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# BMJ Open

## Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-041743
Article Type:	Protocol
Date Submitted by the Author:	17-Jun-2020
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Keywords:	Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH, ACCIDENT & EMERGENCY MEDICINE

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## Title page

**Title:** Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.

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Keywords

Emergency Department, Care planning, Family, Nursing, participatory design.

Wordcount:

3981 words excluding title page, references, figures and tables

For peer review only

## Abstract

**Introduction:** The development of acute symptoms or changes in diseases lead to feelings of fear and vulnerability and the need for health professional support. Therefore, the care provided in the acute medical and surgical areas of the Emergency Department (ED) is highly important as it influences the confidence of patients and families in managing everyday life after discharge. There is an increase in short-stay hospital admissions, related to demographic changes and a focus on outpatient care. Clear discharge information and inclusion in treatment decisions increase the patient's and family's ability to understand and manage health needs after discharge, reducing the risk of readmission. This study aims to develop and test the feasibility of a family inclusive solution to improve outcomes of patients discharged within 24 hours of admission.

**Methods and analysis:** The study comprises the three phases of a participatory design (PD). Phase 1 aims to understand and identify patient and family needs when discharged within 24 hours of admission. A qualitative observational study will be conducted in two different EDs, followed by 20 joint interviews with patients and their families. Four focus group interviews with healthcare professionals will provide understanding of the short pathways. Findings from phase 1 will inform phase 2, which aims to develop a solution to improve patient outcomes. Three workshops gathering relevant stakeholders are arranged in the design plus development of a solution with specific outcomes. The solution will be implemented and tested in phase 3. Effect on patient and family outcomes, will be evaluated by pre-and postintervention questionnaires.

**Ethics and dissemination:** The study is registered with the Danish Data Protection Agency (19/22672). Approval of the project has been granted by the Regional Committees on Health Research Ethics for Southern Denmark (S-20192000-111). Findings will be published in suitable international journals and disseminated through conferences.

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**Strength and limitations of the study**

- ⇒ The proposed study will, through participatory design, combine qualitative, and quantitative methods into the design and test of an innovative solution, seeking to improve patient and family outcomes in connection to their discharge from the ED. This will provide insight into patient and family needs during their ED pathway.
- ⇒ It is a key feature in the study to ensure user involvement from all stakeholders and sustainability of the , as it is drawn directly from patients’, family members’ and healthcare professionals’ statements, experiences and ideas.
- ⇒ The study includes family perspectives, which is limited in previous research from an ED perspective.
- ⇒ A quantitative survey considering only two hospital settings could be a limitation, as findings may not be generalizable to a broader international context.

## Introduction

When patients have an acute episode of symptoms or instability of a chronic disease, they often have feelings of fear and helplessness due to the uncertainty of the situation. This brings patients and their families to the Emergency Department in a vulnerable and distressed situation [1]. The care provided at the ED will influence the patient's and family members' experience of the current stay and influence their ability to understand and use health information for maintaining their health as an outpatient after discharge [1-3]. Family members rank supportive communication with nurses as vital to reduce stress and anxiety [4]. The majority of patients with acute symptoms are initially cared for in a general ED or common acute medical and surgical emergency unit [5]. Emergency nursing care is administered by following systematic guidelines based on e.g. ABCDE principals to support effective patient pathways and identify specific patient needs [6]. Many countries have this organizational structure and systematic approach to ensure rapid and comprehensive assessment along with the improvement of patient flow [7, 8]. The organizational structure has a positive effect on preventing overcrowding, but it is also a result of the reduced number of in-hospital beds [9]. Attention is often on organizational concerns, but there is a need for exploring patient-related aspects as well.

Acute nursing care is characterized by rapid and efficient treatments. This often results in short and fragmented encounters between patients and nurses [2, 10]. Previous research on patient perspectives has shown that patients feel that ED nurses seem to lose interest in the patient's life situation after the most acute treatment has been initiated [11]. In line with this, a Danish National survey revealed that 33% of patients did not experience that their family's perspective was considered important [12]. Furthermore, 30% of the patients participating in this survey reported that they were not involved in the decision-making process of their care [12]. These findings indicate that the international and national health standards for patient involvement are not met [13, 14]. Healthcare professionals' acknowledgment of the family's role and inclusion in care decisions enable the family to improve the patient outcomes, but also ensure that family caregivers understand information and are able to coordinate care and manage practicalities [15]. A way to improve the quality of care would be to give patients and families a stronger voice. This could help identify their needs

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and the resources they use, to enable supportive care to be tailored [16]. To enable nurses to assess and partner with patients and families to meet their needs and tailor care during short nurse–patient interactions, a nurse-led intervention may be useful [17]. Previous research exploring ED patients’ expected outcomes identified four main concerns; understanding diagnosis, symptom relief, reassurance and treatment plans [5, 18]. However, the family perspective was not reported in these studies. Furthermore, research has identified numerous discharge interventions and strategies to prevent readmissions; however, these are primarily concerning elderly, frail patients and not inclusive of family members [19-22]. Sparse research has been conducted focusing on the diversity of ED patients and their families, highlighting the need for interventions on how to assess and tailor care [23-25].

Objective

The overall aim of this study is to improve patient outcomes by nurse assessment and tailoring care for patients and family members discharged from the ED < 24 hours.

Methods

The overall research design and methodology for this study is PD [26]. The Family System Theory [27] and the framework of Medical Research Council [28] for developing complex interventions in healthcare are used to guide the study.

Study design

PD is chosen as research methodology as it includes the participants in the design phase [26]. PD is defined by making innovative solutions to problems in real life through a democratic stance and genuine participation of all relevant participants [29]. It enables the focus to be on future end-users in designing an intervention strategy that provides possibilities to improve patient outcomes in the ED. A PD process conducted in health science is typically performed in three interdependent phases [30] and is characterized by collective “reflection-in-action” iterations. In phase 1, the focus is to identify user needs. In phase 2, a prototype as a solution to cover the identified needs is developed. Finally, the solution is implemented and tested in a clinical setting and its effect and success will be evaluated.

As the three phases are interdependent, phase 1 will provide the information and inform phase 2 and so on. Therefore, phase 2 cannot be predesigned, wherefore an exploratory approach will be used as design [26, 31]. A literature review exploring ED patients' outcomes and clinical interventions will be completed for each phase to ensure understanding of current research to inform the study [32]. To identify patient and family needs and preferences, field observational studies inspired by Spradley [33] will be obtained by the first author, followed by joint semi-structured interviews of patients and family members [34]. Focus groups of health care professionals will enable sustainable and an achievable solution to develop. An intervention plan developed from phase 1 will be constructed and relevant stakeholders and future end-users of the solution will be invited to participate in three workshops to finalize the design. The workshops will be designed to focus on 1) generation of ideas 2) workshop with the intention to create mock-ups for the creation of a final prototype 3) A "laboratory" workshop where this prototype is pretested in a clinical setting [26]. A "laboratory" workshop is characterized as deliberately staged activities during which a controlled environment for exploration is created, and open collaboration between the participants is facilitated [26]. The third and final phase of the study aims to test and evaluate if the solution has an effect on the outcomes described by patients and families in the initial phases. The Medical Research Council [28] framework of developing complex interventions will be used to guide this study 1) development 2) feasibility 3) evaluation in line with the three phases of the study's research design, as illustrated in figure 1.

## Theoretical framework

The theoretical frame is based upon the Family Systems Theory [27] that care is provided holistically with patient and family as one unit of care. According to Wright & Leahey, family members could be spouses, partners, adult children, friends or others from the care-recipient's social network who care for the patient. Family Systems Theory aims to help families to achieve stability in their lives by focusing on their internal relationships, resources and capacity to adapt to new situations caused by illness [27].

## Setting

The study is carried out from September 2020-June 2023, shown in figure 1. Data will be collected at two sites: 1) The ED, Odense University Hospital (OUH). The ED receives 180

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patients per day with a capacity of 42 beds and 30 examination rooms. On average, 32 patients are admitted per day, and 50% are discharged within 24 hours. 2) Department of Emergency Medicine, Hospital of Lillebaelt, Kolding. The department receives 146 patients per day and has 58 beds and 5 trauma rooms beds capacity.

The study is affiliated with the Family Focused Healthcare Research Center (FaCe) at the University of Southern Denmark [35].

Participants

Patients and family members:

Inclusion criteria:

Purposive sampling of patients:  $\geq 18$  years of age, Danish speaking, discharged  $< 24$  hours with medical or surgical symptoms. Family members, invited by the patient, are included. Sampling strategy will ensure equally represented patients with first time visits among patients with multiple ED visits.

Exclusion criteria:

Cognitive impairment assessed by the nurses according to being able to understand the terms of participating in a research study. Highest and lowest triage level according to Danish Emergence Process Triage [36].

Variables: gender, age, civil status, educational level, length and frequency of stay, diagnosis, Charlsons comorbidity score and family relations.

Healthcare professionals:

Nurses and physicians working at the ED  $>6$  months will be included. Inclusion will be done purposively to enable a broad sample of healthcare professionals.

Variables: gender, age, profession, years since graduation years of employment at the ED, educational level.

Collaborators and consultants:

The participants in this category will be identified during the analysis of phase 1. It seems relevant to look into previous research, consulting experienced researchers within PD and looking into exciting interventions in healthcare, IT software engineers, design schools, communication advisors, sociologists, anthropologists and cross-sectoral partners.

## Research objectives

1. To create knowledge about what patients, family members, and health care professionals do and what they say they do, in connection to patients discharged within 24 hours (phase 1a).
2. To assess the needs and preferences of patients and families admitted in the ED to gain an understanding of patients and family needs (phase 1b).
3. To investigate how health care professionals in the ED experience patients and family needs and preferences and how to accommodate these in their care (phase 1c).
4. To design and develop a solution to improve patient outcomes using focus group workshops (phase 2).
5. After implementation, the influence of the solution on patients' and family members' needs and their experience of tailored care during their short stay in the ED will be evaluated (phase 3).

## Phase 1.a: Field observations

### Method:

Field observations will be conducted in both EDs (estimated n= 10 days) to include relevant perspectives in the understanding of patient and family needs and preferences. Field observational studies are chosen as it has the strength to create direct knowledge about what participants do and what they say they do [37], in connection to their treatment and care in the ED. Field observations are planned at different weekdays and times of the day to show the potential diversity. The duality of being a researcher, experienced nurse and employed at the department at the same time will be accessed as objectively as possible by using a template for documentation of field notes, inspired by Spradley [33]. Each day, field notes will be taken and transcribed immediately to secure correct recall [33]. The notes are expected to consist of

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descriptions, illustrations, and short quotations. Approval from the management of the departments was obtained in February 2020.

Phase 1.b: Joint interviews with patients and family members

Method:

Patients and family members from both EDs will be interviewed face-to-face within the first week after their emergency visit (n=20). Recruitment of patients and family members will occur during the observational study. Patients will be approached and provided with a plain language information sheet of the study and asked if they would be interested. Once patients are recruited, family members will be invited into the study. Using purposively sampling will help balance across first-time visitors and patients with multiple visits. Semi-structured, open-ended interviews will be conducted in person as joint family interviews. Interviews will be conducted at a time and place convenient for the patient and family member. Interviewing patients and family members is aimed at identifying both their individual and common experienced needs and preferences. Interviews enable the participant’s perspectives and experiences to be shared to gain understanding of the experience [38]. We will continue until thematic saturation is reached; the point at which no new themes are emerging [38]. We chose this sampling strategy as it is designed to ensure that a full range of themes is elicited within each group.

Phase 1.c: Focus group interviews with healthcare professionals

Method:

Four focus groups will be conducted with approximately n=20 nurses and physicians equally from both sites. Focus groups are an effective way to produce group-level data, based on the interpretation, interaction and norms of social groups [39]. Participants are asked to discuss quotes from patients’ and family members’ interviews to involve healthcare professionals’ perspectives and reactions to these quotes. The interactions between participants can lead to participants contributing spontaneous statements about the given subject, and new ideas are created. The first author moderates the focus group together with one of the more experienced

researchers from the research team. Observations of the non-verbal communication, the group-interaction and elaborating questions will be recorded as field notes [39]. Each focus group will consist of 4-6 participants and work within the organizational boundaries [40].

### Analysis: Phase 1 a-c

Qualitative data from the joint interviews, focus groups interviews and field observational studies will be synthesized and analyzed in a hermeneutics framework. To organize the process of the analysis, the steps from Malterud's [41] systematic text condensation (STC) will be used in NVivo12. The progressive process line in phase one is shown in Figure 2.

### Phase 2: Design and development of a solution in a workshop process

The second phase is the actual development of a solution to improve patient outcomes by nurse assessment and improved tailored care to patients and family members, discharged from the ED < 24 hours.

### Method:

The process of design and development of a solution will be affected by involving participants in workshops and laboratory tests. This will enable discussion of needs, mutual learning, and creativity, ensuring that the solution is innovative and user focused [26]. Initially, an idea-generating workshop will be conducted, followed by a mock-up workshop, creating a temporary prototype of the solution. Workshops will consist of different participants representing different perspectives: patients, family members, various healthcare professionals, IT designers, innovation consultants, the research team a.o.. Collecting a broad variety of participants with different backgrounds, and perspectives will bring nuanced perspectives to the process and the ability to predict possible challenges with the prototype [26, 28]. The workshops will be facilitated as a space for creativity and "reflection-in-action" amongst participants. To facilitate this creative space, visualization tools will be used, such as posters, personas, post-its ect. This allows participants and researchers to work as equal partners, bringing the iterative process into action. A possible solution will be informed by study I and the workshop process. Looking into previous research, intervention examples could be telehealth solutions, discharge follow-up or improved cross-sectoral collaboration [42].

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Finally, a “laboratory” workshop pretesting the prototype sees its feasibility and acceptability in practice. This workshop will include a smaller number of participants as the aim is narrow, compared to the creative, innovative workshops.

The number of workshops and its attendees will depend on the process, but based on previous research using PD [29, 43], it is estimated that at least 3 workshops will be needed.

Analysis:

Data from all workshops will be obtained as pictures, notes on posters, debriefing and recorded discussion during the workshops. The first author will transcribe and systematize the posters, post-it labels and pictures into themes inspired by STC [41] and transform them to a report. The report will be discussed by the research team and relevant collaborators for final adjustments before the test phase. The analysis and development of the model will be conducted iteratively in the following steps: plan, act, observe and reflect. This process is illustrated in figure 3.

Along with the development process, suitable indicators and assessment tool will be discussed in the research group and chosen for phase 3. If the developed solution is suitable for cluster randomized trial, it would be the preferred method in phase 3, but as we do not know if this is possible due to the undeveloped solution, we plan phase 3 with a pre-and post-intervention questionnaire, which is elaborated on in the next section.

Phase 3: Testing in clinical practice

In line with PD [26] and Medical Research Council Guidelines [28], a testing phase is part of developing complex interventions, as it allows us to investigate if the solution matches the study’s aim before up-scaling. After implementation of the solution, this phase aims to evaluate if the solution has an effect on how patients and family members feel their outcomes improved.

Methods:

A pre- and posttest design using questionnaires/assessment tool will seek to achieve feasibility, effectiveness, and acceptability. The final assessment tool and its relevance for measuring this

particular prototype will be informed by findings in phase 1 and 2 and will depend on which outcomes are value by patients and families.

Due to the overall aim of the study, measurements are likely to include patients experienced support or/and involvement during the ED visit. This could be achieved by the Ice Family Perceived Support Questionnaire (ICE-FPSQ) [44] or Patient Reported Experience Measures [45]. Approximately 400 patients/family members will be recruited from the hospitals. This sample size is based on a realistic consideration regarding recruitment in the given setting and time frame. As the assessment tool is yet unknown, the power calculation cannot be more specific. The inclusion periods for the pre- and post-survey are expected to last 12-16 weeks each. The chosen assessment tool will be handed to patients and family members during the pre-implementation period and the post implementations periods.

Statistical analysis will analyze the effect of the implementation and will include confounder control, based on the following variables: gender, age, civil status, educational level, length and frequency of stay, diagnosis, Charlsons comorbidity score and family relations and compared and synthesized to the responses from the assessment tool.

Inclusion and exclusion criteria as in phase 1.

Primary endpoints: Improvement of the patient/family-defined outcomes based on study I and II.

Secondary endpoint: Patients' files will be accessed after oral and written consent to report readmission rates.

### Data management plan, ethics and dissemination:

Oral and informed consent will be obtained after providing thoroughly information [46]. Participation is voluntary, and it is possible, at any time, to withdraw from the study. The study is registered with the Danish Data Protection Agency (19/22672). Approval of the project is obtained from the Regional Committees on Health Research Ethics for Southern Denmark (S-20192000-111).

Data will be stored at Open Patient data Explorative Network (OP\_938)[47]. Findings will be published in suitable journals and disseminated through workshop and conferences.

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Patient and public involvement

The local Patient Council at OUH was consulted in the early design phase of the study, and their perspectives were taken into account. The core element of the study is built around user involvement and its strengths and limitations will be elaborated on in the discussion section.

Discussion

The use of a participatory design provides an innovative approach through the inclusion of users across the health care setting. PD and its methods are very productive research approaches, directing the design of the solution to support patients’ needs and organizational changes in clinical practice [30, 48]. The participatory approach ensures stakeholder involvement and sustainability of the designed solution as it is drawn directly from patients, family members and healthcare professionals. The data will provide a strong foundation to improve patient-valued outcomes and experiences of support. Coproduction and focus on future end-users are increasingly applied in designing and improving healthcare and have shown great potential to improve the quality and value of care [29, 43, 49]. In our study, we base the design and development on a qualitative foundation from the two main groups of end-users; patients’/family members’ and healthcare professionals’ descriptions of needs and preferences. By actively involving participants, the solution will be targeted the main issues [8] in acute care and the likelihood of actually improving family inclusive patient outcomes will increase. By enabling participants to meet and interact with each other, they are able to exchange knowledge, to inspire each other and to find support. We consider this interaction to be one of our study’s main strengths, as we expect it to bring a better understanding of acute care. Collecting data at two different sites is considered a strength, as it will ensure the national generalizability of the findings.

As our protocol is based on coproduction, it may be at risk of logistical and practical challenges by gathering different stakeholders. Challenges posed by engaging health care professionals in workshops relate to staff resources, and this must be addressed [50]. Phase 1 challenges will be to sample enough participants to be representative as the ED has a great diversity of patients with different ages, needs, illness etc. Therefore, purposive sampling is chosen. Also, research in our own field with field observations may entail blind spots or irrelevant focus [33] and risk of the Hawthorne effect [51]. An observation guide inspired by

Spradley will be mandatory to ensure a systematic approach [33]. Although it is expected that both parties (patient and family members) will actively participate in joint interviews, the advantages and disadvantages must be addressed. The main disadvantage is the risk that one of the participants being more conversational and may overrule the other one. However, joint interviews are chosen as the authors want to explore both perspectives and create a social interaction that could bring out their experiences in a nuanced way [39]. Involving participants actively in workshops and working in iterative processes will place demands regarding flexibility and willingness to change direction, if participants say so. This may be time consuming and costs intensive. Challenges in phase 3 are the still unknown and undefined outcomes but already exciting assessment tools are likely to be part of the solution. If the chosen assessment tool includes many questions, it may cause selection bias as some participants may not be able to fill in an extensive assessment tool.

## Summary

By focusing on coproduction, this study is expected to contribute to an improved health outcome of acute illness and an improved understanding of how to support patients and family members to reach the ability to manage their situation after a short ED stay.

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List of abbreviations

- I. Participatory design (PD)
- II. Systematic text condensation (STC)
- III. Emergency Department (ED)

Declarations

**Competing interests:** The authors declare no competing interests.

**Funding:** The study has received grants from The University of Southern Denmark, Odense University Hospital and the Region of Southern Denmark.

**Authors' contributions:** All authors read and approved the final version of the manuscript. All authors contributed to the study concept and design and drafting of the manuscript.

**Ethics:** The study is registered with the Danish Data Protection Agency (19/22672), and data will be stored at a logged server at Open Patient data Explorative Network (OPEN\_938), Department of Clinical Research, University of Southern Denmark. The study is approved by the Regional Committees on health research Ethics for Southern Denmark (S-20192000-111).

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Figure 1:  
Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.

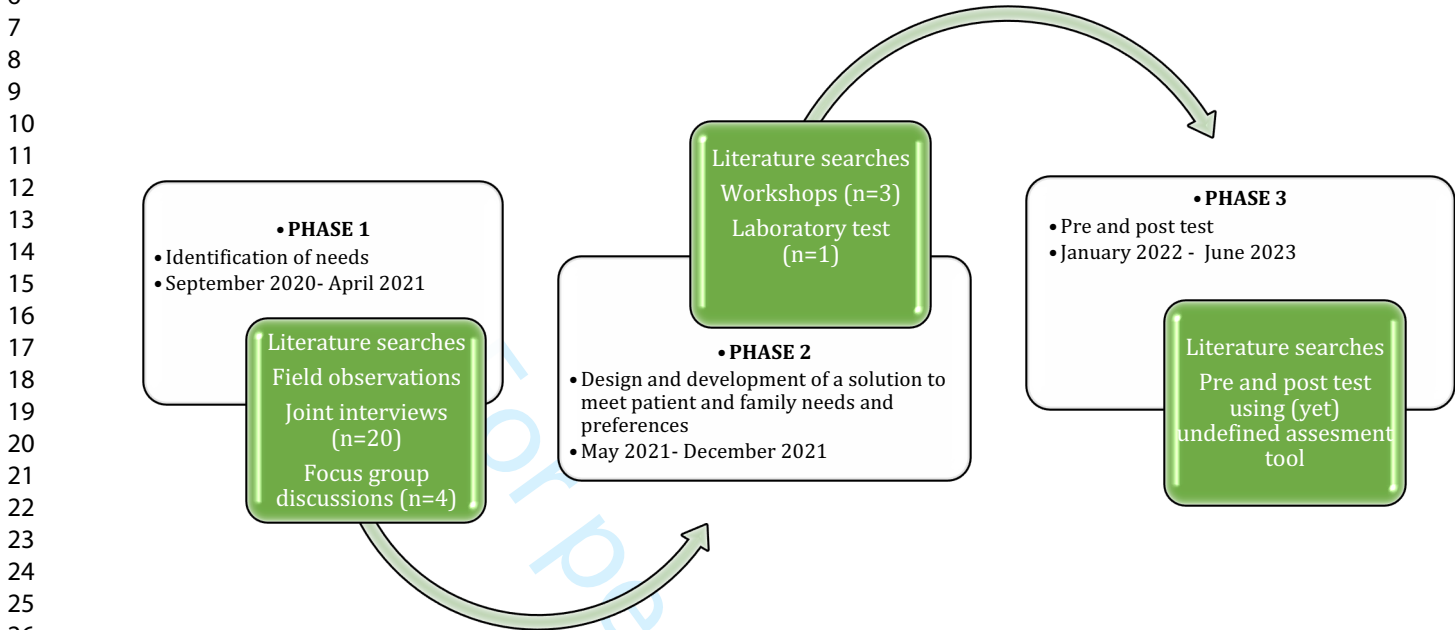


Figure 1. The estimated time frame and methods of the Danish study “Acute Care planning in Emergency departments, The ACE study”

Figure 2:

Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.



Figure 2: Progressive process of phase 1

For peer review only

Figure 3: Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.

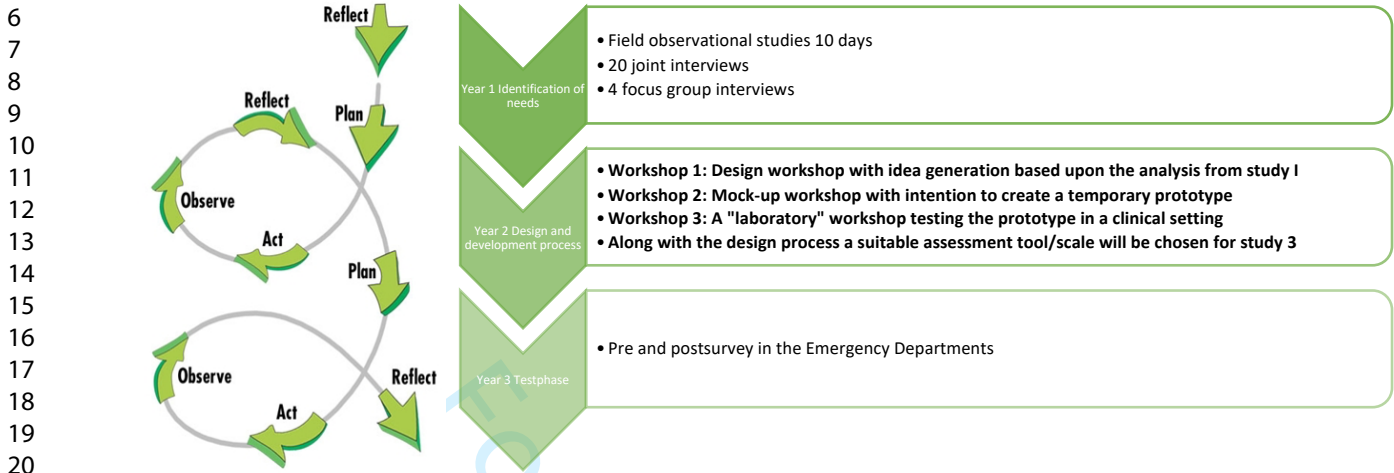


Figure 3: Iterations of phase 2: plan, act, observe, reflect. Figure inspired by Jensen et al. [29].

# BMJ Open

## How to improve emergency care to adults discharged within 24 hours? Acute Care planning in Emergency departments (The ACE study): a protocol of a participatory design study.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-041743.R1
Article Type:	Protocol
Date Submitted by the Author:	06-Aug-2020
Complete List of Authors:	Østervang , Christina ; Odense Universitetshospital, Department of Emergency medicine; University of Southern Denmark Faculty of Health Sciences, Clinical Institute Lassen, Annmarie; Odense University Hospital, Department of Emergency Medicine; University of Southern Denmark Faculty of Health Sciences, Clinical Institute Jensen, Charlotte; Odense University Hospital Department of Orthopaedic Surgery and Traumatology; University of Southern Denmark Faculty of Health Sciences, Clinical Institute Coyne, Elisabeth; Griffith University Faculty of Health; University of Southern Denmark Faculty of Health Sciences, Clinical Institute Dieperink, Karin; Odense University, Department of Oncology; University of Southern Denmark Faculty of Health Sciences, Clinical Institute
<b>Primary Subject Heading</b>:	Nursing
Secondary Subject Heading:	Emergency medicine
Keywords:	Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH, ACCIDENT & EMERGENCY MEDICINE, HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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## Title page

**Title:** How to improve emergency care to adults discharged within 24 hours? Acute Care planning in Emergency departments (The ACE study): a protocol of a participatory design study.

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Keywords

Emergency Department, Care planning, Family, Nursing, participatory design.

Wordcount:

3826 words excluding title page, references, figures and tables

## Abstract

**Introduction:** The development of acute symptoms or changes in diseases lead to feelings of fear and vulnerability and the need for health professional support. Therefore, the care provided in the acute medical and surgical areas of the Emergency Department (ED) is highly important as it influences the confidence of patients and families in managing everyday life after discharge. There is an increase in short-episode (<24 hours) hospital admissions, related to demographic changes and a focus on outpatient care. Clear discharge information and inclusion in treatment decisions increase the patient's and family's ability to understand and manage health needs after discharge, reducing the risk of readmission. This study aims to identify the needs for ED care and develop a solution to improve outcomes of patients discharged within 24 hours of admission.

**Methods and analysis:** The study comprises the three phases of a participatory design (PD). Phase 1 aims to understand and identify patient and family needs when discharged within 24 hours of admission. A qualitative observational study will be conducted in two different EDs, followed by 20 joint interviews with patients and their families. Four focus group interviews with healthcare professionals will provide understanding of the short pathways. Findings from phase 1 will inform phase 2, which aims to develop a solution to improve patient outcomes. Three workshops gathering relevant stakeholders are arranged in the design plus development of a solution with specific outcomes. The solution will be implemented and tested in phase 3. Here we report the study protocol of phase 1 and 2.

**Ethics and dissemination:** The study is registered with the Danish Data Protection Agency (19/22672). Approval of the project has been granted by the Regional Committees on Health Research Ethics for Southern Denmark (S-20192000-111). Findings will be published in suitable international journals and disseminated through conferences.

**Strength and limitations of the study**

- ⇒ The proposed study will, through participatory design, combine methods into the design and test of an innovative solution, seeking to improve patient and family outcomes in connection to their discharge from the ED. This will provide insight into patient and family needs during their ED pathway.
- ⇒ It is a key feature in the study to ensure user involvement from all stakeholders and sustainability of the developed solution, as it is drawn directly from patients', family members' and healthcare professionals' statements, experiences and ideas.
- ⇒ The study includes family perspectives, which is limited in previous research from an ED perspective.
- ⇒ Using participatory design could be time consuming and might be a limitation, as it could be difficult to gather relevant stakeholders at same time.

## Introduction

When patients have an acute episode of symptoms or instability of a chronic disease, they often have feelings of fear and helplessness due to the uncertainty of the situation. This brings patients and their families to the Emergency Department (ED) in a vulnerable and distressed situation [1]. The care provided at the ED will influence the patient's and family members' experience of the current stay and influence their ability to understand and use health information for maintaining their health as an outpatient after discharge [1-3]. Family members rank supportive communication with nurses as vital to reduce stress and anxiety [4]. Emergency nursing care is administered by systematic guidelines based on e.g. ABCDE principals to support effective patient pathways and identify specific patient needs making it possible for nurses to respond rapidly and adequate [5]. The majority of patients with acute symptoms are initially cared for in a general ED or common acute medical and surgical emergency unit [6]. Many countries have this organizational structure and systematic approach to ensure fast, systematic and comprehensive assessment along with the improvement of patient flow [7, 8]. The organizational structure has a positive effect on preventing overcrowding and is also a result of the reduced number of in-hospital beds [9]. Attention is often on organizational concerns, but there is a need for exploring patient-related aspects as well.

Acute nursing care is characterized by rapid and efficient treatments. This often results in short and fragmented encounters between patients and nurses [2, 10]. Previous research on patient perspectives has shown that patients feel that ED nurses seem to lose interest in the patient's life situation after the most acute treatment has been initiated [11]. In line with this, a Danish National survey revealed that 33% of patients did not experience that their family's perspective was considered important [12]. Furthermore, 30% of the patients participating in this survey reported that they were not involved in the decision-making process of their care [12]. These findings indicate that the international and national health standards for patient involvement are not met [13, 14]. Healthcare professionals' acknowledgment of the family's role and inclusion in care decisions enable the family to improve the patient outcomes, but also ensure that family caregivers understand information and are able to coordinate care and manage practicalities [15]. A way to improve the quality of

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care would be to give patients and families a stronger voice. This could help identify their needs and the resources they use, to enable supportive care to be tailored [16]. To enable nurses to assess and partner with patients and families to meet their needs and tailor care during short nurse–patient interactions, a nurse-led intervention may be useful [17]. Previous research exploring ED patients’ expected outcomes identified four main concerns; understanding diagnosis, symptom relief, reassurance and treatment plans [6, 18]. However, the family perspective was not reported in these studies. ED nurses highlight family members as an important resource to obtain information, and needs more research[19]. Furthermore, research has identified numerous discharge interventions and strategies to prevent readmissions; however, these are primarily concerning elderly, frail patients and not inclusive of family members [20-23]. Sparse research has been conducted focusing on the diversity of ED patients and their families, highlighting the need for interventions on how to assess and tailor care [24-26].

Objective

The overall aim of this study is to improve patient outcomes by nurse assessment and tailoring care for patients and family members discharged from the ED < 24 hours.

Methods

The overall research design and methodology for this study is Participatory Design (PD) [27]. The Family System Theory [28] and the framework of Medical Research Council [29] for developing interventions in healthcare are used to guide the study.

Study design

Participatory Design is chosen as research methodology as it includes the participants in the design phase and is relevant to use in research areas with limited knowledge[27]. PD is defined by making innovative solutions to problems in real life through a democratic stance and genuine participation of all relevant participants [30]. It enables the focus to be on future end-users in designing an intervention strategy that provides possibilities to improve patient outcomes in the ED. A PD process conducted in health science is typically performed in three interdependent phases [31] and is characterized by collective “reflection-in-action” iterations.

In phase 1, the focus is to identify user needs. In phase 2, a prototype as a solution to cover the identified needs is developed. Finally, the solution is implemented and tested in a clinical setting and its effect and success will be evaluated. Here we report on the study protocol for phase 1 and 2. As the three phases are interdependent, phase 1 will provide the information and inform phase 2 and so on. Therefore, phase 2 cannot be predesigned, wherefore an exploratory approach will be used as design [27, 32]. With an explorative approach, patient outcomes are not defined in advance but will be identified by the patients and family members in the initial phase of the study. However, the main outcome must be focused on the quality of patient e.g. in areas of quality of care or patient experiences. A literature review exploring ED patients' outcomes and clinical interventions will be completed for each phase to ensure understanding of current research to inform the study [33].

To identify patient and family needs and preferences, field observational studies inspired by Spradley [34] will be obtained by the first author, followed by joint semi-structured interviews of patients and family members [35]. Focus groups of health care professionals will enable sustainable and an achievable solution to develop. An intervention plan developed from phase 1 will be constructed and relevant stakeholders and future end-users of the solution will be invited to participate in three workshops to finalize the design. The workshops will be designed to focus on 1) generation of ideas 2) workshop with the intention to create mock-ups for the creation of a final prototype 3) A "laboratory" workshop where this prototype is pretested in a clinical setting [27]. A "laboratory" workshop is characterized as deliberately staged activities during which a controlled environment for exploration is created, and open collaboration between the participants is facilitated [27].

The Medical Research Council [29] framework of developing complex interventions will be used to guide this study 1) development 2) feasibility 3) evaluation in line with the three phases of the study's research design, as illustrated in figure 1. The Medical Research Council argues that an intervention is complex when it contains several interacting components [29]. Current study is expected to include patients, families, healthcare professionals, and might also include technology, organizational changes etc.. Therefore, complexity in the intervention is expected.

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7 **Theoretical framework**

8 The theoretical framework is based upon the Family Systems Theory [28] that care is provided  
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10 holistically with patient and family as the unit of care. According to Wright & Leahey, family  
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12 members could be spouses, partners, adult children, friends or others from the care-recipient’s  
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14 social network who care for the patient. Family Systems Theory aims to help families to achieve  
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16 stability in their lives by focusing on their internal relationships, resources and capacity to  
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18 adapt to new situations caused by illness [28]. This framework guides the research process  
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20 including sampling, designing intervention and research aims. After episodes of care in  
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22 emergency the family are the main carer and provider of support. Therefore, to improve patient  
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24 outcomes the family inclusion is required to enable family information needs to be met [11].  
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26 **Setting**

27 The study is carried out from September 2020-June 2023, shown in figure 1. Data will be  
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29 collected from the ED at two hospital sites: 1) The Odense University Hospital (OUH), which is  
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31 a 1000 bed university hospital, and covers all specialties and provides care for a population of  
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33 230.000 adults living in four municipalities. The ED seeing 69.000 annual attendees, mean age  
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35 45, treats 180 patients per day with a capacity of 42 beds and 30 examination rooms. On  
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37 average, 32 patients are admitted to the hospital per day, and 50% are discharged within 24  
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39 hours.

40 2) Department of Emergency Medicine, Hospital of Lillebaelt, Kolding. Hospital of Kolding has  
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42 the capacity of 320 beds. The ED seeing 50.000 annual attendees, mean age 45, receives 146  
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44 patients per day and has 58 beds and 5 trauma rooms beds capacity. The EDs are organized as  
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46 they can control the allocation of the in-hospital beds at the rest of the hospital.

47 The Danish health care system is provided with open access and people do not need health  
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49 insurance to be seen by a physician as it is a tax-funded welfare system. Acute patients are  
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51 evaluated in person or by emergency calls by primary care physicians who act as gate-keepers  
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53 before entering the ED. Denmark has a well established and free of charge primary care, public  
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55 pre-hospital emergency transport, and treatment at public hospitals. When patients are  
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57 discharged they can get uncharged follow up by their general practitioner, primary nursing  
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59 care, or in an outpatient clinic.  
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The study is affiliated with the Family Focused Healthcare Research Center (FaCe) at the University of Southern Denmark [36].

## Participants

### Patients and family members:

Inclusion criteria:

Purposive sampling of patients:  $\geq 18$  years of age, Danish speaking, discharged  $< 24$  hours with medical or surgical symptoms. Family members, invited by the patient, are included.

The target study population is shown in table 1.

#### *Target study population features (n=20)*

<i>Age</i>	10 patients $\geq 65$ years of age 10 patients $\leq 65$ years of age
<i>Sex</i>	10 females 10 males
<i>Symptoms</i>	10 patients having surgical symptoms 10 patients medical symptoms
<i>Education level</i>	10 patients with education level above secondary school 10 patients with education level below secondary school
<i>Function level</i>	10 patients receiving primary care 10 patients not receiving primary care
<i>Social status</i>	10 living on their own in independent accommodation 10 living together with someone

*Table 1: Target study population features for sampling patients in phase 1 of the Danish study "Acute Care planning in Emergency departments, The ACE study"*

Sampling strategy will ensure equally represented patients with first time visits among patients with multiple ED visits. Other collected variables: gender, age, civil status, educational level, length and frequency of stay, diagnosis, Charlsons comorbidity score and family relations.

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Exclusion criteria:

Cognitive impairment assessed by the nurses by using Glasgow Coma Scale added by individual clinical judgement according to be able to understand the terms of participating in a research study. Highest and lowest triage level according to Danish Emergence Process Triage [37].

Healthcare professionals:

Nurses, physicians and physiotherapist working at the ED >6 months will be included. Inclusion will be done purposively to enable a broad sample of healthcare professionals.  
Other collected variables: gender, age, profession, years since graduation years of employment at the ED, educational level.

Collaborators and consultants:

The participants in this category will be identified during the analysis of phase 1. It seems relevant to look into previous research, consulting experienced researchers within PD and looking into exciting interventions in healthcare, IT software engineers, design schools, communication advisors, sociologists, anthropologists and cross-sectoral partners.

Phase 1.a: Field observations

Research objective:

To create knowledge about what patients, family members, and health care professionals do and what they say they do, in connection to patients discharged within 24 hours.

Method:

Field observations will be conducted in both EDs (estimated n= 10 days of four hours a day) to include relevant perspectives in the understanding of patient and family needs and preferences. Field observational studies are chosen as it has the strength to create direct knowledge about what participants do and what they say they do [38], in connection to their treatment and care in the ED. Field observations are planned at different weekdays and times of the day to show

the potential diversity. The duality of being a researcher, experienced nurse and employed at the department at the same time will be accessed as objectively as possible by using a template for documentation of field notes, inspired by Spradley [34]. Each day, field notes will be taken and transcribed immediately to secure correct recall [34]. The notes are expected to consist of descriptions, illustrations, and short quotations. Approval from the management of the departments was obtained in February 2020. Data from field observations will actively be used to understand what the patients have experienced and inform the development of the interview guide.

The interviewer is an experienced emergency nurse with a Masters degree (12 years emergency nursing). From previous research she has experience doing intervention- and qualitative research [39, 40]. She is supervised by an experienced research team that is involved in every aspect of the project.

### Phase 1.b: Joint interviews with patients and family members

#### Research objective:

To assess the needs and preferences of patients and families admitted in the ED to gain an understanding of patients and family needs.

#### Method:

Patients and family members from both EDs will be interviewed face-to-face within the first week after their emergency visit (n=20). Recruitment of patients and family members will occur during the observational study. Patients will be approached and provided with a plain language information sheet of the study and asked if they would be interested. Once patients are recruited, family members will be invited into the study. Using purposively sampling will help balance across first-time visitors and patients with multiple visits.

Semi-structured, open-ended interviews will be conducted in person as joint family interviews. The interview guide will be developed from the observation study. The researcher will ask participants to explain incidences that occurred during their emergency visit to gain knowledge about how they were perceived by the patient and family member. Interviews will be conducted at a time and place convenient for the patient and family member. Interviewing patients and

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family members is aimed at identifying both their individual and common experienced needs and preferences. Interviews enable the participant’s perspectives and experiences to be shared to gain understanding of the experience [39]. A question example is: “What have you talked about since discharge?” We will continue until thematic saturation is reached; the point at which no new themes are emerging [39]. We chose this sampling strategy as it is designed to ensure that a full range of themes is elicited within each group.

Phase 1.c: Focus group interviews with healthcare professionals

Research objective:

To understand how health care professionals in the ED perceive patients and family needs and preferences and how they would accommodate these in their care.

Method:

Four focus groups will be conducted with approximately n=20 nurses and physicians equally from both sites. Focus groups are an effective way to produce group-level data, based on the interpretation, interaction and norms of social groups [40]. Participants are asked to discuss quotes from patients’ and family members’ interviews to understand healthcare professionals’ perspectives and reactions to these quotes. The interactions between participants can lead to participants contributing spontaneous statements about the given subject, and new ideas are created. The first author moderates the focus group together with one of the more experienced researchers from the research team. Observations of the non-verbal communication, the group-interaction and elaborating questions will be recorded as field notes [40]. Each focus group will consist of 4-6 participants [41].

Analysis: Phase 1 a-c

Qualitative data from the joint interviews, focus group interviews, and field observational studies will be synthesized and analyzed in a hermeneutics framework. To organize the process of the analysis, the steps from Malterud’s[42] systematic text condensation (STC) will be used

in NVivo12. The budget for professional transcriptionists is considered. Firstly, we will capture a general impression of the data and extract preliminary themes. Secondly, the data will be allocated into meaningful units which is a text section that represents pieces of information about a research question. The meaningful units will be condensed and coded and finally, findings will be synthesized. The author group will work together to enhance validation and the analysis will be discussed afterward[42]. The progressive process line in phase one is shown in Figure 2. The progressive process line in phase one is shown in Figure 2.

## Phase 2: Design and development of a solution in a workshop process

The second phase is the actual development of a solution to improve patient outcomes by nurse assessment and improved tailored care to patients and family members, discharged from the ED<24 hours.

### Research objective:

To design and develop a solution to improve patient outcomes using focus group workshops (phase 2).

### Method:

The process of design and development of a solution will be affected by involving participants in workshops and laboratory tests. This will enable discussion of needs, mutual learning, and creativity, ensuring that the solution is innovative and user focused [27]. Initially, an idea-generating workshop will be conducted, followed by a mock-up workshop, creating a temporary prototype of the solution. Workshops will consist of different participants representing different perspectives: patients, family members, various healthcare professionals, IT designers, innovation consultants, the research team a.o.. Collecting a broad variety of participants with different backgrounds, and perspectives will bring nuanced perspectives to the process and the ability to predict possible challenges with the prototype [27, 29]. The workshops will be facilitated as a space for creativity and “reflection-in-action” amongst participants. To facilitate this creative space, visualization tools will be used, such as posters, personas and note paper. This allows participants and researchers to work as equal partners, bringing the iterative process into action. The results of the analysis will be presented

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for the invited participants by the research group to create direction. After the initial workshop, the research team will include the relevant stakeholders to proceed with the development of the solution. A possible solution will be informed by study I and the workshop process. Looking into previous research, intervention examples could be telehealth solutions, discharge follow-up or improved cross-sectoral collaboration[43].

Finally, a “laboratory” workshop pretesting the prototype sees its feasibility and acceptability in practice. This workshop will include a smaller number of participants as the aim is narrow, compared to the creative, innovative workshops.

The number of workshops and its attendees will depend on the process, but based on previous research using PD [30, 43], it is estimated that at least 3 workshops will be needed.

Analysis:

Data from all workshops will be obtained as pictures, notes on posters, debriefing and recorded discussion during the workshops. The first author will transcribe and systematize the posters, post-it labels and pictures into themes inspired by STC [42] and transform them to a report. The report will be discussed by the research team and relevant collaborators for final adjustments before the test phase. The analysis and development of the model will be conducted iteratively in the following steps: plan, act, observe and reflect. This process is illustrated in figure 3.

Appropriate methods for a test- and evaluation phase will be decided when the most important patient reported outcomes are identified and the intervention is developed during phase 2. The results will inform phase 3.

Data management plan, ethics and dissemination:

Oral and informed consent will be obtained after providing plain language information [44]. Participation is voluntary, and it is possible, at any time, to withdraw from the study. The study is registered with the Danish Data Protection Agency (19/22672). Approval of the project is obtained from the Regional Committees on Health Research Ethics for Southern Denmark (S-20192000-111).

Data will be stored at Open Patient data Explorative Network (OP\_938)[45]. Findings will be published in suitable journals and disseminated through workshop and conferences.

## Patient and public involvement

The local Patient Council at OUH was consulted in the early design phase of the study, and their perspectives were taken into account. The core element of the study is built around user involvement and its strengths and limitations will be elaborated on in the discussion section.

## Discussion

The use of a participatory design provides an innovative approach through the inclusion of users across the health care setting. PD and its methods are very productive research approaches, directing the design of the solution to support patients' needs and organizational changes in clinical practice [31, 46]. The participatory approach ensures stakeholder involvement and sustainability of the designed solution as it is drawn directly from patients, family members and healthcare professionals. The data will provide a strong foundation to improve patient-valued outcomes and experiences of support. Coproduction and focus on future end-users are increasingly applied in designing and improving healthcare and have shown great potential to improve the quality and value of care [30, 43, 47]. In our study, we base the design and development on a qualitative foundation from the two main groups of end-users; patients'/family members' and healthcare professionals' descriptions of needs and preferences. By actively involving participants, the solution will be targeted the main issues [8] in acute care and the likelihood of actually improving family inclusive patient outcomes will increase. By enabling participants to meet and interact with each other, they are able to exchange knowledge, to inspire each other and to find support. We consider this interaction to be one of our study's main strengths, as we expect it to bring a better understanding of acute care. Collecting data at two different sites is considered a strength, as it will ensure the national generalizability of the findings.

As our protocol is based on coproduction, it may be at risk of logistical and practical challenges by gathering different stakeholders. Challenges posed by engaging health care professionals in workshops relate to staff resources, and this must be addressed [48]. Phase 1 challenges will be to sample enough participants to be representative as the ED has a great diversity of patients with different ages, needs, illness etc. Therefore, purposive sampling

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is chosen. Also, research in our own field with field observations may entail blind spots or irrelevant focus [34] and risk of the Hawthorne effect [49]. An observation guide inspired by Spradley will be mandatory to ensure a systematic approach [34]. Although it is expected that both parties (patient and family members) will actively participate in joint interviews, the advantages and disadvantages must be addressed. The main disadvantage is the risk that one of the participants being more conversational and may overrule the other one. However, joint interviews are chosen as the authors want to explore both perspectives and create a social interaction that could bring out their experiences in a nuanced way [40]. Involving participants actively in workshops and working in iterative processes will place demands regarding flexibility and willingness to change direction, if participants say so. This may be time consuming and costs intensive.

Summary

By focusing on coproduction, this study is expected to contribute to an improved health outcome of acute illness and an improved understanding of how to support patients and family members to reach the ability to manage their situation after a short ED episode.

Table 1: Target study population features for sampling patients in phase 1 of the Danish study “Acute Care planning in Emergency departments, The ACE study

Figure 1. The estimated time frame and methods of the Danish study “Acute Care planning in Emergency departments, The ACE study”

Figure 2: Progressive process of phase 1

Figure 3: Iterations of phase 2: plan, act, observe, reflect.

## List of abbreviations

- I. Participatory design (PD)
- II. Systematic text condensation (STC)
- III. Emergency Department (ED)

## Declarations

**Competing interests:** The authors declare no competing interests.

**Funding:** The study has received grants from The University of Southern Denmark, Odense University Hospital and the Region of Southern Denmark.

**Disclaimer:** The funders have no role in the design of the study, in the collection, analysis, or interpretation of data, in the writing of manuscripts or in decisions to publish results.

**Authors' contributions:**

ATL and CØ conceived the study. ATL, CMJ, KBD, EC and CØ designed the study. CØ took the lead in drafting the study protocol manuscript receiving inputs and feedback from ATL, CMJ, EC and KDB. All authors approved the final protocol.

**Ethics:** The study is registered with the Danish Data Protection Agency (19/22672), and data will be stored at a logged server at Open Patient data Explorative Network (OPEN\_938), Department of Clinical Research, University of Southern Denmark. The study is approved by the Regional Committees on health research Ethics for Southern Denmark (S-20192000-111).

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Figure 1:

Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.

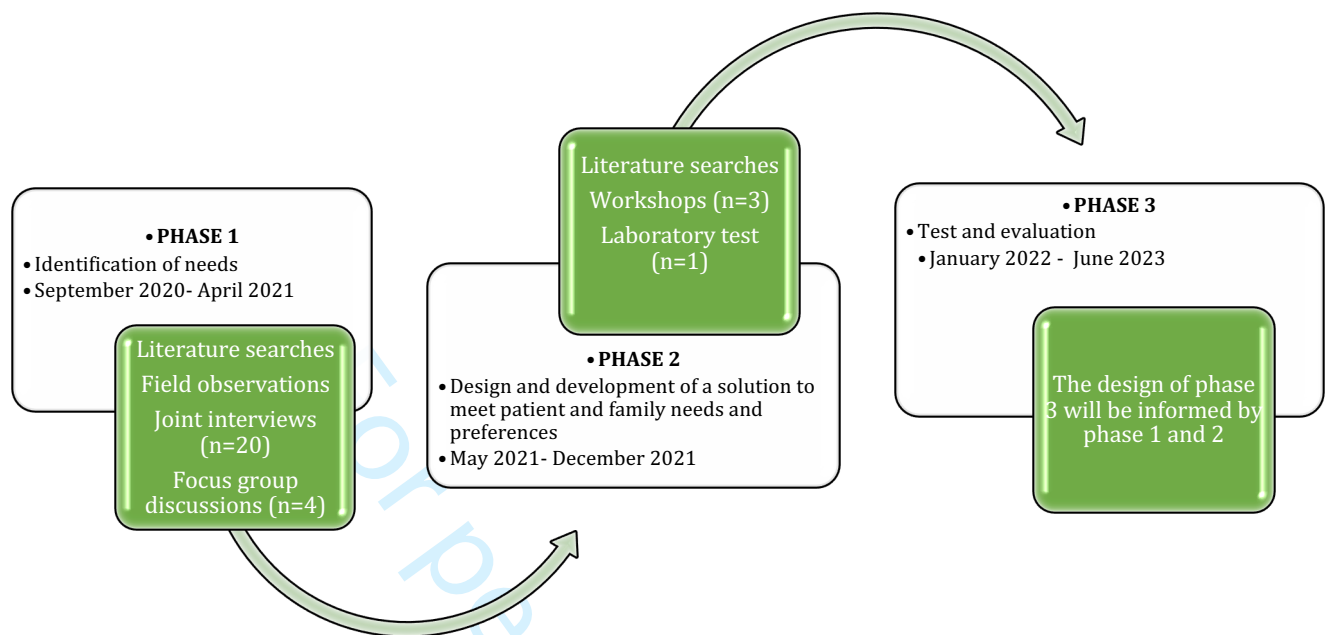


Figure 1. The estimated time frame and methods of the Danish study “Acute Care planning in Emergency departments, The ACE study”

Figure 2:  
Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.



Figure 2: Progressive process of phase 1

For peer review only

Figure 3: Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.

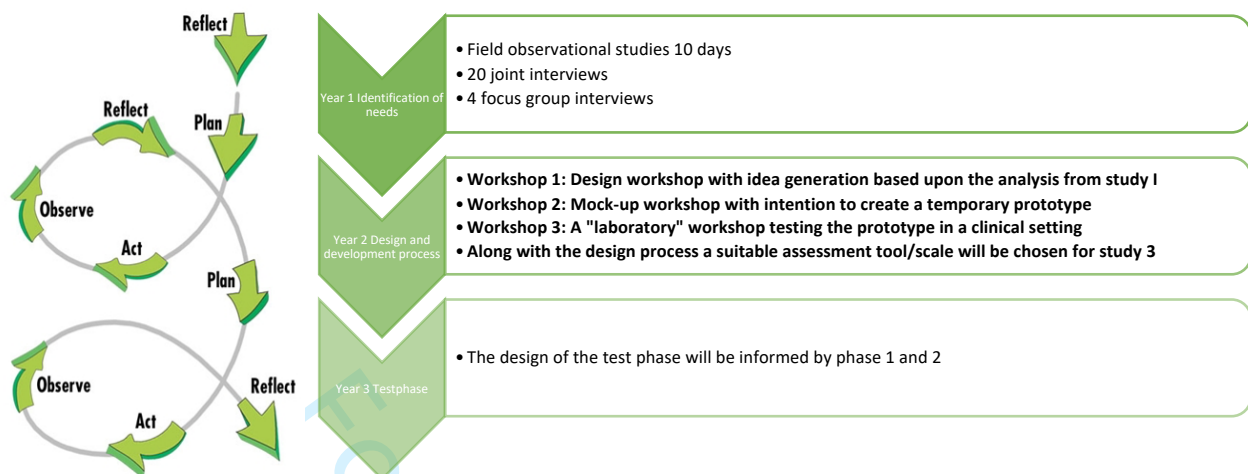


Figure 3: Iterations of phase 2: plan, act, observe, reflect. Figure inspired by Jensen et al. [29].

# BMJ Open

## How to improve emergency care to adults discharged within 24 hours? Acute Care planning in Emergency departments (The ACE study): a protocol of a participatory design study.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-041743.R2
Article Type:	Protocol
Date Submitted by the Author:	10-Nov-2020
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<b>Primary Subject Heading</b>:	Nursing
Secondary Subject Heading:	Emergency medicine
Keywords:	Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH, ACCIDENT & EMERGENCY MEDICINE, HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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## Title page

**Title:** How to improve emergency care to adults discharged within 24 hours? Acute Care planning in Emergency departments (The ACE study): a protocol of a participatory design study.

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Keywords

Emergency Department, Care planning, Family, Nursing, participatory design.

Wordcount:

3874 words excluding title page, references, figures and tables

## Abstract

**Introduction:** The development of acute symptoms or changes in diseases lead to feelings of fear and vulnerability and the need for health professional support. Therefore, the care provided in the acute medical and surgical areas of the Emergency Department (ED) is highly important as it influences the confidence of patients and families in managing everyday life after discharge. There is an increase in short-episode (<24 hours) hospital admissions, related to demographic changes and a focus on outpatient care. Clear discharge information and inclusion in treatment decisions increase the patient's and family's ability to understand and manage health needs after discharge, reducing the risk of readmission. This study aims to identify the needs for ED care and develop a solution to improve outcomes of patients discharged within 24 hours of admission.

**Methods and analysis:** The study comprises the three phases of a participatory design (PD). Phase 1 aims to understand and identify patient and family needs when discharged within 24 hours of admission. A qualitative observational study will be conducted in two different EDs, followed by 20 joint interviews with patients and their families. Four focus group interviews with healthcare professionals will provide understanding of the short pathways. Findings from phase 1 will inform phase 2, which aims to develop a solution to improve patient outcomes. Three workshops gathering relevant stakeholders are arranged in the design plus development of a solution with specific outcomes. The solution will be implemented and tested in phase 3. Here we report the study protocol of phase 1 and 2.

**Ethics and dissemination:** The study is registered with the Danish Data Protection Agency (19/22672). Approval of the project has been granted by the Regional Committees on Health Research Ethics for Southern Denmark (S-20192000-111). Findings will be published in suitable international journals and disseminated through conferences.

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**Strength and limitations of the study**

- ⇒ The proposed study will, through participatory design, combine methods into the design and test of an innovative solution, seeking to improve patient and family outcomes in connection to their discharge from the ED. This will provide insight into patient and family needs during their ED pathway.
- ⇒ It is a key feature in the study to ensure user involvement from all stakeholders and sustainability of the developed solution, as it is drawn directly from patients', family members' and healthcare professionals' statements, experiences and ideas.
- ⇒ The study includes family perspectives, which is limited in previous research from an ED perspective.
- ⇒ Using participatory design could be time consuming and might be a limitation, as it could be difficult to gather relevant stakeholders at same time.

## Introduction

When patients have an acute episode of symptoms or instability of a chronic disease, they often have feelings of fear and helplessness due to the uncertainty of the situation. This brings patients and their families to the Emergency Department (ED) in a vulnerable and distressed situation [1]. The care provided at the ED will influence the patient's and family members' experience of the current stay and influence their ability to understand and use health information for maintaining their health after discharge [1-3]. Family members rank supportive communication with nurses as vital to reduce stress and anxiety [4]. Emergency nursing care is administered by systematic guidelines based on e.g. Airway, Breathing, Circulation, Disability, Exposure (ABCDE) principles to support effective patient pathways and to identify specific patient needs making it possible for nurses to respond rapidly and effectively [5]. The majority of patients with acute symptoms are initially cared for in a general ED or common acute medical and surgical emergency unit [6]. Many countries have this organizational structure and systematic approach to ensure fast, systematic and comprehensive assessment along with the improvement of patient flow [7, 8]. The organizational structure has a positive effect on preventing overcrowding and is also a result of the reduced number of in-hospital beds [9]. Attention is often on organizational concerns, but there is a need for exploring patient-related aspects as well.

Acute nursing care is characterized by rapid and efficient treatments. This often results in short and fragmented encounters between patients and nurses [2, 10]. Previous research on patient perspectives has shown that patients feel that ED nurses seem to lose interest in the patient's life situation after the most acute treatment has been initiated [11]. In line with this, a Danish National survey revealed that 33% of patients did not experience that their family's perspective was considered important [12]. Furthermore, 30% of the patients participating in this survey reported that they were not involved in the decision-making process of their care [12]. These findings indicate that the international and national health standards for patient involvement are not met [13, 14]. Healthcare professionals' acknowledgment of the family's role and inclusion in care decisions enable the family to improve the patient outcomes, but also ensure that family caregivers understand information and are able to coordinate care and manage practicalities [15]. A way to improve the quality of

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care would be to give patients and families a stronger voice. This could help identify their needs and the resources they use, to enable supportive care to be tailored [16]. To enable nurses to assess and partner with patients and families to meet their needs and tailor care during short nurse–patient interactions, a nurse-led intervention may be useful [17]. Previous research exploring ED patients’ expected outcomes identified four main concerns; understanding diagnosis, symptom relief, reassurance and treatment plans [6, 18]. However, the family perspective was not reported in these studies. ED nurses highlight family members as an important resource to obtain information, and needs more research[19]. Furthermore, research has identified numerous discharge interventions and strategies to prevent readmissions; however, these are primarily concerning elderly, frail patients and not inclusive of family members [20-23]. Sparse research has been conducted focusing on the diversity of ED patients and their families, highlighting the need for interventions on how to assess and tailor care [24-26].

Objective

The overall aim of this study is to improve patient outcomes by nurse assessment and tailoring care for patients and family members discharged from the ED < 24 hours.

Following research objectives will guide each phase:

1. To create knowledge about what patients, family members, and health care professionals do and what they say they do, in connection to patients discharged within 24 hours (phase 1a).
2. To assess the needs and preferences of patients and families admitted in the ED to gain an understanding of patients and family needs (phase 1b).
3. To understand how health care professionals in the ED perceive patients and family needs and preferences and how they would accommodate these in their care(phase 1c).
4. To design and develop a solution to improve patient outcomes using focus group workshops (phase 2).

## Methods

The overall research design and methodology for this study is Participatory Design (PD) [27]. The Family System Theory [28] and the framework of Medical Research Council [29] for developing interventions in healthcare are used to guide the study.

### Study design

Participatory Design is chosen as research methodology as it includes the participants in the design phase and is relevant to use in research areas with limited knowledge[27]. PD is defined by making innovative solutions to problems in real life through a democratic stance and genuine participation of all relevant participants which represent future end-users of the field [30]. It enables the focus to be on future end-users in designing an intervention strategy that provides possibilities to improve patient outcomes in the ED. A PD process conducted in health science is typically performed in three interdependent phases [31] and is characterized by collective “reflection-in-action” iterations. In phase 1, the focus is to identify user needs. In phase 2, a prototype as a solution to cover the identified needs is developed. Finally, the solution is implemented and tested in a clinical setting and its effect and success will be evaluated. Here we report on the study protocol for phase 1 and 2. As the three phases are interdependent, phase 1 will provide the information and inform phase 2 and so on. Therefore, phase 2 cannot be predesigned, wherefore an exploratory approach will be used as design [27, 32]. With an explorative approach, patient outcomes are not defined in advance but will be identified by the patients and family members in the initial phase of the study. However, the main outcome must be focused on the quality of care expressed by patients. A literature review exploring ED patients’ outcomes and clinical interventions will be completed for each phase to ensure an understanding of current research to inform the study [33].

To identify patient and family needs and preferences, field observational studies inspired by Spradley [34] will be obtained by the first author, followed by joint semi-structured interviews of patients and family members [35]. Focus groups of health care professionals will enable sustainable and an achievable solution to develop. An intervention plan developed from phase 1 will be constructed and relevant stakeholders and future end-users of the solution will be invited to participate in three workshops to finalize the design. The workshops will be designed to focus on 1) generation of ideas 2) workshop with the intention to create mock-ups for the

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creation of a final prototype 3) A “laboratory” workshop where this prototype is pretested in a clinical setting [27]. A “laboratory” workshop is characterized as deliberately staged activities during which a controlled environment for exploration is created, and open collaboration between the participants is facilitated [27].

The Medical Research Council [29] framework of developing complex interventions will be used to guide this study 1) development 2) feasibility 3) evaluation in line with the three phases of the study’s research design, as illustrated in figure 1. The Medical Research Council argues that an intervention is complex when it contains several interacting components [29]. The current study will include a range of patients, families, healthcare professionals, and organizational changes.

Theoretical framework

The theoretical framework is based upon the Family Systems Theory [28] that care is provided holistically with patient and family as the unit of care. According to Wright & Leahey, family members could be spouses, partners, adult children, friends or others from the care-recipient’s social network who care for the patient. Family Systems Theory aims to help families to achieve stability in their lives by focusing on their internal relationships, resources and capacity to adapt to new situations caused by illness [28]. This framework guides the research process including sampling, designing intervention and research aims. After episodes of care in emergency the family is the main carer and provider of support. Therefore, to improve patient outcomes the family inclusion is required to enable family information needs to be met [11].

Setting

The study is carried out from September 2020-June 2023, shown in figure 1. Data will be collected from the ED at two hospital sites: 1) The Odense University Hospital (OUH), which is a 1000 bed university hospital, and covers all specialties and provides care for a population of 230.000 adults living in four municipalities. The ED seeing 69.000 annual attendees, mean age 45, treats 180 patients per day with a capacity of 42 beds and 30 examination rooms. On average, 32 patients are admitted to the hospital per day, and 50% are discharged within 24 hours.

2) Department of Emergency Medicine, Hospital of Lillebaelt, Kolding. Hospital of Kolding has the capacity of 320 beds. The ED seeing 50.000 annual attendees, mean age 45, receives 146

patients per day and has 58 beds and 5 trauma rooms beds capacity. The EDs are organized as they can control the allocation of the in-hospital beds at the rest of the hospital.

The Danish health care system is provided with open access and people do not need health insurance to be seen by a physician as it is a tax-funded welfare system. Acute patients are evaluated in person or by emergency calls by primary care physicians who act as gate-keepers before entering the ED. Denmark has a well-established and free of charge primary care, public pre-hospital emergency transport, and treatment at public hospitals. When patients are discharged they can get uncharged follow-up by their general practitioner, primary nursing care, or in an outpatient clinic.

The study is affiliated with the Family Focused Healthcare Research Center (FaCe) at the University of Southern Denmark [36].

## Participants

### Patients and family members:

Inclusion criteria:

Purposive sampling of patients:  $\geq 18$  years of age, Danish speaking, discharged  $< 24$  hours with medical or surgical symptoms. Family members, invited by the patient, are included.

The target study population is shown in table 1.

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<i>Patients (n=20)</i>	<i>Specific attributes</i>
<i>Age</i>	≥65 years of age / ≤65 years of age
<i>Sex</i>	Equal male and female
<i>Symptoms</i>	Equal surgical / medical symptoms
<i>Education level</i>	Below / above secondary school
<i>Function level</i>	Receiving primary care / not receiving primary care
<i>Social status</i>	Living independently / living with someone

*Table 1: Patient features in phase 1 of the Danish study “Acute Care planning in Emergency departments, The ACE study”*

Sampling strategy will ensure equally represented patients with first time visits among patients with multiple ED visits. Other collected variables: gender, age, civil status, educational level, length and frequency of stay, diagnosis, Charlsons comorbidity score and family relations.

Exclusion criteria:

Cognitive impairment assessed by the nurses by using Glasgow Coma Scale added by individual clinical judgement according to be able to understand the terms of participating in a research study. Highest and lowest triage level according to Danish Emergence Process Triage [37].

**Healthcare professionals:**

Nurses, physicians and physiotherapist working at the ED >6 months will be included. Inclusion will be done purposively to enable a broad sample of healthcare professionals.

Other collected variables: gender, age, profession, years since graduation years of employment at the ED, educational level.

**Collaborators and consultants:**

The participants in this category will be identified during the analysis of phase 1. It seems relevant to look into previous research, consulting experienced researchers within PD and

looking into exciting interventions in healthcare, IT software engineers, design schools, communication advisors, sociologists, anthropologists and cross-sectoral partners.

## Phase 1.a: Field observations

### Research objective:

To create knowledge about what patients, family members, and health care professionals do and what they say they do, in connection to patients discharged within 24 hours.

### Method:

Field observations will be conducted in both EDs (estimated n= 10 days of four hours a day) to include relevant perspectives in the understanding of patient and family needs and preferences. All sample sizes in the study are based on scientific guidance of qualitative research [38]. Field observational studies are chosen as it has the strength to create direct knowledge about what participants do and what they say they do [39], in connection to their treatment and care in the ED. Field observations are planned at different weekdays and times of the day to show the potential diversity. The duality of being a researcher, experienced nurse and employed at the department at the same time will be accessed as objectively as possible by using a template for documentation of field notes, inspired by Spradley [34]. Each day, field notes will be taken and transcribed immediately to secure correct recall [34]. The notes are expected to consist of descriptions, illustrations, and short quotations. Approval from the management of the departments was obtained in February 2020. Data from field observations will actively be used to understand what the patients have experienced and inform the development of the interview guide.

The interviewer is an experienced emergency nurse with a Master's degree (12 years of emergency nursing). From previous research she has experience doing intervention- and qualitative research[40, 41]. She is supervised by an experienced research team that is involved in every aspect of the project.

## Phase 1.b: Interviews with patients and family members

### Research objective:

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To assess the needs and preferences of patients and families admitted in the ED to gain an understanding of patients and family needs.

**Method:**

Guided by a phenomenological hermeneutical framework patients and family members from both EDs will be interviewed face-to-face or by telephone within the first week after their emergency visit (n=20). Recruitment of patients and family members will occur during the observational study. Patients will be approached and provided with a plain language information sheet of the study and asked if they would be interested. Once patients are recruited, family members will be invited into the study. Using a purposive sampling technique will ensure balance across the different patient features from table 1.

Semi-structured family interviews will be conducted in person. The interview guide will begin by asking participants to share about their visit to emergency. The researcher will ask participants to elaborate on different aspects of their emergency visit from the observation data collected. Interviews will be conducted at a time and place convenient for the patient and family member. Interviewing patients and family members is aimed at identifying both their individual and common experienced needs and preferences. Interviews enable the participant’s perspectives and experiences to be shared to gain an understanding of the experience [42]. A question example is: “What have you talked about since discharge?” We will continue until thematic saturation is reached; the point at which no new themes are emerging [38]. We chose this sampling strategy as it is designed to ensure that a full range of themes is elicited within each group.

**Phase 1.c: Focus group interviews with healthcare professionals**

**Research objective:**

To understand how health care professionals in the ED perceive patients and family needs and preferences and how they would accommodate these in their care.

**Method:**

Four focus groups will be conducted with approximately n=20 nurses and physicians equally from both sites. Focus groups are an effective way to produce group-level data, based on the interpretation, interaction and norms of social groups [43]. Participants are asked to discuss quotes from patients' and family members' interviews to understand healthcare professionals' perspectives and reactions to these quotes. The interactions between participants can lead to participants contributing spontaneous statements about the given subject, and new ideas are created. The first author moderates the focus group together with one of the more experienced researchers from the research team. Observations of the non-verbal communication, the group-interaction and elaborating questions will be recorded as field notes [43]. Each focus group will consist of 4-6 participants [44].

### Analysis: Phase 1 a-c

Qualitative data from the joint interviews, focus group interviews, and field observational studies will be synthesized and analyzed in a phenomenological and hermeneutical framework. The hermeneutic approach allows us to gain an insight into the individual's lived experience and provides an interpretive perspective to explicate meanings and assumptions in the data by studying and interpreting narrative[38].

To organize the process of the analysis, the steps from Malterud's [45] systematic text condensation (STC) will be used in NVivo12. Firstly, we will capture a general impression of the data and extract preliminary themes. Secondly, the data will be allocated into meaningful units which is a text section that represents pieces of information about a research question. The meaningful units will be condensed and coded and finally, findings will be synthesized. To ensure the trustworthiness and rigor of the analysis process we will follow the O'Brien et al standards for reporting qualitative research[46].

The progressive process line in phase one is shown in Figure 2. The progressive process line in phase one is shown in Figure 2.

### Phase 2: Design and development of a solution in a workshop process

The second phase is the actual development of a solution to improve patient outcomes by nurse assessment and improved tailored care to patients and family members, discharged from the ED<24 hours.

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Research objective:

To design and develop a solution to improve patient outcomes using focus group workshops (phase 2).

Method:

A co-design framework will be used. The process of design and development of a solution will be affected by involving participants across all areas in workshops and in the laboratory workshops. This will enable discussion of needs, mutual learning, and creativity, ensuring that the solution is innovative and user-focused [27]. Initially, an idea-generating workshop will be conducted, followed by a mock-up workshop, creating a temporary prototype of the solution. Workshops will consist of different participants representing different perspectives: patients, family members, various healthcare professionals, IT designers, innovation consultants, the research team among others. Collecting a broad variety of participants with different backgrounds, and perspectives will bring nuanced perspectives to the process and the ability to predict possible challenges with the prototype [27, 29]. The workshops will be facilitated as a space for creativity and “reflection-in-action” amongst participants. To facilitate this creative space, visualization tools will be used, such as posters, personas and note paper or post its[30]. The use of creative space allows participants and researchers to work as equal partners, bringing the iterative process into action. The results of the analysis will be presented for the invited participants by the research group to create direction. After the initial workshop, the research team will include the relevant stakeholders to proceed with the development of the solution. A possible solution will be informed by study I and the workshop process. Looking into previous research, intervention examples could be telehealth solutions, discharge follow-up or cross-sectoral collaboration[47]. Finally, a “laboratory” workshop pretesting the prototype sees its feasibility and acceptability in practice[30]. This workshop will include a smaller number of participants as the aim is narrow, compared to the creative, innovative workshops. The number of workshops and its attendees will depend on the process, but based on previous research using PD [30, 47], at least 3 workshops are estimated.

## Analysis:

Data from the workshops will be obtained as pictures, notes on posters, debriefing and recorded discussion during the workshops. The first author will transcribe and systematize the data into themes inspired by STC [45] and present them as a report. The report will be discussed by the research team and relevant collaborators for final adjustments before the test phase. The analysis and development of the model will be conducted iteratively in the following steps: plan, act, observe and reflect. This process is illustrated in figure 3.

The phase 3 evaluation will be developed from patient reported outcomes identified in phase 1 and during the development of the intervention in phase 2.

## Data management plan, ethics and dissemination:

Oral and informed consent will be obtained after providing plain language information [48]. Participation is voluntary, and it is possible, at any time, to withdraw from the study. The study is registered with the Danish Data Protection Agency (19/22672). Approval of the project is obtained from the Regional Committees on Health Research Ethics for Southern Denmark (S-20192000-111).

Data will be stored at Open Patient data Explorative Network (OP\_938)[49]. Findings will be published in suitable journals and disseminated through workshop and conferences.

## Patient and public involvement

The local Patient Council at OUH was consulted in the early design phase of the study, and their perspectives were taken into account. The core element of the study is built around user involvement and its strengths and limitations will be elaborated on in the discussion section.

## Discussion

The use of a participatory design provides an innovative approach through the inclusion of users across the health care setting. PD and its methods are very productive research approaches, directing the design of the solution to support patients' needs and organizational changes in clinical practice [31, 50]. The participatory approach ensures stakeholder involvement and sustainability of the designed solution as it is drawn directly from patients,

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family members and healthcare professionals. The data will provide a strong foundation to improve patient-valued outcomes and experiences of support. Coproduction and focus on future end-users are increasingly applied in designing and improving healthcare and have shown great potential to improve the quality and value of care [30, 47, 51]. In our study, we base the design and development on a qualitative foundation from the two main groups of end-users; patients'/family members' and healthcare professionals' descriptions of needs and preferences. By actively involving participants, the solution will be targeted the main issues [8] in acute care and the likelihood of actually improving family inclusive patient outcomes will increase. We consider participant interaction to be one of our study's main strengths, enabling a deeper understanding of emergency care. Collecting data at two different sites is considered a strength, as it will ensure the national generalizability of the findings.

As our protocol is based on coproduction, it may be at risk of logistical and practical challenges by gathering different stakeholders. Challenges posed by engaging health care professionals in workshops relate to staff resources, and this must be addressed [52]. Phase 1 challenges will be to sample enough participants to be representative as the ED has a great diversity of patients with different ages, needs and diseases. Therefore, purposive sampling is chosen. Field observations may lead to irrelevant focus [34] and risk of the Hawthorne effect [53], however, using an observation guide inspired by Spradley will ensure a systematic approach [34]. Although it is expected that both parties (patient and family members) will actively participate in joint interviews, the advantages and disadvantages must be addressed. The main disadvantage is the risk that one of the participants being more conversational and may overrule the other one. However, joint interviews are chosen as the authors want to explore both perspectives and create a social interaction that could bring out their experiences in a nuanced way [43]. Involving participants actively in workshops and working in iterative processes will place demands regarding flexibility and willingness to change direction, if participants say so. This may be time consuming and costs intensive.

## Summary

By focusing on coproduction, this study is expected to contribute to an improved health outcome of acute illness and an improved understanding of how to support patients and family members to reach the ability to manage their situation after a short ED episode.

Table 1: Patient features in phase 1 of the Danish study “Acute Care planning in Emergency departments, The ACE study”

Figure 1. The estimated time frame and methods of the Danish study “Acute Care planning in Emergency departments, The ACE study”

Figure 2: Progressive process of phase 1

Figure 3: Iterations of phase 2: plan, act, observe, reflect.

## List of abbreviations

- I. Participatory design (PD)
- II. Systematic text condensation (STC)
- III. Emergency Department (ED)
- IV. The Odense University Hospital (OUH)

## Declarations

**Competing interests:** The authors declare no competing interests.

**Funding:** The study has received grants from The University of Southern Denmark, Odense University Hospital and the Region of Southern Denmark.

**Disclaimer:** The funders have no role in the design of the study, in the collection, analysis, or interpretation of data, in the writing of manuscripts or in decisions to publish results.

### **Authors' contributions:**

ATL and CØ conceived the study. ATL, CMJ, KBD, EC and CØ designed the study. CØ took the lead in drafting the study protocol manuscript receiving inputs and feedback from ATL, CMJ, EC and KDB. All authors approved the final protocol.

**Ethics:** The study is registered with the Danish Data Protection Agency (19/22672), and data will be stored at a logged server at Open Patient data Explorative Network (OPEN\_938), Department of Clinical Research, University of Southern Denmark. The study is approved by the Regional Committees on health research Ethics for Southern Denmark (S-20192000-111).

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Figure 1:  
Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.

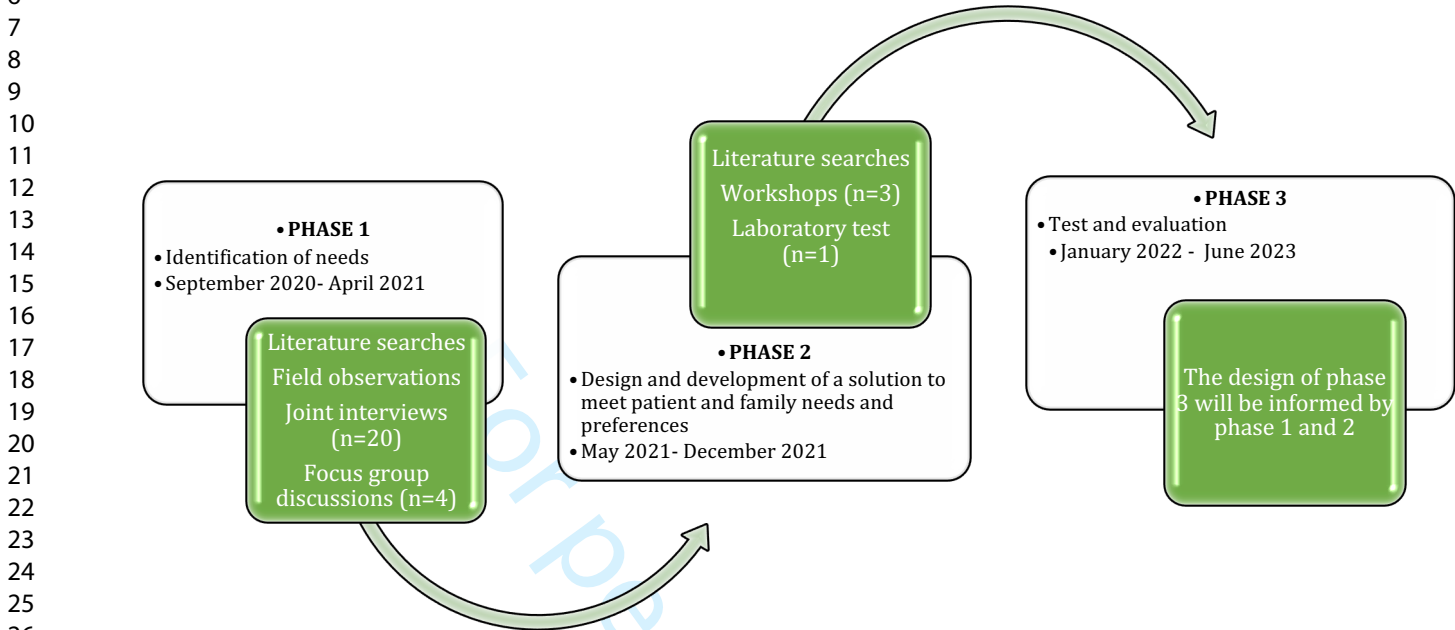


Figure 1. The estimated time frame and methods of the Danish study “Acute Care planning in Emergency departments, The ACE study”

Figure 2:

Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.



Figure 2: Progressive process of phase 1

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Figure 3: Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.

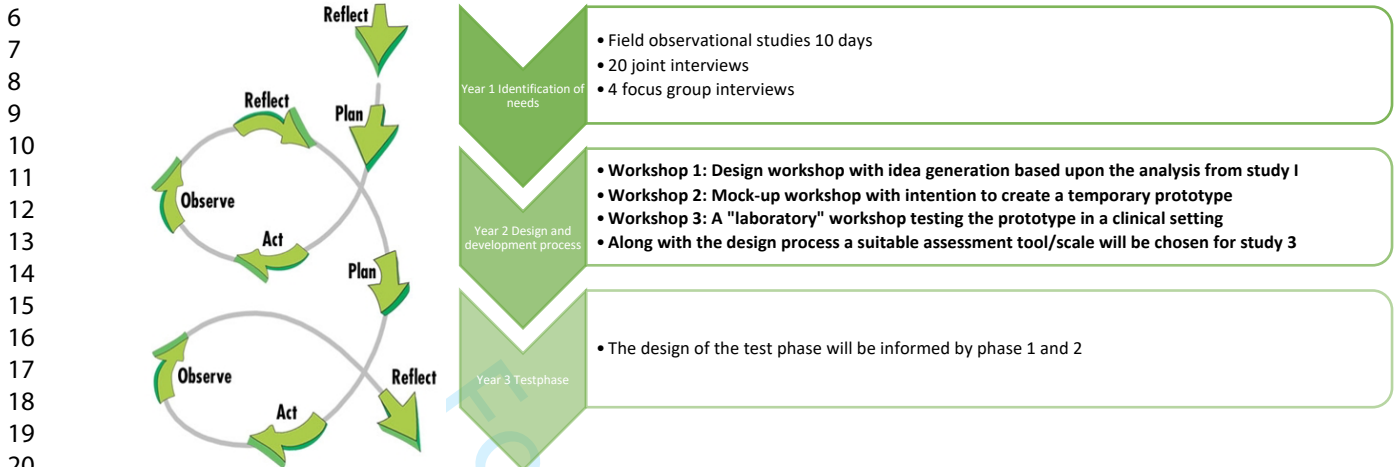


Figure 3: Iterations of phase 2: plan, act, observe, reflect. Figure inspired by Jensen et al. [29].

# BMJ Open

## How to improve emergency care to adults discharged within 24 hours? Acute Care planning in Emergency departments (The ACE study): a protocol of a participatory design study.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-041743.R3
Article Type:	Protocol
Date Submitted by the Author:	27-Nov-2020
Complete List of Authors:	Østervang , Christina ; Odense Universitetshospital, Department of Emergency medicine; University of Southern Denmark Faculty of Health Sciences, Clinical Institute Lassen, Annmarie; Odense University Hospital, Department of Emergency Medicine; University of Southern Denmark Faculty of Health Sciences, Clinical Institute Jensen, Charlotte; Odense Universitetshospital, Department of Orthopedics Surgery and Traumatology; University of Southern Denmark Faculty of Health Sciences, Clinical Institute Coyne, Elisabeth; Griffith University Faculty of Health, School of Nursing and Midwifery, Logan Campus; University of Southern Denmark Faculty of Health Sciences, Clinical Institute Dieperink, Karin; Odense University Hospital, Department of Oncology; University of Southern Denmark Faculty of Health Sciences, Clinical Institute
<b>Primary Subject Heading</b>:	Nursing
Secondary Subject Heading:	Emergency medicine
Keywords:	QUALITATIVE RESEARCH, ACCIDENT & EMERGENCY MEDICINE, HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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## Title page

**Title:** How to improve emergency care to adults discharged within 24 hours? Acute Care planning in Emergency departments (The ACE study): a protocol of a participatory design study.

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Keywords

Emergency Department, Care planning, Family, Nursing, participatory design.

Wordcount:

3950 words excluding title page, references, figures and tables

## Abstract

**Introduction:** The development of acute symptoms or changes in diseases lead to feelings of fear and vulnerability and the need for health professional support. Therefore, the care provided in the acute medical and surgical areas of the Emergency Department (ED) is highly important as it influences the confidence of patients and families in managing everyday life after discharge. There is an increase in short-episode (<24 hours) hospital admissions, related to demographic changes and a focus on outpatient care. Clear discharge information and inclusion in treatment decisions increase the patient's and family's ability to understand and manage health needs after discharge, reducing the risk of readmission. This study aims to identify the needs for ED care and develop a solution to improve outcomes of patients discharged within 24 hours of admission.

**Methods and analysis:** The study comprises the three phases of a participatory design (PD). Phase 1 aims to understand and identify patient and family needs when discharged within 24 hours of admission. A qualitative observational study will be conducted in two different EDs, followed by 20 joint interviews with patients and their families. Four focus group interviews with healthcare professionals will provide understanding of the short pathways. Findings from phase 1 will inform phase 2, which aims to develop a solution to improve patient outcomes. Three workshops gathering relevant stakeholders are arranged in the design plus development of a solution with specific outcomes. The solution will be implemented and tested in phase 3. Here we report the study protocol of phase 1 and 2.

**Ethics and dissemination:** The study is registered with the Danish Data Protection Agency (19/22672). Approval of the project has been granted by the Regional Committees on Health Research Ethics for Southern Denmark (S-20192000-111). Findings will be published in suitable international journals and disseminated through conferences.

**Strength and limitations of the study**

- ⇒ The proposed study will, through participatory design, combine methods into the design and test of an innovative solution, seeking to improve patient and family outcomes in connection to their discharge from the ED. This will provide insight into patient and family needs during their ED pathway.
- ⇒ It is a key feature in the study to ensure user involvement from all stakeholders and sustainability of the developed solution, as it is drawn directly from patients', family members' and healthcare professionals' statements, experiences and ideas.
- ⇒ The study includes family perspectives, which is limited in previous research from an ED perspective.
- ⇒ Using participatory design could be time consuming and might be a limitation, as it could be difficult to gather relevant stakeholders at same time.

## Introduction

When patients have an acute episode of symptoms or instability of a chronic disease, they often have feelings of fear and helplessness due to the uncertainty of the situation. This brings patients and their families to the Emergency Department (ED) in a vulnerable and distressed situation [1]. The care provided at the ED will influence the patient's and family members' experience of the current stay and influence their ability to understand and use health information for maintaining their health after discharge [1-3]. Family members rank supportive communication with nurses as vital to reduce stress and anxiety [4]. Emergency nursing care is administered by systematic guidelines based on e.g. Airway, Breathing, Circulation, Disability, Exposure (ABCDE) principles to support effective patient pathways and to identify specific patient needs making it possible for nurses to respond rapidly and effectively [5]. The majority of patients with acute symptoms are initially cared for in a general ED or common acute medical and surgical emergency unit [6]. Many countries have this organizational structure and systematic approach to ensure fast, systematic and comprehensive assessment along with the improvement of patient flow [7, 8]. The organizational structure has a positive effect on preventing overcrowding and is also a result of the reduced number of in-hospital beds [9]. Attention is often on organizational concerns, but there is a need for exploring patient-related aspects as well.

Acute nursing care is characterized by rapid and efficient treatments. This often results in short and fragmented encounters between patients and nurses [2, 10]. Previous research on patient perspectives has shown that patients feel that ED nurses seem to lose interest in the patient's life situation after the most acute treatment has been initiated [11]. In line with this, a Danish National survey revealed that 33% of patients did not experience that their family's perspective was considered important [12]. Furthermore, 30% of the patients participating in this survey reported that they were not involved in the decision-making process of their care [12]. These findings indicate that the international and national health standards for patient involvement are not met [13, 14]. Healthcare professionals' acknowledgment of the family's role and inclusion in care decisions enable the family to improve the patient outcomes, but also ensure that family caregivers understand information and are able to coordinate care and manage practicalities [15]. A way to improve the quality of

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care would be to give patients and families a stronger voice. This could help identify their needs and the resources they use, to enable supportive care to be tailored [16]. To enable nurses to assess and partner with patients and families to meet their needs and tailor care during short nurse–patient interactions, a nurse-led intervention may be useful [17]. Previous research exploring ED patients’ expected outcomes identified four main concerns; understanding diagnosis, symptom relief, reassurance and treatment plans [6, 18]. However, the family perspective was not reported in these studies. ED nurses highlight family members as an important resource to obtain information, and needs more research[19]. Furthermore, research has identified numerous discharge interventions and strategies to prevent readmissions; however, these are primarily concerning elderly, frail patients and not inclusive of family members [20-23]. Sparse research has been conducted focusing on the diversity of ED patients and their families, highlighting the need for interventions on how to assess and tailor care [24-26].

Objective

The overall aim of this study is to improve patient outcomes by nurse assessment and tailoring care for patients and family members discharged from the ED < 24 hours.

Following research objectives will guide each phase:

1. To create knowledge about what patients, family members, and health care professionals do and what they say they do, in connection to patients discharged within 24 hours (phase 1a).
2. To assess the needs and preferences of patients and families admitted in the ED to gain an understanding of patients and family needs (phase 1b).
3. To understand how health care professionals in the ED perceive patients and family needs and preferences and how they would accommodate these in their care(phase 1c).
4. To design and develop a solution to improve patient outcomes using focus group workshops (phase 2).

## Methods

The overall research design and methodology for this study is Participatory Design (PD) [27]. The Family System Theory [28] and the framework of Medical Research Council [29] for developing interventions in healthcare are used to guide the study.

### Study design

Participatory Design is chosen as research methodology as it includes the participants in the design phase and is relevant to use in research areas with limited knowledge[27]. PD is defined by making innovative solutions to problems in real life through a democratic stance and genuine participation of all relevant participants which represent future end-users of the field [30]. It enables the focus to be on future end-users in designing an intervention strategy that provides possibilities to improve patient outcomes in the ED. A PD process conducted in health science is typically performed in three interdependent phases [31] and is characterized by collective “reflection-in-action” iterations. In phase 1, the focus is to identify user needs. In phase 2, a prototype as a solution to cover the identified needs is developed. Finally, the solution is implemented and tested in a clinical setting and its effect and success will be evaluated. Here we report on the study protocol for phase 1 and 2. As the three phases are interdependent, phase 1 will provide the information and inform phase 2 and so on. Therefore, phase 2 cannot be predesigned, wherefore an exploratory approach will be used as design [27, 32]. With an explorative approach, patient outcomes are not defined in advance but will be identified by the patients and family members in the initial phase of the study. However, the main outcome must be focused on the quality of care expressed by patients. A literature review exploring ED patients’ outcomes and clinical interventions will be completed for each phase to ensure an understanding of current research to inform the study [33].

To identify patient and family needs and preferences, field observational studies inspired by Spradley [34] will be obtained by the first author, followed by joint semi-structured interviews of patients and family members [35]. Focus groups of health care professionals will enable sustainable and an achievable solution to develop. An intervention plan developed from phase 1 will be constructed and relevant stakeholders and future end-users of the solution will be invited to participate in three workshops to finalize the design. The workshops will be designed to focus on 1) generation of ideas 2) workshop with the intention to create mock-ups for the

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creation of a final prototype 3) A “laboratory” workshop where this prototype is pretested in a clinical setting [27]. A “laboratory” workshop is characterized as deliberately staged activities during which a controlled environment for exploration is created, and open collaboration between the participants is facilitated [27].

The Medical Research Council [29] framework of developing complex interventions will be used to guide this study 1) development 2) feasibility 3) evaluation in line with the three phases of the study’s research design, as illustrated in figure 1. The Medical Research Council argues that an intervention is complex when it contains several interacting components [29]. The current study will include a range of patients, families, healthcare professionals, and organizational changes.

Theoretical framework

The theoretical framework is based upon the Family Systems Theory [28] that care is provided holistically with patient and family as the unit of care. According to Wright & Leahey, family members could be spouses, partners, adult children, friends or others from the care-recipient’s social network who care for the patient. Family Systems Theory aims to help families to achieve stability in their lives by focusing on their internal relationships, resources and capacity to adapt to new situations caused by illness [28]. This framework guides the research process including sampling, designing intervention and research aims. After episodes of care in emergency the family is the main carer and provider of support. Therefore, to improve patient outcomes the family inclusion is required to enable family information needs to be met [11].

Setting

The study is carried out from September 2020-June 2023, shown in figure 1. Data will be collected from the ED at two hospital sites: 1) The Odense University Hospital (OUH), which is a 1000 bed university hospital, and covers all specialties and provides care for a population of 230.000 adults living in four municipalities. The ED seeing 69.000 annual attendees, mean age 45, treats 180 patients per day with a capacity of 42 beds and 30 examination rooms. On average, 32 patients are admitted to the hospital per day, and 50% are discharged within 24 hours.

2) Department of Emergency Medicine, Hospital of Lillebaelt, Kolding. Hospital of Kolding has the capacity of 320 beds. The ED seeing 50.000 annual attendees, mean age 45, receives 146

patients per day and has 58 beds and 5 trauma rooms beds capacity. The EDs are organized as they can control the allocation of the in-hospital beds at the rest of the hospital.

The Danish health care system is provided with open access and people do not need health insurance to be seen by a physician as it is a tax-funded welfare system. Acute patients are evaluated in person or by emergency calls by primary care physicians who act as gate-keepers before entering the ED. Denmark has a well-established and free of charge primary care, public pre-hospital emergency transport, and treatment at public hospitals. When patients are discharged they can get uncharged follow-up by their general practitioner, primary nursing care, or in an outpatient clinic.

The study is affiliated with the Family Focused Healthcare Research Center (FaCe) at the University of Southern Denmark [36].

## Participants

### Patients and family members:

Inclusion criteria:

Purposive sampling of patients:  $\geq 18$  years of age, Danish speaking, discharged  $< 24$  hours with medical or surgical symptoms. Family members, invited by the patient, are included.

The target study population is shown in table 1.

<i>Patients (n=20)</i>	<i>Specific attributes</i>
<i>Age</i>	$\geq 65$ years of age / $\leq 65$ years of age
<i>Sex</i>	Equal male and female
<i>Symptoms</i>	Equal surgical / medical symptoms
<i>Education level</i>	Below / above secondary school
<i>Function level</i>	Receiving primary care / not receiving primary care
<i>Social status</i>	Living independently / living with someone

*Table 1: Patient features in phase 1 of the Danish study “Acute Care planning in Emergency departments, The ACE study”*

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Sampling strategy will ensure equally represented patients with first time visits among patients with multiple ED visits. Other collected variables: gender, age, civil status, educational level, length and frequency of stay, diagnosis, Charlsons comorbidity score and family relations.

Exclusion criteria:

Cognitive impairment assessed by the nurses by using Glasgow Coma Scale added by individual clinical judgement according to be able to understand the terms of participating in a research study. Highest and lowest triage level according to Danish Emergence Process Triage [37].

Healthcare professionals:

Nurses, physicians and physiotherapist working at the ED >6 months will be included. Inclusion will be done purposively to enable a broad sample of healthcare professionals.

Other collected variables: gender, age, profession, years since graduation years of employment at the ED, educational level.

Collaborators and consultants:

The participants in this category will be identified during the analysis of phase 1. It seems relevant to look into previous research, consulting experienced researchers within PD and looking into exciting interventions in healthcare, IT software engineers, design schools, communication advisors, sociologists, anthropologists and cross-sectoral partners.

Phase 1.a: Field observations

Research objective:

To create knowledge about what patients, family members, and health care professionals do and what they say they do, in connection to patients discharged within 24 hours.

Method:

Field observations will be conducted in both EDs (estimated n= 10 days of four hours a day) to include relevant perspectives in the understanding of patient and family needs and preferences.

We chose four to six hours as time frame for the field observations based on National standards stating that patients in the Danish EDs should receive a treatment plan within four hours[38]. All sample sizes in the study are based on scientific guidance of qualitative research [39]. Field observational studies are chosen as it has the strength to create direct knowledge about what participants do and what they say they do [40], in connection to their treatment and care in the ED. Field observations are planned at different weekdays and times of the day to show the potential diversity. The duality of being a researcher, experienced nurse and employed at the department at the same time will be accessed as objectively as possible by using a template for documentation of field notes, inspired by Spradley [34]. Each day, field notes will be taken and transcribed immediately to secure correct recall [34]. The notes are expected to consist of descriptions, illustrations, and short quotations. Approval from the management of the departments was obtained in February 2020. Data from field observations will actively be used to understand what the patients have experienced and inform the development of the interview guide.

The interviewer is an experienced emergency nurse with a Master's degree (12 years of emergency nursing). From previous research she has experience doing intervention- and qualitative research[41, 42]. She is supervised by an experienced research team that is involved in every aspect of the project.

## Phase 1.b: Interviews with patients and family members

### Research objective:

To assess the needs and preferences of patients and families admitted in the ED to gain an understanding of patients and family needs.

### Method:

Guided by a phenomenological hermeneutical framework patients and family members from both EDs will be interviewed face-to-face or by telephone within the first week after their emergency visit (n=20). Recruitment of patients and family members will occur during the observational study. Patients will be approached and provided with a plain language information sheet of the study and asked if they would be interested. Once patients are

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recruited, family members will be invited into the study. Using a purposive sampling technique will ensure balance across the different patient features from table 1.

Semi-structured family interviews will be conducted in person. The interview guide will begin by asking participants to share about their visit to emergency. The researcher will ask participants to elaborate on different aspects of their emergency visit from the observation data collected. Interviews will be conducted at a time and place convenient for the patient and family member. Interviewing patients and family members is aimed at identifying both their individual and common experienced needs and preferences. Interviews enable the participant’s perspectives and experiences to be shared to gain an understanding of the experience [43]. A question example is: “What have you talked about since discharge?” We will continue recruitment until thematic saturation is reached; the point at which no new themes are emerging [39]. This will include a minimum of 20 participants to secure maximal variation of the target group but will be continued if the thematic saturation is not reached within this sample size. We chose this sampling strategy as it is designed to ensure that a full range of themes is elicited within each group.

Phase 1.c: Focus group interviews with healthcare professionals

Research objective:

To understand how health care professionals in the ED perceive patients and family needs and preferences and how they would accommodate these in their care.

Method:

Four focus groups will be conducted with approximately n=20 nurses and physicians equally from both sites. Focus groups are an effective way to produce group-level data, based on the interpretation, interaction and norms of social groups [44]. Participants are asked to discuss quotes from patients’ and family members’ interviews to understand healthcare professionals’ perspectives and reactions to these quotes. The interactions between participants can lead to participants contributing spontaneous statements about the given subject, and new ideas are created. The first author moderates the focus group together with one of the more experienced researchers from the research team. Observations of the non-verbal communication, the group-

interaction and elaborating questions will be recorded as field notes [44]. Each focus group will consist of 4-6 participants [45].

### Analysis: Phase 1 a-c

Qualitative data from the joint interviews, focus group interviews, and field observational studies will be synthesized and analyzed in a phenomenological and hermeneutical framework. The hermeneutic approach allows us to gain an insight into the individual's lived experience and provides an interpretive perspective to explicate meanings and assumptions in the data by studying and interpreting narrative[39].

To organize the process of the analysis, the steps from Malterud's [46] systematic text condensation (STC) will be used in NVivo12. Firstly, we will capture a general impression of the data and extract preliminary themes. Secondly, the data will be allocated into meaningful units which is a text section that represents pieces of information about a research question. The meaningful units will be condensed and coded and finally, findings will be synthesized. To ensure the trustworthiness and rigor of the analysis process we will follow the O'Brien et al standards for reporting qualitative research[47].

The progressive process line in phase one is shown in Figure 2. The progressive process line in phase one is shown in Figure 2.

### Phase 2: Design and development of a solution in a workshop process

The second phase is the actual development of a solution to improve patient outcomes by nurse assessment and improved tailored care to patients and family members, discharged from the ED<24 hours.

### Research objective:

To design and develop a solution to improve patient outcomes using focus group workshops (phase 2).

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A co-design framework will be used. The process of design and development of a solution will be affected by involving participants across all areas in workshops and in the laboratory workshops. This will enable discussion of needs, mutual learning, and creativity, ensuring that the solution is innovative and user-focused [27]. Initially, an idea-generating workshop will be conducted, followed by a mock-up workshop, creating a temporary prototype of the solution. Workshops will consist of different participants representing different perspectives: patients, family members, various healthcare professionals, IT designers, innovation consultants, the research team among others. Collecting a broad variety of participants with different backgrounds, and perspectives will bring nuanced perspectives to the process and the ability to predict possible challenges with the prototype [27, 29]. The workshops will be facilitated as a space for creativity and “reflection-in-action” amongst participants. To facilitate this creative space, visualization tools will be used, such as posters, personas and note paper or post its[30]. The use of creative space allows participants and researchers to work as equal partners, bringing the iterative process into action. The results of the analysis will be presented for the invited participants by the research group to create direction. After the initial workshop, the research team will include the relevant stakeholders to proceed with the development of the solution. A possible solution will be informed by study I and the workshop process. Looking into previous research, intervention examples could be telehealth solutions, discharge follow-up or cross-sectoral collaboration[48]. Finally, a “laboratory” workshop pretesting the prototype sees its feasibility and acceptability in practice[30]. This workshop will include a smaller number of participants as the aim is narrow, compared to the creative, innovative workshops. The number of workshops and its attendees will depend on the process, but based on previous research using PD [30, 48], at least 3 workshops are estimated.

Analysis:

Data from the workshops will be obtained as pictures, notes on posters, debriefing and recorded discussion during the workshops. The first author will transcribe and systematize the data into themes inspired by STC [46] and present them as a report. The report will be discussed by the research team and relevant collaborators for final adjustments before the test

phase. The analysis and development of the model will be conducted iteratively in the following steps: plan, act, observe and reflect. This process is illustrated in figure 3.

The phase 3 evaluation will be developed from the most important patient reported outcomes identified in phase 1 and targeting the intervention in phase 2. The evaluation phase 3 will be published in a separate study protocol.

### Data management plan, ethics and dissemination:

Oral and informed consent will be obtained after providing plain language information [49]. Participation is voluntary, and it is possible, at any time, to withdraw from the study. The study is registered with the Danish Data Protection Agency (19/22672). Approval of the project is obtained from the Regional Committees on Health Research Ethics for Southern Denmark (S-20192000-111).

Data will be stored at Open Patient data Explorative Network (OP\_938)[50]. Findings will be published in suitable journals and disseminated through workshop and conferences.

### Patient and public involvement

The local Patient Council at OUH was consulted in the early design phase of the study, and their perspectives were taken into account. The core element of the study is built around user involvement and its strengths and limitations will be elaborated on in the discussion section.

### Discussion

The use of a participatory design provides an innovative approach through the inclusion of users across the health care setting. PD and its methods are very productive research approaches, directing the design of the solution to support patients' needs and organizational changes in clinical practice [31, 51]. The participatory approach ensures stakeholder involvement and sustainability of the designed solution as it is drawn directly from patients, family members and healthcare professionals. The data will provide a strong foundation to improve patient-valued outcomes and experiences of support. Coproduction and focus on future end-users are increasingly applied in designing and improving healthcare and have shown great potential to improve the quality and value of care [30, 48, 52]. In our study, we

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base the design and development on a qualitative foundation from the two main groups of end-users; patients'/family members' and healthcare professionals' descriptions of needs and preferences. By actively involving participants, the solution will be targeted the main issues [8] in acute care and the likelihood of actually improving family inclusive patient outcomes will increase. We consider participant interaction to be one of our study's main strengths, enabling a deeper understanding of emergency care. Collecting data at two different sites is considered a strength, as it will ensure the national generalizability of the findings.

As our protocol is based on coproduction, it may be at risk of logistical and practical challenges by gathering different stakeholders. Challenges posed by engaging health care professionals in workshops relate to staff resources, and this must be addressed [53]. Phase 1 challenges will be to sample enough participants to be representative as the ED has a great diversity of patients with different ages, needs and diseases. Therefore, purposive sampling is chosen. Field observations may lead to irrelevant focus [34] and risk of the Hawthorne effect [54], however, using an observation guide inspired by Spradley will ensure a systematic approach [34]. Although it is expected that both parties (patient and family members) will actively participate in joint interviews, the advantages and disadvantages must be addressed. The main disadvantage is the risk that one of the participants being more conversational and may overrule the other one. However, joint interviews are chosen as the authors want to explore both perspectives and create a social interaction that could bring out their experiences in a nuanced way [44]. Involving participants actively in workshops and working in iterative processes will place demands regarding flexibility and willingness to change direction, if participants say so. This may be time consuming and costs intensive.

## Summary

By focusing on coproduction, this study is expected to contribute to an improved health outcome of acute illness and an improved understanding of how to support patients and family members to reach the ability to manage their situation after a short ED episode.

Table 1: Patient features in phase 1 of the Danish study “Acute Care planning in Emergency departments, The ACE study”

Figure 1. The estimated time frame and methods of the Danish study “Acute Care planning in

Emergency departments, The ACE study”

Figure 2: Progressive process of phase 1

Figure 3: Iterations of phase 2: plan, act, observe, reflect.

## List of abbreviations

- I. Participatory design (PD)
- II. Systematic text condensation (STC)
- III. Emergency Department (ED)
- IV. The Odense University Hospital (OUH)

## Declarations

**Competing interests:** The authors declare no competing interests.

**Funding:** The study has received grants from The University of Southern Denmark, Odense University Hospital and the Region of Southern Denmark.

**Disclaimer:** The funders have no role in the design of the study, in the collection, analysis, or interpretation of data, in the writing of manuscripts or in decisions to publish results.

### **Authors' contributions:**

ATL and CØ conceived the study. ATL, CMJ, KBD, EC and CØ designed the study. CØ took the lead in drafting the study protocol manuscript receiving inputs and feedback from ATL, CMJ, EC and KDB. All authors approved the final protocol.

**Ethics:** The study is registered with the Danish Data Protection Agency (19/22672), and data will be stored at a logged server at Open Patient data Explorative Network (OPEN\_938), Department of Clinical Research, University of Southern Denmark. The study is approved by the Regional Committees on health research Ethics for Southern Denmark (S-20192000-111).

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Figure 1:

Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.

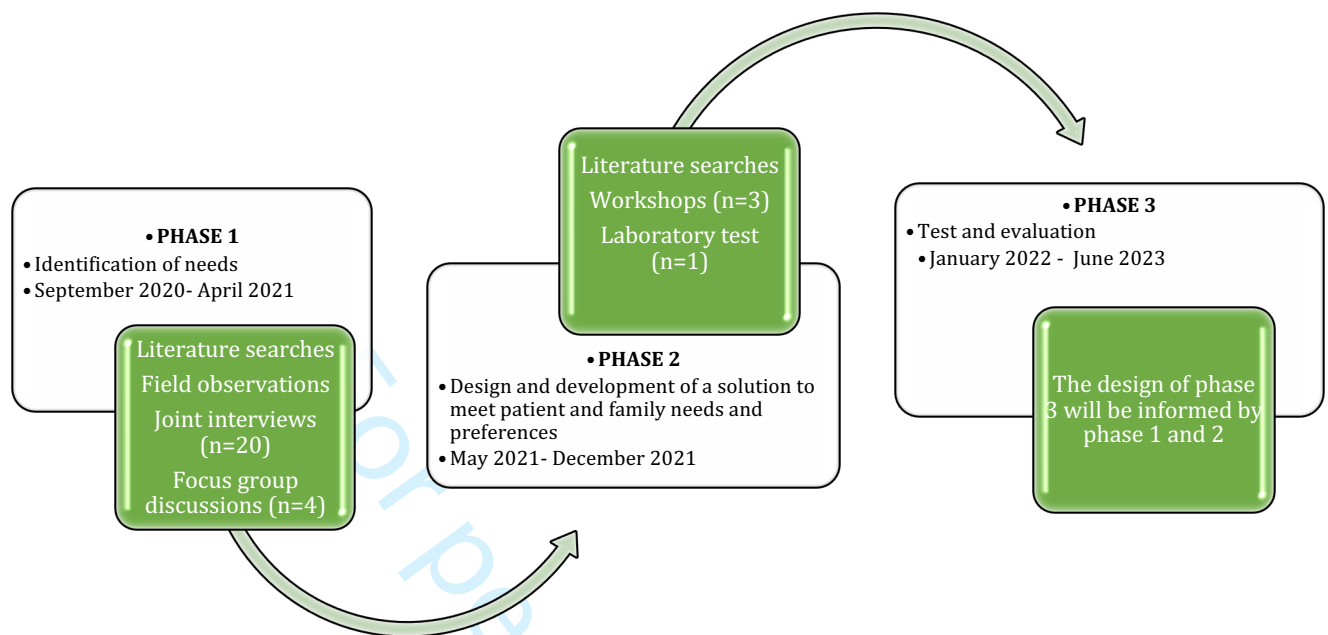


Figure 1. The estimated time frame and methods of the Danish study “Acute Care planning in Emergency departments, The ACE study”

Figure 2:  
Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.



Figure 2: Progressive process of phase 1

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Figure 3: Acute Care planning in Emergency departments (The ACE study): protocol of a participatory design study.

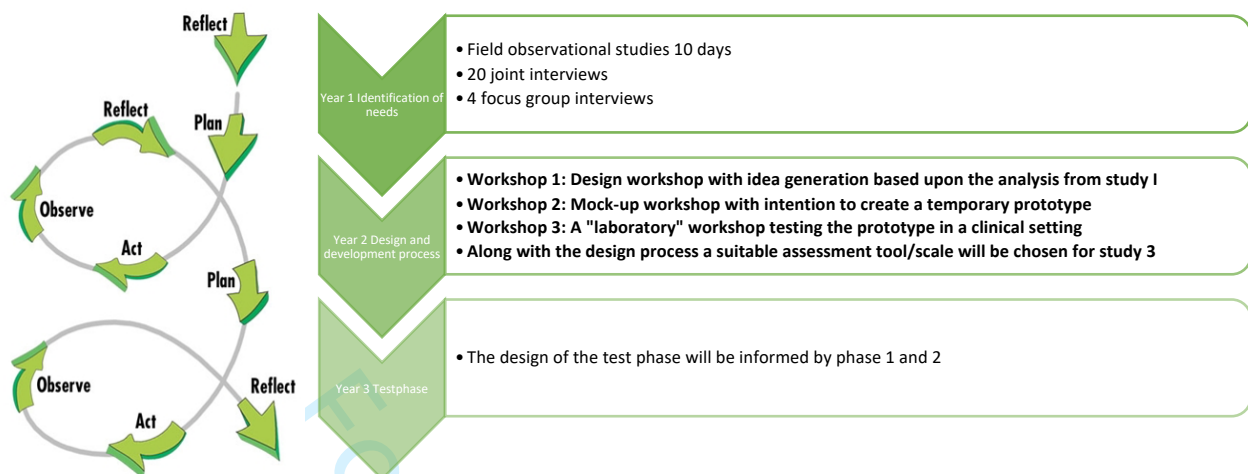


Figure 3: Iterations of phase 2: plan, act, observe, reflect. Figure inspired by Jensen et al. [29].