

Development of a health information system to promote emergency care pathways: A participatory design study

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Abstract

Objective: The successful development and implementation of sustainable healthcare technologies require an understanding of the clinical setting and its potential challenges from a user perspective. Previous studies have uncovered a gap between what emergency departments deliver and the needs and preferences of patients and family members. This study investigated whether a user-driven approach and participatory design could provide a technical solution to bridge the identified gap.

Methods: We conducted four workshops, and five one-to-one workshops with patients, family members, healthcare professionals, and information technology specialists to codesign a prototype. Revisions of the prototype were made until an acceptable solution was agreed upon and tested by the participants. The data were analyzed following iterative processes (plan → act → observe → reflect).

Results: The participants emphasized the importance of a person-centered approach focusing on improved information. An already implemented system for clinicians' use only was redesigned into a unique patient module that provides a process line displaying continually updated informative features, including (1) person-centered activities, (2) general information videos, (3) a notepad, (4) estimated waiting time, and (5) the nurse and physician responsible for care and treatment.

Conclusion: Participatory design is a usable approach to designing an information system for use in the emergency department. The process yielded insight into the complexity of translating ideas into technologies that can actually be implemented in clinical practice, and the user perspectives revealed the key to identifying these complex aspects. The iterations with the participants enabled us to redesign an existing technology.

Keywords

Emergency department, information system, qualitative research, patients, family members, healthcare professionals, participatory research, e-health

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Introduction

Research on the design and development of health technologies has been conducted for decades to promote a holistic approach to sustainable healthcare.^{1,2} Currently, health technologies are found in various designs and used for diverse purposes, including self-care support,^{3,4} organizational dashboards for performance status,⁵ robots for rehabilitation,⁶ and self-monitoring.^{7–9} However, implementing health technologies in clinical practice is difficult and not easily translated into sustained practice.^{10–12} Implementation challenges are often caused or/and affected by organizational perspectives, workload, resistance to change, and, most importantly, unsustainability of the health technology from a user perspective.¹¹ Therefore, the successful development and implementation of sustainable technologies within healthcare require an understanding of (1) the clinical setting and (2) its potential challenges from a user perspective.^{13,14}

The current research team recently conducted a study on the needs and preferences of patients and family members having a brief (<24 hours) emergency department (ED) stay.¹⁵ The main findings identified (1) a need for improved opportunities to acquire information continually during the hospital stay, (2) a need for a person-centered summary of discharge information, and (3) improved inclusion of patients' families.¹⁵ In continuation of the study, we identified a gap from an organizational perspective¹⁶ and concluded that healthcare professionals (HCPs) are aware that ED patients and their families need to have a relationship of trust with HCPs to feel reassurance. This relationship begins with prompt assessment and ongoing person-centered communication.¹⁶ However, the busy environment in EDs fragments and interrupts encounters, providing little time to build a relationship of trust between HCPs and the patient and family.^{15–19} The end result is impersonal patient care and, upon discharge from the ED, inadequate information on self-management at home.^{20–22} Suggestions for improved information could be realized in the form of a technical solution to provide timely information while the patient is in the ED.^{15,16,23} The unique characteristics of the ED population are acute symptom occurrence, a short stay, and quick diagnosis, and most of the patient's treatment is completed directly in the ED or through out-patient follow-up with no further interaction with the ED.²⁴

Participatory design (PD) is a research methodology that promotes the participation of users of the research field in the process of developing a health technical solution.²⁵ PD aligns research with users' needs through close collaboration with users in the process of investigating needs and developing a solution to address the identified needs.^{13,26} Therefore, we chose the PD methodology to embrace the benefits of user involvement in designing and developing a health technical solution to meet the unmet needs described by ED patients and their family members.^{15,16}

To our knowledge, very few studies have been conducted internationally that involved patients and families in developing health technological solutions to promote ED patient pathways.²⁷

Objective

The study aimed to design and develop a health technological solution based on patients', family members', and HCPs' needs. This article provides a detailed description of the design and development process involving patients, family members, HCPs, engineers, information technology (IT) designers, and researchers in creating a personalized information system in the ED.

Method

Study design

The overall study was framed by PD and conducted in three phases^{25,28} as illustrated in Figure 1, with the overall objective being to identify the needs for ED care and develop a solution to improve the outcomes of patients discharged within 24 hours of admission.²⁸ This article reports on the second phase, *Design and development* (see Figure 1). All the phases were conducted in iterative cycles comprising the process steps of *plan*, *act*, *observe*, and *reflect*.²⁹ In this way, a plan is continually revised based on the reflections of participants during the process. This iterative nature emphasizes one of the key elements of PD, which is mutual learning among the participants.³⁰ To succeed in fostering mutual learning, the designers must acknowledge users' needs and suggestions regarding the form and content of the prototype. Likewise, the designers provide technological knowledge and possibilities in the design process from their field of expertise.¹³

Setting and overview of the workshops

The study was conducted as a collaboration between two EDs in the Region of Southern Denmark: the ED at Odense University Hospital and the ED at Hospital Lillebaelt. The workshops and testing for creating a final, functional prototype were conducted from June 2021 through May 2022. Four workshops with HCPs were conducted at the hospitals (see Figure 2).

- Workshop 1 focused on generating ideas based on the needs assessment of phase 1 as illustrated in Figures 3 and 4 and described in depth elsewhere.^{15,16}
- Workshop 2 transformed the ideas into a specific solution concept.
- Workshop 3 supported HCPs in developing an initial prototype and its content based on feedback from patients and family members.

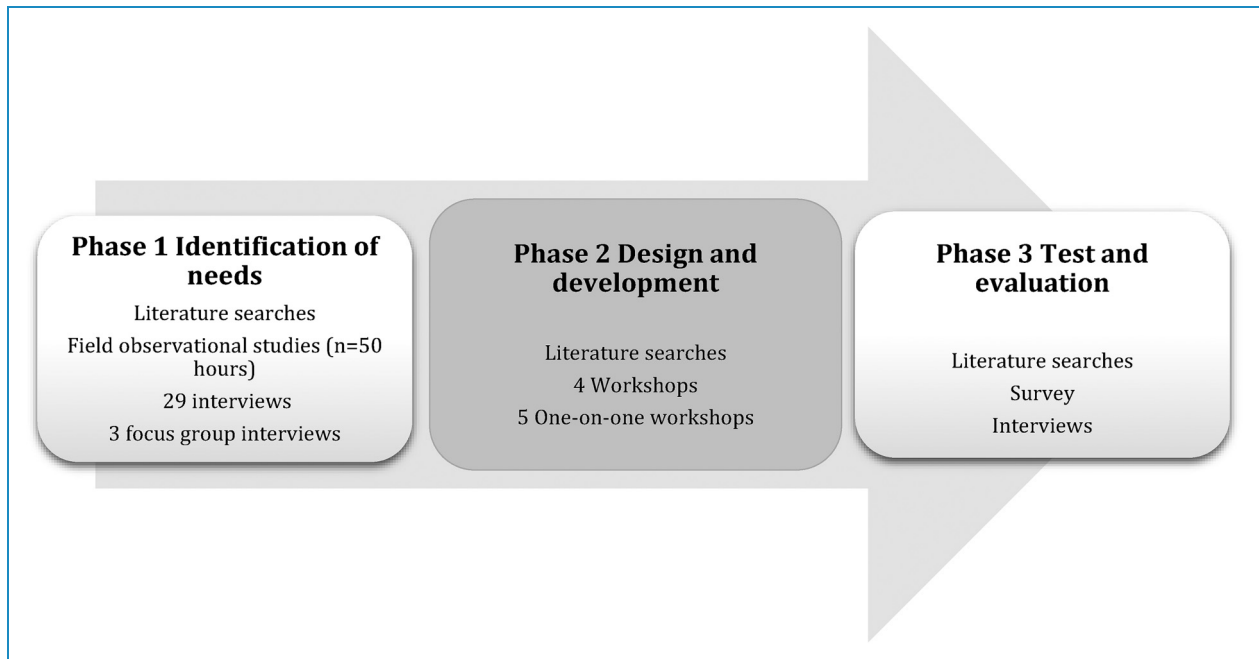


Figure 1. The three phases of the overall project highlighting phase 2 (reported in this article).

- Workshop 4 was a laboratory test in an environment resembling clinical practice; final adjustments were made toward creating a functional prototype ready for testing in the clinical setting.

Furthermore, one-to-one workshops with patients and family members were conducted between workshops 2 and 3 and workshops 3 and 4. The workshops were conducted using telephone interviews as well as field observations and short, open-ended interviews in the ED.

Recruitment

Recruitment of health and technical professionals. HCPs were purposively sampled on the basis of possessing the competencies to work independently in the ED. They were invited via their work email. Technical professionals from the hospital were also purposively invited by email on the basis of expertise in specific areas identified as targets of interest.

Recruitment of patients and family members. At the time of the workshops, COVID-19 restrictions prevented the research group from inviting patients and family members to join the workshops physically. Therefore, we conducted one-to-one workshops with patients and family members during their admission in the ED between workshops 2 and 3 and workshops 3 and 4. The patients and family members admitted in the ED had no prior connection to the study. Their comments and suggestions for changes or improvement of the technology were included in the

following group workshop where no patients and family members were physically present. This method of enabling patients and family members' involvement has been successful in other research projects.^{3,31} (For further details, please see the supplemental material and Table 1.)

Data collection and analysis

A clear aim and various activities for each workshop were recorded in a script prior to each workshop. Parts of the script were illustrated by a graphic artist before each workshop, for example, the agenda of the day and various assignments for the participants. The graphic artist provided illustrations for each workshop that summarized the results of the previous workshop.

Generating ideas toward a solution concept (workshops 1 and 2). Workshops 1 and 2 were arranged as 3 hour sessions with the specific aim of generating ideas for a solution concept. The findings from phase 1,^{15,16} shown in Figures 3 and 4, informed the processes in the initial workshops.

The workshops were initiated with graphical illustrations of the results of phase 1.¹⁵ As no patients were present, personas³² were used as a method to enable their voices to be expressed in the workshop. Personas were informed by data generated in phase 1, and illustrated in the form of poster with drawings and patient quotes. In workshop 1, the participants were asked to have an open mind and adopt the mindset of "the sky's the limit" whereas, in workshop 2, they were asked to generate ideas limited to those informing

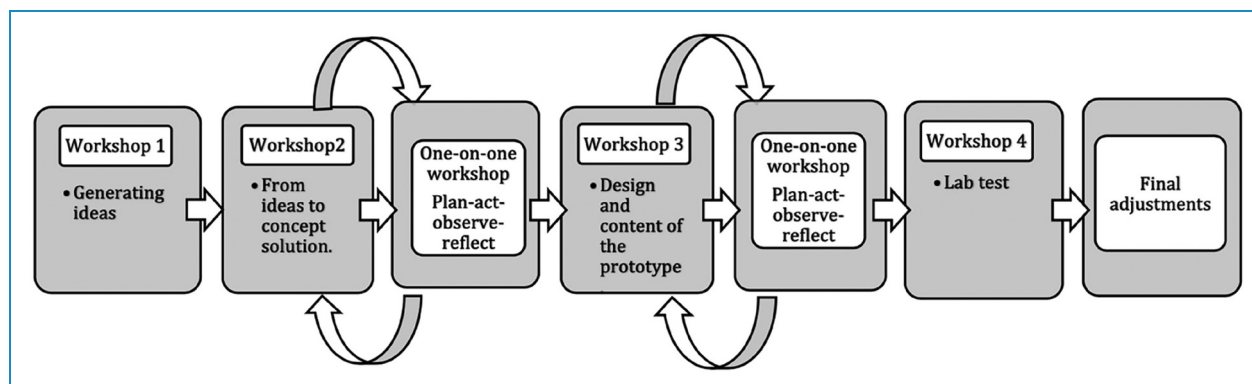


Figure 2. Overview of activities in phase 2 showing the process and plan-act-observation-reflect iterations during the workshops.

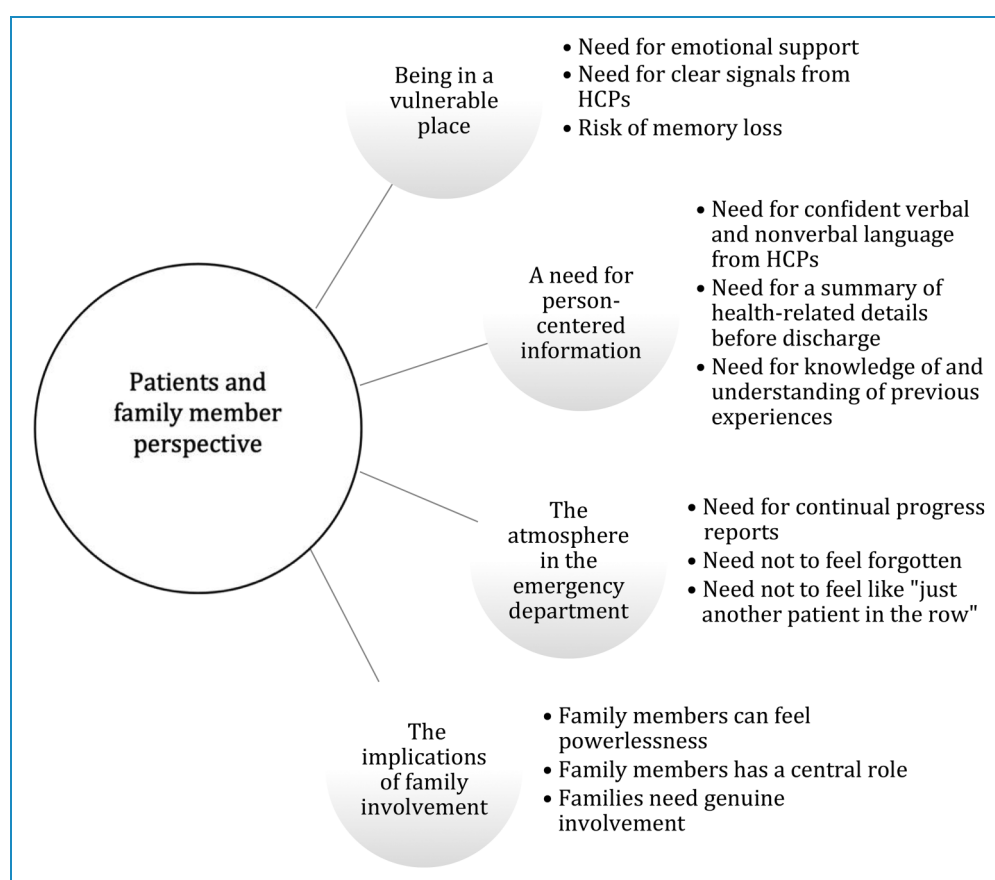


Figure 3. Needs and preferences emerging from phase 1 from a patient and family member perspective. HCP: healthcare professional.

a solution concept based on the ideas voted for at the end of workshop 1. Both workshops were audio-recorded and documented in notes and photos. (For a detailed description of the personas and activities in the two workshops, please see the supplemental material.)

One-to-one workshops. Between workshops 2 to 3 and 3 to 4, the abovementioned ideas generated by the HCPs were

discussed with patients and family members using illustrations, quotes, and pictures. The ideas were discussed with and commented on by patients and family members while they were admitted to the ED and in follow-up telephone interviews 2 to 4 days after discharge. The participants' characteristics are shown in Table 1. The telephone interviews were conducted using an interview guide and lasted for 30 to 60 min.

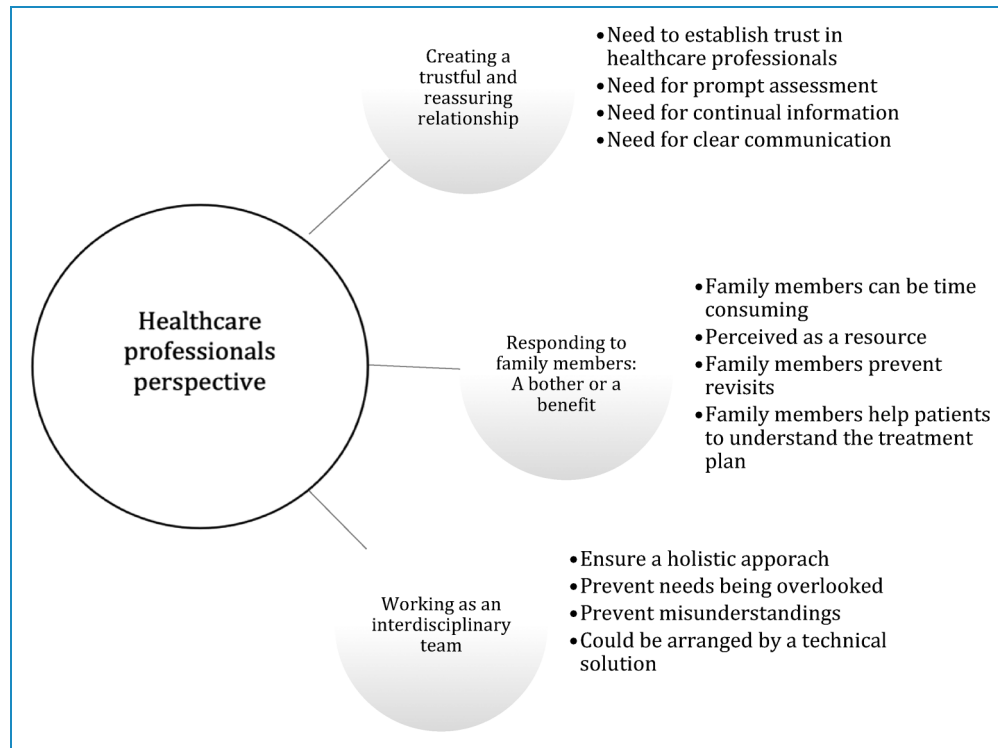


Figure 4. Needs and preferences emerging from phase 1 from the healthcare professionals' perspective.

Mock-up workshops (workshops 3 and 4). The research group consulted relevant IT specialists at the hospital after the final suggestions for a solution concept were agreed upon at workshop 2. In collaboration with the IT specialists, a low-fidelity prototype was created. The prototype was an information system intended to provide information on the activities during a patient's stay in the ED as a personal process line. Both mock-up workshops aimed to elaborate and further detail the prototype's content. Finally, we conducted a workshop with a technological focus to test the functionality of the prototype in a laboratory setting resembling clinical practice in the ED. Details on the process of workshops 3 and 4 are found in the supplemental material.

Data analysis. For each workshop, the combined data comprised recorded sound files, photographs, illustrations, and notes written by the participants. Immediately after each workshop, selected parts of the sound files were transcribed.

To systemize the transcripts systematic text condensation inspired by Malterud³³ was used. The strategy consist of four steps: (1) total impression—from chaos to themes; all transcripts were read several times to get a total impression looking for preliminary themes associated with the research question; (2) identifying and sorting meaning units—from themes to codes, transcripts were searched line by line for meaning units, which were marked into codes; (3) condensation—from code to meaning, all meaning units were re-read

to reduce the content into condensates; (4) synthesizing—from condensation to descriptions and concepts, lastly, the meaning of the condensates was synthesized by generalizing descriptions and concepts. The process was supported by Microsoft Word.³⁴ Photographs, illustrations, and notes were grouped according to their content. After each workshop CØ performed the initial analysis. The themes derived from the text condensation and content grouping were discussed with co-authors (KDB and CMJ) after each workshop. The analysis team discussed their reflections, providing reflexivity in the data analysis. To ensure transparency and trustworthiness member checking was used in each workshop to confirm the results and thereby provide validity of the data analysis.³⁵

Being inspired by the PD approach, we followed the four steps of *plan*, *act*, *observe*, and *reflect* according to the methodology of iterative processes.³⁶ This ongoing process helped plan the next workshop according to the results and experiences of the just completed workshop, regardless of whether it was a one-to-one or group workshop.

The "Consolidated Criteria for Reporting Qualitative Studies" was followed.³⁷

Results

Description of participants

In total, the workshops included physicians (n=4), nurses (n=8), software engineers (n=2), IT specialists (n=3),

Table 1. Overview of participants' characteristics and participation in workshops.

Participant characteristics	Participation in workshop number					
	1	2	One-on- one	3	One-on-one	4
Patient, female, 39 years			X			
Patient, female, 54 years			X			
Patient, female, 49 years			X			
Patient, male, 73 years					X	
Patient, female, 63 years					X	
Patient, female, 19 years						X
Patient, male, 81 years						X
Patient, female, 50 years						X
Family member, daughter, 38 years			X			
Family member, daughter, 52 years			X			
Family member, mother, 55 years						X
Nurse, female, ED, Kolding	X	X				
Clinical nurse specialist, female, ED, Kolding	X	X		X		
Nurse, female, ED, Odense	X	X				
Nurse, female, ED, Odense	X	X		X		
Clinical nurse specialist, female, ED, Odense	X	X				
Clinical nurse specialist, female, ED, Odense	X	X		X		
Clinical nurse specialist, female, ED, Odense		X		X		
Nurse leader, female, ED, Odense		X				
Physician, male, ED, Odense	X					
Physician, male, ED, Odense	X					
Physician, female, ED, Odense	X					
Physician, male, ED, Odense				X		
Graphic artist	X	X		X		
Core searchers	X	X		X		X
Software engineer		X				

(continued)

Table 1. Continued.

Participant characteristics	Participation in workshop number					
	1	2	One-on-one	3	One-on-one	4
Digital engineer		X				
IT specialist				X		X

ED, emergency department; IT, information technology.

a graphic artist (n = 1), and researchers (n = 3). The one-on-one workshops included patients (n = 8) and family members (n = 3).

From idea to final design

Below, parts of the content from across the complete dataset are presented and complemented with pictures and illustrative quotations.

Results of workshops 1 and 2

The two initial workshops explored the findings of phase 1^{15,16} as shown in Figures 3 and 4. As mentioned, treatment in the ED created a need for continual information for the patients. The participants reflected on various ideas to meet this information need. Among the suggestions were robotics, generic informational videos, reorganized workflows with improved multidisciplinary teamwork, and interactive communication systems in the ED.

Maybe we could rethink how we work together? Could we design a workflow where we are better aligned with what information the patient is already given? In that way, we could minimize discrepancy in the given information and ensure that all patients were properly informed at time of discharge. (Nurse)

Another finding from phase 1 was that patients expressed having difficulty in remembering the information provided, as they found themselves temporarily cognitively impaired, describing themselves as being in a “shock-like” state of mind.¹⁵ In support of this need, a nurse elaborated:

When you are acutely ill, you need to have information repeated many times. But we meet the patients for such a short period of time, I am not sure we are able to fulfill that need. Maybe technology can help us repeat information. (Nurse)

At the end of workshop 1, the participants voted for the two most important areas to continue with: (1) person-

centered information to revisit after discharge and (2) a system to provide person-centered information regarding activities during the stay in the ED (Figure 5).

In workshop 2, the participants continued working on the design and development of a new way of providing information in a solution concept. They suggested an interactive process line showing the patients’ and family members’ specific activities.

If the patients could follow their trajectory in the ED in terms of a process line, I think we would be able to reduce many questions from both the patients and the family members. (Nurse)

The workshop participants discussed their reflections on General Data Protection Regulation, safety issues, and the ability to correspond with existing systems and dissemination methods.

We have to be aware of the resources it would take to introduce a new system but also have an awareness of how we can avoid patient information being stored in more than one system, as it affects patient safety negatively. (Physician)

In an extension of workshop 2, patients and family members commented on the idea of an interactive process line. The patients endorsed a process line that would enable them to follow their trajectory in the ED and suggested that information be provided in the form of videos. A patient stated:

I am not able to concentrate or absorb information in writing in the ED. My mind is stressed; maybe I am in pain or having other concerns. Information in sound clips or videos would be great. (Patient)

The family members commented on the information system and pointed out that it should resemble a process line visual in the hospital treatment room and not an application. In this way, they could review completed and upcoming activities.

It would help me. My mother cannot remember everything. And she is tired. I am not sure she remembers what the plan

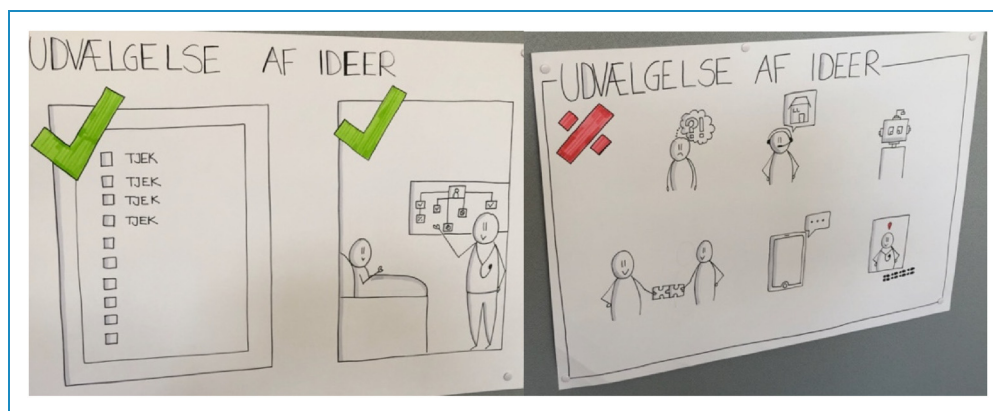


Figure 5. Illustration of the selected ideas agreed upon in workshop 1.

is. A process line would provide me the information without disturbing the HCPs. Then, I would feel more confident and able to help my mother. (Daughter)

A plan-act-observe-reflect iteration was made, and the insights from the patients and family members were merged into the results of workshops 1 and 2.

Results of workshop 3

Between workshops 2 and 3, IT specialists provided knowledge on the possibilities of (1) an interactive process line, (2) providing information in the form of videos, and (3) an electronic discharge letter. No existing system was found capable of providing all three features. As the Region of Southern Denmark had implemented a new electronic patient record system when this study was conducted, we were not able to integrate an electronic discharge letter, as no large changes to the system were allowed in the first 12 months of its implementation.

In workshop 3, the participants elaborated on the content in the informational videos using storyboards. From the initial one-to-one workshops, nine specific headlines for the videos were suggested by the patients: *Your ED stay*, *Discharge*, *If you feel pain*, *Waiting time*, *Blood samples*, *X-rays and scans*, *Food and drinks*, *Family members*, and *Parking*. The participants argued that the videos had to be short, illustrative, and provided in plain language.

We could tell the patients lots of information, but there is a need-to-know and a nice-to-know—I think we should put an effort into finding the balance. (Physician)

In the second part of the workshop, the participants discussed the content of the technology for providing the process line on activities. The HCPs already used a clinical logistics system, Cetrea, as a clinical tool to visualize and maintain an overview of various tasks and activities for each patient, for example, booking an X-ray examination. It

was suggested that the same system could be further developed to display content for a “patient module.” Therefore, the participants worked on the design and content of the process line for providing an overview of completed and planned activities in the ED and for displaying the informational videos for patients in the hospital room. The content was visualized and discussed with the patients in one-to-one workshops, and their comments were incorporated into the system.

Results of workshop 4 and final design

In the lab test, three patients and one family member gave feedback on the functionalities in the prototype (Table 1), for example, noting that the font size was too small. This was adjusted by the IT specialist and shown to the patients repeatedly until approved. Moreover, the participants asked for clear indications of the professions of the HCPs displayed. The IT specialist suggested that the prototype be tested on a personal computer with a “flip over” function for better stability when standing on the bedside table, large enough for patients to adequately see the information on the screen. This was also tested and commented on by the patients. The prototype was presented to system owner representatives from Getinge. Afterward, they actively took part in further adjustments, and ongoing meetings were held. The research group and the system owners named the prototype Cetrea Clinical Logistics for Patients (CCL for Patients). Figure 6 shows the final prototype, with numbers explaining its functionality.

1. Hospital room number;
2. Name of department;
3. Patient name (no sensitive information displayed);
4. Name and picture of nurse responsible for care;
5. Name and picture of physician responsible of treatment;
6. Process line with activities, displaying nurse assessment, blood samples, electrocardiogram, physician assessment, X-ray, etc.;

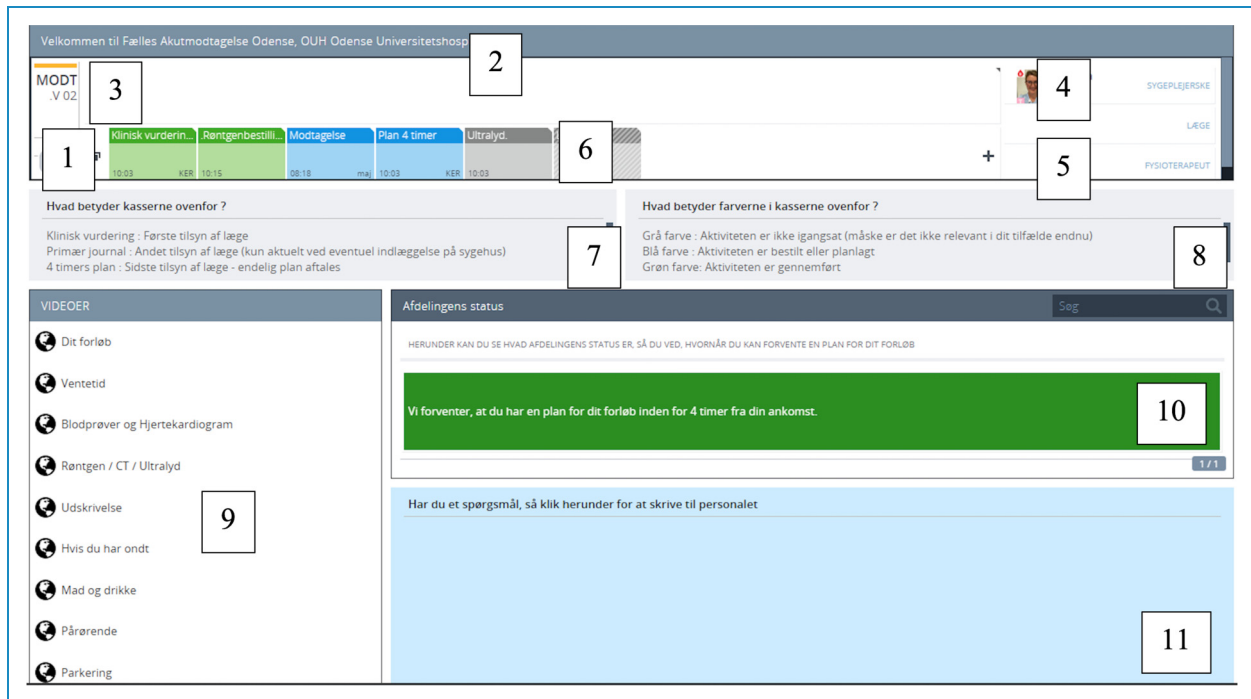


Figure 6. Screen shot of Cetrea Clinical Logistics for Patients and its functionalities.

7. Explanation of the different colors in the process line.
Gray: not activated; blue: activity planned; green: activity completed;
8. Explanation of selected activity names;
9. Link to informational videos, including information on discharge;
10. Waiting time. The various colors indicate expected waiting time $< / > / = 4$ h;
11. Interactive notepad for patients to write down questions for HCPs.

Discussion

Principal findings

The workshops guided the development of a prototype of an ED information system, CCL for Patients. The content of the system was designed and developed in collaboration with HCPs and IT specialists and informed by the patients and family members' voices from a prior study¹⁵ and one-to-one workshops. The iterative process enabled us to continuously revise, redesign, and evaluate the design and content of the technology until the representatives of future users agreed it reflected their needs.

Moving from "the sky's the limit" to what is feasible in a clinical practice

The value of conducting research informed by user-driven activities and user participation has been acknowledged

for many years.^{13,38} The approach has yielded benefits for patient safety,³⁹ quality in healthcare,⁴⁰ improving patient pathways,³ and developing health technologies.²⁵ Our study planned to gather patients and family members to collaborate with HCPs and IT specialists as an essential part of the user-driven research process,²⁶ but COVID-19 restrictions made that impossible; moreover, the patients and family members were reluctant to participate more than once in the development process. Our results show how an alternative approach to the collaborative process was initiated and successfully completed.

A British study by Blackwell et al.,²⁷ which aimed to improve palliative care in the ED and involved patients and families, presents a critical approach to a codesigning process in the ED setting. The researchers found that the ED is recognized as a fast-paced environment that hosts a great diversity of patients with complex needs. The study further found that ED patients were more willing to enroll when they could participate from home by providing one-to-one feedback prior to assembling the rest of the stakeholders.²⁷ The flexibility of a codesign process was found to be essential for giving patients and families a voice in "what matters most." Forcing them to be physically present could result in some not participating at all.²⁷

Likewise, our study found that, due to restrictions and the participants' reluctance, flexibility in the choice of methods, techniques, and tools was a main factor in successfully involving the ED population. We identified that flexibility and creativity in getting patients' voices heard

may be an important step to enable user-driven activities in an acute setting. Unlike out-patient clinics, the ED does not necessarily see the same patient more than once. Therefore, could researchers ethically ask them to invest their time and resources to improve the ED setting when they might not visit the ED again for many years, if ever? The same concern was found in a study completed in New South Wales, Australia.⁴¹ One of the main challenges in completing a codesign study in the ED was enabling the involvement of the patients throughout the whole process, as the patients were no longer interacting with the ED and thus believed they had little to contribute.⁴¹ Various suggestions were made for enabling codesign processes in the ED despite difficulties in maintaining patients' interest. One suggestion, in line with our study, was to enroll new patients continually.⁴¹

In our study, the participants worked to design and develop a technology for future users. During the process, the participants learned from each other's fields of expertise through the use of personas. The IT specialists and HCPs learned about patients' and family members' needs and, conversely, the patients and HCPs learned from the IT specialists about possibilities in developing technology. Moreover, continually sampling new patients enabled us to validate and adjust the information system. However, as different patients were involved throughout the process, the iterations implemented by the researchers were crucial to including the perspectives of the patients in the prototype. Simonsen and Robertson highlight²⁶ ethical reflections on PD and its usability, noting that researchers must carefully consider the involvement of participants to ensure genuine involvement and mutual learning.²⁶ Even though other studies^{27,41} have found the ED population and context difficult in codesign, we report results that show ways to conduct a PD study in an ED with positive results. From a realistic point of view, our study shows that it would be difficult to address all concerns using a single technology. However, the mutual learning process among the participants provided insight into various aspects, and the participants agreed that information was most important element to work on.

We identified two aspects of information that needed to be prioritized: continual information pertaining to the ED stay and information related to discharge. Creating an information system that presents an overview of activities during the ED stay might not only give patients a greater feeling of control of their trajectory in the ED but also potentially give family members access to information, whether or not HCPs are available. The patients and family members described the informational videos and having a better understanding of the procedural flow as empowering. The access to information increased their understanding and trust in the HCPs, as they were able to keep track of activities completed and those to come. This is in line with the findings of a recent scoping review on interventions to

promote relational practice with families in acute care settings.⁴² Nine papers were identified that described interventions targeting relational family practices in acute settings and pointing to the need for better management and support.⁴²

Another critical and emerging demand was that the participants wanted an interactive information system that could possibly transfer data from the ED visit to an unspecified application afterward. Various organizational constraints hindered the development of such a system, which highlighted the complexity of healthcare systems. Introducing new technologies can be expensive, be difficult to accommodate, and bring the risk of resistance from users.¹⁰ The iterations with the patients and family members enabled us to redesign an existing technology originally developed and implemented for use by clinicians only. The fact that the system is already familiar to the HCPs and part of their everyday workflow might prevent implementation resistance. A study from Israel that aimed to develop a system to provide patients with dynamically updated information in the ED found that the developers had to tackle providing information to patients without disrupting the ED workflow for the system to be a success.²³ We demonstrated how to work alternatively in a codesign process in such a way that the chosen needs and preferences could be integrated into an existing system that is already actually workable in clinical practice.

Limitations and strengths

Our study demonstrated how to successfully codesign and develop a well-implemented technology in the health system. This is considered a strength, as the complexity of health systems may present a major risk of failure when implementing new technologies.¹⁰ In the planning stage, we had a preconception that physical participation in the workshops would be preferred due to the core elements of PD. However, we found the iterative process, which involved the researcher acting as a messenger between the workshops and the patients and family members, to be a viable alternative for implementing the codesign process. The participatory approach is also seen as a strength, as it may have improved system quality due to better, more accurate user requirements, thus providing a greater likelihood of the inclusion of features that users actually want.¹³

This study also has limitations. The patients and family members who participated in the study cannot be considered fully representative, as the ED population is extremely diverse. The influence of COVID-19 restricted the number of participants, and recruiting them continually may have made it more difficult to cover all aspects than if we had been able to follow up. However, we still succeeded in including a variety of participants in terms of age and gender. No doubt the information system will have usability limitations for various patients, for example, those suffering from dementia. Nevertheless, we consider that the content

and usability of the system would be adequate for most patients and/or family members accompanying patients.

Conclusions and implications for clinical practice

This study demonstrates that PD is a usable approach to designing an information system for use in the ED. We succeeded in designing a solution that combines continual and timely information to patients and family members. The creative codesign process identified how to redesign, adjust, and transform an existing technology that clinicians already used in practice to make information visible to patients and family members. We learned that, even though user activities in research are highly relevant, it is crucial to critically review the setting and its population to adjust the process of producing ideas and fostering mutual learning in collaborative workshops. By using appropriate tools and techniques, we illustrated how to create an environment that could support the genuine involvement of participants who represent future end users. This study also provides insight into the complexity of translating ideas into technologies that can actually be implemented in clinical practice. The user perspectives showed us the key to identifying these aspects before implementation. The usability and evaluation of the information system will be addressed in future research to complete and evaluate the user-driven research process in an ED.

Abbreviations

HCP	healthcare professional
IT	information technology
ED	emergency department
PD	participatory design.

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