Patient-Centered Design Recommendations for AI-Generated Discharge Summaries

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***Abstract*—Hospitals are rapidly adopting generative AI to draft discharge documentation, increasing the importance of how discharge information is organized, consumed, and shared—especially for people living with chronic illnesses whose capacity to engage in care and information needs can change over time. We conducted an inpatient interview study with 20 adults hospitalized with chronic heart failure that included task-based design probe activities with a digital discharge summary. Current engagement with discharge summaries was limited: 13 participants recalled receiving paper summaries, but only two had viewed the digital version after discharge, and only four reported reviewing summaries at all. During the design probe tasks, participants preferred listening over reading summaries and wanted easier ways to share discharge information with caregivers. We translate these findings into patient-centered design recommendations for AI-generated discharge summaries in portal settings, emphasizing reduced navigational burden, multimodal access, and ease of sharing.**

***Index Terms*—Discharge summary, Patient-centered design, User study, Qualitative study.**

I. Introduction

Hospital discharge marks a high-stakes transition in which patients must carry forward a care plan from an inpatient setting into daily life at home. A *discharge summary* is the primary record of that transition: it documents what happened during the hospitalization (e.g., diagnoses, procedures, clinical course), what changed (e.g., medications), and what patients are expected to do next (e.g., follow-up appointments, diet/activity guidance, symptom monitoring, and when to seek care) [1]. In many health systems, discharge summaries are now delivered not only as paper packets at the bedside, but also through patient portals (e.g., via an electronic "hospitalization summary" in the personal health record), creating the expectation that patients can revisit instructions, look up details, and share information with caregivers after discharge [2]. Yet discharge summaries are historically authored to support clinical communication and billing, and they often remain written in provider-oriented language and structure [1]. As a result, patients frequently encounter discharge information that is difficult to navigate, difficult to understand, and hard to use in the moments when it matters most—contributing to low uptake of portal-based discharge documentation despite widespread availability [3].

More recently, patient portals have begun to incorporate generative AI—especially large language models (LLMs)—in ways that may soon reshape how discharge information is produced and experienced by patients [4]–[6]. Some health systems have already started deploying AI assistants to help draft provider messages to patients [7], [8], lowering the barrier to portal-based communication and increasing the volume of patient-facing text [4]–[6]. Research prototypes have also explored LLM-based assistants that answer patients' questions about discharge documentation [9]. However, question-answering alone assumes that patients know what to ask when and can translate their needs into queries [10]. In practice, patients' health literacy, digital literacy, and capacity to engage with information can vary widely and fluctuate over time, suggesting that portals may need to support both *a stable reference summary* and *interactive assistance* that helps patients make sense of it.

In parallel, a growing body of work has applied LLMs to discharge summaries themselves, typically to produce a generally "patient-friendly" version by simplifying medical terms, improving readability, or restructuring content [11], [12]. Beyond rewriting, emerging systems propose moving toward *personalized* discharge support using retrieval-augmented generation (RAG), drawing on clinical records and follow-up interactions to tailor responses [9], [13]—an approach that could plausibly be integrated into portals where those interactions already occur. Together, these developments signal a shift from discharge summaries as static documents to discharge information as something that can be transformed, queried, and tailored. Yet the prevailing portal experience remains a static, often provider-oriented PDF (Figure 1), raising a key gap: we do not yet know how patient portal interfaces should evolve to support AI-enabled tailoring of discharge information in ways that fit patients' real-world needs. We therefore ask: *How should AI-generated discharge summaries, that can be personalized to patients, be presented in patient portal settings?*

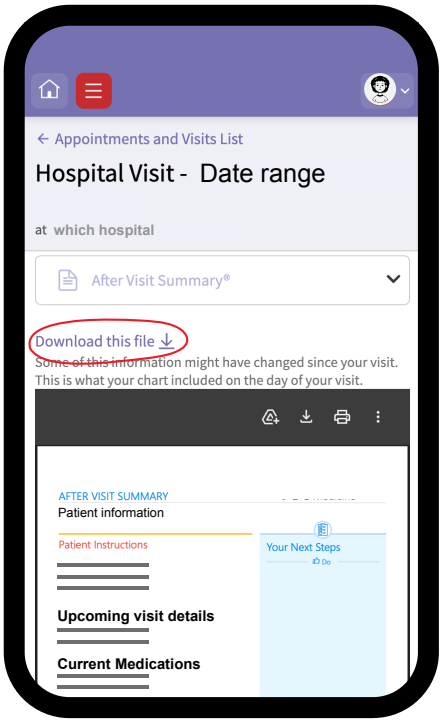

Fig. 1. The current patient portal experience. Patients often encounter a static discharge summary in their patient portal that must be downloaded as a PDF

To investigate this question, we conducted a qualitative user study with adults hospitalized with chronic heart failure at the University of Illinois Hospital (UI Health), a safety-net setting that serves a large proportion of African American and Hispanic/Latinx patients. Because disparities persist in access to and use of electronic health records across racial and socioeconomic groups [14], and because smartphones are a common pathway to portal access even in lower-income populations [15], we focused on a smartphone-based, portal-like discharge summary experience. We developed a design probe that emulates AI-enabled tailoring of discharge information, and used task-based probe activities embedded in inpatient interviews to surface breakdowns and preferences that are difficult to elicit through conversation alone. Our contributions are: (1) empirical evidence on patients' current engagement with discharge summaries and what they need from portal-based summaries; (2) interaction-level findings on how patients make sense of tailored discharge information, including how they interpret tailoring controls and outputs; and (3) patient-centered design recommendations for AI-generated, personalizable discharge summaries in portal settings.

II. Related Work

Discharge summaries play a central role in care transitions, yet patients often struggle to understand and use them. We organize related work into three parts: hospital discharge summaries, patient experience with discharge materials, and AI-generated discharge summaries.

A. Hospital discharge summaries

Discharge summaries are a core artifact of hospital-to-home transitions and are intended to support continuity of care after hospitalization. Government agencies and accrediting institutions mandate that discharge documentation include specific elements, reflecting the importance of discharge planning for safe transitions and preventable readmissions [16], [17]. For example, the U.S. Joint Commission specifies that discharge summaries include the reason for hospitalization, significant findings, procedures and treatments provided, the patient's discharge condition, instructions for the patient and family as appropriate, and the attending physician's signature [16]. In practice, discharge summaries often serve as the primary—and sometimes only—document that accompanies the patient into the next setting of care (e.g., to primary care physicians), making their completeness and clarity consequential for post-discharge follow-up [1].

Discharge summaries are especially salient for people living with chronic illnesses, who may experience repeated hospitalizations and must integrate discharge instructions into long-term self-management. Chronic conditions last for more than a year and require ongoing monitoring or treatment, often demanding complex medication management, lifestyle changes, symptom monitoring, and sustained engagement with care. Heart failure (HF) is one prominent example: it is a prevalent chronic condition in the U.S., and hospitals face financial penalties for high 30-day readmission rates, underscoring the stakes of effective discharge processes [18]. These dynamics position discharge summaries as a key mechanism for communicating the hospital course and "what to do next" across repeated episodes of care.

At the same time, prior work highlights a structural tension in how discharge summaries are authored and used. Discharge summaries must support provider-to-provider communication and documentation needs while also serving patients and informal caregivers who rely on the summary to make informed decisions and enact post-discharge care [19], [20]. These audiences differ substantially in goals, health literacy, preferences, and capacity to interpret medical language, yet a single discharge summary is typically produced to serve all of them. Unsurprisingly, dissatisfaction with current discharge summaries has been documented among both physicians and patients [1], [3], [21]. For example, one study found unexplained medical acronyms and jargon in more than 70% of discharge summaries [21]. In a national survey of U.S. physicians, while many respondents viewed patients as an important audience for discharge summaries, fewer endorsed writing summaries in language accessible to patients, and many supported the idea of separate summaries for patient use versus provider-to-provider communication [1]. This tension shapes patients' day-to-day experience of discharge materials.

B. Patient experience with discharge materials

Patient dissatisfaction with discharge summaries is well-documented, primarily regarding poor readability and comprehension [3]. In one heart failure (HF) study, only 10% of

patients understood all six key self-care aspects: exercise, diet, weight monitoring, medications, follow-ups, and worsening symptoms [22]. This gap is not uniform; patients without higher education or non-native English speakers face higher misunderstanding and readmission risks [22], with similar challenges reported in adults over 65 [23].

These difficulties stem from both content and design. Summaries often feature abundant medical jargon, reflecting a provider-to-provider handoff focus rather than patient needs [21], [24], [25]. Patients describe materials as poorly presented [26], incomplete, and unclear regarding next steps [27]. While prior work proposes general usability improvements like avoiding all-caps or improving typography [3], [28], much of this guidance assumes a uniform audience. Less is known about how materials should adapt to a patient's shifting health literacy and engagement capacity—factors that fluctuate over the course of chronic illness.

C. AI-generated personalizable discharge summaries

Rather than assuming a uniform patient audience, generative AI offers a mechanism for producing discharge summaries that can be rewritten and tailored to individual needs. This has motivated growing work on AI-generated discharge summaries, including efforts aimed at patient-friendly formatting and emerging approaches to personalization.

Recent work suggests that generative AI is beginning to reshape discharge summaries along two (often overlapping) directions: automating provider-facing documentation [29]–[32] and producing patient-facing versions that are easier to read. On the provider side, studies have evaluated LLMs (e.g., LLaMA3 [33], ChatGPT-4 [34]) as drafting tools by comparing AI-generated summaries to clinician-written ones, emphasizing efficiency, structure, and completeness [33], [34].

In parallel, a smaller but growing body of work examines whether AI-generated discharge summaries are more readable and acceptable to patients or their informal caregivers than those written by clinicians [35]. For example, in a quality-improvement survey, parents compared ChatGPT-generated tonsillectomy discharge summaries to clinician-written summaries and rated AI summaries as easier to read [35]. Other work explores AI support *around* discharge documents rather than rewriting them. PaniniQA, for instance, frames discharge support as an interactive question-answering and education workflow: it generates questions grounded in discharge instructions and provides answer verification and feedback [13]. Finally, emerging systems are moving beyond one-size-fits-all rewriting (e.g., simplifying medical terminology and patient instructions) toward *personalized* discharge support using retrieval-augmented generation (RAG), where tailoring is driven by patient-specific context [9].

We are seeing rapid momentum toward AI-powered discharge experiences that can be rewritten, searched, and increasingly tailored. However, most prior work treats personalization as a content-generation problem (e.g., rewriting, simplifying, summarizing, or tailoring text). As a result, we still lack evidence about how patients may engage with personalizable discharge summaries in practice.

III. Design Probe: myPHA

To understand how to present AI-generated discharge summaries to patients in portal settings, we iteratively developed myPHA (My Personalized Hospitalization Account). myPHA is a design probe: an intentionally incomplete but concrete prototype that participants could work with during an interview, allowing the artifact to surface expectations, breakdowns, and preferences that are difficult to elicit through conversation alone [36], [37]. In human–computer interaction (HCI) research, design probes are used to make future-facing design possibilities tangible and discussable. myPHA was designed to reveal what patients find useful, confusing, and easy or difficult to navigate when discharge information is delivered digitally.

In designing myPHA, we focused on adults hospitalized with chronic heart failure (HF) because discharge information is central to post-discharge self-management and continuity of care in this population. HF is one of the most prevalent chronic conditions in the U.S. and is among the most expensive conditions treated in U.S. hospitals, with particularly high readmission rates among adults aged 65 and older [38]. Many HF-related readmissions are considered preventable through improved post-discharge care and careful continuity planning [39]. HF also foregrounds a core challenge for patient-facing discharge communication: patients' capacity to engage with care and information can shift over time and across contexts—during hospitalization, in early recovery at home, and later as they resume daily routines or experience new complications. Managing HF requires patients to integrate medication changes, symptom monitoring, lifestyle guidance (e.g., diet and activity), and follow-up plans under these changing conditions. Together, these characteristics make HF a strong case for examining how AI-generated discharge summaries can support post-hospitalization continuity of care across settings (e.g., home, community healthcare, outpatient) and over time.

To characterize patients' discharge information needs and translate them into probe requirements, we conducted a formative pilot with adults hospitalized with HF at the cardiology service of a large academic medical center. Participants were recruited as a convenience sample during their inpatient stay in collaboration with the clinical team, and interviews were scheduled to minimize disruption to clinical care. The pilot consisted of bedside, hour-long semi-structured interviews that were audio-recorded and transcribed; participants were hospitalized for HF-related reasons and spanned a wide range of ages (28–83) and backgrounds. Across interviews, patients described what they try to learn from discharge materials and what becomes difficult to carry forward after leaving the hospital, highlighting needs around understanding the hospitalization course, medication regimens and changes, symptom-response planning, follow-up care, and continuity across multiple hospitalizations. These pilot insights informed the content

and interaction priorities we explored in subsequent myPHA design iterations.

Building on these requirements, we refined myPHA through multiple iterations that combined team-based design activities with formative evaluation. First, we held design meetings with a multidisciplinary project team: physicians and nurse practitioners advised on patient education elements critical for continuity of care, health informaticians advised on how discharge information is represented and accessed across systems, and a cardiologist provided domain-specific input on HF self-management priorities. We used these discussions to translate pilot-derived requirements into concrete design decisions intended to address breakdowns in patients' likely conceptual models. Second, we conducted a heuristic evaluation of an interactive prototype to identify usability issues that could undermine the use of discharge summaries post-hospitalization.

Third, we conducted a formative session with three patient advisors, who completed representative tasks with the prototype and provided post-task and end-of-session feedback. These sessions surfaced additional breakdowns in discoverability and conceptual clarity, including how participants interpreted the purpose of "personalization." This matters because, for patient-facing discharge summaries, personalization is where generative AI meaningfully changes the interaction: it can tailor content and explanations to patients' health literacy and current engagement capacity, which may fluctuate during hospitalization and after discharge—creating an opportunity for AI-generated summaries to remain usable over time. However, if tailoring is not clear to patients or introduces new confusion, these benefits may be lost. We incorporated these insights into the final version of myPHA, described next.

In its final form, myPHA was a portal-like discharge summary design probe with three defining characteristics: low-burden navigation, explicit personalization, and multimodal access (Figure 2). myPHA presented all core functions on the landing page—rather than behind shortcuts or hidden menu elements (e.g., navbars or hamburger menus)—so features were available at a glance and could be vertically scrolled on smaller screens. The probe also made "personalization" explicit through a plain-language explanation of what could be tailored and why, framing AI-generated discharge summaries as adaptable to patients' capacity to engage and health literacy.

To operationalize these tailoring factors within the probe, myPHA included brief self-report measures. Engagement capacity was captured using the Patient Activation Measure (PAM), presented as "participation" with an explanation and sample items such as "I am the person who is responsible for taking care of my health," "I know what each of my prescribed medications do," and "I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself," answered on a Disagree Strongly to Agree Strongly scale (with N/A) and summarized into an activation level from 1 (overwhelmed) to 4 (motivated to participate in self-care) [40]. Health literacy was captured using a three-item questionnaire with Likert-style responses [41], including: "How confident are you filling out forms by yourself?", "How often do you have someone help you read hospital materials?", and "How often do you have problems learning about your medical condition because of difficulty reading hospital materials?" Each question was paired with a brief explanation to support interpretation. The interface used a higher-contrast palette for readability, and myPHA provided an audio version of the generated summary for eyes-free engagement; these audios were manually generated using a natural-voice text-to-speech service. This final version of myPHA served as the design probe used in our task-based inpatient interviews (Figure 2).

IV. User Study

We next used myPHA as a design probe in an inpatient interview study with adults hospitalized with chronic heart failure. The goal of the study was to understand how patients engage with discharge information today, and how that engagement changes when the same information is presented in a portal-like, AI-generated format (i.e., personalized). Through task-based activities with myPHA embedded within semi-structured interviews, we examined what participants found actionable or confusing and how they preferred to consume discharge information (e.g., reading vs. listening).

A. Methods

We conducted a qualitative user study with adults hospitalized with chronic heart failure (CHF) at the University of Illinois Hospital (UI Health). Each session had three parts. First, participants provided demographic information and answered questions about their current use of discharge summaries, including both paper and digital versions (e.g., whether they review discharge instructions after discharge and what they like or dislike about how discharge information is currently provided). Second, sessions followed a think-aloud protocol in which participants verbalized their thoughts while completing a set of predefined tasks with the myPHA design probe. Third, participants took part in a semi-structured interview reflecting on their interaction with myPHA. Interview prompts included how often participants would listen to a summary instead of reading it, whether and how they would want to share discharge information with others, what they liked or disliked about myPHA, and how they understood tailoring controls and outputs in the interface, and whether these would support use.

1) Study Tasks: Participants completed four scenario-based tasks with myPHA (Table I): (1) review a default hospitalization summary, (2) find information (e.g., the meaning of "CHF"), (3) tailor the summary, and (4) listen to the tailored summary. Participants did not review or interact with their own discharge summary during the study to minimize privacy risks and reduce bedside coordination burden associated with retrieving and displaying individual portal documents. Instead, we created a set of 20 de-identified HF discharge summaries from the patient pool of UI Health via the electronic health record (EHR) and presented these summaries in myPHA. All

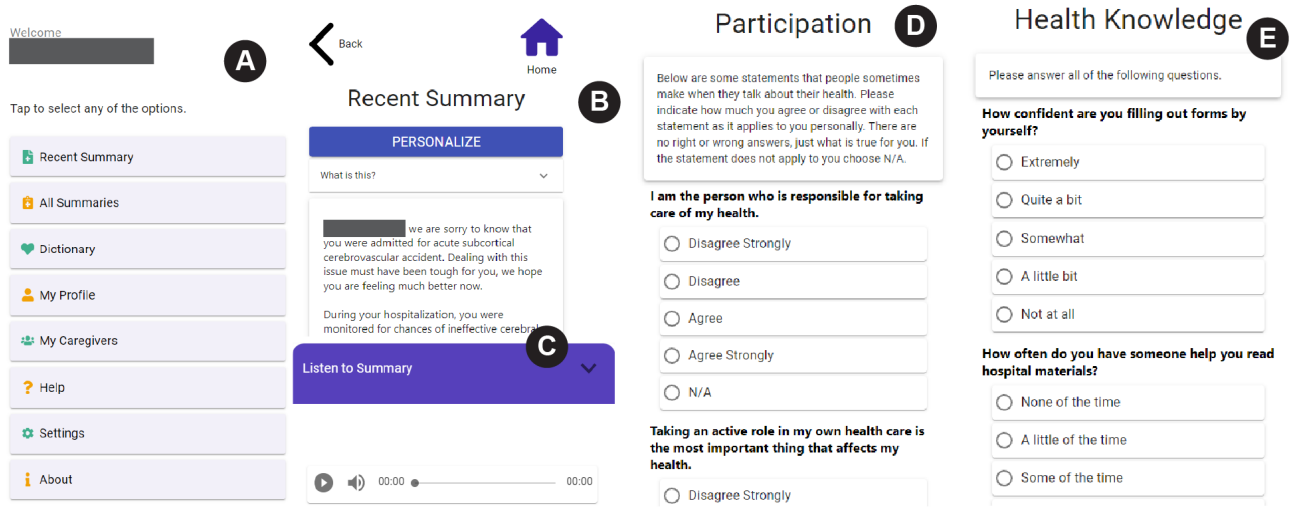

Fig. 2. User interface screens from the myPHA design probe: (A) landing screen, (B) summary page with a personalization option, (C) an audio option, (D) questions assessing patient engagement capacity, and (E) questions assessing health literacy.

project activities were approved by the authors' university-wide institutional review board (IRB).

TABLE I
PARTICIPANTS COMPLETED FOUR TASKS DURING THE STUDY.

Task No.	Task Name	Task Description
1	Review default summary	Imagine that you have been recently discharged from the hospital. Review the hospitalization summary from your last hospitalization.
2	Find health information	Imagine that you do not know what congestive heart failure (CHF) means. Find out what CHF means. Once you find that out, please tell us what it means.
3	Personalize summary	Personalize your most recent hospitalization summary. Once you are done, review the summary.
4	Listen to the summary	Try to listen to your recent hospitalization summary.

To represent an AI-enabled tailoring workflow without evaluating a generative model, myPHA implemented a rule-based AI layer [42], [43]: a set of deterministic heuristics that adjusted how the de-identified summaries were presented based on participants' inputs related to participation (engagement capacity) and health literacy (described in the design probe section). We chose this approach to reduce risks that are difficult to control in a bedside study—including hallucinations, variability across prompts, and limited transparency into why a model produces specific wording—while keeping the underlying summary content stable. This enabled us to systematically vary presentation and explanation in ways that emulate what patients might request from a generative AI assistant (e.g., "make this easier to understand" or "summarize key actions without overwhelming me"). Accordingly, our objective was to evaluate patients' interaction with a portal-like interface for tailored, AI-enabled discharge information—what they found actionable or confusing, how they preferred to consume it (e.g., reading vs. listening), and what might support revisiting and sharing—rather than the clinical correctness or performance of a summary-generation engine. Future implementations may not require explicit questionnaire inputs; tailoring factors could be inferred from other patient-provided information or portal context.

2) Recruitment and procedure: Patients with HF were recruited in collaboration with clinical collaborators and social workers using nurse handoff data, and potential participants were screened for their current hospitalized condition (i.e., ability to take part in the study). One HCI researcher (first author) and one health informatics researcher (second author) conducted the sessions at the hospital. The study was approved by the institutional IRB, and written informed consent was obtained from all participants. Sessions were video recorded using a mobile phone camera positioned to capture participants' hands and gestures, and the myPHA interaction was screen-recorded using the device's native screen-record feature. To reduce setup burden and variability, all sessions were conducted on the same study device (iPhone XS Max). No time limit was imposed for task completion; sessions lasted approximately 45 minutes. Participants received a $20 gift card.

3) Data collection and analysis: For each participant, we collected (1) a video recording of the interaction, (2) an audio recording of the interview, and (3) an interaction log capturing clicks and scrolling gestures. We analyzed the audiovisual data using *reflexive thematic analysis* [44] to develop an interpretive account of how participants engaged with discharge information and with myPHA as an AI-enabled, portal-like interface. The first and second authors independently conducted an initial round of open coding in ATLAS.ti, iteratively refined the codebook through analytic memoing and discussion, and met bi-weekly with the broader project team to review emerging interpretations, resolve differences through dialogue, and ensure codes remained grounded in the

TABLE II
PARTICIPANT CHARACTERISTICS.

Patient	Age	Gender	First hospitalization
P1	78	F	2016
P2	56	M	2 years
P3	41	M	5 years
P4	54	F	June 2017
P5	60	M	20 years
P6	57	M	2019
P7	57	M	2004
P8	69	F	1990
P9	57	F	6 years
P10	48	M	just found out
P11	44	M	two months
P12	27	M	8 years
P13	62	F	1969
P14	34	M	since I was 19
P15	63	F	first time for HF
P16	85	F	in my 40s
P17	53	M	2016
P18	62	F	in my 20s
P19	34	F	a week ago
P20	47	M	7 years ago

data. Initial codes captured patterns related to current non-use of discharge summaries, preferences for reading versus listening, sensemaking of tailoring controls and outputs in the interface, and anticipated sharing with caregivers. We then organized and refined codes into candidate themes, revisited the dataset to check coherence and coverage, and finalized higher-level themes that informed our patient-centered design recommendations for AI-generated discharge summaries in portal settings.

B. Results

1) Participants: We recruited 20 adults hospitalized with chronic heart failure who owned a touch-enabled smartphone. Participants included 9 women, with a median age of 56.5. All participants reported using a smartphone more than twice per day, although a small subset described primarily using their phone for basic communication (calling or texting). Most participants had owned a smartphone for more than five years; a few reported more recent adoption. In addition, 17 participants reported at least one prior hospitalization. In the task-based portion of the study, Tasks 1–4 were successfully completed by 19, 17, 18, and 19 participants, respectively. Table II reports age, gender, and self-reported timing of first HF-related hospitalization.

2) Limited engagement with discharge summaries: Many participants reported rarely using discharge summaries, and some were unsure whether they had received a discharge summary at all. Thirteen participants reported typically receiving paper discharge materials at discharge, while only two reported having viewed the digital discharge summary (e.g., via *myChart*) after leaving the hospital. Some participants did not remember receiving anything they would call a discharge summary and described the paperwork as overwhelming.

> "no summary. Some paperwork and the other papers .... were too much and so many pages." (P11)

> "It was a wrongful discharge, so I literally received nothing. It was nothing they gave it to me ...unbelievable." (P12)

Most participants reported that they did not review discharge summaries frequently ("read it couple years ago" –P9) or repeatedly. When they did return to them, it was typically driven by an immediate need—for example, to locate a specific detail or to prepare for a follow-up visit.

> "a month ago. wanted to find what did they say to do ..." (P4)

> "When I leave the hospital I read them at home and then I might read them again sometimes." (P2)

When discharge information *was* useful, participants described a consistent set of content they looked for: medication lists, diet guidance, follow-up visit instructions, and care instructions. They emphasized that these details should be easy to find and straightforward to interpret.

> "got the paper and liked the paper and knowing about medicine. they got the best staff and tried to educate you; they talk about chances and being upfront." (P2)

> "I'm used to it. Usually, medication list and how to use it. And something if you need care instructions like wash something clean etc. I used to see these discharge summaries, so I know what I'm looking for ... usually has scheduled appointments, the ones you should schedule, and the number you should call." (P13)

At the same time, participants highlighted a tension between wanting discharge information to be concise and needing it to be comprehensive enough to capture what happened during their hospitalization (e.g., procedures and treatments). Several participants described difficulty extracting a clear, understandable account of their hospital course from current summaries.

> "[...] give me a summary of what it is which is understandable ...I don't want to read 4 5 pages with front and back" (P11)

> "This [pointing to his previous paper summary] doesn't say anything that happened to me in the hospital, every time I get this usually I want to know here that you were treated like this there is nothing here that I can find" (P12)

Overall, these accounts suggest that current discharge summaries are often treated as discharge paperwork rather than a resource patients can easily revisit. Participants' comments point to the need for patient-facing discharge information that clearly explains what happened during the hospital stay and what to do next, without being hard to read or hard to find.

3) Portal-based discharge summary needs: Many participants described a clear set of needs for discharge summaries delivered through patient portals. When asked what they would want to find quickly, they consistently pointed to practical, "use-right-away" information: an up-to-date medication list

and instructions for how to take medications, diet and activity guidance, follow-up appointments (including what to schedule), and clear care instructions for home. Participants also wanted a simple way to find who to contact with questions and what to do if symptoms worsen. As P13 explained, they look for "medication list and how to use it… scheduled appointments ... and the number you should call."

Beyond specific content, participants emphasized how portal-based summaries should be organized to support fast access and repeat use. They wanted a brief, understandable overview that avoids lengthy, densely formatted pages, while still capturing what happened during the hospitalization—especially the procedures and treatments that explain why their regimen changed. In practice, this meant participants asked for summaries that are both concise and complete: short enough to read without feeling overwhelmed, but detailed enough to answer "what did they do to me?" and "what changed?" As one participant noted, they wanted "a summary ... which is understandable," without having to "read 4–5 pages," while another described frustration that their paperwork did not clearly describe what happened during the stay. Together, these comments suggest that portal-based discharge summaries should prioritize clarity and scanability, while making the hospital course and concrete next steps easy to locate and revisit when needed.

4) Making sense of tailored summaries: Many participants were interested in the idea of a tailored discharge summary, but their interactions with myPHA showed that tailoring must be straightforward to interpret and use. During the tasks, participants sometimes struggled to predict what would change when they selected the tailoring option or what the system was doing on their behalf. In these moments, tailoring created extra work: participants had to infer what had been modified and why, rather than immediately benefiting from the tailored view. This difficulty was closely tied to how participants understood the concept of "personalization" in this context.

Several participants conflated tailoring with customization—expecting that selecting "personalize" would allow them to directly edit the summary or "make it my own" (P12), rather than receiving a system-generated version adapted to their needs. Others described personalization more broadly as making information "more about me" (P4) or "only to me" (P13). When asked for examples, participants referenced familiar forms of personalization such as product recommendations ("Walmart, Amazon ... personalize things for me," P7) as well as non-digital services ("home health care ... personalize everything for me like what I need at home or nutrition," P4). These accounts suggest that AI-enabled tailoring controls in patient portals require clear framing so patients understand whether the system is editing for them, letting them edit, or reorganizing and explaining information on their behalf.

When participants did perceive the effects of tailoring, they described it as most valuable when it made the summary easier to act on. Participants wanted tailoring to adjust how much detail they see at once, simplify medical language, and highlight information they return to most often (e.g., medications and follow-up plans). In other words, tailoring mattered most when it changed the *presentation* of discharge information—making it easier to scan, understand, and revisit—rather than solely changing the underlying content. These findings suggest that patient-facing, AI-enabled discharge summaries should treat tailoring as an interaction design problem: the system must make tailoring understandable while ensuring the tailored view reduces effort for patients.

5) Multimodal consumption: Participants frequently described audio as a valuable way to consume discharge information in portal settings. Fourteen out of twenty participants reported preferring listening to the discharge summary on a smartphone rather than reading it. They framed listening as reducing the effort of engaging with dense text, especially when reading is inconvenient or difficult.

> "Listening is great for a lot of people cause they need glasses but listen to it that's perfect." (P7)

Participants also emphasized that audio could be faster and easier to fit into daily routines.

> "listening it is faster, and also I can still listen to it while I'm moving around." (P10)

Audio was also described as supporting repeat review. Even participants who did not typically listen to health information said they could imagine using audio to remind themselves of key instructions after discharge.

> "I don't listen that's why I'm coming back but if I had to listen to remind myself that's a great idea you came with it" (P7)

At the same time, participants did not describe audio as a replacement for text. Several wanted both modalities available so they could listen for an overview while still being able to reference the printed details when needed.

> "It's nice to listen and still see the print [...] I like using audio.. it's faster and easier, but I also want to see what is actually printed." (P3)

One boundary case came from the youngest participant (27 years old), who preferred reading over listening but still viewed audio as useful in the hospitalization and recovery context.

> "I don't think that I ever listen to anything ... I'd rather read ... I honestly think it's [listening] a great addition just for the older folk who maybe don't have their glasses or somebody just got out of surgery and on anesthesia and can't read ... I've never seen an option like that or I haven't looked, but I think it's cool." (P12)

Overall, these accounts suggest that portal-based, AI-enabled discharge summaries should support both reading and listening, and make it easy to switch between modalities so patients can choose the format that best fits their capacity and situation at a given moment.

6) Sharing and handoff: Participants described discharge information as something they often need to communicate beyond themselves, particularly when coordinating care after

discharge. Most participants (12/20) expressed a preference for sharing their discharge summaries with family members and informal caregivers, framing sharing as a way to make care needs visible and to coordinate support.

> "know what I actually need help at" (P7)
>
> "In terms of my health with my girlfriend, my mother, father, brother sister, I would sign my consent for them to read everything." (P12)

Participants also described sharing as a practical response to questions from others involved in their care, using the summary to communicate what they are dealing with and what actions are needed.

> "probably if they ask me question I will show them here is my summary so they know what I'm dealing with" (P20)

These accounts position the discharge summary as both a personal reference and a handoff artifact. Participants' comments suggest that sharing is most valuable when it is low-effort and supports real-world coordination, such as helping with scheduling follow-up appointments, tracking medications, or recognizing when symptoms warrant medical attention. When sharing is cumbersome—for example, requiring navigation through long documents or relying on patients to explain medical terms—the burden shifts back to patients at a time when their capacity to engage may be limited. Overall, these findings highlight sharing as a core requirement for patient-facing, portal-based discharge summaries.

V. Discussion

Our findings show that patients' engagement with discharge summaries is limited even when summaries are available digitally, largely because current materials are difficult to navigate, difficult to understand (consistent with prior reports [3], [21]), and hard to revisit (e.g., misplaced paper copies). When patients do use discharge information, they prioritize concrete, actionable content (e.g., medications, follow-up, diet/activity, and what to do when symptoms worsen) and want summaries that balance conciseness with a clear account of what happened during the hospitalization.

AI-enabled tailoring introduces additional interaction challenges: participants often struggled to anticipate what tailoring would change and needed clearer framing of what was being adapted and why. Finally, participants valued multimodal access—most preferred listening over reading on a smartphone—and many wanted low-effort ways to share discharge information with family and informal caregivers.

A. Design Recommendations

Currently, discharge summaries are typically presented as a single, standalone document that patients can view digitally or print (Figure 1). This format makes it difficult to use discharge information in smaller, practical ways—for example, quickly returning to key instructions, bookmarking or saving specific sections, sharing only what a caregiver needs, or making sense of changes across multiple hospitalizations. While patients can sometimes accomplish these tasks by downloading a copy and using third-party tools, doing so adds steps and complexity, especially for those with lower digital proficiency or limited health capacity. We therefore recommend **presenting discharge information in portals as structured sections with corresponding quick actions.** In our study, participants wanted multiple "views" of the same discharge information—such as a brief overview and a more detailed view, an action-oriented view that highlights next steps, and a shareable snapshot designed for caregiver handoff.

Such a sectional presentation also **creates a natural scaffold for AI-enabled tailoring.** Different sections can be parameterized for different recipients and situations—for example, emphasizing clear instructions for an older adult immediately after hospitalization, providing more clinical detail for a caregiver who is a nurse, offering simplified guidance for an older adult spouse, or generating a handoff-oriented view for a community health worker.

Current patient portals typically support sharing through broad mechanisms such as proxy access, but offer limited support for sharing discharge information in the targeted ways patients described. Patients can download and forward a PDF, yet this all-or-nothing workflow adds burden: patients must find the right content, decide what to send, and explain it to others. In our study, participants often wanted to share discharge information with family caregivers, but preferred sharing only relevant sections (e.g., medications, follow-up, warning signs, contact information) rather than the entire document. We therefore recommend designing discharge summaries for shared use: **provide a caregiver-friendly, shareable view that can be exported with minimal effort** (e.g., a "share snapshot" button for selected sections), and allow patients to save shared versions within the portal (e.g., in the messaging area) for easy retrieval and re-sending.

We also recommend **using AI to reduce the navigational burden of sectioned discharge summaries**—for example, by reordering sections based on patient priorities, clinical urgency, or provider recommendations. This is especially important because patient portals are feature-rich and optimized for breadth rather than specific user's needs. For instance, prior work shows that older adults experience greater difficulty navigating complex interfaces than younger users [45]–[49], often due to difficulty recognizing navigation structures, reluctance to explore unfamiliar menus, and confusion between similar icons and buttons [45], [50], [51]. These challenges are amplified on smartphones, where users may overlook tab menus or scrollable tab bars and avoid side drawers in favor of staying within visible content [45], [50], [51]. Consistent with this, our participants returned to discharge information to answer specific questions, making scroll-heavy layouts and buried functions costly to use. We therefore **recommend a scannable structure that surfaces high-priority content and core actions up front** (e.g., medications, follow-up, warning signs, and who to contact), supported by lightweight shortcuts such as in-page anchors, a persistent "Next steps" area, and clearly labeled action callouts.

We also recommend **supporting multimodal access to discharge information—particularly seamless switching between reading and listening.** Many participants preferred listening to the summary on a smartphone, describing audio as faster, less effortful, and easier to use when tired, recovering, or without glasses. At the same time, participants did not view audio as a replacement for text; they wanted to listen for an overview while still being able to reference specific details (e.g., medication instructions or follow-up plans). We therefore recommend designing discharge summaries with integrated text-and-audio views, including a prominent "listen" option within each section, quick toggles between modalities, and replayable highlights that emphasize key actions and warning signs. **Making audio available at the section level** (rather than only as a single full-document narration) can further reduce burden by letting patients listen to what they need in the moment without scrolling or searching.

Finally, we recommend **making AI-enabled tailoring transparent to patients** by clearly signaling what is being adapted, why, and based on what inputs. Many emerging personalization efforts implicitly rely on signals available in portals—such as prior interactions, messages, or usage patterns—to tailor content [9]. However, portal use is not always a clean proxy for an individual patient's needs: caregivers may share credentials or co-use the account, and a patient's engagement may fluctuate around hospitalization and recovery. To avoid "invisible" personalization that feels confusing or arbitrary, portals should make tailoring transparent and user-facing. Concretely, **interfaces should preview how a tailored view differs from the default** (e.g., what was simplified, shortened, or highlighted), provide a brief rationale (e.g., "showing key actions first"), and indicate which inputs informed tailoring (e.g., discharge day, stated preferences, or a short questionnaire) without requiring patients to infer the system's logic. Offering explicit audience views—such as "for me," "for my caregiver," and "for my provider"—can further support shared use while preserving clarity about who the tailored version is intended to help.

B. Limitations

Findings reflect a single-site study using a smartphone-based prototype; results may differ after discharge or on personal devices. Because myPHA emulated AI tailoring with rule-based logic to ensure bedside safety and content stability, this study evaluates interaction design and patient preferences rather than the performance, accuracy, or safety of specific generative AI models. Additionally, the sample was limited to a single chronic condition (heart failure) in an inpatient setting. Future work should examine fully generative systems through longitudinal, multi-site deployments in real-world environments.

VI. Conclusion

The transition to AI-generated discharge summaries must be more than a technical upgrade in documentation; it must be a fundamental shift in patient agency. Our findings reveal that while patients currently ignore static summaries, they are eager for multimodal, shareable tools that fit into their daily lives. For AI to truly bridge the gap between hospital and home, it must move beyond simply "summarizing the past" and begin orchestrating the future. The success of clinical AI will not be measured solely by the accuracy of its prose but by its ability to turn a passive recipient into an empowered participant in their own recovery.

Acknowledgments

Research reported in this publication was supported by the National Cancer Institute of the National Institutes of Health under award number R01CA225446.

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