18 patient navigators)

The functionality of the app was also evident, with 83.3% of users uploading wound or drain images correctly and maintaining a daily self-managed drain log (50%). One of the patients highlighted the value of uploading images through the app for himself and his caregivers: "I live 1.5 h away. How else can they tell what's going on? Photos are helpful. I'm 67 years I had a support team, a wife, and a daughter. They got the data into the computer for me. I don't have to be savvy." However, other patients found a limited value of the image upload function: "My incisions were all glued – skin glue. I did not need to upload images." Regarding communication between patient app users and the care team, 55.5% of patient users believed that *PatientNav* helped them connect with their providers easily (Table 2). However, most patient app users commented that having more "check-in ability" or "feedback loops" would be more helpful.

Furthermore, surveys assigned as tasks tailored to patient needs (Depression PHQ2, pain, and SRS-13

Fatigue survey) were accessed and filled at 100%, 94.1%, and 90.4%, respectively (Table S7). Patient app users emphasized during virtual interviews that these assigned survey tasks were beneficial in "understanding what to expect." Other patient app users mentioned: "The question that was really helpful was about my feeling. It helped me understand how I feel every day" and "anxiety levels go down with understanding."

Regarding the app's reliability, none of the patient app users reported any technical issues accessing *PatientNav* throughout the study period. One of the patient participants mentioned during the virtual interviews that their favorite part of *PatientNav* is how easy it is to use: "It's not cumbersome. It's one-stop, I hit the button, and there it is. It's very easy to access." (Table 2).

A qualitative assessment revealed that patients relied on reminder prompts through the app to log their daily input "The app helps me be more diligent rather than lazy. I get my email reminder, which makes tracking a

Table 2 Summary of online virtual interview responses assessing patient overall impressions of PatientNav usability. Representative responses are displayed as positive, neutral, or negative input

Virtual Interview Questions	Positive Response	Neutral Response	Negative Response
<p>1. Was the content in the app helpful or informative?</p> <p>2. What task/article helped you the most and why?</p>	<p>"Absolutely yes. The video on resection was very interesting and helpful. I found it very helpful."</p> <p>"Extremely helpful. I made my husband watch the videos with me so he would understand. It gave him confidence knowing what was going to happen going into the surgery."</p> <p>"The question that was really helpful was about my feeling. It helped me understand how I feel every day."</p> <p>"The videos were extremely informative. I looked again the other day as refresher course. Videos were strong."</p>	<p>"Half of it was. I know since I wasn't a cancer patient but that this was geared for. Having milestones about recovery."</p> <p>"A couple didn't make sense. Pain and fatigue would make more sense as a daily check-in."</p>	<p>"It was not very informative. It was fine prior to surgery but maybe not after surgery."</p>
<p>3. Did you find the videos helpful?</p>	<p>"It helps me be more diligent rather than being lazy. I get my email reminder which makes tracking a lot easier."</p> <p>"Yes, it was helpful. Walking. Blood pressure. My BP was low when I left the hospital. I was entering BP data even before I got home from hospital."</p>	<p>"It just was something that I log in. To me, I intend on doing these activities so it's not a reminder to do, just a reminder to log in and enter the data."</p> <p>"For myself, it didn't do a lot. For my doctor she is worried about infection, so yes for her sake there was a need."</p>	<p>"Not all were helpful. The videos should put a face with the doctor. Humanize the doctor while explaining what they do. Sometimes they use terms above my schooling level."</p>
<p>4. Did it help you manage all of the different tasks you had to do (for example, tracking walks, blood pressure, weight, temperature, blood sugar and/or pain)?</p> <p>5. Helpful to prepare or recover from surgery?</p>	<p>"It did help me communicate with health-care team. One time, I put my blood sugar (109) in the temperature section. I got a call the next day because they thought I had a fever."</p> <p>"Yes. We are always talking. Always sharing information. It's more convenient for me. It's not always easy to find someone to talk to when I call."</p> <p>"Yes. I know the recovery process and help me understand what to expect. Anxiety levels go down with understanding."</p>	<p>"If my doctor is looking at that info, then it helps. For me, I know she is busy I don't feel like calling every day or sending text messages. If it helps her check on me when she has time, I good with that."</p> <p>"Somewhat. The best thing for me is being organized. The first day I was writing everything down, after second day I would open the app and punch in my numbers."</p>	<p>"It did not help me prepare for my surgery. I have been monitoring and staying healthy. I don't write down the data."</p> <p>"I can't say that it did help me. But I was enlightened. I shared it with my family."</p>
<p>6. Did it help you communicate with care team?</p>	<p>"Yes. I know the recovery process and help me understand what to expect. Anxiety levels go down with understanding."</p>	<p>"Somewhat. The best thing for me is being organized. The first day I was writing everything down, after second day I would open the app and punch in my numbers."</p>	<p>"I don't stress. It's against my religion. It might help other people. I'm happy every day."</p> <p>"It did not help me know when to call the doctor. I just know that." [points to own head]</p>
<p>7. Did it help you with feeling with less anxious or stress level?</p> <p>8. Did the app help you understand when to call the doctor? For example, when problems arise?</p>	<p>"Yes. I know the recovery process and help me understand what to expect. Anxiety levels go down with understanding."</p>	<p>"Somewhat. The best thing for me is being organized. The first day I was writing everything down, after second day I would open the app and punch in my numbers."</p>	<p>"I don't stress. It's against my religion. It might help other people. I'm happy every day."</p> <p>"It did not help me know when to call the doctor. I just know that." [points to own head]</p>

Table 2 (continued)

Virtual Interview Questions	Positive Response	Neutral Response	Negative Response
9. Was the app helpful in managing your drains and wounds including assessing problems?	"I live 1.5 h away. How else can they tell what's going on? Photos are helpful. I'm 67 years I had a support team wife and daughter. They got the data into the computer for me. I don't have to be savvy." "Anything that centralizes communication with the doctor is helpful. If it makes it easier for the doctor to help you, I am all for it."		"It was not. My incisions were all glued – skin glue. Why doesn't everyone get skin glue all the time."
10. How likely are you to recommend the app?	"The app probably saved my life. My surgeon put me back into the hospital. She saw the pictures of my drain I was uploading. She called immediately and told me to come to the hospital." "The ease of use. It's not cumbersome. It's one stop, I hit the button and there it is. It's very easy to access."		"In current state, I recommend the informative video describing the surgical procedure mostly."
11. What did you like about this app?			
12. If you could change anything about the app, what would you change?	"Add Hack ideas. For example, for chemotherapy patient, some maple syrup takes the metal taste out of food." "More check-in ability. More feedback loops."	"Add a way to send a message via the data link. I would like more choices regarding exercise/physical activity." "Formulate it in a customized to you, that would be better."	"I would like option of applicable or not applicable. I want to hit button that says, 'not applicable.' If not applicable, I want to move on." "Booking appointments through the app."

lot easier." In addition, there were patient-specific experiences that also reflected the reliability of *PatientNav* functions in communicating with the healthcare team: "One time, I put my blood sugar (109) in the temperature section. I got a call the next day because they thought I had a fever"; "The app probably saved my life. My surgeon put me back into the hospital. She saw the pictures of the drain I was uploading. She called immediately and told me to come to the hospital."

Care team navigators were overall satisfied with the functionality of the app. They were able to review data and images in an organized and timely manner. Regarding efficiency and workload, care team navigators commented that "putting everything in one place would save everyone a lot of time." When asked for feedback on improving *PatientNav* functions, the staff member navigator suggested connecting the app to the EMR system to schedule surgeries and book appointments through the app (Table S8).

Subgroup analysis: high vs. low assigned task use

To further elucidate the characteristics of individuals who exhibited high usage of the *PatientNav* assigned task functions, we divided our cohort based on the median number of tasks used ($N=75$ total tasks). The total number of tasks not only reflects the number of unique tasks assigned to each user but also accounts for the multiple times users completed each task (numerous entry points) over the duration of the study. Individuals with a total number of tasks used <75 were grouped into low function usage ($N=12$); those with total tasks used ≥ 75 were considered high function users ($N=9$) (Fig. S1). Among low function users, the number of tasks used ranged between 4 and 45 data point entries, whereas among high function users, the number of tasks used ranged between 76 and 485. The univariable comparison showed that high function users were older, with a median (IQR) age of 61.5 (57.8, 71.3) compared to 52.2 (34.5, 65.7) years among low function users. No differences were observed based on gender, racial distribution, living condition, or occupation (Table S9). However, 41.7% of low function users had Medicare/Medicaid insurance, whereas all high function users had private or combined insurance.

Discussion

Our *PatientNav* app is an innovative digital application that serves as a 2-way communication tool between patients and providers based on validated patient-reported outcome measures that allow a patient-centered approach during the cancer care journey. This pilot study is a phase I trial aimed at evaluating the dual-facing *PatientNav* app using identified standards of usability,

functionality, and reliability among two end-users: patient and provider navigators.

The findings in our pilot study highlight the potential of *PatientNav* in improving patient experience, satisfaction, and efficiency of care. A high overall usability rate of 95.4% was observed, with 100% of users reporting that using *PatientNav* was easy or somewhat easy, comparable or more increased to other studies [41, 42]. Notably, users expressed their satisfaction with the app's educational material, specifically video uploads before and after surgery. Patient app users completed daily tasks assigned by the care team, with the highest use noted for easily quantifiable measures such as weight (80.9%) and walking distance (90.4%). Utilizing the *PatientNav* app fostered patient-provider connection, enhancing self-care commitment and deepening comprehension of emotional and physical well-being, with patients expressing interest in incorporating a notification feature indicating provider data review. To manage patient expectations and enhance transparency in the communication process, we have implemented a notification feature in the app as part of phase II that informs patients when their messages have been reviewed by the care team, even if a direct response is not provided. This feature assures patients that their data has been seen and considered. It is essential to highlight that the *PatientNav* app is not intended to replace urgent medical attention for critical situations. Patients were educated during the initial clinic visit and through educational materials within the app about the importance of contacting their care team directly by phone or seeking medical attention in case of emergent needs, especially if there's a potential risk to their health or well-being. Finally, we plan to establish clear response protocols for the care team, defining which messages require immediate attention and establishing specific timeframes for addressing other messages, ensuring effective communication between the care team and patients.

A vital component of the study was user feedback which played a pivotal role in refining the app's usability and functionality, driving its evolution for the upcoming phase II trial. Expectedly, patients were more likely to use the features in the app and complete assigned tasks when they were tailored to individual needs. For instance, patient users who did not complete the assigned task of uploading an image of their wound or drain reported that they did not need to perform the task. Furthermore, Depression PHQ2 and SRS-13 Fatigue surveys assigned as tasks tailored to patient needs were more likely to be accessed and filled by patient app users. These findings emphasize the importance of a patient-centered approach in assigning tasks through *PatientNav* that are individualized to the needs and situations of each patient. While manually assigning tasks provided flexibility and

personalization, it could benefit from more efficient ways of matching tasks to patient needs, including options for patient input in selecting tasks that align with their preferences and requirements. Future updates involve iterative improvements to the user interface and data analytics tools to enhance provider utilization of information for education, individualized task assignments based on patient needs, and communication prioritization.

Socioeconomic features of end-users are considered a crucial element for the usability and functionality evaluation of a technological application, as evidenced by the increasing evidence in the literature on disparities in access to equitable healthcare services and outcomes [43, 44]. A racially diverse group was included in our study as well as a wide variety of occupations (airplane pilot, engineer, cashier, waitress, etc.) that can serve as a surrogate for education status. Furthermore, our subgroup analysis revealed that participants successfully navigated *PatientNav* regardless of their marital status, living condition, comorbidities, or occupation. Interestingly, older individuals were more likely to have a higher use rate of app features. In addition, older individuals almost always had a family member or a caregiver, which emphasizes the potential of *PatientNav* to be a supportive tool for the caregiver in documenting their care to patients and communicating with the provider team.

A core element of our study was including input from care team navigators in the usability and functionality assessment of the app. Navigators of the care team expressed that *PatientNav* was easy to use after a short training course. Care team navigators volunteered their time for phase I of this study; they expressed their belief that *PatientNav* is valuable for remote patient monitoring and focusing on the concerns and matters that must be addressed. Even though tasks were assigned manually, it was regarded as necessary for the workflow process to improve efficiency further. Furthermore, the *PatientNav* app allowed the care team to perform daily monitoring of their patients post-operatively and provide more efficient pre-operative teaching and post-operative instructions. A particular area of improvement highlighted by the care team was improved automation of task assignments that would be even more time efficient. In addition, designing 2-way communication through the app connected to the EMR can improve communication and decrease workload if implemented, allowing organizing patient concerns and follow-up and reducing the inefficiency of tracking patients through phone calls and avoidable clinic and ER visits.

While it is true that certain features we have implemented can be found in other apps (*PittPHR*, *TouchStream*, *Carer Guide*, *GenieMD*), our *PatientNav* app

fills a specific gap in the market by integrating validated patient-reported outcome measures (PROMs) [23, 24, 41, 42]. Incorporating PROMs distinguishes our app from others by providing a standardized and evidence-based approach to monitoring patient outcomes and well-being. Furthermore, our thorough needs assessment (Table S4) was based on input and limitations published by other apps providing a 2-way communication tool between patients and providers. The prospective nature of our study with planned phases II and III will include randomization and adjustments to the app design in each phase. A 2019 usability study of the PittPHR app integrated app-collected personal health data with hospital records [41]. The PittPHR app includes six functional areas, health records, patient history, patient tracking, contacts, appointments, and resources. Researchers at Duke Health enabled their EPIC-based EHR to be interoperable with both patient-facing and provider-facing apps using the Substitutable Medical Apps & Reusable Technology on the FHIR approach. We acknowledge the importance of interoperability and consolidation of available tools with electronic software at a system level in improving efficiency in the coordination of patient care.

There are several limitations inherent to this study that should be acknowledged. First, the phase I trial and the needs assessment and app design process took place amidst the COVID-19 pandemic with difficulty recruiting participants due to decreased volume of elective surgery. Adopting and incorporating virtual meeting platforms in our study design was essential in mitigating these challenges. Informed consent for research participation and survey questionnaires obtained through the app open the horizon to a new era of designing and conducting research in a challenging setting. Second, the design and dissemination of novel technological tools have an inherent disparity bias based on race, language, and health literacy. While our study attempted to account for health equity with a diverse racial and socioeconomic participant group, definitive correlations could not be obtained with a small cohort. Future studies with a larger cohort would allow tailoring app features to specific patient needs and individualized care plans. Third, the study was limited to a narrow range of provider specialties. This reinforces the need for full integration with provider workflow to allow for better access and communication with the multidisciplinary team involved in cancer care for each patient. Finally, the study participants were employed and had a higher education level, which may not accurately represent the broader population of patients or individuals in caregiving roles, limiting the generalizability of our study.

Addressing limitations identified in phase I of this study will shape our future directions and develop a sustainability plan for phase II implementation. A limitation in our study is the multi-step endeavor needed for integrating the PatientNav app with the electronic health record, which has been successfully demonstrated by recently published app designs that demonstrated the feasibility of EHR integration. Addressing this limitation in future studies will allow us to demonstrate further advantages, especially for care team workflow and patient experience. Furthermore, our phase II study design will address recruiting more study participants, comparing patient-reported outcomes to a control group, and evaluating specific outcomes such as delays in care delivery.

Conclusion

PatientNav is a mobile-ready application designed by a multi-disciplinary team based on the needs of patients and their providers that still need to be added to current practice. Our phase I pilot study showed that *PatientNav* is a feasible, usable, and functional technological tool that enables patients with complex HPB diagnoses and their care team to interface in real-time using PROMs. *PatientNav* is a reliable tool that can be used by clinical and support staff to help navigate patients through surgery and aftercare and by patients to assist in navigation and self-management. The modular design of the app allows flexibility within the tool to tailor tasks to individual patient needs. Our results highlight a significant opportunity for hospital administrators, healthcare providers, and stakeholders to implement user-centered tools of greater quality that address the unmet needs to close the gap between patients and their care team. Limitations identified in this study are particularly valuable for phase II of the project, which will test scalability, interoperability, and additional outcomes measurement, including cost-effectiveness.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s44247-023-00049-6>.

Additional file 1: Table S1. Commission on Cancer Requirements Relating to Patient Navigation. **Table S2.** Evidence on Patient Needs from Patient Navigation (PN). **Table S3.** Value of Enhanced Navigation to Stakeholders. **Table S4.** Decision-making for the Final *PatientNav* app design based on Evidence-based Recommendations Identified in Needs Assessment Process. **Table S5.** In-App Survey Questionnaire assigned to patient navigators as a task through the app. **Table S6.** Clinical Characteristics, Services and Peri-operative Management in Overall Cohort ($N=22$). **Table S7.** Usage rate in patient access to education material and assigned tasks on *PatientNav*. **Table S8.** Summary of Online Virtual Interview Responses Assessing Care Team Navigators Impressions and Feedback on *PatientNav* usability. **Table S9.** Univariable Comparison of High ($N=9$) and Low ($N=12$) Function Usage in *PatientNav* App with Patient App Users Grouped Based on Overall Number of Tasks Used. **Figure S1.** (A)

Distribution of patient app users into low and high function users based on number of *PatientNav* tasks used. (B) Comparison of difference in median age [52.2 vs. 61.5 years; $P = 0.058$].

Additional file 2.

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None

Authors' contributions

S.S. performed data analysis, manuscript preparation, and graphic results presentation. G.D. participated in study design, design of data services platform, participated in writing manuscript. J.O. assisted patient care and study enrollment, conducted post-hoc analysis. L.G. writing manuscript. M.Y. lead engineer, architect and systems analyst. G.V. lead technical engineer and solutions architect. P.K. patient consultation, consenting, and product design. T.F. clinic operations lead and communications. K.U. clinical research oversight, communications and editing. E.W. led the design of the study, supported patient enrollment and clinical navigation role, conducted analysis of data, prepared and reviewed written document.

Authors' information

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Availability of data and materials

The study protocol, consent forms, and individual participant data collected during the trial (after de-identification) are available on request from the corresponding author to anyone who wishes to access the data. Instructions for anonymous evaluation of the *PatientNav* app are provided in Supplementary File 2. Supplementary File 2 includes statement declaring permission to use company logo.

Declarations

Ethics approval and consent to participate

This study was conducted in accordance with the principles of the Declaration of Helsinki and was approved by the Institutional Review Board (IRB) of Georgetown University. All methods described in this study were performed in accordance with relevant guidelines and regulations, including Good Clinical Practice guidelines and applicable laws and regulations. Informed consent was obtained from all subjects and/or their legal guardian(s). The confidentiality and anonymity of the study participants were protected, and no identifiable information was included in the study. Further information and documentation to support this should be made available to the Editor on request.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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