PROCESS REPORT

How might we improve the support and increase the focus on relatives within palliative care of terminal patients?

Study programme: MSc Service Systems Design // Theme: Healthcare
Project duration: 8th of September to the 21st of December 2016
Supervisor: Fanny Giordano // Group: 9

MEET THE TEAM

KALINKA

I have a bachelor education specializing in concept development from KEA. I have a solid knowledge of quantitative & qualitative research, digital marketing, project management and experience from multiple creative projects.

CHRISTEL

I am an educated Multimedia Designer and Digital Concept Developer from Copenhagen School of Technology and Design. I have flair for graphic design and human centered design and I have experience working with digital marketing.

CHRIS

I have a background in technology management and marine engineering, this combined with my craftsmanship degree has given me a profound understanding of machinery and a practical problem-solving approach. With this project I hope to develop a better understanding of wicked problems and how they can be tackled In collaboration with others.

RAKEL

I have an AP diploma in Designtechnology and PBA in Sustainable Purchasing from KEA. I´m interested in innovative solutions and design. I have experience working with sustainabilty, CSR, implementing new strategies as well as developing and making products.

KASPER

I have a bachelor degree in IT Product Design from Institute of Computer Science, Aarhus University. I have skills in programming, sketching and physical design and computing. I am very interested in innovation theory, this amounts at the moment to reading books on social and frame innovation.

CONTENTS

PREFACE

During the first semester of The Master programme (Service Systems Design), we have been working on a project that will be delivered in a form of two different reports, a *Product* and a *Process Report*. This is the *Process Report* and it will show decisions, methods, tools and most importantly how all of these have been applied throughout the project.

It is important to understand that the project's objective changes throughout the report in the form of problem statements and target groups. These changes was made on the basis of research, interviews and discussions within our group. Therefore the project objective in the beginning is not equal to the final one. When enough information on the subject is gathered, fluctuations in the objective and problem statement will begin flattening out. At this point the system design begins and the objective of the design of this system will correspond to what the current problem statement is.

Additionally, the purpose of the Process Report is to explain how we as a group have reached different conclusions, why one method or tool was chosen over another and how they were applied. It has been to illustrate the phases we have been through when designing the service. The Process Report helps teachers and supervisors understand these factors, for this reason it is not well suited for "showcasing" the final product, but rather to give insights into the process of how the final product was reached.

Copenhagen Healthtech Cluster have supplied the group with the original concept and proposal, which is why the project focuses on designing or redesigning parts of the healthcare sector that may improve the end-of-life experience for terminally chronically ill[1] patients and their families here in Denmark.

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[1] Terminal Chronically Ill will be referred to by the abbreviation TCI.

READING GUIDE

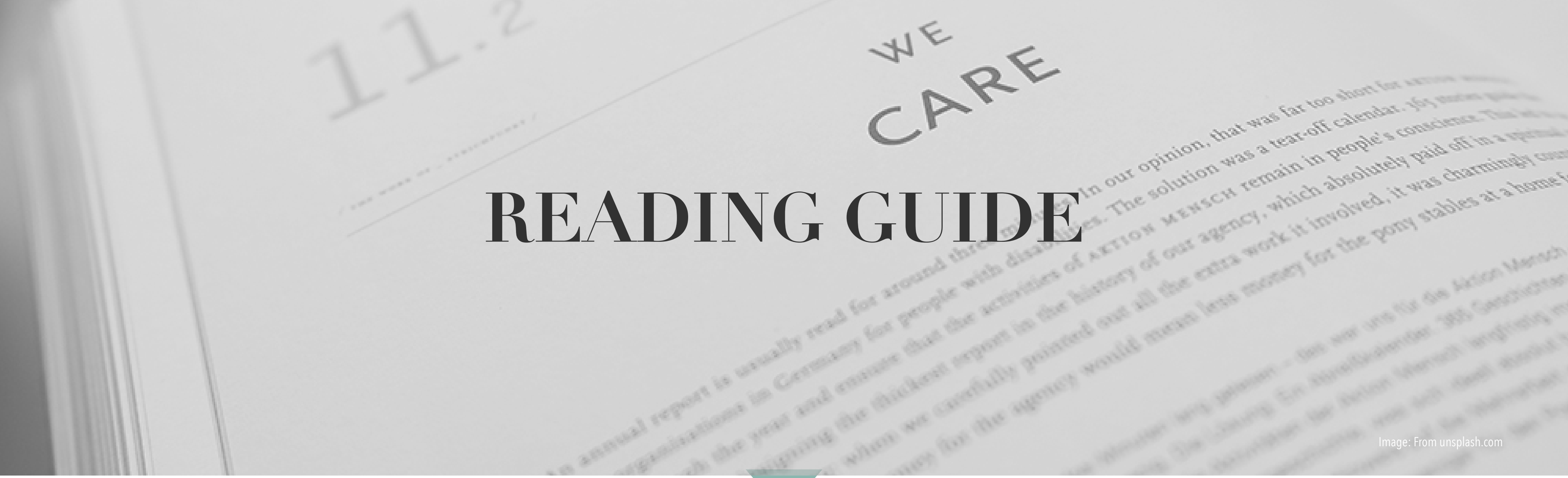

Image: From unsplash.com

Main terms used throughout the report have been defined in the Definitions Chapter. We suggest that the reader is familiar with these before continuing with the report.

For reading purposes terms, names or other words that impact the flow will be abbreviated after their first appearance, this is done in the footnotes of the report.

The reader can stumble upon repetitions throughout the report, but they are made to make the reading experience easier and will be used to keep the reader aware on certain matters, without needing to go back and forth in the report or remembering certain phrases by heart.

Throughout this report the APA method is used for referencing. Only illustrations that are not the authors will include sources. The appendix will be used for material that is too long to be included in the main body of the report, but still has a significant importance for its understanding.

For links or other web based references embedded in the text the link is changed to a google link in order to shorten the length and make the text more fluid

ABSTRACT

There is a common understanding among researchers that the majority of terminally ill patients wish to die at their homes. Through this report we will investigate how we can help patients and stakeholders grant this wish. We involve users from the beginning of the design process, identifying their needs and what factors are important for them, based on this information we locate the most important users as well as create personas that help us understand and empathize with the parties involved. We do this to keep the user in the centre and to help us maintain a certain focus on them throughout the entire design process. In order for the patient and relatives to go through a harmonious palliative treatment, there has to be equally focus on their spiritual, mental, physical and social health. We saw that relatives tend to be forgotten, especially after the patient dies. Some of the relatives were not willing to take upon the very difficult task of caring for their loved ones at home. Because the relatives are such a big part of the patients chances of ending their lives at home we decided that the best way to grant the patient's wish, as well as secure a better palliative experience for relatives, was to create a service that officers to help relatives with daily tasks and chores. By freeing up time from their schedule with tasks, we believe that it can enable them to take better care of their loved ones. Research and prototypetests showed that relatives were wary of using a service like this, they had a need of trust when it came to encounters strangers or volunteers with these tasks.

DEFINITIONS

The purpose of this chapter is to explain and define important terms to the reader which will improve the overall understanding of the subject.

HOSPICE

In danish and english the word "hospice" describes two different things. Through the report the hospice visited by the group is located in Denmark, thus the Danish definition for these will be used, Sundhed.dk defines a hospice as:

- *a place, that provides professional care, comfort and pain relief for terminally ill patients.*

A person can spend their last days in a hospice if they have a serious illness with no prospect of recovery.

HOME HOSPICE

Because some patients wish to die in their own home, the majority of the Danish hospices have a "home hospice unit" this unit works in close collaboration with the general practitioner (GP) and home care, the patient and relatives have direct phone contact to this unit all hours of the day. However many patients who wish to die at home spend their final days in the hospice itself. (sundhed.dk)

TERMINAL ILLNESS

A patient is terminally ill when there is no treatment available that can prevent or stop the illness from killing the patient in the near future. Sundhed.dk defines terminal illness as: *"a progressive disease where death as a consequence of that disease can be reasonably be expected within 6 months"*.

PALLIATIVE CARE

The World Health Organization defines palliative care as: *"…an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"*

Image: From unsplash.com

Furthermore, WHO[1] mentions nine important objectives that palliative care addresses, among these are the following:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.*

The full definition together with the nine focus points of palliative care can be found in the appendix (Appendix 1).

SPECIALIZED PALLIATIVE CARE

The Danish Health Authorities have defined two levels of palliative care, a basic and a specialized palliative level.

The basic palliative level is defined as: *"The palliative effort at basic level concerns the effort at general hospital wards and in the patients' homes. The effort at the hospitals is performed by the hospital staff and the patients' homes by the general practitioner (GP) and home care services".*

The specialist level is defined as: *"The palliative effort at specialist level concerns the patient who has a complex symptomatology and who demands a specialised and / or an inter-professional effort, including support for psychosocial and existential problems. The tasks of the palliative specialist care teams, are in collaboration with the GP and the community nurse, to improve the patient's ability to stay at home during the palliative period, to die at home and avoid unnecessary admittances to hospitals"* (Danish National Board of Health - Recommendations for Palliative care, 2011).

PALLIATIVE HOME CARE

"Palliative home care includes all palliative care services performed in the patient's homes for patients living in a nursing home, the nursing home is considered their home and the palliative care effort performed at nursing homes should therefore be included in palliative home care." (Brogaard T., 2011)

SHARED CARE

Patients in home care are most often in contact with GP's, community nurses (CNs), hospital consultants, and sometimes also with a palliative specialized team. Shared care may be an approach to organise collaboration between professionals involved. (Brogaard T., 2011)

Pritchard and Hughes define shared care as: *"... The responsibility for the healthcare of the patient is shared between individuals or teams who are part of separate organizations or where substantial organizational boundaries exist."* (Pritchard & Huges,1995) Another definition is made by Hickman et al.: *"... the joint participation of general practitioners and hospital consultants in the planned delivery of care patients with a chronic condition, informed by an enhanced information exchange over and above routine discharge and referral letters."* (Hickman, et al., 1994)

ANTINEOPLASTIC TREATMENT

The definition of this medical term is extracted from a medical dictionary. *"A regimen that includes chemotherapy, aimed at destruction of malignant cells using a variety of agents that directly affect cellular growth and development."* (https://goo.gl/Q2Od5V)

HJEMMEPLEJER

This is a danish word and means a home helper. Hjemmehjælpere helps patients unable to care for themselves by coming to their private homes. They are supported by the municipality and help with personal needs and practical chores.

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[1] World Health Organization

INTRODUCTION

This chapter introduces the reader to the project, it elaborates on the project's background, discusses the findings during the initial research and the direction chosen on the basis of these findings, finally the chapter identifies the goals and objectives of the project.

BACKGROUND

CHC[1] has defined 5 different problems we had the freedom to choose from. Our group had a discussion about every single one of them and decided that the one which interested us the most involved terminally ill patients. The proposal and overall goals of this problem statement have been taken from the official client's brief document and are the following: *How to reduce the number of terminally chronically ill patients dying in hospitals by 5%?*

CURRENT STATE

- *Developing Hospital Bornholm has set the goal that they want to reduce terminal expected dead at hospital with 5%.*
- *We need to identify the problem more closely in collaboration with patients, caregivers, palliative teams etc. and to research state of the art in the caring of terminal patients.*
- *We know little of vendors and what they can offer both in DK and abroad.*

FUTURE STATE

- *Patient must feel safe and receive the right professional care and treatment in their own home.*

INITIAL DESK RESEARCH FINDINGS

On the basis of CHC's proposal the group conducted a set of initial desk research to help identify the wishes of the patient and their relatives, to better understand what the patient's needs are, and to gain an overall understanding of the subject and palliative care as a whole.

WHAT DISEASES ARE PATIENTS SUFFERING FROM?

CHC mentioned a specific group of patients who are in their final stages of a life threatening disease. Palliative care is offered to anyone with a life-threatening disease, or other palliative needs, as well as to the patient's family members. Cancer patients are those that represent the largest group of patients currently receiving specialized palliative care in Denmark. The Danish National Board of Health (2011) concluded, that 96% of the Danish patients who received specialized palliative care, were cancer patients. The knowledge of palliative needs and requirements for different patients and diseases is also greatest within the field of cancer. (Danish National Board of Health - Recommendations for Palliative care, 2011)

WHAT ARE THE PREFERENCES OF THE PATIENTS?

Research papers are identifying the same trend (Higginson & Sen-Gupta, 2000) that: *"...most patients and their families would prefer a home death."* (Fainsinger, 2000). Fainsinger is not alone with this perception, Ashby M. and Wakefield M. (Ashby & Wakefield, 1993) conducted a public opinion survey that supports Fainsinger's viewpoint. If what researchers say is true and most terminally ill patients wish to die within the confinement of their own home, it is not only in the interest of the hospitals but also in the best interest of the patient to explore how needs and wishes can be fulfilled. According to Higginson and Sen-Gupta, in Western countries the preference for dying at home among terminal patients is 53% – 88% depending on the country. For example, a study in England shows, that more than 50% of cancer patients would prefer dying at home, but evidences show that less than 25% of cancer deaths are occurring at home (Thomas et al., 2004). In Denmark there is a similar trend, numbers from the Danish Register of causes of death show that in 2005, the amount of cancer patients dying at home was 25.8%, compared to 55,1% dying in hospitals during the same year. (Brogaard T., 2011).

On the basis of our initial findings, we can conclude:

- There is mismatch between where the patients wish to die, and where they in fact die.
- There is a vast majority of cancer patients receiving palliative care - 96%

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[1] Copenhagen Healthtech Cluster

FIRST REDEFINING OF THE PROBLEM FORMULATION & TARGET GROUP

Until now, we knew that the topic of the project is very broad and it might be problematic for us to be focused and to follow a structure. For this reason, after the initial desk research, a few questions arose about how we can redefine the given problem in order to narrow down the subject. On the basis of the key findings of the desk research, we decided to focus on cancer patients, because they are the majority of the terminal patients. In addition, we will be focusing on patients who are 18+ years old, meaning that they are already adults and are capable in taking their own decisions. According to the insights, the patients wanted to die at their private homes, however this happens very rarely. All of this information helped us transform the CHC's problem formulation into the following:

> HOW MIGHT WE ASSIST TERMINAL CANCER PATIENTS IN HELPING THEM UNDERSTAND THE POSSIBILITIES OF WHERE THEY CAN DIE?

LEARNING GOALS

The aim of this project is for us to gain different skills, knowledge and competences during our first semester of Service Systems Design. These competences are officially described within the curriculum of this programme: *"[...] to develop students' ability to analyse and propose syntheses of products and services with high service/technology content, focusing on the interaction aspects between users and the service, human and technologies, and machine to machine".* (Curriculum for the Master's Programme in Service Systems Design, 2016)

From this project we will complete and obtain the following qualifications:

SKILLS

- Able to analyse the products' interplay with users and take into consideration and account for the contextual circumstances that necessitate a particularly active behaviour and analysis.
- Able to carry out an analysis of problem areas relating to the design of the interaction between products and their users.
- Able to synthesise technical, time and interaction related, social and cultural aspects into a design proposal.

KNOWLEDGE

- Able to understand time and interaction related issues in specific service cases
- Able to apply appropriate methods and tools to organise sequences of events and interactions in a service.
- Able to understand technological, material, social and cultural aspects relating to the design of services and interaction.

COMPETENCES

- Able to design products and services integrating technical and user aspects through proposal making (synthesis) and assess their integration.
- Able to adequate competences to present the project and the process in a professionally appropriate way by applying relevant media and techniques

Besides these official learning goals we will strive to improve following skills, knowledge and competences as a group:

- Understand how a Service System works from a holistic point of view
- To get a better understanding of how to use and apply different methods and tools that are available as a service designer and within sensitive research topics
- To understand and solve the problems among different actors within the healthcare sector.
- Acquire experience with writing academics papers in a group.

METHODOLOGY

Methodology; *"a body of methods, principles, and rules used for a specific activity or branch of knowledge."* (Tollestrup, 2004, p. 4)

THE CHOICE OF THE METHODOLOGY

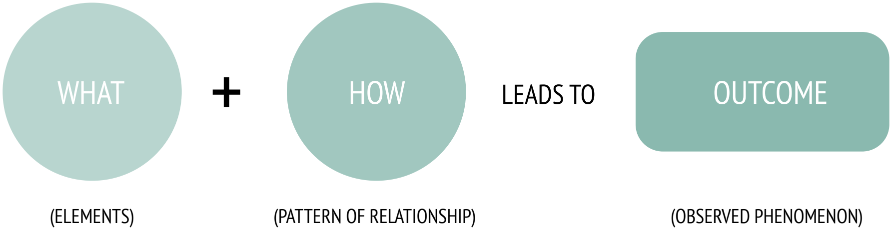
Since the beginning of the project we have considered that we will be changing the problem definition regularly when acquiring new knowledge. Therefore we deliberated that it was important to include the following technique to help us structure this process.

FRAMES

We have decided to keep a focus on our use of frames in order to structure the changes of the problem formulation. Frames have the role of cognitive shortcuts that people use to help make sense of complex information.(Kaufman et al 2013) Each party in a problem has its own perception and understanding of their agenda such as: the relevance of various issues, their priorities, the opportunities and risks involved with the different choices.(ibid) We therefore look into the frames, in order to help us understand why their problem exists, what actions are important to them, why the user acts as they do, and how we should act in response.(ibid)

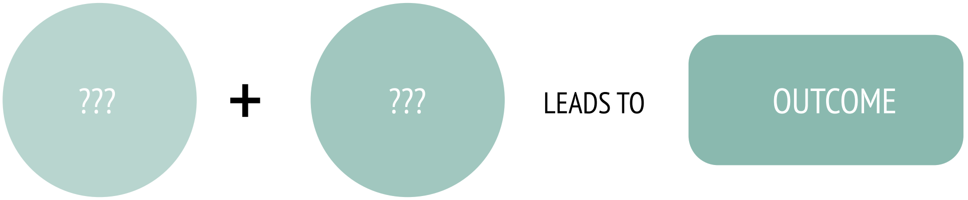
DESIGN AS REASONING

Kees Dorst introduces in his book Frame Innovation (Dorst, 2015) a frame of seeing design as a form of reasoning. On the basis of Roozenburg and Eekels work in 1995, he explains the world as at the very simplest level to exists of "elements", such as people and things. The connections between these elements, captured in a "pattern of relationships" that we can observe through the interactions of these elements, and the "outcome" of a process in which the elements have interacted.(ibid)

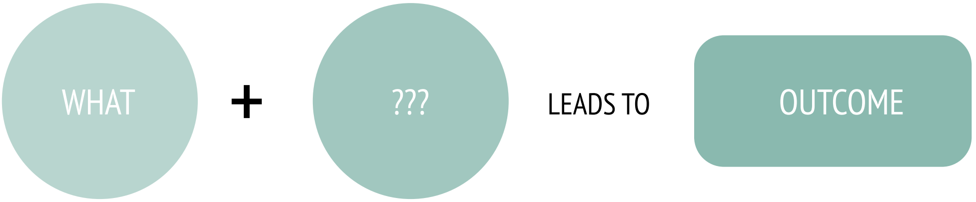


This three-way distinction between elements, patterns of relationships and outcomes can be used to describe the basic reasoning patterns that humans use in a problem solving. (ibid) These are deduction, solid reasoning from cause to effect, induction, discovering patterns, normal abduction, solid problem solving based on experience and the last that is important to our process: the designerly abduction, that from two unknowns leads to a process of creative exploration.

In design abduction, the starting point is that we only know something about the nature of the outcome, the desired value of what we want to achieve (ibid). The challenge is to understand what new elements we need to create that together with a how, a pattern of trusted relationships will lead to a desired outcome.



The further we get into the process, we can be more sure that we have the right outcome, and based on that we can choose our focus. The design project will therefore be what patterns of relationships can lead our what to.



It is beneficial that these changes and the reframing will be happening throughout the whole process of the project. This brings a sense of security that we have had thoroughly thought about the project and the different frames that it belongs to.


Image: From one of our first group meetings

After deciding on a technique that will ease the course of redefining the problem formulation, we researched which methodology will be the most suitable to structure the project process. A few different methodologies were already introduced to us throughout the lectures of this semester. The ones, which we found the most interesting were the Multilevel System Design Method and Value and Vision Based Methodology, which are represented in the next two pages. Furthermore, we will include The Design Thinking approach which is familiar to all of us. The following section will describe these methodologies briefly and explain our final choice.

The Multilevel System Design Method was inspired by a design research process according to which *'the criteria for evaluating new design methods should be process detail, invention, relevance, and extensibility.'* (Patricio et al. 2011, p. 183). The model focuses on designing service systems for improving the customer's experiences. The MSD method includes four steps: studying the customer experience, designing the service concept, designing the firm's service system and last but not least, designing the service encounter. (Patrício et al. 2011).

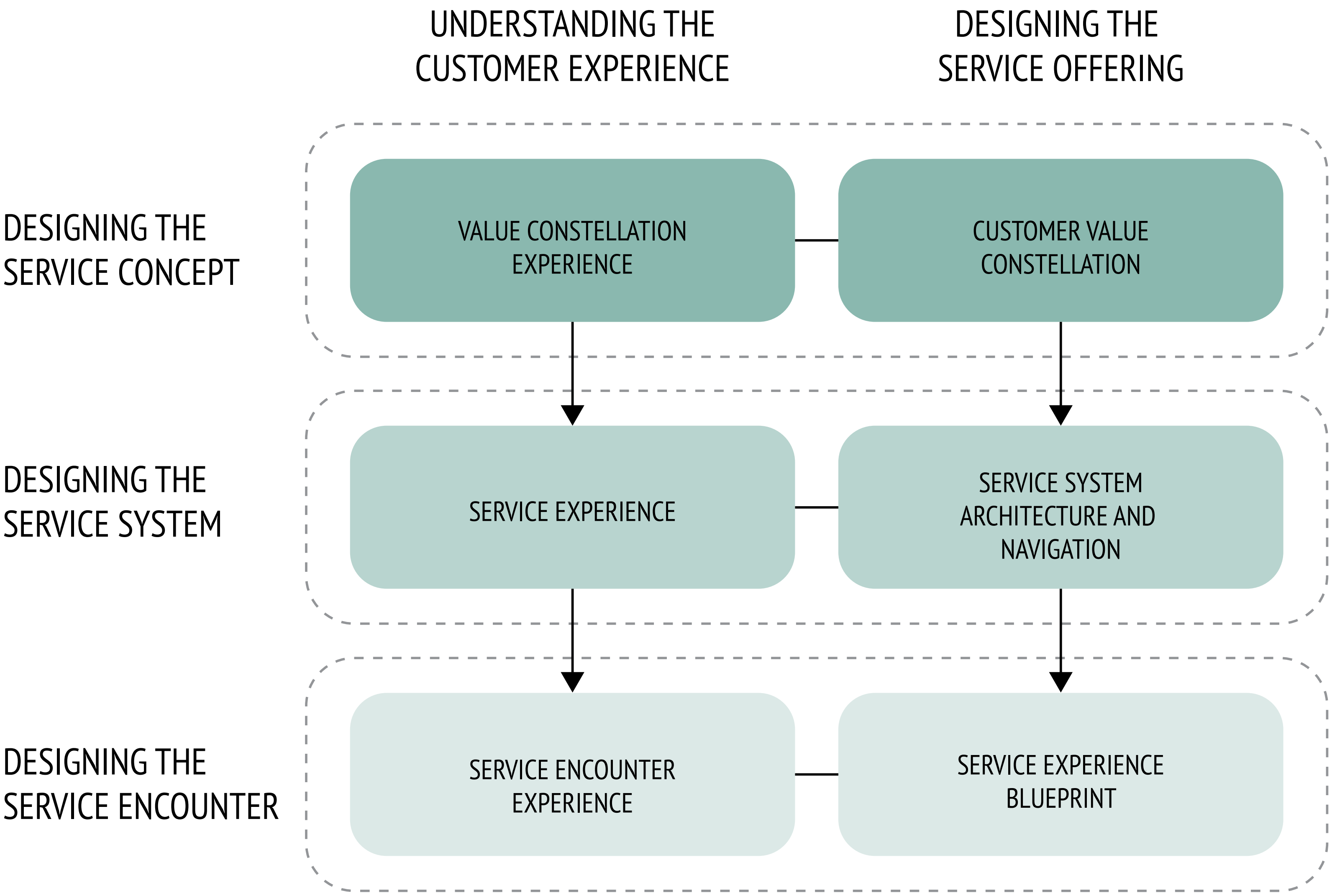


Illustration: General model of Multilevel Service Design

Lerik Lerdahl's thesis divides the Vision Based Methodology into a four level pyramid model which helps describing the different connections between them. (Tollestrup, 2004) The four different levels are spiritual, contextual, principal and material. The first two levels of the pyramid stand for the immaterial aspects of a product and the lower two are the material aspects of it, which are also more complex than the first two.

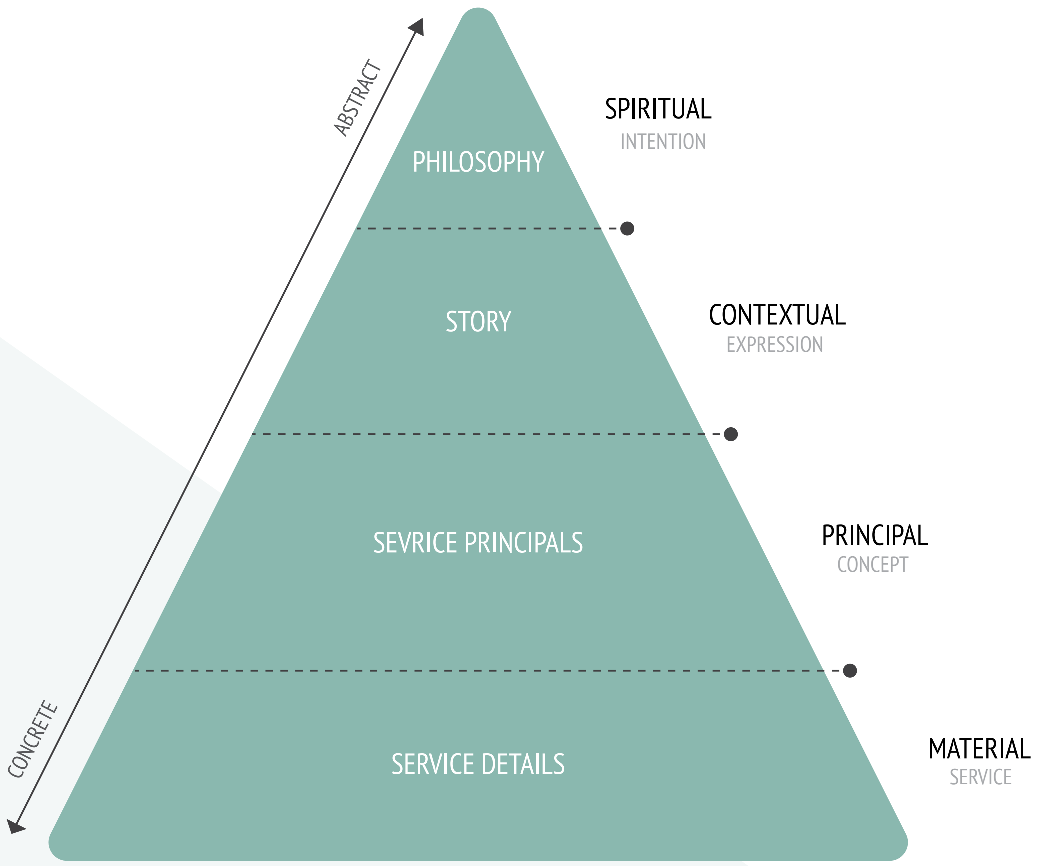


Illustration: Vision Based Pyramid Model

> *“Remarkable things can happen when empathy for others plays a key role in problem-solving” -* (Batterbee et al. IDEO 2016)

As mentioned in the beginning of the chapter, we have been introduced to the Design Thinking approach from previous educations which proved to be very beneficial for the numerous projects we have participated in. In addition, the same approach was presented to us during the lecturers' presentation about this project. It consists of five steps: Empathize, Define, Ideate, Prototype and Test. (Plattner, 2010) The process allows going back and forth between the different phases, which will enable us to achieve optimal results.

Both the MSD method and the Vision Based Methodology could be very valuable for the structure of the project process however they are also very complex and new for all of us. Furthermore, we consider that it is essential to use a methodology, that will keep the primarily focus on the stakeholders, especially on our target group. Considering all of this, we agreed on the Design Thinking approach to be the most suitable for this project. It will not only structure the process, but enable us to fully understand our users' needs and struggles. (Plattner, 2010)

Moreover, in order to solve, reduce or improve problems within the design field, an empathic approach would be ideal. We consider the weltanschauung[1] of seeing the understanding phase as an “empathize” phase instead as very interesting in a human centered approach.

Empathic Design is a User Centered Design (UCD) approach or also called a Human Centered Design (HCD) approach. The approach focuses on the user's feelings towards a product or service and was defined by Rayport and Leonard-Barton in 1997. Its goal can be to identify latent needs in order to create products that the users don't even know they desire. Moreover, Empathic Design was created with an interdisciplinary approach in mind, where teams of specialists with different backgrounds support the design process, and make it easier to create a satisfying solution for the project (Kelly & Littman, 2001). One of the leading practitioners of Empathic Design is the design company IDEO, which has also developed the methodological design approach we decided to use throughout the project. Within the IDEO's 5 Design Steps you will find the following phases: 1. Empathize, 2. Define, 3. Ideate, 4. Prototype, 5. Test. (Kelly & Littman, 2001).

The next section of this chapter will include The Design Thinking Process steps, as well as the choices of methods and tools, which will be used during the Process Report.

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[1] World perspective

IDEO’S PHASES

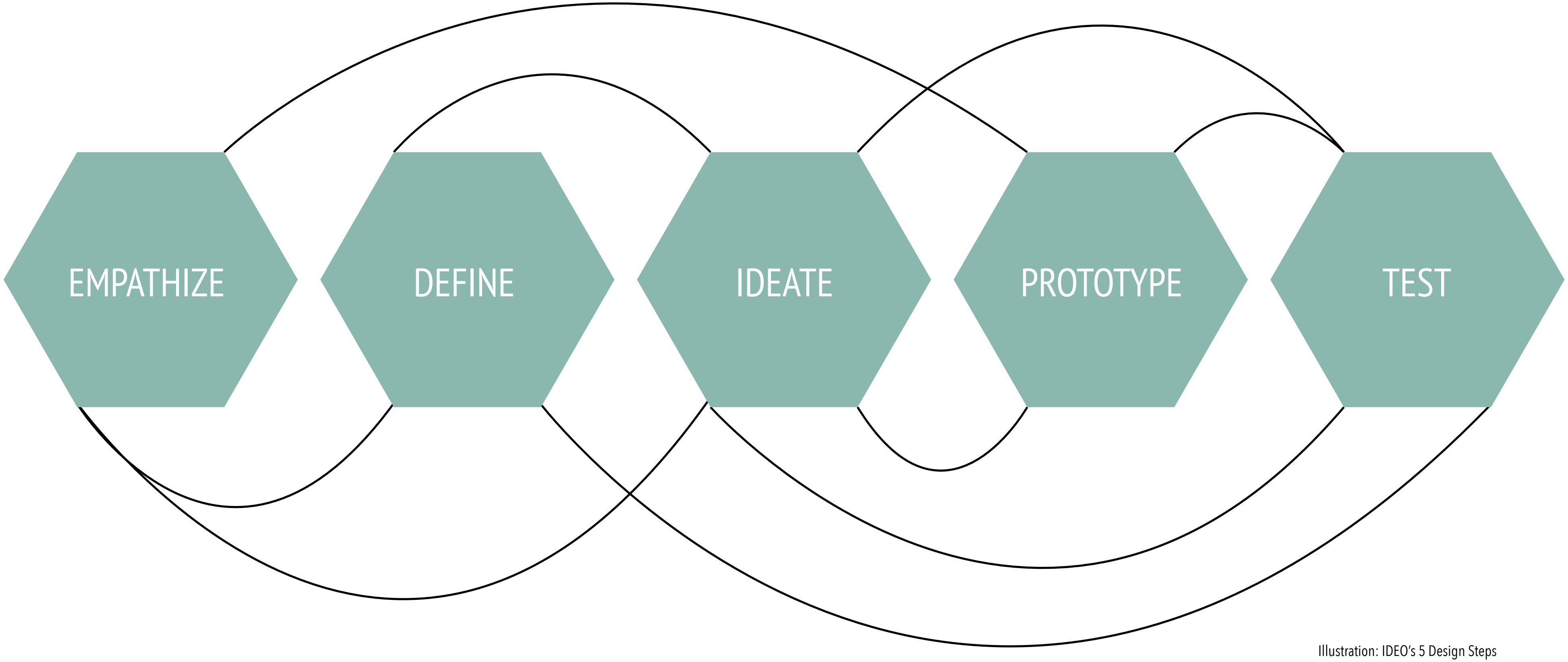


Illustration: IDEO’s 5 Design Steps

EMPATHIZE

This is the phase which will allow us to focus on fully understanding the stakeholders. We will use different tools and methods, which will assist us in learning more about their values and needs. It is essential to gather as much information as possible during this phase, because it will give us clues on how to tackle the different issues of the project. (Plattner, 2010)

METHODS & TOOLS

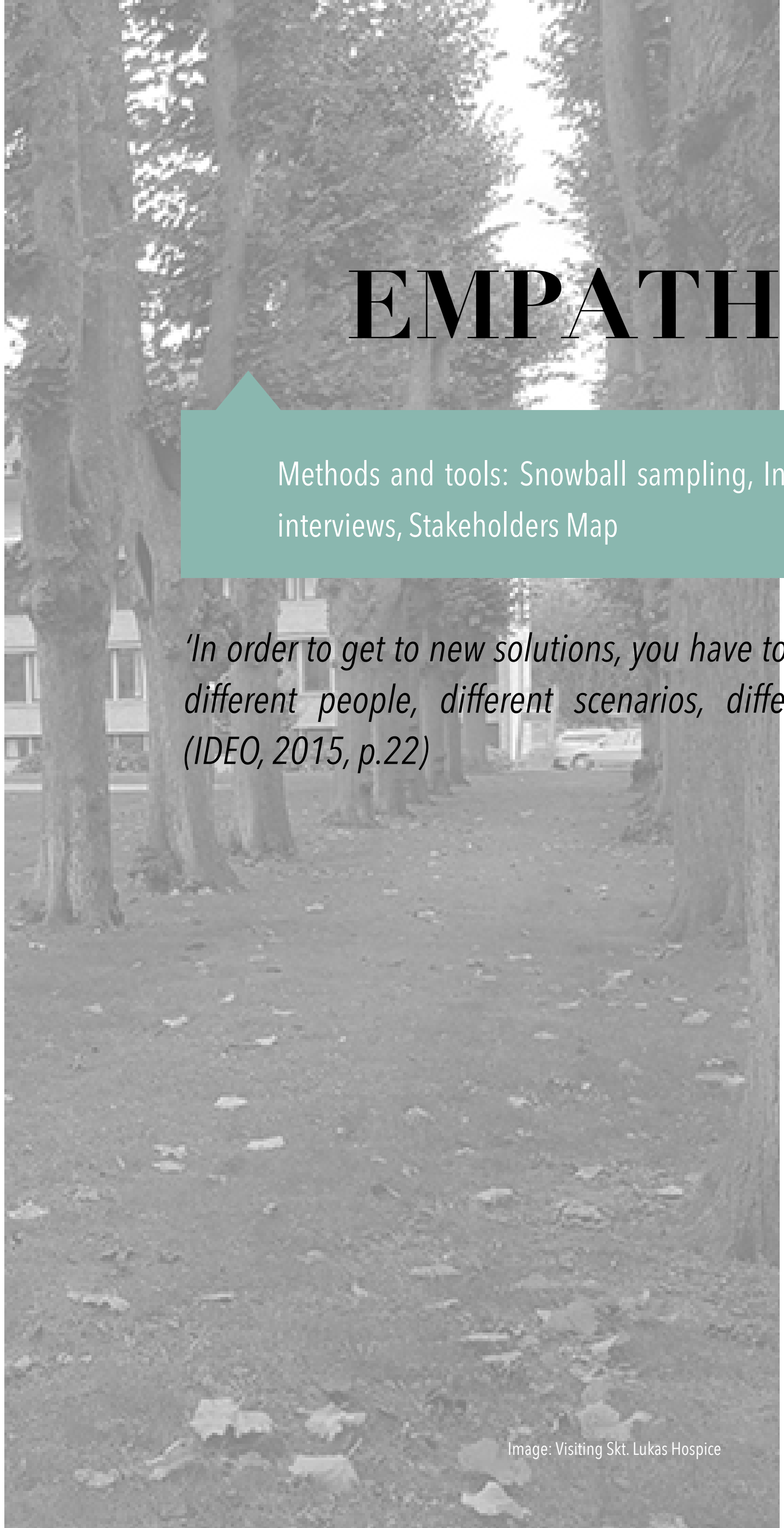
Snowball sampling, In-depth interviews, Stakeholders Map.

First and foremost, we will outline the most important actors of the project by using a stakeholders map, which will help us conclude who should be included in the upcoming interviews. Furthermore, it will describe the different responsibilities and who communicates with whom.

When conducting the qualitative research we considered that it would be very challenging for us to get in contact with terminal patients, however it is still necessary to get a better understanding about them by using other methods than a direct contact. Therefore, we will use a particular strategy called snowball sampling where we will have to involve well-placed actors and experts with knowledge about the topic and the user. (https://goo.gl/ILDrBP)

In-depth interviews or also called 'key-informant interviews' will be conducted with the purpose of giving us detailed information about the subject of 'palliative care'. This interview method is mostly used in situations, where the topics are quite sensitive and complex issues, which need to be clarified.

The use of question techniques will vary from whom we will talk to and the direction of the interview. In some cases we will use interpreting and verifying questions to make sure that the responses will be described correctly. Due to the complexity of this subject, it is important to use direct questions most of the time to seek information and clear precise statements, followed by specifying questions that encourage the participants to go further in details or elaborate on the answer. (Qualitative Methods, Thomas Bjørner)



EMPATHIZE

Methods and tools: Snowball sampling, In-depth interviews, Stakeholders Map

'In order to get to new solutions, you have to get to know different people, different scenarios, different places.' (IDEO, 2015, p.22)

Image: Visiting Skt. Lukas Hospice

DEFINE

Methods and tools: Personas, Scenarios, Customer Journeys, Cross Parameter Map, Card Sorting Techniques (e.g. Affinity Diagram)

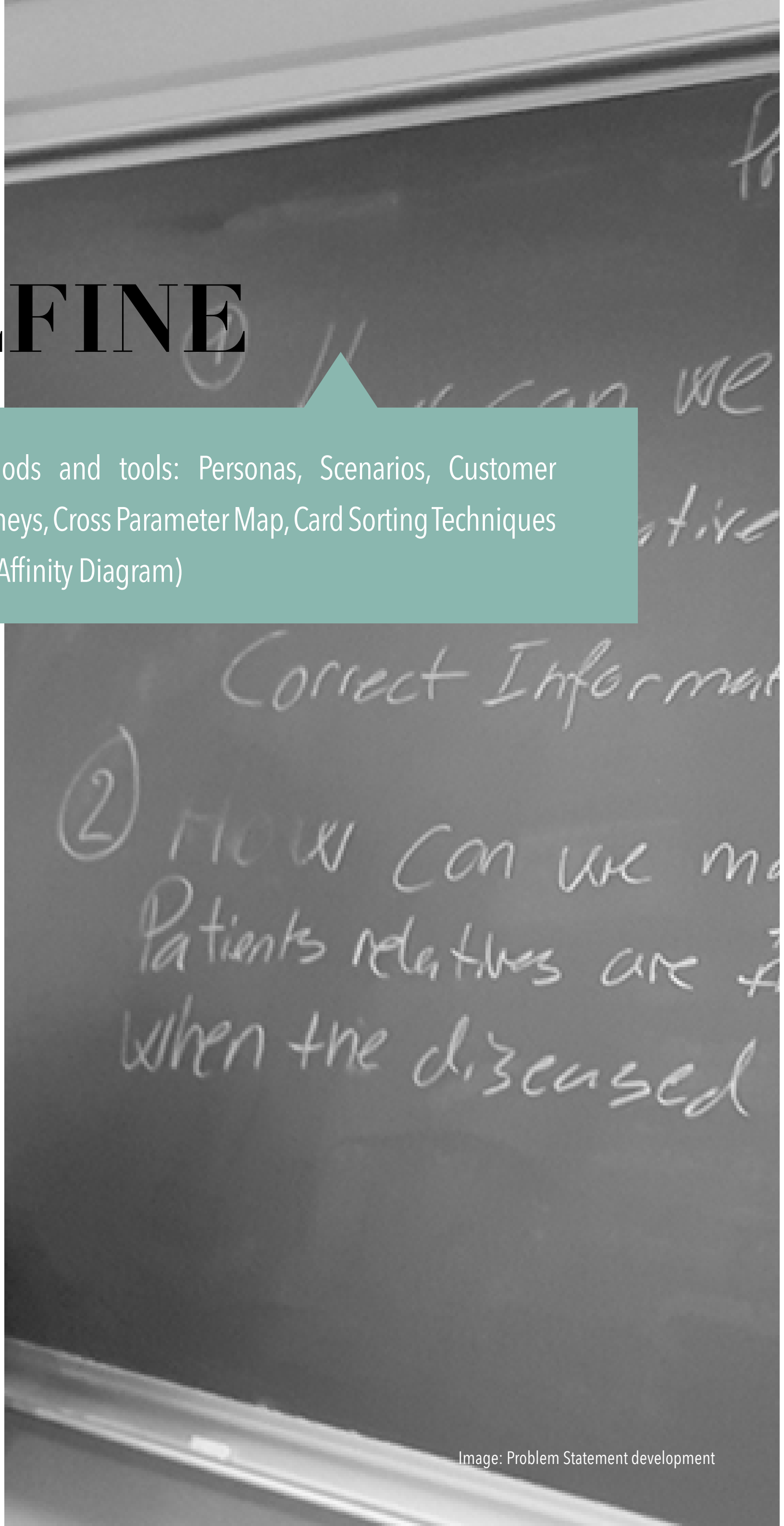


Image: Problem Statement development

DEFINE

During this phase, we will use all the data and insights gathered at the beginning of the project to better grasp our target group's needs and struggles. All the different aspects of the project will be considered, and if there are newly found problem statements according to the gathered insights.

METHODS & TOOLS

Personas, Scenarios, Customer Journeys, Cross Parameter Map, Card Sorting Techniques (e.g. Affinity Diagram)

The scenarios will be added to the personas, which will enable us to understand the users properly. Furthermore, an emotional map will be used to build on the personas and give a better overview over their feelings. The customer journey will assist us in understanding how the stakeholders move through the process and highlight problems of the existing infrastructure. Card sorting refers to a number of techniques concerned with understanding how people classify and categorize things (Benyon p. 164, 2010). The card sorting techniques are used to understand patterns in gathered information, and can help us, both understand the information we have, as well as align our understanding about the situation and problems therein.

Affinity diagrams are simple but very effective. They are made on the basis on perspectives and information gathered from the interviews and desk research common themes can be identified. (Benyon p. 299, 2010) We will have to write down on post-it notes all the things we can think of about the situation., which should cover both wishes for new systems, needs and positive comment about the existing one. The writing should be fairly succinct, a word of two, a stench at most, but not an essay. This is repeated until there are several post-its, preferable in the hundreds. The affinity diagram is built bottom-up by identifying common themes and structures. By grouping the notes down, the groups of post-its will define their own categories. (Benyon p. 299 2010) In the end of the exercise, we should have several defined problems that are core to the problem we will be facing and can be looked further into during the project.

IDEATE

This is the phase where all the knowledge gained will be transformed into ideas. In order to create the best solution possible, we will aim to involve some of the most important stakeholders. However, we will once again consider that there is a possibility, where we will not be able to share the ideas with our target group because of their medical condition.

METHODS & TOOLS

Brainstorming, Card Sorting Techniques (e.g. Affinity Diagram), and What if…

We will be using brainstorming and card sorting techniques for the idea generation process. These methods will be used to begin the process. To continue we will look into the What if… method in an attempt to provoke new ideas that would not be generated through brainstorming and card sorting.

IDEATE

Methods and tools: Brainstorming, Card Sorting Techniques (e.g. Affinity Diagram), and What if…

'In the Ideation phase you'll share what you've learned with your team, make sense of a vast amount of data, and identify opportunities for design.' (IDEO, 2015, p.75)

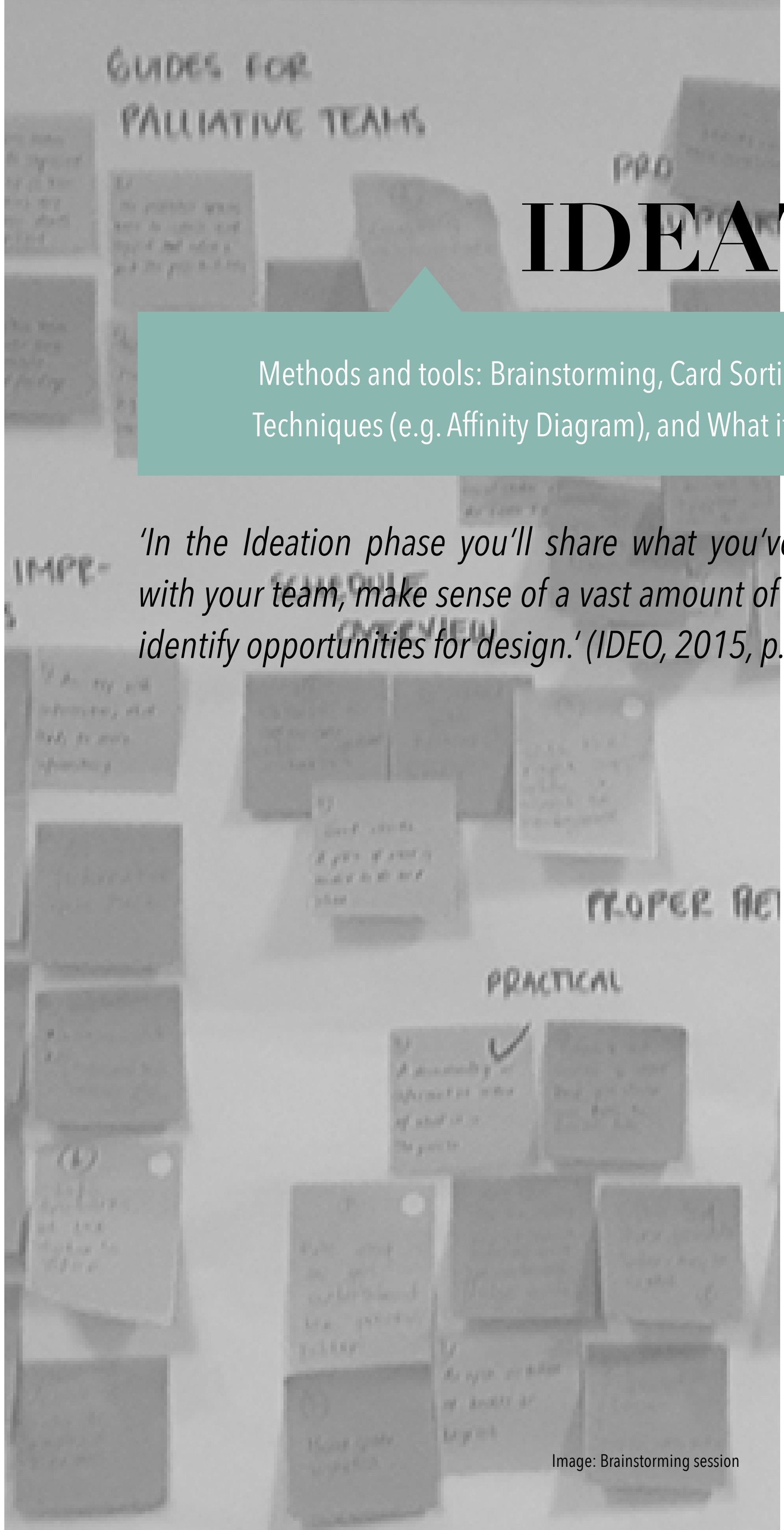


Image: Brainstorming session

PROTOTYPE

Methods and tools:Pretotypes, Prototype.

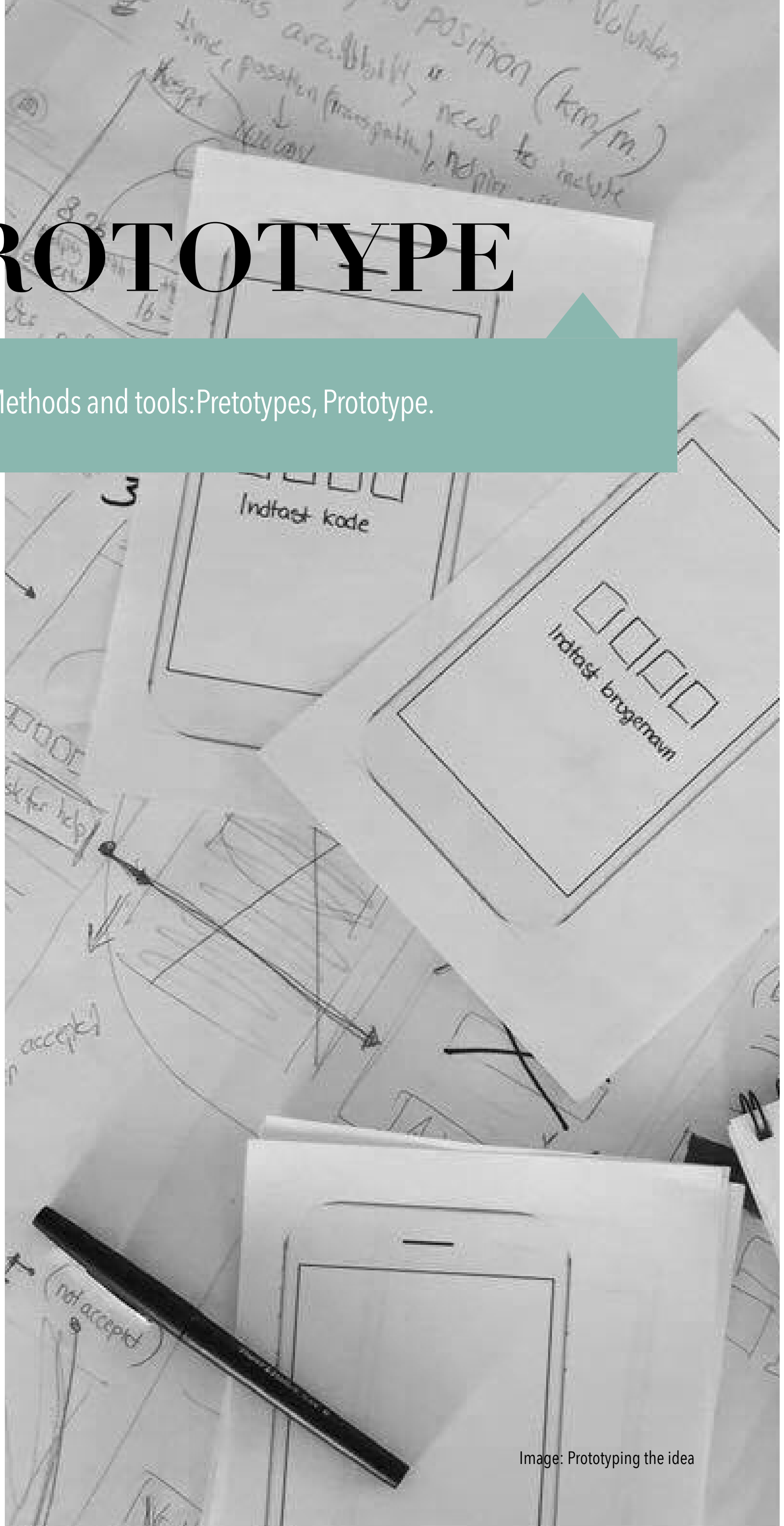


Image: Prototyping the idea

PROTOTYPE

During this stage, an idea from the Ideation process will be chosen and created into a prototype together with the different stakeholders. They will have the opportunity to share their opinions, which will minimize potential pitfalls in the final solution. (Krause, 2016)

METHODS & TOOLS

Pretotypes, Prototype

To make sure that our initial ideas are worthwhile to continue on with, we will be using a pretotype method to help us test the need of our idea. This will help not to spend time on developing concepts which will not be needed from the target group. After the pretotyping and reviewing the results gathered, we will create a prototype from the idea we think will meet the user's needs the most. These iterations are done to make sure we will detect any easy pickings before we go on to testing phase.

TEST

This phase will be for testing the prototype with our stakeholders. They will be able to interact with it and provide us with valuable feedback, which will be used in iterating on our prototype until towards it being a final solution.

METHODS & TOOLS

Prototype, Think Out Loud, Service Blueprint, Service Ecology Map.

The testing of the prototype will be conducted with the help of functioning prototype and think out loud testing. Moreover we will create a Service Ecology Map, which will illustrate all the stakeholders involved,the hierarchy between them and their connection. Last but not least, a Service Blueprint will make sure that we have filled the gaps we initially saw in the customer journey. It will also enable us to use it as a representation tool to discuss the prototypes and feedback gained during the prototyping phase.

All the methods and tools included in this chapter will support and improve the process of the project. They will aim to investigate the existing service by including all the actors during IDEO's phases, which will outline existing problems and lead us to create a successful solution.

TEST

Methods and tools: Prototype, Think Out Loud, Service Blueprint, Service Ecology Map

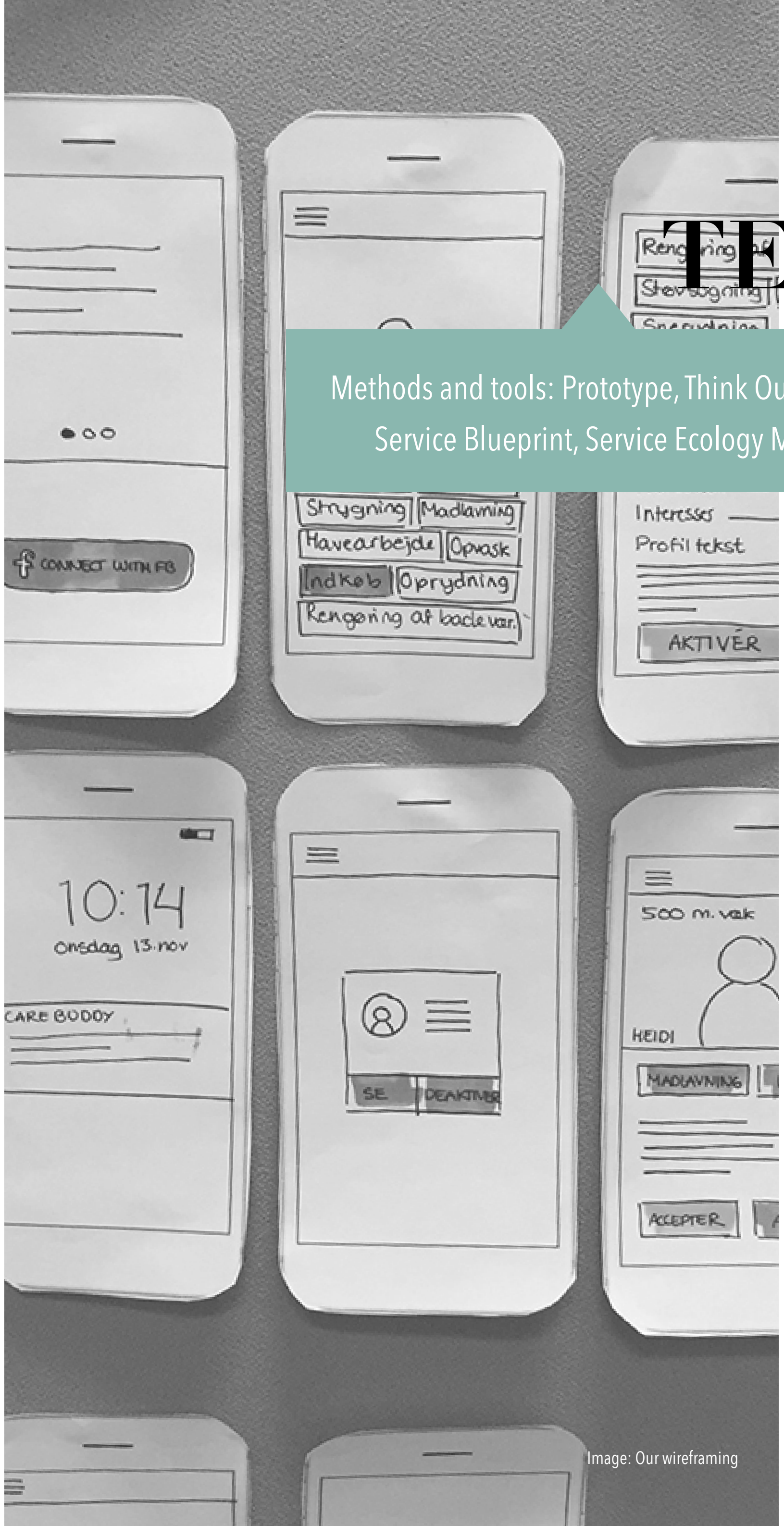


Image: Our wireframing

DESK RESEARCH

This chapter will aim to build on the initial desk research, which we conducted in the first few weeks of the project. It is of a great importance that the research provides us with insights, which are needed to better outline the implications that the terminally ill patients experience after being diagnosed. For that reason, it aims to investigate the process of palliative care, how the healthcare sector functions when it comes to terminally ill patients, meaning what are the possibilities they have when it comes to financial and moral support. Another aspect of the chapter will concentrate on the patients' families and closest ones. A Phd thesis will help us identify their needs and feelings, as well as what problems occur during the last months of their lives.

WHAT IS PALLIATIVE CARE?

“Palliative care focuses on improving the symptoms, dignity and quality of life of people approaching the end of their lives and on the care of and support for their families and friends.” (Hall et al., 2010)The term “palliative care” has been around since the early 1990’s, but at that time, the term could easily be mistaken for what we today call “end-of-life care”. Palliative care has somewhat the same definitions, but the most well defined and quoted was created by the World Health Organization.

As already explained during the Definitions’ Chapter of the report, WHO’s definition of palliative care seeks to comfort the patient in several aspects of their life. The definition addresses four main aspects in relation not only to the patient, but to their families and closest ones. The four main aspects are their mental, physical, social and spiritual condition which can be also seen on the illustration below.

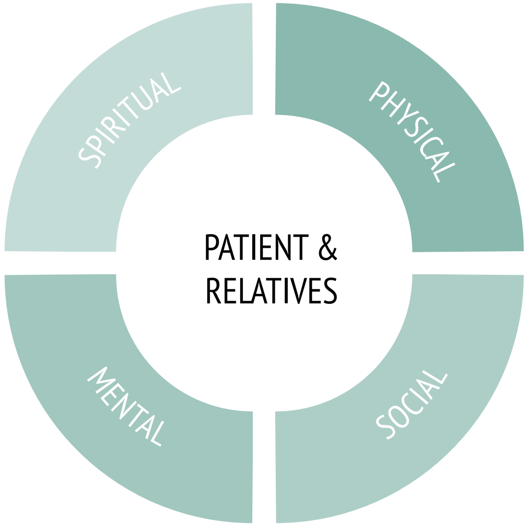


Illustration: Four Main Aspects of Palliative Care

The patients who receive palliative care suffer from different forms of cancer and/or heart and lung diseases. (WHO, National Cancer Control Programmes, 2002) Nonetheless, as mentioned earlier, 96% of patients receiving special palliative care in Denmark are diagnosed with cancer (Danish National Board of health, 2011). There are many obstacles that arise during the final stages of a course of a terminal disease, which have their origins in the earlier stages. Therefore, the principles of palliative care should be applied as early as possible in any terminal disease course, e.g. from the moment of the diagnosis. (WHO, National Cancer Control Programmes, 2002) Moreover, a palliative medicine is the medical term for soothing treatment, which has the purpose of promoting quality of life for the patients. The palliative medicine is also referred to the term of taking care of patients who are going to die within 9-12 months. (https://goo.gl/qMeQgC)

A report from 2015, created by the the Danish palliative database (DMCG PAL, 2015) shows that the efforts referral of patients requires improvements and the palliative sector must receive a higher number of patients. Meaning that the patients are introduced to the palliative treatment very late in their disease. The report suggests that the health sector’s departments and doctors should become more active in introducing the concept to the patients at earlier stages in the course of their disease. The goal is that the application should take no more than 10 days.

Last but not least, palliative care can be performed at the patient’s own home with the help from the GP (General Practitioner) and at the municipality homecare (Hjemmeplejen), as well as nursing homes or in a clinical hospital. The palliative care can be practised by palliative medical departments, hospitals, hospices or by specialized palliative teams. (https://goo.gl/AJjnd2)

PALLIATIVE CARE OVER COURSE OF A TERMINAL DISEASE

An illustration of the course of a terminal disease can be seen in the illustration below. It shows that the palliative care begins steadily from the moment when a diagnosis has been given (American Medical association institute for medical ethic, 1999). In the early stages of the diagnosis, the palliative care is offered as a part of the treatment, and it usually involves treatment of anxiety, fatigue or mental care. It is commonly known that detecting cancer early, significantly increases the patient's chances of survival. Therefore if the disease is detected and cured within this early stage of the palliative care, the palliative care will cease. (Danish National Board of Health, 2011) The overall care for both the family and the patient increases over the course of the disease and for the family it will even continue after the death occurs. An end-of-life care (https://goo.gl/gdrvIB) is a stage within the palliative treatment and it begins when a patient is considered to be in their final year of living. The life-prolonging treatment decreases as the patient comes closer to the end of their lives, although it does not necessarily stop completely (Hall et al., 2010).

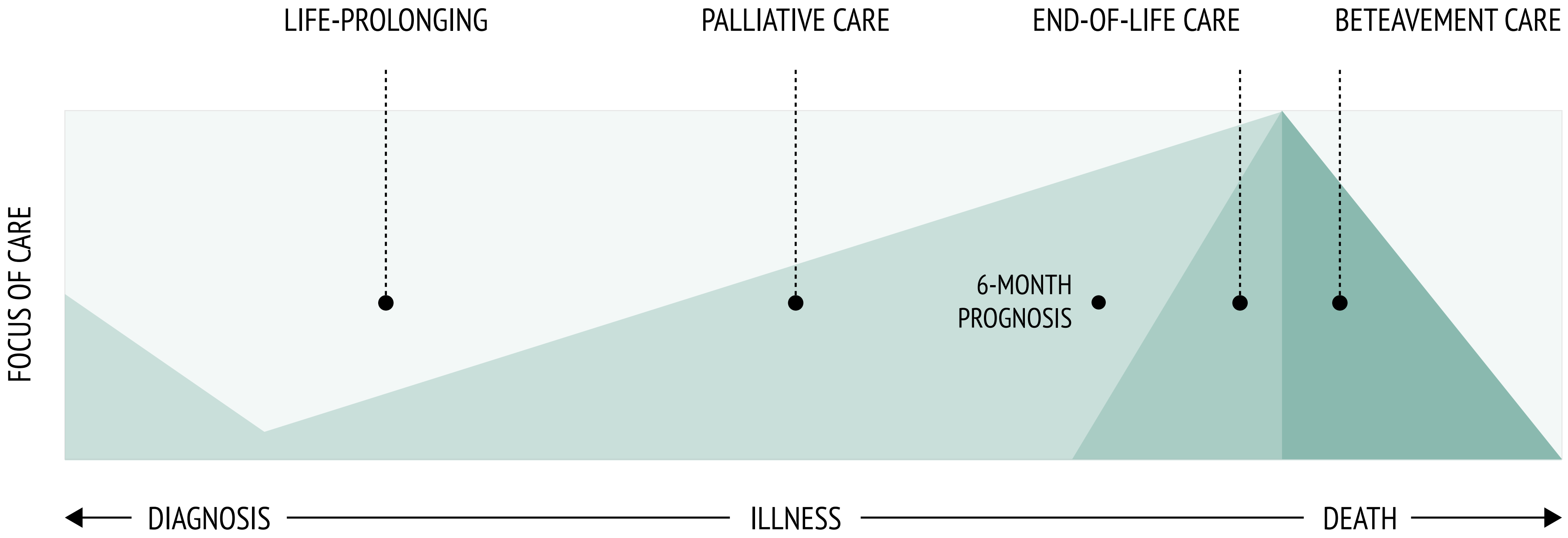


Illustration: Continuum of Palliative Care

A PhD thesis which was written by Trine Brogaard (2010), divides the palliative care into three separate stages: the early palliative stage (years left to live), the late palliative stage (months left to live), and the terminal palliative stage (from few days to weeks left to live). Below is an illustration of these stages as well as the treatment.

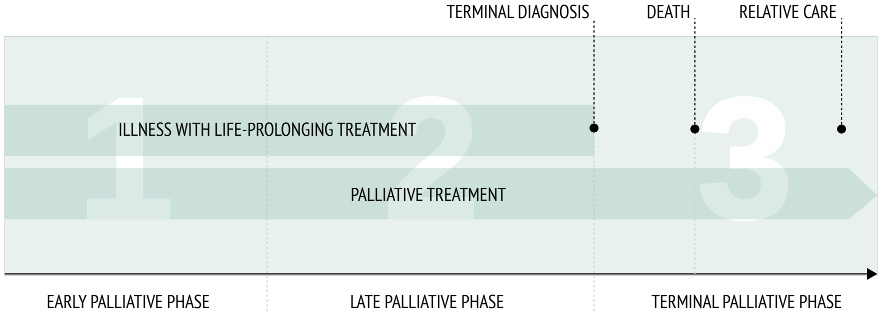


Illustration: 3 Stages of palliative Care

Another source that supports Brogaard's definition of the different palliative care stages comes from REPHA (Videncenter for Rehabilitering og Palliation) (https://goo.gl/GYE7pH). According to REPHA, there are also three main palliation stages. The first one is the early stage, which has the purpose of prolonging the patient's life through different medical treatments and can continue for years. The second stage refers to the period where a medical life prolonging treatment is no longer possible, so the focus is kept on the terminal patient's quality of life. The period of the second stage is a few months. The third and final phase of the palliative treatment means that the terminally ill patient has only a few weeks or days left to live. As in the second stage the medical life prolonging treatment is stopped and a professional help is offered to the relatives after the death of their loved ones.

WHAT HAPPENS AFTER A PATIENT RECEIVES A TERMINAL DIAGNOSIS?

When patients get informed about their condition, many questions arise such as:

- How much time do I have left?
- Where do I want to die?
- How long can I stay at home?
- Do I have to be at the hospital? What other possibilities do I have?
- What about my relatives?
- What about the financial aspects?

Usually after the patients and their relatives have been informed about a terminal diagnosis, a meeting with doctors or nurses is scheduled. (https://goo.gl/Zpvk5q)

There is an ongoing communication between the nurses and doctors, in order for them to successfully cover most of the patient's individual needs. It is essential that they find a balance between being too optimistic or too pessimistic when explaining the patient's condition, both to the patient and their families. This is done in order not to give too much hope for the future of the patient, nor make them worry more than they already do. The meetings depend on the type of the disease and what treatment is possible for the individual patient. The relatives take the role on being the moral support during the meeting.

The diagnosis not only changes the patient's life, but demands much higher financial obligations then they have had before being diagnosed. Different studies have shown that the financial aspect of being terminally ill, effects the patients for the most part. (https://goo.gl/Zpvk5q)

Image: From unsplash.com

They worry about how their condition will affect their economy, because as it often happens the patients lose their ability to work. There are multiple options that might cover their previous income such as: health insurance or support from the social welfare. (https://goo.gl/jvoozJ) Besides the financial help that is offered to the patients there are different channels where they can seek information and support from. For example, *Kræftens Bekæmpelse* (https://www.cancer.dk/) has lots of useful information about cancer, different prognosis and treatments.

WHAT POSSIBILITIES DOES A TERMINALLY ILL PATIENT HAVE?

AT HOME

The Danish healthcare system allows the terminally ill patient to have a choice. They can choose to spend the last weeks of their lives in their private homes, a hospice, or a hospital. (https://goo.gl/aj7f5P) If a terminally ill patient chooses to die at their private homes they are usually in a need of someone who can care for them most of the time. This someone takes upon themselves the role of a caregiver, who is eligible to apply for financial support, which is being covered by the municipality. The support is granted to the caregiver as a compensation for lost working hours. It is not necessary that he/she is a family member, it could also be a person who has a very close relationship with the patient. The conditions under which this type of financial support can be granted are:

- That a doctor has estimated that there only can be offered palliative medicine for the patient and their lifetime will be short.
- That the dying person has nursing needs.
- That the relative and patient are in a agreement on the terms of the job.
- That the palliative care only takes place in the patient's or relative's home.

If all the requirements are met the caregiver is being hired through their municipality, and the amount of the payment is 21.546 DKK per month (2016). (https://goo.gl/KQpX3n)

HOSPITALIZATION

As mentioned in the initial desk research, many of the patients would rather die in their own homes, however it might be that a few days before their death a hospitalization is often necessary. It is a vital because the disease symptoms are too severe to be managed in their private homes, or often the family members feel exhausted and can not provide the same intensive care as they did earlier. (https://goo.gl/gcugtJ)

HOSPICE

It might be very draining not only for the patients, but also for the families to maintain the home care. If this happens the patients have also the opportunity to spend the last weeks of their lives in a hospice, which means that there is no prospect for them to be cured. There are 18 hospices in Denmark with 220 available beds in total. (https://goo.gl/3Ktv9c) A hospice offers a palliative treatment, which is performed by nurses, doctors, physical therapist, priests and psychologists. It is required that the patient wishes to go to a hospice and the life prolonging treatment is completed. The palliative care in a hospice is soothing, not curing. If these requirements are fulfilled the patient is admitted to a hospice. They can apply either through their doctor or contact the chosen hospice directly. If there is a case where the patients have a caregiver at their private homes, but would rather move to a hospice, the caregiver will no longer be eligible for the financial support, which was described earlier in the chapter. (https://goo.gl/5EijUA)

PATIENTS WITH LIMITED NETWORK/FAMILY

It happens sometimes that the terminally ill patient does not have a family, or if they do, the family doesn't have the possibility to care for them. This might be due to their location, busy lifestyles or them not willing to take on this very difficult assignment. It is a full-time job and can exhausts the ones involved.

If the patients find themselves alone, they can be visited by a voluntary in the last couple of hours before they die. In Denmark these volunteers are called "Vågetjeneste" and they only visit the patients in their private homes. The Red Cross opened a "Vågetjeneste" service in 2005, which has grown rapidly since then. Today there are about 75 departments in Denmark providing this service and they have around 700 registered vågekoner. Many of them are retired nurses and would like to continue their work within the healthcare sector, which they successfully do by becoming a vågekone. They can be very beneficial to the employees of the hospitals, who are often under pressure, as well as the relatives, who either live far or are very busy. (https://goo.gl/rVBVR9)

In Fyn there is a volunteer network, called the *Palliative Frivillige Netværk Fyn* (https://goo.gl/XB4GgF). This network of volunteers is trained by a palliative care team to gain more knowledge of the patient's needs. Their main purpose is to visit terminally ill patients at their homes and assist them with various tasks. The hospices in Denmark have volunteers as well, who help mainly with preparing food, lighting candles, setting flowers and going with the patients out for a walk.

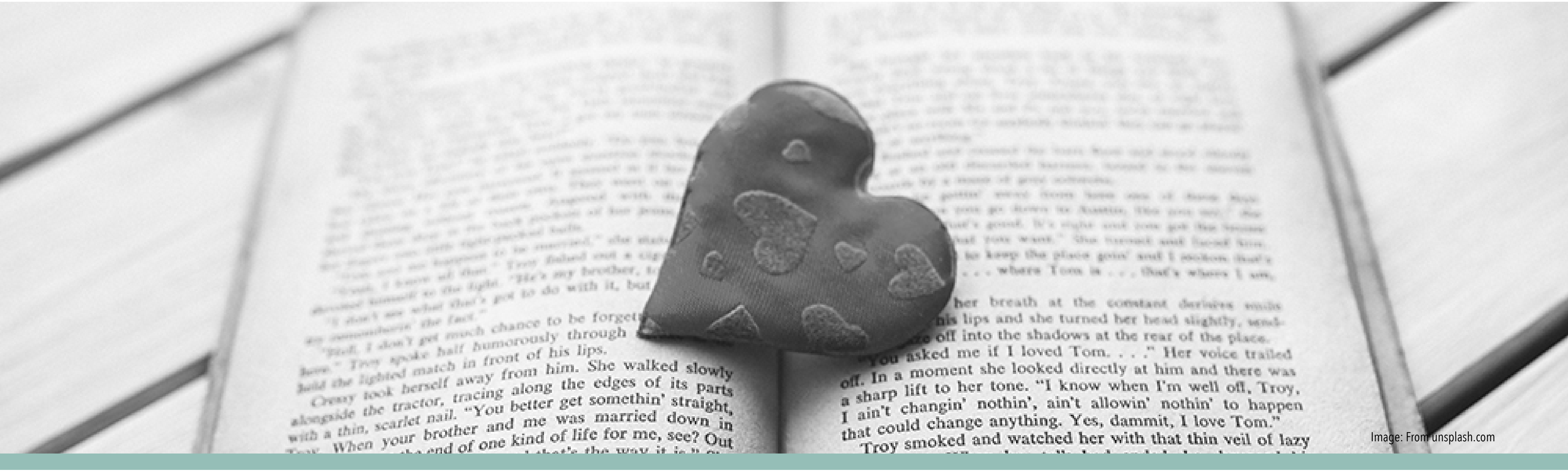


Image: From unsplash.com

HOME IS WHERE THE HEART IS

COORDINATING CARE AND MEETING NEED IN PALLIATIVE HOME CARE. / TRINE BROGAARD / 2010.

We decided to look into a PhD thesis , which was written by Trine Brogaard in 2010. The title is *"Home is where the heart is. Coordinating care and meeting need in palliative home care."* The aim of the thesis is: " *… to explore current challenges in palliative home care, focusing on family caregivers' perception of burden, patient's' wishes regarding end-of-life care and the coordination of care in palliative pathways."* (2.6.1. The overall aim of the thesis, p. 14)

We choose this specific work due to its' relevance to the project. Trine Brogaard zooms successfully in the palliative home care of terminally ill patients. She has had the opportunity to include 96 participants in her research and follow their journey. All the participants were suffering from cancer and were no longer receiving a antineoplastic treatment. It is worth mentioning that 83 of the patients died during the two years of writing the PhD thesis. Furthermore, throughout the thesis Brogaard has conducted numerous interviews with patients, professionals and relatives which will be also inspirational for the qualitative research of this project.

Considering the sensitive condition of the target audience it is a big challenge for us to interview them. Therefore their testaments, which are included in the thesis will help us empathize with them better and understand where it is exactly they need our assistance.

Trine Brogaard takes the relatives' perspective, too. They are a very important factor in the terminally ill patients' lives, because in many of the cases they can become the primary caregivers, which can be very challenging times for them. Therefore the palliative teams who help the patients, support also the families, although the primarily focus is still on the terminally ill.

With her PhD, Brogaard also manages to investigate the involvement of the different professionals during the palliative home care, which will provide us with more information about the most important actors during this period.

PATIENTS & RELATIVES' KEY FINDINGS

- 71% of the participants preferred to die at home.
- 48% of the patients who stated they would like to die at home had their wish fulfilled
- The median age among the participants was between 66 to 72 years old
- 71 of the participants were married or living with a partner, where 25 of them were single, divorced or widowed. This is important to be marked as a key finding because the decisions of where these patients want to die are very much affected by their families and closest ones.
- The number of the relatives' participants was 75, where the majority were women and being spouses or partners of the patients. The median age among them was 62 years old.
- The patients find the happiness of their families very important and would like not to burden them with their terminal disease. The palliative home care is for both patients and families, but the primarily focus is still kept on the terminally ill. The thesis suggests a further research into the area of increasing the focus on the relatives during the home care and after the death of their loved ones.

EXPERTS' KEY FINDINGS

- There is a conflict between the General Practitioner (GP), the Community Nurse (CN), the families and the terminally ill patient about who is the primary key worker during the home care period.
- According to the patients they consider themselves and their relatives as primarily key workers. From the GPs' point of view the primary key worker is the hospital doctor and the CNs' opinion is pointing to themselves as primary key workers.
- Both the patients and relatives' opinion is that the perfect key worker for them will be the GP, followed by the hospital doctor.
- *"A clear definition of responsibility among professional is essential: however, there may be a severe lack of explicit agreement of toles distribution amount lay and professionals involved in palliative home care."* (8.1. Organisation of palliative care, p.124)
- There is a room for improvement in the communication between the terminally ill patients, their families and the professionals during the home care period.
- The patients preferred to talk more about where they would like to die with their trusted GP. According to the thesis' findings they feel more comfortable sharing it with someone they know.

The research gained us valuable insights in the areas of palliative care, the different possibilities, that a terminally ill patient has, as well as who is involved during the process and to what extend. One of the key findings was that the majority of the terminally ill patients suffer from cancer, which was something we already discovered from the initial desk research. However, a palliative care was a relatively new and unknown term for us, but essential part of the journey of a terminally ill patient. Despite of it being such an important part of the process, a report from 2015 reveals that a patient is introduced to the palliative treatment very late in the course of their disease. This is a very important finding, which hints to where an improvement is possible. The research brought to light all the opportunities, which the healthcare sector offers to a patient with a terminal diagnosis. By understanding all the options they have, we can better empathize with them and understand all the difficult decisions they must take.

In the beginning of the project we assumed that the main focus should be on the terminally ill patient. After all, the research uncovered that the families are vital part from the moment of the terminal diagnosis to the last moments of the patients' lives. It brought lots of discussions between us and ideas around increasing the focus on the family. We decided to use the qualitative interviews in order to investigate and gain more knowledge about it.

Referring to the introduction of the chapter Trine Brogaard's PhD thesis brought us closer to the journey of the terminally ill patients. She manages to successfully outline their thoughts and opinions. In addition, she also includes the professionals (GPs and CNs) in her research, which presents us with their perspective, too. All in all, the desk research is very beneficial and will allow us to extend our knowledge within the topic of the project, as well as create more relevant questions for the people, who will participate in the interviews.

STAKEHOLDERS

In order for us to have a better understanding about all the actors involved in the terminal patient's journey, a stakeholder map was created (Stickdorn, 2011, p. 150). The choice of the stakeholders was made after the initial desk research, where a short description of every actor was included. This helped us decide who are the most essentials stakeholders and whom we should contact for qualitative interviews.

We have chosen to include hospitals, hospices and health organizations. We do not consider these particular stakeholders to be physical spaces but professionals, who are still working or have been working with terminal patients. The desk research gave us a detailed knowledge about the different roles of the professionals, involved during the process. We managed also to understand who communicates with whom and what are the different connections between them.

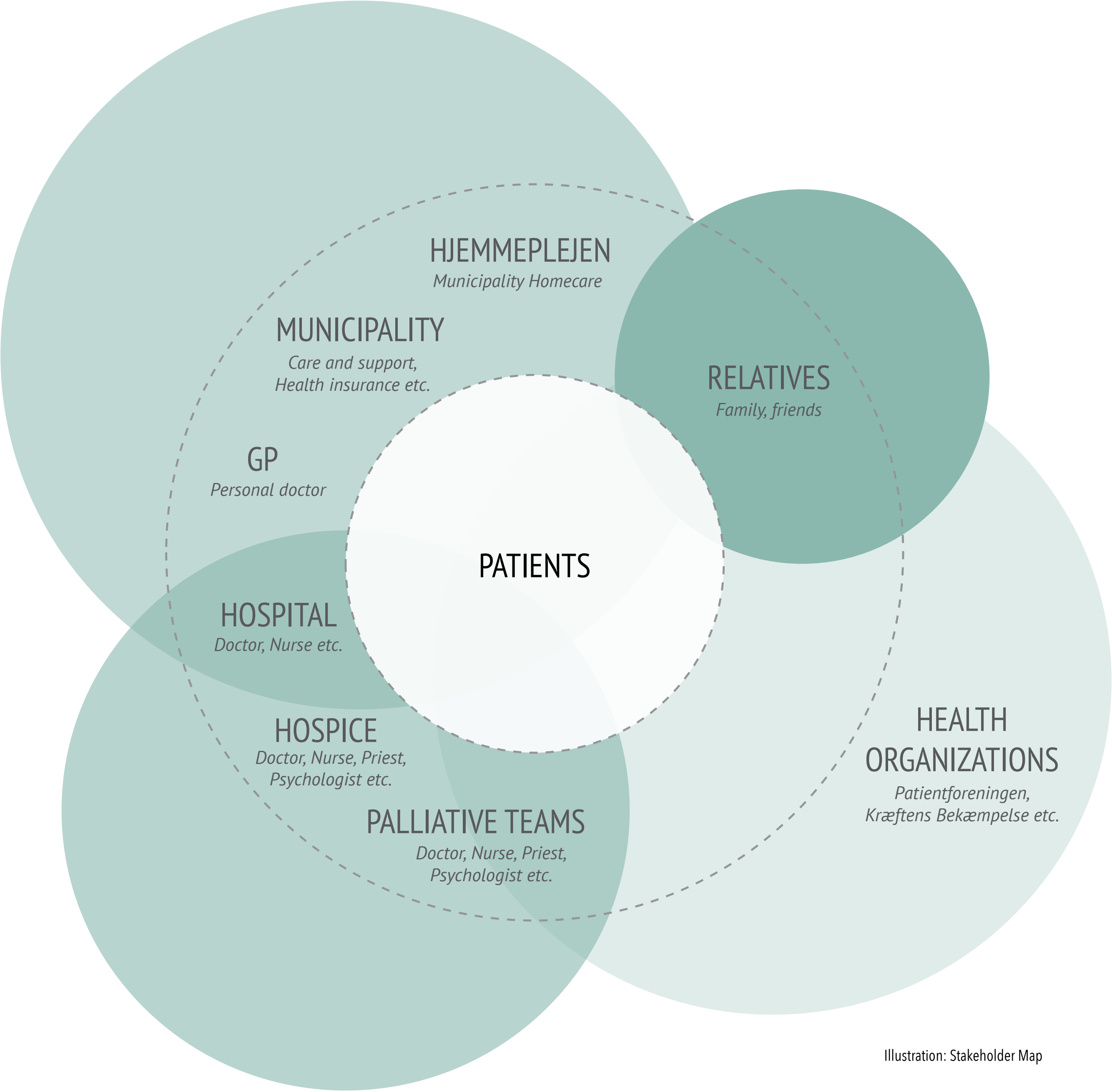


Illustration: Stakeholder Map

PATIENTS

The terminal patient can be found in the center of the stakeholder map because they are considered to be the most important actor among all the actors. They are the main factor that will be thought-out during the whole process.

COMMUNICATING WITH:

The patients are connected to the physical health professionals through their treatment and pain management. They are expected to explain their situation to family and friends regularly. The palliative teams are also closely connected with the patient's emotional and physical state. There are also professionals who provide palliative care to the patient even though they might not use this official terminology. Some of these professionals can be a psychiatrist and a priest, who help the patients reach realization of their current condition by using different tools and techniques. Furthermore, they assist them in tackling mental issues which are the result of their illness. Home care and their private doctor are very much involved in the patient's journey. Influencing the patient are also private organisations such as The Red Cross and The Cancer Society. They are all interested in improving the patient's daily life.

FRIENDS & FAMILY

In some cases where the disease is not yet as violent, the patient still has the opportunity to keep on some of their daily activities such as: volunteering, attending the local sports club, travelling and so on. This means that they will be surrounded daily by friends, family, colleagues (if they are still working), or other volunteers. This group of stakeholders are all concerned about the patient's condition, and they should be taken into consideration when taking certain decisions, which are linked to their disease.

COMMUNICATING WITH:

The friends and family are one of the most important actor among all the stakeholders. They keep an ongoing communication with all the stakeholders who are actively involved in the treatment of their loved one, as well as the patient themselves. These are the people who also have the power to influence the patient's decisions when it comes to their treatment, e.g. where they want to die, do they really want to continue with the treatment, etc. According to the desk research these are also the people who do not receive enough attention. This is very unfortunate, because they are the ones who are left after the patient's death. They are also the ones (in most cases) who will take the burden of caring for the patients if they choose to die at their private homes.

HOSPITALS, PALLIATIVE TEAMS

By a hospital stakeholder we do not consider the physical place itself, but all the healthcare professionals working there such as doctors, palliative teams, nurses, psychologists, etc. They are an essential part of the patients and the relatives' journey. They are the professionals who do not only help with the physical pain, but they provide guidance to the terminal patients and their families. They have the power to affect the patient's situation and this is why they are very important to consider.

The palliative teams are considered part of the hospital stakeholder, however they are an eco system that functions on its own so this is why is important to explain how these teams function. They consist (https://goo.gl/osfGjB) of doctors, physiotherapists, nurses, psychiatrists and social advisors. Their responsibilities are overlapping with the other healthcare professionals. The palliative teams can be found mostly in hospices, however a few hospitals in the Hovedstaden Region of Denmark have such teams such as: Bispebjerg, Hvidovre and Herlev Hospital (Lisbeth Christiansen, Klinisk udviklingssygeplejerske, Sankt Lukas Hospice,2016, Interview). When a terminally ill patient is being hospitalised they are assigned with a personal nurse, who becomes their daily contact throughout the stay. This is done to create a more stable environment around the patient. The doctor checks the patient daily and prescribes the medication that is required, sometimes in discussion with the nurse as well as the mental professionals like psychologists, in case they are assigned to assist during the patient's treatment. Psychologists and priests enter the patient's hospitalization if the nurse considers it relevant, because of their mental well being, anxiety of death, etc. Home visits are done in a similar fashion, the team tries not to be there at the same time to overburden the patient. The professionals check the patient depending of the severity of the disease. If there is no need of a doctor every second day or every week, he is only coming when the patient is in need of professional assistance.

COMMUNICATING WITH:

All of the health professionals mentioned above are closely communicating with the terminal patients and their families. Their involvement is very important, because they do not only offer a treatment, but also emotional support for the families. After the passing of the patient they sometimes are in contact with the relatives even though they are not required to do so.

HOSPICES (SPECIALIZED NURSES, DOCTORS)

Such as the hospitals, the hospices are an important stakeholder to acknowledge. As discovered during the desk research the hospices have specialized palliative teams who are taking care for the patient. The purpose of a hospice is not to cure the patient but rather take care of their emotional condition and ensure that the last days of their life are as good as possible. In order for the patient to be admitted to a hospice, the life prolonging treatment must be finished and the patient should be willing to go to a hospice. They can contact a hospice on their own or their doctor should contact one for them.

COMMUNICATING WITH:

They are in close communication with the patient and their families. The hospice's team is very interested in their emotional well-being. Moreover, they are communicating with the doctor of the patient if they are the ones calling to admit the patient.

MUNICIPALITY

The Municipality is a very important stakeholder, because of the help they provide to the patients and their families. They are providing financial support to the relatives if they decide to apply for it and become a primary caregiver to the patient. It is essential to note that the financial support and the rules in order for a relative to receive them might differ from municipality to municipality. The municipality is also the actor that assigns a home helper to the patient.

COMMUNICATING WITH:

The municipality is in close contact with home helpers, patients and their relatives.

GP (GENERAL PRACTITIONER)

The GP is the patient's private doctor. In most of the cases this the doctor who has been in their life for a while. This is the doctor who takes care for the general health of the patient, but doesn't give the terminal diagnosis. If there is a fear that the patient might be seriously ill they will refer them to a specialized hospital doctor. According to Trine Brogaard and the patients involved in her research, they are more like to trust their GP and are feeling more comfortable in their company.

COMMUNICATING WITH:

The GP is having an ongoing communication with the patient and their families, as well as with the specialized hospital doctor.

HJEMMEHJÆLPEN

Hjemmeplejer, the home care assistant, is an educated person who is hired by the municipality and is sent to the patient's home, in order to help them with their personal needs and everyday practical chores. The service is paid through the taxes and exists for people who can not take care of themselves due to serious illness, being handicapped or too old. The patient can be helped with the process of getting home care by their doctor and their municipality. It is normal that the patient is visited by the municipality in order to understand how much and what kind of help the patient needs. (https://goo.gl/uFjp6P). For terminal patients homecare is promised to be for all hours of the day, but the reality paints a different picture of failures in the system and not as encompassing as the home care companies project. Furthermore is the reality a negative version of what the homecare companies promise, because of saving times for the municipality both the availability and range of service is decreasing. (https://goo.gl/St1kWA) (https://goo.gl/PQQqlR) (https://goo.gl/QbfWf6)

COMMUNICATING WITH:

The home helpers are in contact with the municipality, the patient, the relatives and if there is a need with the health professionals. The primary communication is between them and the patient whom they meet a few times per week.

PRIESTS & PSYCHOLOGISTS

The psychologist work with the patients starts with a reference from the nurse, that a psychologist is needed either to help with the patient or a relative. During a conversation with the patient or the relative is then considered what is needed to help them. The psychologist uses conversation and self-help tools to heal the patient.

The hospital's priest can get referenced to go to a patient like the psychologist, but he also roams around the hospital on the difference wards to see if any feel also to the nurses and doctors. The daily work therefore consists of grief groups, visits on wards and specific agreements with patients, as well as consistent conversations with nurses about their work. The priest tries to keep an informal way of conversing with the patients compared to the psychologists professional relationship. The priests are mostly used for personal non-documented conversations about life, death and existence. To both of them it is important that that conversation is done with a goal.

COMMUNICATING WITH:

Both the priest and psychologist have contact with the health professionals, such as nurses and doctors in their daily work. They focus not only on the mental problems of the patient, but always the relatives and professionals that work with end-of-life care. When the patient is dead, there is still relatives and professionals who had been close to the patient, that might have trouble coming to terms with their grief.

ORGANIZATIONS:

Outside the direct participation of the services surrounding the patient are the health organizations that are interested in helping the patients and their relatives. These are for examples organizations like The Cancer Society or The Red Cross that have offers to solve problems.

COMMUNICATING WITH:

The health organizations are not in direct contact with the patient but they are available if the patients and their relatives need assistance and information during the process.

This chapter helped us once again to look into the different stakeholders and outline the most essentials ones. The gathered qualitative data and desk research helped us during the process, as well as we did better understand how they communicate with one another. We have eliminated a few actors of the initial stakeholders' map. It was very important for us to focus only on the ones who have the biggest influence during the whole process. All of the above mentioned stakeholders are very important and have essential roles during the last period of a terminal patient's life.

INTERVIEWS

The aim of this chapter is to walk you through our in-depth interviews, which were conducted in parallel with an ongoing desk research.

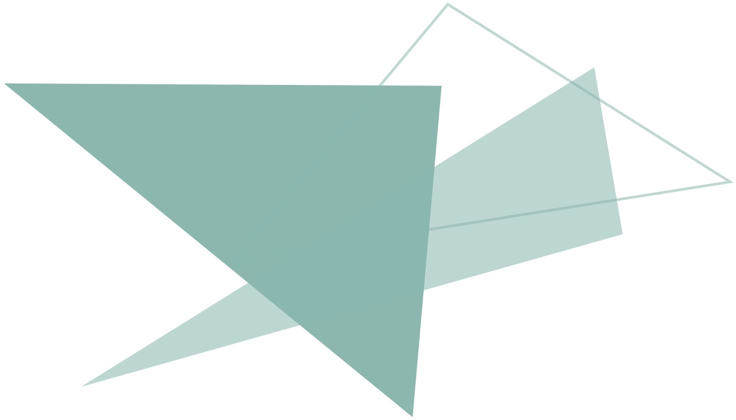
The desk research has already defined a few problem areas, such as: a terminal patient would rather die at their private homes, however this happens rarely. Furthermore, it hinted to the fact that there is not enough attention on the relatives and they need more support during the course of the terminal disease and after their loved one passes away. The qualitative interviews will aim to investigate these statements once again.

During a period of approximately three weeks we have conducted 10 interviews with hospice's and hospital's nurses, a GP who has also worked as a doctor at Sankt Lukas Hospice, relatives, priests and the organization Patientforeningen. Due to the high number of interviews, only the most important ones will be included in the chapter, while the rest of them can be found in the appendix section (Appendix 2) . We have conducted these interviews in order to get a holistic overview of the end-of-life system together with a better understanding of each actor's position and knowledge within the subject. During these interviews it has been essential to inform ourselves about certain issues, which they are facing during their daily life.

Before conducting any interviews the group decided on certain questions and themes for each stakeholder. Furthermore, each group member was responsible for contacting at least one of the stakeholders by using our personal networks, making phone calls or sending out e-mails. A few days later the first interview with Sankt Lukas Hospice was arranged. We redefined our interview questions in plenum and discussed our interview technique.

ABOUT THE INTERVIEWS

The interviews took place at the participant's workplace or private home. In order to show our appreciation we brought a small dessert, which created more friendly atmosphere for the interview. By having the chance to visit their workplace we could take a short tour around, e.g we had the chance to see Sankt Lukas Hospice's facilities. Last but not least, we found it important to double check the equipment and make sure that we were on time for the meeting. We used a semi structured interview guide where we created questions before hand but with room for reordering during the interviews. This worked as guidelines so we always had something to fall back on and in the same time it allowed us to include additional questions in response to our participants' answers and reactions.



INTERVIEW ACTIVITIES TIMELINE

10.10.2016	14.10.2016	16.10.2016	20.10.2016	22.10.2016	25.10.2016	02.11.2016	03.11.2016	07.11.2016
Send out emails to relevant stakeholders.	**Expert Interview** with Nurse from the Hopsice Sankt Lukas Stiftelsen - Lisbet Christiansen.	**Expert Interview** with former Doctor at Sankt Lukas, now working as a GP - Henri Goldstein.	**Expert Focus Group Interview** with 3 nurses from the Palliative Team in Hvidovre Hospital.	**Relatives Interview** with Yasin whose father has been givin a terminal cancer diagnose.	**Expert Interview** with a Hospital Priest at Bispebjerg Hospital - Karsten Thomsen.	**Expert Interview** with the chairman of the organization Patientforeningen - Niels Langkilde.	**Expert Interview** with a Priest - Henning Nabe Nielsen.	**Relatives interview** with Icelandic Arna, who lost her husband to cancer.

Illustration: Interview Activities Timeline

KEY-FINDINGS FROM INTERVIEWS

In this section, we will describe all the interviews' key-findings, memorable quotes and pictures taken during the process.

EXPERT INTERVIEW 14.10.2016 - NURSE LISBET CHRISTENSEN, SANKT LUKAS HOSPICE: The interview was conducted at Sankt Lukas Hospice situated in Hellerup Copenhagen, which is the first and biggest hospice in Denmark. This was the first conducted interview and within the initial empathizing phase of the process, where we discovered that the structure needs to be redefined. The participated nurse was kind and open to answer all questions. However, she did not fully understand our education and the goal of the interview. She has experience in talking with students and expected us to have more knowledge within the subject. This was in an early stage of the process, where the angle and direction of the project still were a bit broad. In the group, we discussed that having too open topic we are risking to not receive the right information. We considered the nurse's feedback and decided to be more specific in the upcoming interviews.

KEY-FINDINGS: There is a huge focus on cancer patients in Denmark. This is due to Kræftens Bekæmpelse, which is a strong and well-known organisation. In addition, there is more research about the different types of cancer, which results in higher-level of expertise on how to treat those patients.

Patients are dying in hospitals because they get too ill, so they cannot stay at home in the very end. ***"Even if the patient's wish is to die at home, it needs a lot of resources and is highly demanding and difficult for the family."*** (L. Christiansen, Nurse at Sankt Lukas, October 14, 2016).

Images: Skt. Lukas Hospice

Patients have to be terminal diagnosed in order to be accommodated in a hospice. It is a requirement that the patients admitted to a hospice are in the final stage of their palliative treatment, as well as having a reference from their doctor. ***"The average time a patient stays at the hospice is 17-21 days"*** [...] ***"We primarily have cancer patients between 65-68 years old."*** (L. Christiansen, Nurse at Sankt Lukas, October 14, 2016). Approximately 1 out of 4 people wanting to go to a hospice do not get admitted.

> *“Even if the patient’s wish is to die at home, it needs a lot of resources and it’s highly demanding and difficult for the family.” […] “Sometimes the family cannot fulfill the patient’s need.”*

The patients’ relatives are quite important for the hospices. They are involved in everything if they wished to be. ***“The hospice’s philosophy is to have a holistic approach to treatment. Both the physical, mental as well as social and spiritual aspects are taken into consideration. These different needs are equally important.”*** (L. Christiansen, Nurse at Sankt Lukas, October 14, 2016).

In Denmark people want to die at home, but those who come to hospices prefer to die there instead. ***“People can get palliative care at home from palliative teams which Bispebjerg, Hvidovre, Herlev, Sankt Lukas and Diakonissen provide.”*** […] ***“The patient want security. If the patient feels safe, they prefer to die where those aspects are being fulfilled.”*** […] ***“They are asked in the beginning when their needs are not the same as in the end. This can also be the reason why they don’t die at home. And Sometimes the family cannot fulfill the patient’s needs.”*** (L. Christiansen, Nurse at Sankt Lukas, October 14, 2016).

When asked about the patient’s’ condition Lisbet says that the patients can have all kind of emotions. In her opinion, it is only natural that everyone informed about a condition like this will have some kind of crises: ***“However many patients have a good life quality. Our main focus is to improve the patient’s life quality in the end of their life.”*** (L. Christiansen, Nurse at Sankt Lukas, October 14, 2016).

EXPERT FOCUS GROUP INTERVIEW 20.10.2016 - 3 NURSES, PALLIATIVE TEAM AT HVIDOVRE HOSPITAL: This interview was conducted at the Palliative Unit in Hvidovre Hospital where we interviewed Pia, Lisbeth and Mona from the department. The interview went good and the team was very kind and we felt an open and cozy environment. This focus group interview was conducted in an informal way and it is therefore difficult for us to know or remember who said what, this is why we will refer to the speaker as "the palliative team".

KEY-FINDINGS: In the palliative unit in Hvidovre Hospital you will mostly find 65+ years old patients. In here all symptoms will be considered equally. Anxiety will e.g. be considered as pain. Here you will find 99% cancer patients. At the moment that is 10 patients in the hospital and 139 patients enrolled at their homes. ***"In most of the palliative teams cancer is a requirement due to the money we get from cancer fonds. But you will see more and more patients with other diagnoses although we still get money from the same fonds."*** (Palliative Team Hvidovre, October 20, 2016)

In the palliative unit you will find a team of different actors such as nurses, doctors, physiotherapists, psychologists and priests. ***"We don't have a formal and structured sparring but we are good in helping each other in the department."*** (Palliative Team Hvidovre, October 20, 2016). Opposite to a hospice, the palliative team in Hvidovre Hospital helps patients to die at home. ***"Here you will hear about life, not death. We hear a lot of great life stories. Here there is time to talk about other stuff than diseases."*** (Palliative Team Hvidovre, October 20, 2016)

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> *"There is a lack in the structure of treatment within the after phase. We are not required to call the relatives and offer treatment after the patient dies."*

Image: The Palliative Team, Afd. 126

Priests and psychologists often talk with the patients. The psychologists are required to take notes, the priests are not, why it might feel more comfortable to talk to the priest. Though it seems like the relatives are neglected a bit during the palliative treatment. ***"The relatives are a part of the palliative treatment as well as the patient. They get psychological help if needed. Especially children up till 28 years old get help."*** [...] ***"There is a lack in the structure of treatment within the after phase. We are not required to call the relatives and offer treatment."*** [...] ***"I actually think they should have the offer of getting a phone call when their relative dies."*** (Palliative Team Hvidovre, October 20, 2016)

There is the ongoing debate about prolonging life within the health sector. ***"Should we keep giving the patient chemo? What life quality do they get in that period of time? So many side effects are connected to it. Sometimes it makes sense. Sometimes it doesn't."*** (Palliative Team Hvidovre, October 20, 2016)

It is quite different from patient to patient in how active they are and how their physical shape is. ***"It is actually not the pain that bothers patients. It is the chronic fatigue. The patients get weaker at the end of course."*** [...] ***"Some people are still working part-time jobs during their palliative treatment."*** (Palliative Team Hvidovre, October 20, 2016).

The team talks with the patients and asks them quite often about where they prefer to die. They are aware that they can change their minds during the process. ***"We are aware that some patients want to come back to the hospital and not die at home. That can be due to that many relatives find it hard and can't manage the job."*** [...] ***"Sometimes we have to tell the patient that their relatives are not up for the job."*** (Palliative Team Hvidovre, October 20, 2016) Many of the patients enrolled to the palliative team have a small network. Patients that are often alone have difficulties getting home. The home care (Hjemmeplejen) will come visit, but they will be quite alone during the day.

RELATIVES INTERVIEW 22.10.2016 - YASSIN, WHOSE FATHER IS DIAGNOSED WITH TERMINAL CANCER: Yassine's father, Abdel is 61 years old and has been diagnosed with prostate cancer for 2-3 years, which now has developed to a bone cancer. He now has a terminal diagnosis in an early stage which allows him to work and travel now and then, while going to regular check-ups at Rigshospitalet every third month. Yassine opened up to us in a very sensitive interview where he shared detailed information about his father that gave us great insights in the mind of a terminal diagnosed father. This provided us with further knowledge about the patients, the issues they're facing and how they're tackling the day to day life.

KEY-FINDINGS: Abdel went to his own GP because he urinated blood. His GP sent him to some further tests at Amager Hospital where he got the diagnose. Now he is enrolled at Rigshospitalet for check-ups. Abdel is not strongly affected by the side effects of his disease yet. He takes hormones that stabilise the cancer. This affects his hair growth. He has a hard time urinating and he sweats a lot at night. The change in hair growth means a lot to him because of his religion. ***"We are religious in our family and he has always has had a big beard so I think that's difficult for him."*** (Yassine, October 22, 2016)

Abdel sounds like a very strong man and the longer we get into the interview the more contend he sounds. It has to do a lot with his culture and religion as well. ***"He told me, that he was sick 1 year after he got diagnosed."*** [...] ***"He doesn't show how he is feeling."*** [...] ***"He seems fine with the situation. He has spent his whole life preparing for his death. It can be something he is hiding but he tells us that he has achieved good in life."*** (Yassine, October 22, 2016) Abdel seems like the kind of person that would never complain about his condition and situation. He seems like a great father who would like to retain his pride and not let to be controlled by his disease.

"He doesn't want anyone to know about his disease. " [...] ***"He often travels to our family in Morocco but our family over there doesn't know about his disease."*** (Yassine, October 22, 2016)

Yassine and his family have been a dissatisfied during the process. There have been two different doctors during the process. ***"When something as critical as this happens to my father, he asks about every little thing, but we didn't experience getting his questions answered by the doctors. Maybe the doctors don't have the answers or maybe it requires some bigger insight and effort."*** (Yassine, October 22, 2016)

> *"He didn't experience getting his questions answered by the doctors."*

Something changed when Abdel got diagnosed. Although he doesn't want to talk about it, Yassine notices things that it has changed his father. ***"My father has always been well structured and worked on a routine. When he got sick his whole routine fell apart. That was his identity."*** [...] ***"It has been challenging to change his life."*** [...] ***"We feel like we have to be cautious and let him react in his own way."*** [...] ***"He wouldn't like me to articulate him being different than before. I try avoiding that. But all of this has changed him."*** (Yassine, October 22, 2016)

Yassine and his family has not been offered any palliative care yet. His father has been offered psychological help through his insurance but the family has not. Yassine is not quite sure if his father has thought about where he wants to end his last days. ***"Maybe he wants to die in Morocco. I don't think he has thought about it."*** (Yassine, October 22, 2016)

EXPERT INTERVIEW 02.11.2016 - NIELS JØRGEN LANGKILDE, CHAIRMAN OF THE BOARD OF PATIENTFORENINGEN: We went out to meet with Niels Jørgen Langkilde who works for Patientforeningen - an organization that deals with the patient's legal rights. Besides working within the field of patient's rights, he also had some very interesting stories to tell from his own experiences. Niels lost his wife from cancer 2 years ago. She chose to die at home, so he gave lots of valuable information from both the patient's and relative's point of view.

KEY-FINDINGS: As mentioned before Niels' wife decided to stay and die at home although he didn't ask her "where do you want to die?", he asked her "where do you want to be?", and it was clear to him that she wanted to be home in a safe and comfortable environment. In fact, according to him, it in our nature to wish for dying where you feel safe the most. ***"It is primordial human to want to die in your nest. Many animals die together like this. No one wants to die in a cold and sterile environment. No one would like to die at the hospital. That's the most dangerous place to be in. The place with most diseases gathering."*** [...] ***"People panic when dead is near. People have a primordial force to fight for their lives."*** [...] ***"Some people fight for a long life. One I know pledged his whole life to receive some treatment in Germany and he probably lived for one week more and his family was totally broke afterwards."*** (N. Langkilde, Chairman of Patientforeningen, November 2, 2016).

Patientforeningen is very fond of hospices. Niels have the impression that every patient and relatives enrolled to hospices have been very satisfied and according to him it is very important that there is a focus on the patient, that the system listens to the patient's needs and the patient has options. He had a very good experience with the system when his wife was terminal at home. ***"The municipality has this really nice setup where nurses came immediately if something was wrong. It could happen that my wife fell and I couldn't get her up. Then after 2-3 minutes someone was there***

> *"The municipality has this really nice setup where nurses came immediately if something was wrong. It could happen that my wife fell and I couldn't get her up. Then after 2-3 minutes someone was there to help."*

> *“When my wife died no one contacted me as a relative in this.” […] “If I was you, I would design a system that starts automatically. To tell the patient what information to seek through the municipality and help with everything.”*

to help. When she died, not even 8 hours went by before every equipment, bed and stuff was removed from our place.” […] ***“She was in a familiar environment. That meant a lot and it was the right thing to do for her.”*** (N. Langkilde, Chairman of Patientforeningen, November 2, 2016).

Niels would prefer to die at home himself but he knows that it can be a very hard job for the relatives. ***“I would prefer to die at home, if I could see that I wouldn’t be a burden. My second priority is a hospice and last priority is the hospital.”*** […] ***“My mother in law is terminal right now. She has been unconscious on and off for the last 14 months. Taking care of her requires 4 men at home with her together with family and doctors. That’s a really tough job.”*** (N. Langkilde, Chairman of Patientforeningen, November 2, 2016).

According to Niels there is a lack in the system that requires new business models. ***“The money follow the patient. If the government knows that you’re terminal, then you have to chose whether you want to go to the hospital, be at home or in a hospice, and to chose what to buy home to you. If you chose the hospital, the hospital will receive the money from the state. That means that the money will run out fast if the patient lives long. New business models must be developed for this to work for every part involved.”*** […] ***“The municipality are willing to pay for terminal patients because they can see it’s transient. It is totally different with handicapped people e.g. - then they know it’s a permanent thing.”*** (N. Langkilde, Chairman of Patientforeningen, November 2, 2016).

When talking about making a service design solution within the system, Niels had an interesting suggestion. ***“When my wife died no one contacted me as a relatives in this.”*** […] ***“If I was you, I would design a system where people get diagnosed terminal. A system shall start automatically. To tell the patient what information to seek through the municipality and help with everything.”*** […] ***“It should not be difficult for the patient or the relatives. A third person must ask and talk with the patient about different things.”*** (N. Langkilde, Chairman of Patientforeningen, November 2, 2016).

EXPERT INTERVIEW 03.11.2016 - PRIEST, HENNING NABE-NIELSEN: We conducted an interview with a hospital-priest working at Rigshospitalet in Copenhagen. Besides his primary job where he has to be available for patient and relatives at the hospital, Henning also works at a church where he does service.

KEY-FINDINGS: Besides being available for talking with the patients and relatives enrolled in Rigshospitalet, Henning also do supervisions with the clinical team at the hospital. ***"I'm teaching the clinical department here in the hospital in talking with patients. Many nurses and doctors think it's very difficult to talk to patients."*** (H. Nabe-Nielsen, Priest, November 3, 2016). He assumes that most of his conversations are with younger people. ***"As an 80 years old you'll have a bigger understanding of the disease. As a 41 years old with family and a carrier it can be very difficult."*** (H. Nabe-Nielsen, Priest, November 3, 2016). He thinks that talking with a priest during a disease process can seem more convenient than talking with the clinical department in the hospital. ***"Here we have confidentiality. It's a confidential space. And when working in a confidential space conversations can be very intimate and confidential. Unlike the nurses and doctors who must keep records."*** (H. Nabe-Nielsen, Priest, November 3, 2016).
He thinks that there is a certain common feeling among patient in the hospital. It is a common thing to seek for hope and meaning with life among dying people. ***"The hospital feels like a warzone."*** [...] ***"In the trenches there are no atheists. People ask for meaning when they're sick. Many people use religion to tackle situations."*** [...] ***"Once I talked to a terminal patient whose only wish was to get a Fiat 500. The family asked if that was such a good idea. I listened to her wishes of a Fiat 500. To me it shows hope that denies death."*** (H. Nabe-Nielsen, Priest, November 3, 2016).

Although he is surrounded by death in his daily life he doesn't think that the great death exists. ***"I don't think the great death exists. The best way of dying is to be full of regular days and fall asleep and die. But I don't think death will ever be good. Then life wouldn't be worth living."*** (H. Nabe-Nielsen, Priest, November 3, 2016).

> *"As an 80 years old you'll have a bigger understanding of the disease. As a 41 years old with family and a carrier it can be very difficult."*

RELATIVES INTERVIEW 07.11.2016 - ARNA SÆMUNDSDÓTTIR WHO LOST HER HUSBAND EGILL TO CANCER EARLIER THIS YEAR: Arna lives in Iceland and she has been living there during her husband's disease and through his death. Although the Icelandic healthcare system is different from the Danish one, we thought that we might need qualitative insights and inspiration for our project from Arna's experience. She tells us about her experience being caregiver of her terminal diagnosed husband in their own home in Iceland while her husband gets more and more ill.

KEY-FINDINGS: Egill got diagnosed with lung cancer and they found a black spot in one of his lungs. The doctors thought they could surgically remove the cancer but when they operated on him they saw that the cancer has spread to the rest of the lung. They finished the operation and because of the operation wounds Egill had to wait 3 months for his treatment. The doctors said that it is a normal practice to admit him to a surgery without more detailed medical examinations. This whole experience has disappointed Arna very much. ***"The worst thing was how he was diagnosed. It was a medical malpractice and almost a neglection not double checking his condition before the surgery was made. That slowed the process of the treatment. I could have pressed charges against the doctors, but that would not helped me or bring me back Egill. So I choose not to do that."*** (A. Sæmundsdóttir, Relative to Egill, November 11, 2016).

> "There is totally missing the part, where you receive all the information needed at once."

After Egill's terminal diagnosis the family felt lost in where to seek the right information. They received information from different professionals within the healthcare system, but some of it seemed to be delayed and other quite irrelevant for their situation. Besides having difficulties finding the right information they also felt quite alone. ***"There is totally missing the part, where you receive all the information needed at once. When patients are diagnosed, it's such a jungle of information but in different places. There's no collaboration or coordination between places and people. No one tells you in the beginning about your rights and what you can apply for."*** [...] ***"You have to seek all of this information by yourself. No one comes to you and talks to you about these things."*** (A. Sæmundsdóttir, Relative to Egill, November 11, 2016).

Egill always refused to stay at the hospital when he went there for consultations. He wanted to be at home and didn't want to sleep there. ***"He felt that if he stayed at the hospital, the disease had won. He felt if he was at home, he still could control the disease."*** (A. Sæmundsdóttir, Relative to Egill, November 11, 2016). Arna could not get financial support for being a caregiver in Iceland, which is why Egill had to keep going to work every day. He somehow managed to work each day, until he felt too weak to continue. ***"He was worried about being too much of a financial burden to us. He was also waiting to be that sick, he could take a leave of absence from work."*** (A. Sæmundsdóttir, Relative to Egill, November 11, 2016).

Taking care of Egill was a hard job for Arna who once turned to the municipality for help but got rejected. ***"When I realized how hard this job was for me, I went to a social worker at the hospital to ask about my possibilities to apply for such a financial support. She basically said it was very difficult to receive this kind of support and it was in other more extreme cases, where the caregiver could apply for that."*** (A. Sæmundsdóttir, Relative to Egill, November 11, 2016).

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“I felt I couldn’t manage the task of taking care of him at home.”

The week before Egill’s death Arna took him out, so they could visit a hospice. She said to him that even though he went to a hospice he could always go back home again. The day before his death he agreed on going to the hospice. ***“The day before he died, he was in so much pain and I felt I couldn´t manage the task of taking care of him at home. At this point, he was very drugged and later that day lead to the bowel paralysis. Fortunately, I brought him to the hospice the day, before that happened. It would have been way too much work for me alone and totally out of my control.”*** (A. Sæmundsdóttir, Relative to Egill, November 11, 2016).

Egill died in the hospice and he spent his last hours with his whole family. The priest was together with them 40 minutes after he died. Arna and Egill’s daughter is atheist and has strong opinion about religion. The priest has been very understanding and added that even though she is not religious we all have the same feelings. The family members opened up and everyone said some nice words about Egill. ***“This was a very good way to say goodbye to Egill and so helpful for us who are left behind after he passed away. Somehow, saying goodbye in that way, made the situation much better and had a soothing effect on us.”*** (A. Sæmundsdóttir, Relative to Egill, November 11, 2016).

Arna had a very good experience with the hospice and palliative team. The palliative team has contacted her a few times after Egill’s death which she has found really helpful. ***“The nurses from the outgoing palliative team are so nice. They still contact me to see how I’m doing and asking if they can do anything to help me. They are even coming to me soon for a visit and to talk about all of this. They have called me about 4-5 times since he died in March this year, and once they came to me and stayed for few hours, just to chat and to see how I am doing.”*** (A. Sæmundsdóttir, Relative to Egill, November 11, 2016).

In conclusion to our conducted interviews different patterns have shown between qualitative findings. Among those findings was that it is quite clear that there is a wish between Danes to die at home. It is a common thing among patients that most of them don't want to show and complain about their disease. Most of them would rather stay at home and be sick than being at the hospital. This goes hand in hand with the fact that the patients want to stay at home rather than the hospital because they would rather stay where they feel safer.

Our conducted interviews showed a huge focus on cancer patients. 99% of all patients enrolled in the palliative team in Hvidovre Hospital are cancer patients. This also appears within the hospice and home-hospice area where most of the patients die from cancer. This might be due to the fact that 1 out of 3 Danes suffers from this disease.

But why are most of the patients dying in hospitals when they would rather die at home? According to the experts in our conducted interviews it's probably because of two things: 1. The patients who are dying at hospitals come to the hospital because they get too ill at some point. 2. The patients' relatives cannot manage the caregiver job and they feel quite alone in their situation.

Another important finding is that there is huge division in opinions and policies within the clinical teams about life quality and giving patients hope during their disease. Some doctors think that it is for the patient's best to prolong their life and give treatment till the very end, and others would rather focus on giving the patient life quality in their last days in the form of better days without medication.

When a patient is terminal diagnosed a kind of crisis will arise. Most people have a primordial force to fight for their lives and they will often panic. Many of the terminal patients find peace in talking with a priest. There is a certain confidential space when talking with a priest. The priests have no agenda and they don't report the conversation. The priests often talk with the patients about the patient's relations, what the meaning with life is and what will happen with them after their death.

When a patient gets a terminal diagnosis we have discovered a common pattern in the lack of focus on the relatives. According to the palliative team in Hvidovre Hospital, the relatives can receive all the help that is needed both informative and psychological. However, they admitted that they haven't got any structured guidelines of what to do for the relatives during the process especially regarding the phase after the patient's death. From the conducted interviews with relatives, we have found out that it is hard for them to seek the right and relevant information and they feel quite alone, especially those of them who would like to be caregivers for the terminal patient at home. According to the chairman of Patientforeningen, there is a need for a system where patients and relatives can receive the information they need - a system that must start automatically when the patient gets the terminal diagnose.

REFLECTION, CONCLUSION, REDEFINING OF THE PROBLEM FORMULATION & TARGET GROUP

Both the qualitative interviews and the desk research findings were very much alike. Both relatives and professionals stated that there is a miscommunication between them, as well as between the hospitals and the GPs. The priests and nurses are focusing a lot on the patient's emotional problems, especially on discussions about death and life. The priests also talk about the ethical issues of the treatment, such as when it is okay to stop it and let people die in peace. Furthermore, the research showed that there is not enough focus on the patient's relatives and loved ones. This is unfortunate, considering their power in the situation and that they are often the ones becoming the primary caregiver, if the patient decides to die at home.

As a result of these findings the problem formulation is redefined a second time to have a greater focus on how to improve the overall end-of-life care experience. Instead of mainly concentrating the on how to get the patient out of the hospital. Our redefined problem formulation is as follows:

> HOW MIGHT WE USE SERVICE DESIGN TO IMPROVE END-OF-LIFE CARE FOR TERMINAL CHRONICALLY ILL PATIENTS?

THE USER

Image: Workshop - working with personas

INITIAL PERSONAS

On the basis of the first two interviews, we decided to create a few personas that could help us better understand the patients and their relatives, as well as identify and empathise with them. Personas are a good tool used for gathering insights about the user, their problems, needs and pain. They also help with presenting who the user is, who are we really designing for. Søren Kierkegaard has a very accurate quote that summarizes how personas can help the designer: *"Indeed, to be able to help another person, I must understand more than he does – yet, first and foremost I must understand what he understands. If I do not, my greater understanding will not help him at all."* (Søren Kierkegaard, 1848)

We must first understand the user, before we truly know what they need. Personas can be used to maintain the focus on the user, Lene Nielsen (2004) suggests supplementing the design phase with personas to do just that: "If the design team members have a number of persona descriptions in front of them while designing, the personas will help them maintain the perspective of the users".

After creating the initial personas found in this section, we compared them with the information we received from the ongoing interviews to see if they actually could be found in the system.

SONJA

“I havn’t had one bad experience in my life.”

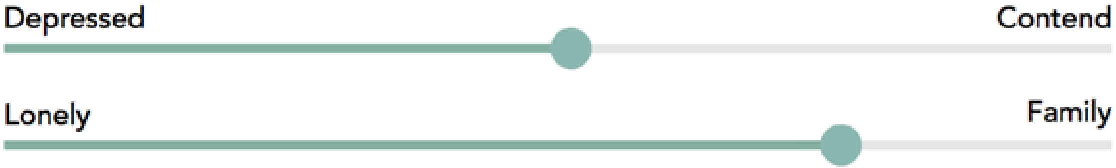
AGE	75
OCCUPATION	Retired
STATUS	Husband
KIDS	3 kids
LIVES IN	Gentofte
DIAGNOSED	Ovary Cancer
TERMINALLY	2nd state
LOCATION	The Hospital
ARCHETYPE	The optimistic

ABOUT SONJA

Sonja is a 75 years old former secretary with a husband and 3 grown up kids. She is a succesful elderly woman with no adversity in her life besides this terminally diagnose that seems like the worst thing ever happened to her. She hides her feelings and seems contend during her disease. She misses her dog a lot and she’s often thinking about missing out on bridge every tuesday night with her friends. She is diagnosed 2nd state terminally overy cancer and she is in the local Hospital.

NEEDS

- Talk with a priest
- To be with her family
- Have her everyday routine back
- Pain relief



BRIAN

"I feel like the world is against me."

AGE	41
OCCUPATION	Mechanic
STATUS	Wife
KIDS	2 kids
LIVES IN	Amager
DIAGNOSED	Bowel Cancer
TERMINALLY	2nd state
LOCATION	The Hospice
ARCHETYPE	The depressed

ABOUT BRIAN

Brian is a Mechanic from Amager who enjoy fixing his car, cruising around and enjoying the nature. Brian is in the Hospice but he has difficulties finding piece with his terminally diagnose, and he cries every night in his room. His wife and 2 small kids visits him every day, but they can't find piece in the situation and cries a lot.

NEEDS

- Comfort
- Want to talk with somebody
- To see his kids
- Pain relief

LOTTE

"I wanted to see and experience my grandchildren"

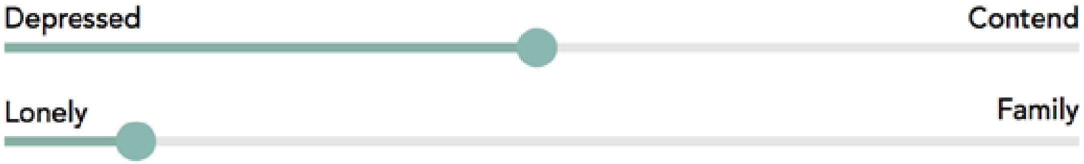
AGE	58
OCCUPATION	Pedagogue
STATUS	Single
KIDS	1 son in Germany
LIVES IN	Sydhavnen
DIAGNOSED	Lung Cancer
TERMINALLY	2nd state
LOCATION	At home
ARCHETYPE	The lonely one

ABOUT LOTTE

Lotte on 58 is a pedagogue and now at home for palliative treatment because of her terminally condition. She lives in Sydhavnen where she has been most of her time alone due to her son lives in Germany, and where her sister is now taking care of her. Lotte is a DIY type who enjoy making patchwork and she reads a lot of books. She finds joy in smoking cigarettes although it's not making her situation less difficult. Lotte is afraid that she will die alone and she wish for her son to come home.

NEEDS

- Cigarettes
- To keep herself busy
- For her son to come home
- Professional visitations
- Pain relief



KARSTEN

"I wish I had learned how to cook"

AGE	82
OCCUPATION	Retired
STATUS	Wife
KIDS	No kids
LIVES IN	Frederiksberg
DIAGNOSED	Brain Cancer
TERMINALLY	3rd state
LOCATION	Hospice
ARCHETYPE	Pieceful one

ABOUT KARSTEN

Karsten has always been a very active and social man during his 82 years. With no kids to raise, he has had great enjoy in being a foodball coatch and doing other humanitary work. Besides football and swimmingclasses, he has been working as a GP in the Frederiksberg Municipality. Due to his doctor experience, he also has great knowledge in his own condition. That's also why he is very contend about his terminally diagnose, although he would have wished that he'd learned to cook.

NEEDS

- Quality time with his wife
- To say goodbye to his colleagues and the football team
- Pain relief
- Cooking lessons

CROSS PARAMETER MAP

Based on our initial personas and the interviews conducted up until this point, we found two attributes that could help us group the patients. When identifying these attributes we used our initial problem statement as a guideline to identify, which of them are an important factor in fulfilling the wish of more patients dying at home. A large part of our decision was based on our findings through the research chapter and the knowledge gained from talking with experts. We learned that relatives are an important factor for a patient's home-well-being, some of them are so sick that they require several assistants, such as the mother in law of Niels Langkilde. (N. Langkilde, Chairman of Patientforeningen, November 2, 2016).

However, we also learned that even though patients have support from their relatives in some cases they are not up for the task (Palliative Team Hvidovre, October 20, 2016). Another key factor was the patient's *spiritual and psychological state*, and if they have come to terms with their situation. We learned that some patients continue in a state of denial, which makes it hard for them to accept their situation, and getting through just one day without being depressed is almost impossible. We also found a correlation between the patient being content and the family also being content, in one specific case the calm and clear state of the patient was reflected onto relatives. (Yassine, October 22, 2016) (L. Christiansen, Nurse at Sankt Lukas, October 14, 2016)

We made a cross parameter diagram where we placed family situation on the abscissa axis and their emotional status (how content they are with their situation) on the ordinate axis, which can be seen in the illustration to the right.

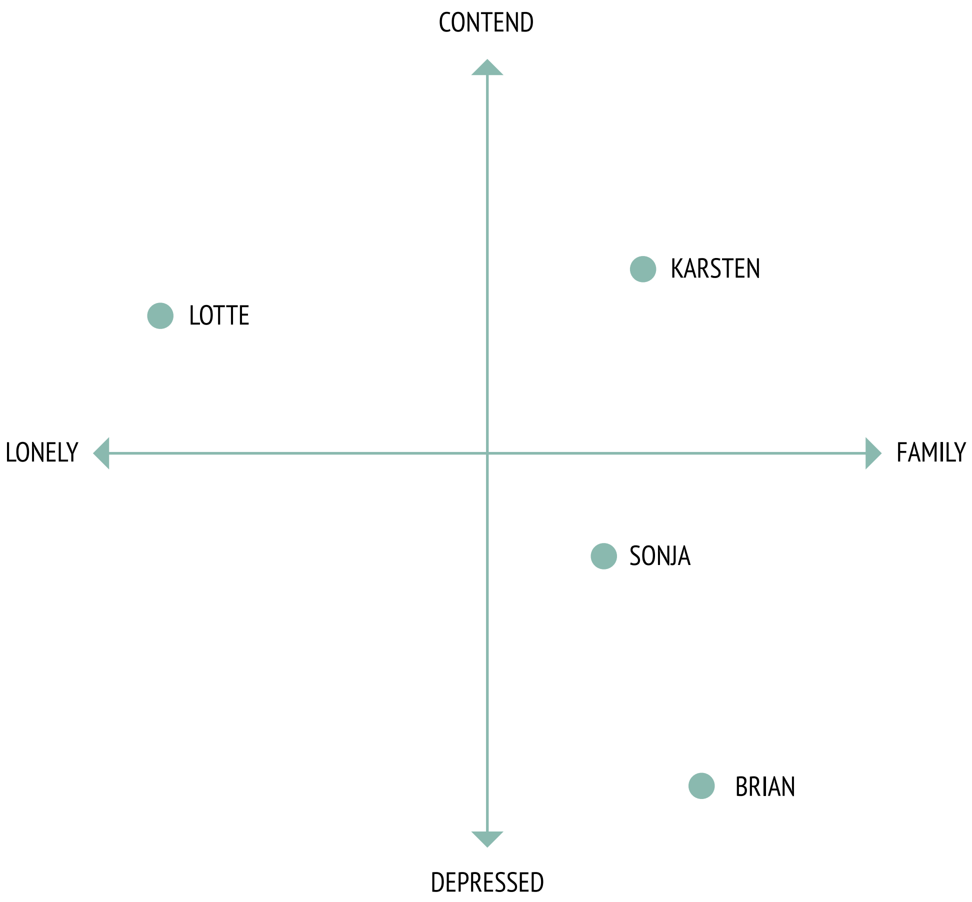


Illustration: Cross Parameter Map

> *"A customer journey map provides a high-level overview of the factors influencing a user experience, constructed from the user's perspective.."* (Stickdorn & Schneider, 2011, p.158)

INITIAL CUSTOMER JOURNEY

To better understand and relate to the user's experience, a user journey was made by using one of the personas. By doing this we will identify where problems occur and the different touch points of our persona's interaction with the healthcare sector. Furthermore, it will provide us with knowledge which later will identify the sections needing improvement.

SONJA'S CUSTOMER JOURNEY

MEDICAL JOURNEY	EMOTIONAL JOURNEY	PALLIATIVE JOURNEY
She discovered a bump/lump in her breast.	Slightly worried.	
+7 days. Has meeting with GP, who makes examinations/send her to further examination	Worried.	GP gives slight palliative care
+10 days. Diagnosis. Family is informed.	Terror, anxiety, worried, fear of death,	Early Palliative phase begins:Spiritual, Mental and social support, pain relief. Attempt to give normal life)
+1 Days. Treatment begins +	… + Hope	
+2 Months. Surgery (breast removal)	… + …+ feels ugly + Less feminine	
Surgery successful. +3 months. Closely monitored	… + Relief, + Hope +fear of relapse + Hope of reconstruction surgery	
+4 months. Relapse +New treatment (Kemo)	Disbelief, Terror, anxiety, worried, fear of death, Losing Hair, Feels ugly / Less feminine	Late Palliative phase begins: Pain relief continues
Disease modifying Treatment halts	…+ Anger,	
Disease is Terminal + Chronicle	…+…+ Acceptance of death	Terminal Palliative phase begins:
+1 month. Decision of place of death (Palliative department admittance)	Wants to die at home, feels loved. Feels alone, tired, loss of energy	
+1 month. Sent home + Home care	Afraid of leaving children, family behind Economical pressure. Relationship pressure	
Death		Post Death Palliative care begins for family

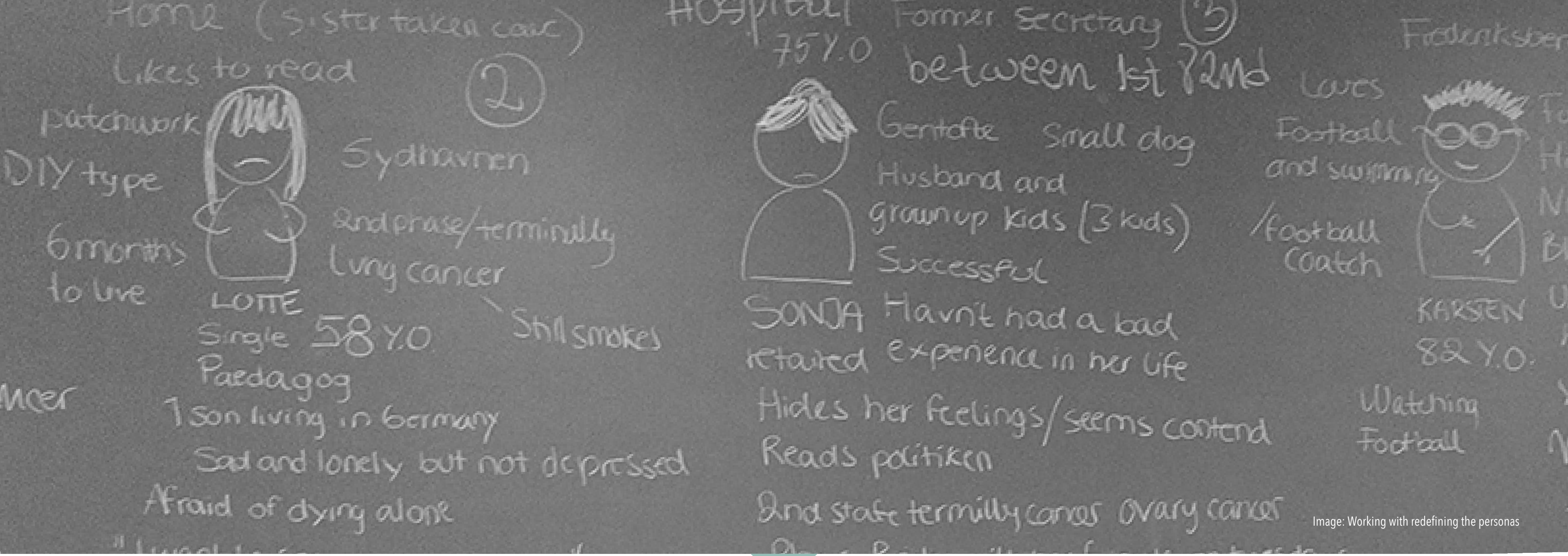


Image: Working with redefining the personas

REDESIGNED PERSONAS

The initial personas have helped us to better understand and empathize with our users also during the interviews. These first personas helped us visualize our future users, which we used as guidelines on what questions we should ask the participants and what information we want to gain by asking these questions. The personas were reviewed together with our supervisor, who suggested to personalize them by adding images and scenarios. We considered it as a great advice and after all the interviews were finalized, we saw certain aspects of our current personas that needed to be redesigned. Based on new knowledge and our redefined problem scope, we also found that we needed to introduce new personas and persona type. Because of the importance of relatives, we now decided to move the focus from only having patient personas, to having patient and relatives. The following personas and scenarios are the result of this. They will be used throughout the whole process of the project and we will constantly be going back to them, in order to create an optimal final solution.

HENRIK / PATIENT

“I don’t want to be a burden to my family.”

AGE	59
OCCUPATION	Mechanical Engineer
STATUS	Married
KIDS	2
LIVES IN	Frederiksberg
DIAGNOSED	Lung Cancer
TERMINALLY	3rd phase
LOCATION	Home untill his dead at Hospice
ARCHETYPE	The abnegator

NEEDS

- Doesn’t want to be a burden
- Doesn’t want to show and tell about his disease.
- Doesn’t want to be at the hospital.
- Wants to be at home with his wife.
- Doesn’t want to admit that he’s terminal.

ABOUT HENRIK

Henrik is a mechanical engineer who specializes in oils and consults companies what kind of oil is the most suitable for specific machines or motors. He enjoys spending time with his wife and family. In his spare time Henrik enjoys watching football and to go for a drive with his car. He has had lung cancer for 2,5 years. The doctors said to him when he was diagnosed, he could live up to 18-24 months. His body is getting very weak and he knows he doesn’t have much time left. He does not want to be at the hospital, because he feels if he stays there he is admitting he is a patient. Henrik is living a bit in denial and tries to be strong the whole time. He does not want to worry his wife and family and he does not want to be a burden. Therefore, he works almost to his very last day. He is able to get more flexible hours and can work from home the days when he is feeling very bad. But work is very important to him and it is a certain fuel for him to pull himself up together and get up each day.

SCENARIO

”I had been having pain in my back and shoulder for some time. My wife was always telling me to go to my doctor for a check-up. Finally after a longer period of time with pain, I went to my GP for a consultation. My doctor sent me to the hospital for a thorough examination. The results from the test showed I had a lung cancer. The doctors were optimistic and said they were able to surgically remove the cancer. They rushed me in surgery. Before the surgery was made, I told my oncologist I was in much pain and I asked him if that was normal. The oncologist said I should not worry. There were complications in the surgery. When the doctors opened me, they saw the cancer had spread around my whole lungs. They could not see how bad it was in the scanning that was made and they could not remove it with the surgery. They had to close me together again. A simple check could have prevent them to open my chest. My wound had to recover for three months before I could go to chemotherapy. The surgery slowed down the whole process and when curing and treating cancer, time is essential. If only I went sooner to my GP and only if the doctors saw in the scanning how bad the cancer was.”

ANNA / RELATIVE

"I don't receive the right and relevant information"

AGE	57
OCCUPATION	Florist
STATUS	Widow to Henrik
KIDS	2
LIVES IN	Frederiksberg
LOCATION	Home
ARCHETYPE	The caregiver
ROLE	Married and home-caregiver to cancer patient

NEEDS

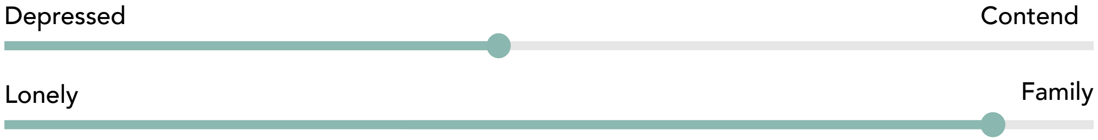
- To take care of her dying husband.
- To receive right and relavnt information about palliative care.
- To get help and support
- To get financial support

ABOUT ANNA

Anna is a florist, living in Frederiksberg. She loves spending time with her loved ones, but also enjoys quiet time reading books and to go for a swim in her neighbourhood swimmingpool. Anna's husband is diagnosed with lung cancer and he wants to stay at home during his illness. She does everything she can in order to help him at home. She has to find a new temporary job with shorter working hours. After helping her husband at home more and less for 2,5 years, she is totally exhausted and feels she cannot do it any more. She is afraid the end is going to be so hard for her, both physically and mentally, that she cannot handle the task. She convinces her husband to go to the hospice, even though he was not fond of the idea at first.

SCENARIO

"My husband got a terminal diagnosis after a couple of years battling with lung cancer, chemotherapies and surgeries. In the beginning, the doctors thought they could remove the cancer by surgery, but when operating on Henrik they found out that the cancer has spread. Because of the surgery the treatment process was postponed with 3 months, so his wounds could recover first. I had to stay strong for my husband's sake though, and hold on to the thought and hope for a cure. My husband refused to stay at the hospital. We all had to adjust to his illness and I found a new job so I could be his primary caretaker at home.I tried to apply for a financial support from the municipality when I realized how tough the task was for me to be his private caretaker. When my application for financial support was denied, everything became much harder. I felt quite alone in this situation and I had difficulties in finding the right and relevant information about this. My husband did not want to be a burden in any way but I was very physically and mentally exhausted. In his very last day, the task of taking care of him at home was too hard for me. I convinced him to go to a hospice. He died after his first night at the hospice."



SALEM / PATIENT

“I’m happy with what I have achieved in life”

AGE	61
OCCUPATION	Warehouse worker
STATUS	Wife
KIDS	2 kids
LIVES IN	Amager
DIAGNOSED	Prostate Cancer
TERMINALLY	1st phase
LOCATION	Home
ARCHETYPE	Religous one

NEEDS

- Quality time with family in Morroco
- Keep the disease a secret to family and friends
- Avoid confrontations
- To go to mosque and prepare for death

ABOUT SALEM

Salem is a 61 years old warehouse worker living with his family in Amager. He is diagnosed with terminally prostate- and bone cancer and he’s now working part time. He loves to travel and he’s visiting his family and friends in Morocco as often he can. He just got home from a vacation and he’s leaving again in December. The Moroccan family doesn’t know about his disease. Salem is a very strong, proud and a contend man - a person who wouldn’t talk openly about his problems. He is very aware of his body signals and his diagnose. He has achieved good in life and he has prepared for death throughout his whole life.

SCENARIO

“I had not had any specific symptoms until the day I called my doctor. This morning I got up and urinated blood. I asked my wife if it was something I should be concerned about. She insisted that I called the doctor right away. I did that. My own doctor said I should stop by for an examination the same day. I got the feeling that it could be quite serious. I went a few days waiting for a response. My doctor rang me up and told me that it might well seem that I had prostate cancer. He referred me to Amager Hospital, where I had to go for some further examinations. Here they told me that it was cancer for sure. At Amager Hospital, I was put into the process and next referred to Rigshopsitalet where treatment and monitoring should continue.”

QASIM / RELATIVE

“I want to know what the entire process is beforehand”

AGE	26
OCCUPATION	Social Advicer
STATUS	Single
KIDS	None
LIVES IN	Amager
LOCATION	Home with parents
ARCHETYPE	Young one
ROLE	Relative to Salem

NEEDS

- Wants to be a part of his father’s process and appointments
- To receive ongoing information about his father’s disease.
- To feel secure and be in control.
- To not loose his father.

ABOUT QASIM

Qasim is a social and highly spiritual person. He prays and goes to the mosque and he believes that you must treat others kindly. He is tolerant, content and thinks before he talks. Qasim is well spoken and well educated, he wants to know the process his father is going through and he dislikes surprises and unknown factors. Qasim is organized, he plans ahead, prepares and doesn’t like unexpected things. Qasim’s father has cancer and Qasim has put a big effort into understanding the different consequences of his father’s disease but still feels overwhelmed with the chaotic state of the ”system”. He feels there is no easy access to what he needs. He does not appreciate the process, and a structure is lacking. The family care for his father, and he lives at home with his parents. Qasim feels his father is the head of the house, and is not used to seeing him as weak as he is in his current state.

SCENARIO

”One year past before I heard about my father’s disease. At the time I was in a very busy part of my life, juggling school and work as well as being a volunteer for many of the refugees that at the time entered the country. I felt overwhelmed and concerned at the beginning of the news, but because my father has an aura of peacefulness as well as an understanding and acceptance of his current situation, me ad my family quickly found peace. I’m joining for all appointments, I’m fluent in Danish and Arabic, therefore I’m able to fully comprehend the meaning of what the doctors are saying, even though my father speaks Danish, I help by translating to ensure he also gets the full meaning of what they are telling. My father is terminal and has recently retired from his job. My family and I am doing the best to get through this, and at the moment we are still living a somewhat normal life with the disease. My father is still able to continue his life, taking medicine to slow the disease.”

REDESIGNED CUSTOMER JOURNEYS

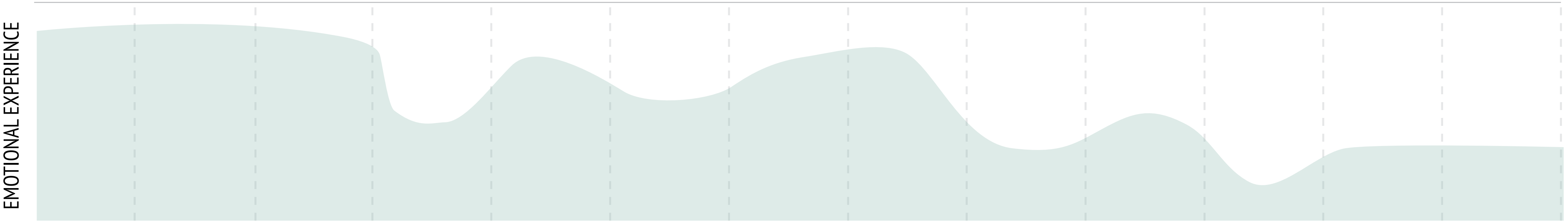
Based on the findings and the created personas we decided to use user journeys. We will use them to create a detailed timeline of the personas' experience. Our focus is both on patients and relatives, therefore this chapter will include both. The user journeys will be based on the gathered insights, as well as real facts and experiences gained from the interviews' participants.

A PATIENT'S USER JOURNEY - HENRIK, 58 YEARS OLD

THOUGHTS & EMOTIONS

- I FEEL PAIN IN MY SHOULDER AND BACK — PAIN
- WHAT CAN IT BE? MAYBE IT'S SERIOUS? — WONDERING
- CANCER? WHAT? — IN SHOCK
- OK. SURGERY. SO THEY'LL REMOVE IT. — HOPE
- SO THE CANCER HAD SPREAD. NOW WHAT? — DISAPPOINTED, SAD, SCARED
- WHAT TREATMENT? WHAT NOW? LET'S DO SOMETHING. — HOPE, WONDERING
- WILL I SURVIVE THIS? — HOPE, WONDERING, SCARED
- TERMINAL? FUCK. SHIT. WHAT? BUT I HAVE A FAMILY.
- I WILL NOT STAY AT THE HOSPITAL. I WANT TO BE AT HOME.
- I WILL GO TO WORK. I WILL NOT BE A FINANCIALLY BURDEN.
- THERE MIGHT BE A WAY OUT OF THIS NIGHTMARE.
- OK. NOW I FEEL TO WEAK. MY RELATIVES CAN'T TAKE IT ANYMORE. — LOST ALL HOPE
- I WILL DIE FROM THIS.
- FEEL LOVED

JOURNEY	WITH	PLACE
FIRST CHECK UP	GP, RELATIVE	GP
GOES TO HOSPITAL FOR TESTS	DOCTORS, NURSES	HOSPITAL
WAITING FOR RESULTS	RELATIVE	HOME
CANCER DIAGNOSIS	DOCTORS, NURSES	HOSPITAL
SURGERY	DOCTORS, NURSES	HOSPITAL
INFORMED ABOUT COMPLICATIONS IN SURGERY	DOCTORS, NURSES, RELATIVES	HOSPITAL
WAITING FOR WOUNDS TO RECOVER	RELATIVES	HOME
CHEMOTHERAPY	DOCTORS, NURSES	HOSPITAL
TERMINAL DIAGNOSIS	DOCTOR, RELATIVE	HOSPITAL
PALLIATIVE CARE AT HOME	RELATIVE	HOME
ENROLLED TO HOSPICE	DOCTORS, NURSES, RELATIVES	HOSPICE
DEATH ✝	DOCTORS, NURSES, RELATIVES	HOSPICE
UNITED GOODBYE TOGETHER WITH PRIEST	DOCTORS, NURSES, RELATIVES. PRIEST	HOSPICE

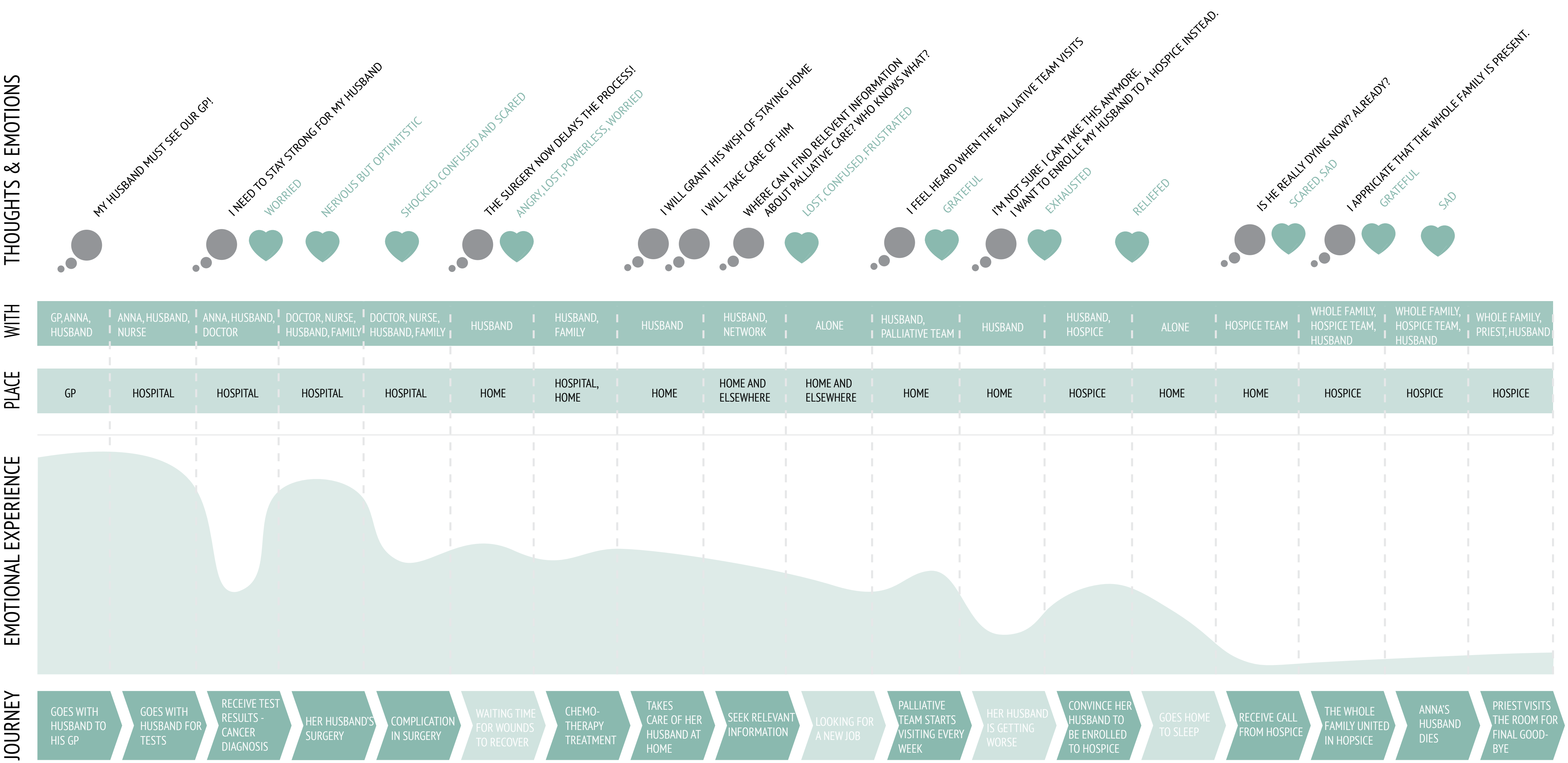


PAIN POINTS / PROBLEMS

- ● COMPLICATIONS IN SURGERY DELAYS HENRIK'S TREATMENT
- ● IT GETS TO DIFFICULT FOR HIS RELATIVES, WHY HE'S ENROLLED TO HOSPICE INSTEAD OF DYING HOME.

▶ TOUCHPOINTS ▷ NOT A PART OF THE SERVICE ● PAINPOINTS ♥ FEELINGS 💭 THOUGHTS

A RELATIVE'S USER JOURNEY - ANNA 56 YEARS OLD



THOUGHTS & EMOTIONS

MY HUSBAND MUST SEE OUR GP!

I NEED TO STAY STRONG FOR MY HUSBAND

WORRIED

NERVOUS BUT OPTIMITSTIC

SHOCKED, CONFUSED AND SCARED

THE SURGERY NOW DELAYS THE PROCESS!

ANGRY, LOST, POWERLESS, WORRIED

I WILL GRANT HIS WISH OF STAYING HOME

I WILL TAKE CARE OF HIM

WHERE CAN I FIND RELEVENT INFORMATION ABOUT PALLIATIVE CARE? WHO KNOWS WHAT?

LOST, CONFUSED, FRUSTRATED

I FEEL HEARD WHEN THE PALLIATIVE TEAM VISITS

GRATEFUL

I'M NOT SURE I CAN TAKE THIS ANYMORE.
I WANT TO ENROLLE MY HUSBAND TO A HOSPICE INSTEAD.

EXHAUSTED

RELIEFED

IS HE REALLY DYING NOW? ALREADY?

SCARED, SAD

I APPRICIATE THAT THE WHOLE FAMILY IS PRESENT.

GRATEFUL

SAD

JOURNEY	WITH	PLACE
GOES WITH HUSBAND TO HIS GP	GP, ANNA, HUSBAND	GP
GOES WITH HUSBAND FOR TESTS	ANNA, HUSBAND, NURSE	HOSPITAL
RECEIVE TEST RESULTS - CANCER DIAGNOSIS	ANNA, HUSBAND, DOCTOR	HOSPITAL
HER HUSBAND'S SURGERY	DOCTOR, NURSE, HUSBAND, FAMILY	HOSPITAL
COMPLICATION IN SURGERY	DOCTOR, NURSE, HUSBAND, FAMILY	HOSPITAL
WAITING TIME FOR WOUNDS TO RECOVER	HUSBAND	HOME
CHEMO-THERAPY TREATMENT	HUSBAND, FAMILY	HOSPITAL, HOME
TAKES CARE OF HER HUSBAND AT HOME	HUSBAND	HOME
SEEK RELEVANT INFORMATION	HUSBAND, NETWORK	HOME AND ELSEWHERE
LOOKING FOR A NEW JOB	ALONE	HOME AND ELSEWHERE
PALLIATIVE TEAM STARTS VISITING EVERY WEEK	HUSBAND, PALLIATIVE TEAM	HOME
HER HUSBAND IS GETTING WORSE	HUSBAND	HOME
CONVINCE HER HUSBAND TO BE ENROLLED TO HOSPICE	HUSBAND, HOSPICE	HOSPICE
GOES HOME TO SLEEP	ALONE	HOME
RECEIVE CALL FROM HOSPICE	HOSPICE TEAM	HOME
THE WHOLE FAMILY UNITED IN HOPSICE	WHOLE FAMILY, HOSPICE TEAM, HUSBAND	HOSPICE
ANNA'S HUSBAND DIES	WHOLE FAMILY, HOSPICE TEAM, HUSBAND	HOSPICE
PRIEST VISITS THE ROOM FOR FINAL GOOD-BYE	WHOLE FAMILY, PRIEST, HUSBAND	HOSPICE

EMOTIONAL EXPERIENCE

PAIN POINTS / PROBLEMS

- ● COMPLICATIONS IN SURGERY DELAYS HER HUSBAND'S TREATMENT
- ● CAN'T FIND RELEVANT AND RIGHT INFORMATION ABOUT HER AND HER HUSBAND'S SITUATION.
- ● CAN'T MANAGE THE JOB OF TAKING CARE OF HER HUSBAND.

TOUCHPOINTS

NOT A PART OF THE SERVICE

● PAINPOINTS

♥ FEELINGS

THOUGHTS

After the creation of the user journeys we feel more confident in our understanding of the patients and relatives' struggles from the moment of the terminal diagnosis. We were able to outline when during the process they feel lost and where there is a need for improvements. We confirmed once again that there is a lack of information which leads for both parties feeling confused and decreases their trust in the healthcare system. This chapter will be used during the ideate phase which will help us in the creation of the different ideas.

WORKSHOP

Image: Workshop

FINISHING EMPATHIZE AND DEFINE PHASE

In order to finalize the Empathize and Define phase successfully, we decided to facilitate a workshop. The goal of the workshop was to continue aligning our perspectives by understanding what problems we had been able to uncover throughout the desk research and qualitative interviews. We began the workshop with a card sorting technique. Through the use of a card sorting technique such as an affinity diagram the goal was to let the information create groups for itself that could be used in the further work on the project.

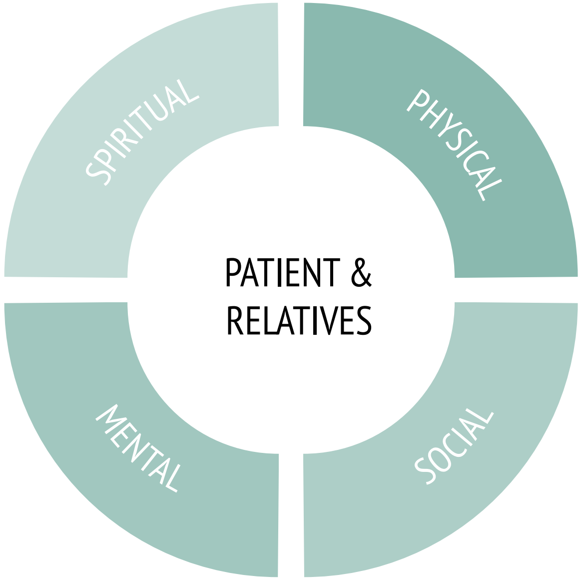
The day started out with morning coffee and cake to create a relaxed atmosphere. From here a brainstorming session was initiated to gather all problems, wishes, needs there were in the existing system and in our minds. All these bits of information were written down on their own post-it notes.

When we felt that enough has been written down, we took the workshop to the next phase, putting the post-its on the wall together, so they could be categorized together. To make sure that we placed the different post-it notes in what we considered under the correct category, we looked through them all once again. A few post-it notes were repositioned towards other problems that were better than their initial position.

All these groupings were written down, with the major ones being:

- Patients
- Information
- Problems with doctors
- Death choice
- Mental health
- Relatives

To try to see if it was possible to observe other patterns we tried to map the information out on the care diagram we had been given through the hospice interviews. This care diagram, as seen in the illustration below, shows the 4 different focus points, which the nurses and doctors have in their daily work: The physical, social, mental and spiritual.



This mapping showed that a lot of the problems were concentrated around the patient (in the center), there were many problems between the physical professionals or the professionals taking care of the physical needs and the social area, that of relatives.

From here we were able to take our list of major groupings and write them into three final problems which we considered as covering most of the groups. These were:

- No focus on the patient's relatives
- Miscommunication between professionals and patients
- No talk about death

These three problems we used as a starting point to continue our process. The workshop was a well spent day. It helped us to categorize and group all the findings we had gathered throughout the interviews and the desk research. The mapping onto the care focus of the hospice helped us funnel all the groups into specific problems, which we could decide upon to continue with in the further parts of the design process.

REFLECTIONS, CONCLUSION, REDEFINING OF THE PROBLEM FORMULATION & TARGET GROUP

The workshop was used to take all the gathered information from the earlier stages of the process and try to structure it. With the card sorting technique and the affinity diagram, we succeeded in listing all the different problems in several major groupings, which were later separated into three final problems.

In a group meeting we discussed which questions would be more interesting to look into, which one would have the greatest effect, and what would be possible to test properly. After the discussion, we judged that the problem of lack of focus on relatives would be the best choice.

From this our target group changed to also include the relatives in a even greater degree. Our goal with the project is still improving end-of-life care of terminal patients, but now through improving the daily life of the relative, both physical and emotional. Another consequence of increased focus is also that more patients will be able to die at home by having strong relatives who are able to carry the burden it is to care for a patient in this stage. Our new problem formulation is therefore:

HOW MIGHT WE IMPROVE THE SUPPORT AND INCREASE THE FOCUS ON RELATIVES WITHIN PALLIATIVE CARE OF TERMINAL PATIENTS?

BRAINSTORMING SESSION

Image: Brainstorming Session

BRAINSTORMING SESSION

To get on from our different problems statements and start prototyping, we chose to make a quick one hour brainstorm to successfully begin the Ideate Phase of the project. We wanted to improve upon our brainstorm from the workshop which was described in the workshop chapter of the report. For inspiration we used Tom Kelly's "The Perfect Brainstorm" [The Perfect Brainstorm, Tom Kelly, 2000], where he explains his ways of making sure that maximum results will be achieved during a brainstorm session.

We, therefore, took our problem statement *"There is not enough focus on the relatives"* and broke it up into smaller sub problem statements. The aim was to answer every single one of them separately, which created more structure. Even though we never reached all of Kelly's recommended hundreds of ideas, we were satisfied with the 70 we ended up with. We categorized them by using the affinity diagram method, which we already have affiliated us with. It helped us to categorize all 70 ideas which were connected with how to improve upon the focus on the relatives during the palliative care. The categories were the following:

- Guides for palliative teams
- Professional support
- Information improvements
- Schedule overview
- Proper preparation (for the death or for the care process at the home)
- Peer to peer
  - P2P emotional
  - P2P practical

After categorizing all the post-it notes we choose the ideas which we considered to be the most suitable ones. The ideas were around eight and we agreed to reduce the number to five. These five ideas would then be pretotyped. The ideas were as follows:

OUR 5 IDEAS

1

CAREGIVER-BUDDY NETWORK

A caregiver can receive help with chores e.g. picking up a package or needing help with grocery shopping. With this online service the caregivers will be able to ask for help among volunteers at any time. By using the service it will more manageable for them to take care of the terminally ill patient at home.

2

THE TERMINAL GUIDE

A digital platform where either a patient or a relative can seek relevant information. Software algorithms will display personalized information depending on the stage of the illness. They will find information such as: what medical equipment can be borrowed from the municipality, list of important contacts, financial help, etc.

3

SUPPORT GROUPS

Where relatives and caregivers can meet and talk with one another. It will have the function of a safety net for them, where they will be able to share their thoughts and feelings without judgement. This will help them to release stress and gather strength, which they can use in caring for the terminally ill patient.

4

PEER TO PEER PLATFORM

Where the relatives can receive a certain mentor or a support person who they can talk with about daily challenges or thoughts about their situation.

5

INFORMATIVE WEBSITE

A very close website idea to the Terminal Guide. Here the patients and relatives will be able to find all information they need at one place.

Image: Brainstorming Session

With the help of Tom Kelly on how to improve upon the brainstorm workshop we were able to successfully ideate and be satisfied with the results of the process. We observed that by using his suggestions, the ideas were created quicker and they were more connected with the problem statement. Having to read our ideas out loud while writing them down, also allowed everyone else to associate things from the conversations and build upon each other's ideas that were on the table, as well as create new ones.

PRETOTYPING

PRETOTYPE

As mentioned in the previous chapter after the brainstorm workshop we have chosen five main ideas, which would be created into pretotypes and then tested. This will enable us to quickly create concepts out of the ideas and validate if they would actually be relevant for the patients and their relatives. This chapter will have the aim to describe the testing process of the preotypes and include the final results. Moreover, it will begin with explaining the ethical issues of the pretotyping process which we considered.

PRETOTYPING METHOD

Before applying this method, we had a discussion about the ethical issues in regards to the how the people might react, as well as the consequences on using it in a sensitive topic such as end-of-life care. Alberto Savoia's booklet (2011) helped us to better understand our concerns when using pretotyping. He (2011) writes, that it is natural that some people will be bothered by this method from an ethical standpoint. According to him, he has thought about it himself and concludes that: *"Pretotyping can save you, and your potential customers, from wasting a lot of time and money on wrong its."* (Savoia 2011). He thereafter recommends that as long as you use your judgement and sense of ethics you should be able to sleep well at night.

Based on this we came to the conclusion, that the classical ethical dilemma of the ends justifying the means is thus in this situation seen as the means being a necessary evil to be able to complete the goal. As a result we decided to conduct the testing in a way that will not negatively affects the participants. It will be very positive for us and the process to be able to quickly identify if our service will actually be something people need, and most importantly will be willing to use.

RELATIVES FEEDBACK

We conducted two interviews with relatives of deceased cancer patients. In complete contrast to the earlier interviews, these two interviews were conducted with an unstructured approach and there was a free-flowing conversation. No specific questions were created before the interviews, besides the presentation of the five different concept ideas. The goal of the interviews was to identify which of the services would be most needed, and to see if the received feedback could improve the service in an unseen way.

ARNA S. SÆMUNDSDÓTTIR, 57 YEARS OLD, AND LIVES IN ICELAND. SHE LOST HER HUSBAND TO CANCER AND WAS HER PRIMARY CAREGIVER.

Arna has already participated during the qualitative research of the process and even though she is from Iceland we asked her for feedback again. As mentioned earlier in the report she lost her husband to cancer this year and she was taking care of him at home. All five concepts were presented to her and we gathered the most essential points of her feedback:

Arna thought that **The Terminal Guide** and **The Informative Website** are very good ideas because in her opinion when facing such a difficult situation people really need to have the relevant information. *"It will be a great thing to have the most important things at one place."* - Arna

The Terminal Guide or **The Informative Website** might decrease the stress levels for both the patients and their relatives, because they just need to use only one platform for everything they need to know.

Arna thought that **The Peer to Peer** concept would be great for the relatives, but later on in the process. They tend to think primarily for the patient´s needs and it is later in the process, when they become exhausted and drained. This is when this service would be perfect.

The Caregiver Buddy Network idea would be more suitable for people who do not have big families. According to Arna, the family members help to one another in such a difficult situation.

The Support Groups will be perfect for when a caregiver feels the necessity of emotional support and a safe place where they can talk with people experiencing the same challenges.

To summarize Arna's thoughts and feedback, she felt that the need for information was very big, and having it in one place would have helped her a lot. She felt that The Caregiver Buddy Network and the Support Groups are good ideas, but more suitable during the final stages, having a big and supportive family she didn't see much need for neither.

JEANETTE WOER HANSEN IS 47 YEARS OLD LIVING IN COPENHAGEN. SHE LOST HER MOTHER 20 YEARS AGO AND SHE WAS TAKING CARE OF HER IN HER MOTHER'S HOME FOR ALMOST 6 MONTHS BEFORE SHE DIED.

The concepts were also presented to the relative Jeanette. She has been taking care of her dying mother and she can relate to the issues around lack of focus and support for relatives during the palliative process. She was not included during the qualitative research but she was a perfect candidate for this phase of the process. Her feedback was great and it supported our research.

Jeanette's two favourite ideas were **The Terminal Guide** and **The Caregiver Buddy Network**. She would certainly use an informative service such as **The Terminal Guide**. "*The perfect moment when an informative service could be introduced to the patients and their relatives would be after receiving the terminal diagnosis. These ideas can be merged together with The Terminal Guide one.*" - Jeannette. She liked that the information can be personalized depending on the patient's condition, preserving what is relevant to each family.

In her opinion **The Peer to Peer** and **The Support Groups** ideas are not so good because she would never share her personal experiences with people she doesn't know, she was uncomfortable with the idea.

She was really excited about the **The Caregiver Buddy** concept. *"When receiving financial help the caregiver of the terminally ill patient doesn't receive any additional help from the state, because they are being paid to care for everything. This is where the The Caregiver Buddy Network idea would be perfect."* - Jeannette

Although she liked the idea, she's not sure if she would have used the service after all. When she needed help with chores, she would rather call a friend or a family member in her network instead.

The need for more information was something Jeanette felt was very much needed and would be used after the terminal diagnosis is given. She saw many possibilities such as extra help from the Caregiver Buddy Network, however she reconsidered if there might be a trust issue and she would rather ask for help a family member.

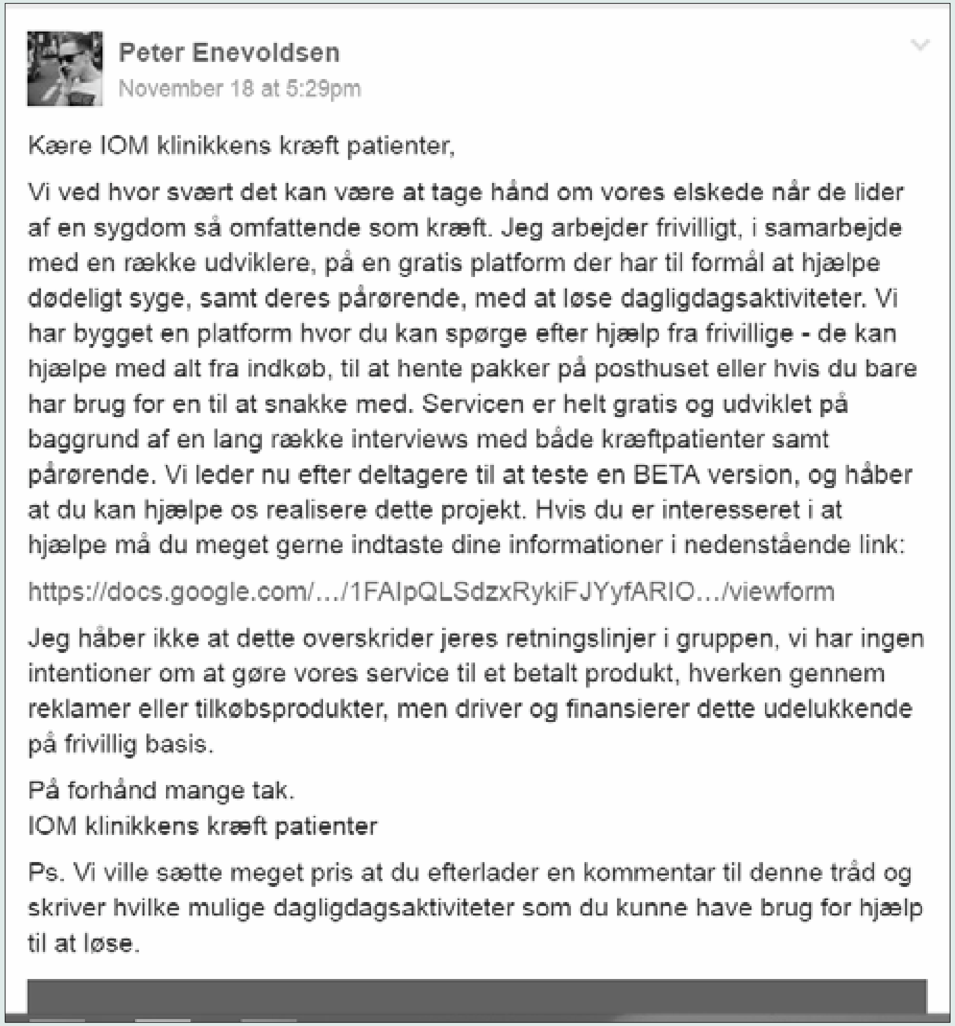
We can conclude that certain tasks require a certain level of trust and will consider how this trust could be established with the final solution.

> “BUILDING THE RIGHT **IT**
> BEFORE BUILDING **IT** RIGHT”

PRETOTYPING

This section will present the results of testing the pretotypes on relevant social media groups and forums. We will include screenshots of the differents posts together with the comments and likes. We reached an agreement that some of the ideas are very close to each other and for this reason we decided to test and include the results of three of the concepts, excluding the Informative Website and the Peer To Peer Network.

The main difference pretotyping has from regular questionnaires, such as *“will you use this or that service”* is that the participants will be of the impression that the service is already there, the idea or concept is pitched in a way that gives the impression that if the participant is willing to use the service, he can.



Peter Enevoldsen
November 18 at 5:29pm

Kære IOM klinikkens kræft patienter,

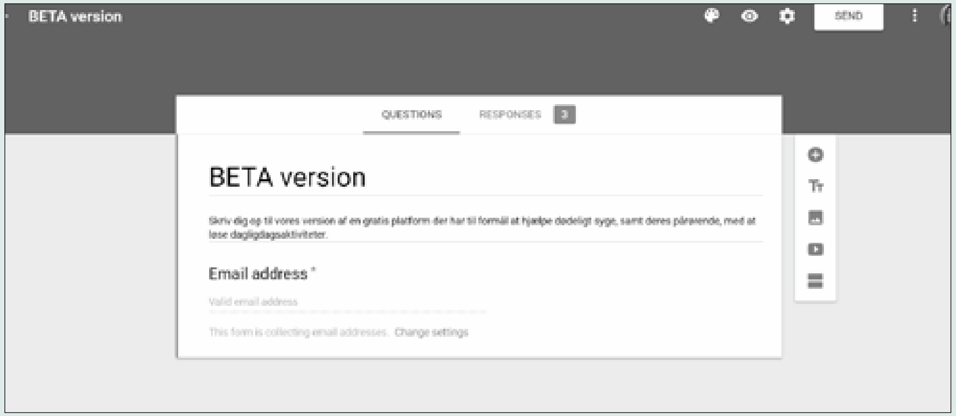
Vi ved hvor svært det kan være at tage hånd om vores elskede når de lider af en sygdom så omfattende som kræft. Jeg arbejder frivilligt, i samarbejde med en række udviklere, på en gratis platform der har til formål at hjælpe dødeligt syge, samt deres pårørende, med at løse dagligdagsaktiviteter. Vi har bygget en platform hvor du kan spørge efter hjælp fra frivillige - de kan hjælpe med alt fra indkøb, til at hente pakker på posthuset eller hvis du bare har brug for en til at snakke med. Servicen er helt gratis og udviklet på baggrund af en lang række interviews med både kræftpatienter samt pårørende. Vi leder nu efter deltagere til at teste en BETA version, og håber at du kan hjælpe os realisere dette projekt. Hvis du er interesseret i at hjælpe må du meget gerne indtaste dine informationer i nedenstående link:

https://docs.google.com/.../1FAIpQLSdzxRykiFJYyfARIO.../viewform

Jeg håber ikke at dette overskrider jeres retningslinjer i gruppen, vi har ingen intentioner om at gøre vores service til et betalt produkt, hverken gennem reklamer eller tilkøbsprodukter, men driver og finansierer dette udelukkende på frivillig basis.

På forhånd mange tak.
IOM klinikkens kræft patienter

Ps. Vi ville sætte meget pris at du efterlader en kommentar til denne tråd og skriver hvilke mulige dagligdagsaktiviteter som du kunne have brug for hjælp til at løse.



BETA version

Skriv dig op til vores version af en gratis platform der har til formål at hjælpe dødeligt syge, samt deres pårørende, med at løse dagligdagsaktiviteter.

Email address *

Valid email address

This form is collecting email addresses. Change settings

CAREGIVER-BUDDY NETWORK

This concept was pretotyped on social media and forum groups, we made a post where people were informed about the service and how it worked, and most importantly they were able to sign up actively through Google form. We pitched the idea in a way that made it sound as if volunteers are already in place and the platform is ready to be tested.

- Tested as a post on two Facebook groups and on a few ones on cancerforum.dk
- Three signups and emails, including cancerforum.dk
- Two comments under the posts either negative or positive, however used as a feedback for the service.
- Didn't trigger any strong reactions among the relatives and the terminally ill patients.
- The posts made on cancerforum.dk have been deleted because they conflicted with the website's policies.

THE TERMINAL GUIDE / INFORMATIVE WEBPAGE

We made a post on a group on Facebook where we described the content on the webpage and how we gathered everything so it is easy to access. We used Google form to identify users who signed up for the service. because the webpage was not made at all we proposed to give "early" access to the page for users who were willing to sign up.

- Tested as a post on one Facebook group.
- The concept gathered nine signups with only six emails, which shows that there was interest but the people didn't want to give their emails for some reason.
- There were eight comments under the post, which were once again neither negative or positive.
- The comments weren't connected with the concept itself but rather people discussing if it acceptable to have such a post in the group.

The need for gathering information found across various organizations was there, several people decided to sign up for the service. We believe that if the service was introduced for example at a hospital to patients and relatives that recently received the diagnosis it would be more successful. However, this being a school project where we are in fact not going to create the full service, we felt this would be stepping beyond our ethical boundaries.

Christel Woer Hansen
Yesterday at 3:53pm · København

Er du eller har du været pårørende til en terminal kræftpatient?

Jeg arbejder frivilligt på et projekt, der skal optimere den palliative behandling og øge fokus på pårørende i en sådan proces. I samarbejde med nogle udviklere har vi udarbejdet en hjemmeside (Terminalguiden), der skal guide dig og patienten igennem den terminale process og give jer de rette og relevante informationer afhængigt af hvilken terminal fase patienten måtte være i. Der er tale om et samlingssted for informationer så som: liste over steder I kan søge relevant hjælp og rådgivning, financielle informationer og måder hvorpå I kan søge støtte mv.

Servicen er gratis og udviklet på baggrund af en lang række interviews og brugerundersøgelser.

Jeg leder nu efter personer, der måtte være interesseret i vores løsning og eventuelle deltagere, der har lyst til at teste vores BETA guide.

Hvis du er interesseret i at hjælpe os realisere dette projekt, må du meget gerne indtaste din mailadresse i linket nedenfor.

Jeg håber ikke, at det overskrider retningslinjerne i gruppen.

Skulle du sidde inde med feedback, kommentarer eller spørgsmål omkring projektet, må du meget gerne rette henvendelse til mig enten via. kommentarfeltet eller min Facebookprofil.

På forhånd mange tak.

Ikke-navngiven formular
Skriv din e-mail nedenfor
○ Valgmulighed 1

Terminaguiden
Tak fordi du viser interesse for projektet. Jeg vender tilbage til dig med vores BETA guide.
DOCS.GOOGLE.COM

Terminaguiden
Tak fordi du viser interesse for projektet. Jeg vender tilbage til dig med vores BETA guide.
DOCS.GOOGLE.COM

Helene-Marie Sandberg Det er trist at patienter med hjernetumor næsten pr definition skal sidestille med en terminalpatient.
Der findes mange hjernetumor patienter som aldrig når til dette punkt, som følge af deres tumor.
Denne patientgruppe skæmmes let ud af gruppen.
Like · Reply · Yesterday at 4:06pm · Edited

Christel Woer Hansen Hej Helene. Jeg er ked af, hvis det virker som om, jeg forbinder hjernetumor patienter med terminale patienter. Det er naturligvis (og heldigvis!) ikke altid sådan. Men skulle der alligevel være nogle i gruppen, der har erfaring med terminal og palliative behandling, så kunne det være en stor hjælp for videreudviklingen af projektet.
Like · Reply · 1 · Yesterday at 4:11pm · Edited

Write a reply...

Charlotte Marie Silka Lynge Jeg er helt ok med, du søger, som du gør. Og nu taler jeg for mig selv, jeg er ikke bange og bliver ikke skræmt nogen steder. Hjernetumor og følgerne deraf er meget forskellige og jeg kan godt klare, at læse ting, som ikke berører mig.
Unlike · Reply · 2 · Yesterday at 4:14pm

Helene-Marie Sandberg Det jeg skriver om, handler ikke om at blive skræmt af indholdet men om at blive skræmt fra at tale om sine egne "småting" når der primært tales om alvorligt syge.
Like · Reply · Yesterday at 4:18pm

Charlotte Marie Silka Lynge Jeg er en af dem med 40 timers arbejdsuge, 2 små børn og formand for et dyreinternat. Jeg har flere gange lavet opslag herinde og har aldrig følt, det blev taget som småting.
Like · Reply · 2 · Yesterday at 4:21pm

Helene-Marie Sandberg Jeg har i de måneder jeg har fulgt debatten ikke oplevet nogen videre kommunikation på lavgradstumor området og efterhånden kan jeg se mønstret.
Like · Reply · Yesterday at 4:29pm

Charlotte Marie Silka Lynge Det er måske med "hvilke øjne, man læser med"? Jeg kan f.eks. se mit eget opslag fra 3 nov. som handler om, jeg har fået nogle små skinner til mine fingre. Og jeg skrev lidt frem og tilbage med andre om det.
Like · Reply · 3 · 20 hrs · Edited

Write a reply...

Susanne Gerner-Rasmussen Det kan jo desværre også være en side af det at være hjernetumorpatient og pårørende til samme. Det er ikke længe siden, at vi andre kunne læse en opdatering fra en pårørende om sorg, afmagt og brug for råd og vejledning. Måske havde der været råd at hente her, hvem ved🙂
Like · Reply · 5 · Yesterday at 5:19pm · Edited

Nivi Poulsen Helene-Marie Sandberg, jeg oplever gruppen her som meget rummelig og med plads til både pårørende og patienter med lavgradstumorer og højgrads - og jeg tænker at det er op til os i gruppen at præge den med opslag/temaer/spørgsmål, vi hver især finder r... See More
Unlike · Reply · 5 · 20 hrs

Write a comment...

Jonas Berg Bonde
19. november kl. 15:35

Middag til intersserede

Hej allesammen, jeg har for nyligt mistet et højt elsket og nært familiemedlem til kræft. Når jeg kigger tilbage, syntes jeg det var rigtig hårdt, at være placeret på "sidelinien" og følte selv at der manglede mere støtte eller fokus på pårørende. Jeg har læst om palliativ behandling, og ser at der netop står at både patient og pårørende er modtagere. En ting jeg manglede var at snakke med andre som stod i en ligende situation uden at føle jeg var medlem af en "sorge gruppe", og jeg tænkte under forløbet desværre ikke på at blive medlem af en gruppe på facebook eksempelvis. Jeg vil gerne tilbyde én ting som jeg tænker, jeg ville have været lykkelig for, når jeg ser tilbage.

Jeg har tænkt mig at holde en middag eller frokost, med spil og underholding til dem som måtte være interreseret. En dag hvor man kan grine, møde nye mennesker og tale om alt mellem himmel og jord. Skriv endelig en kommentar hvis du/i er interesseret, alternativt kan man skrive direkte til mig.

PS: Jeg tænker at holde det enten i København eller Odense.

Update: Det Bliver i København

God weekend

Sanne Werner Bach Jensen Kondolerer ...Det var da en super dejlig idé, håber der er nogle som synes det samme . God weekend
Synes godt om · Svar · 19. november kl. 15:46

Jonas Berg Bonde Tak, jeg håber jeg kan nå ud til nogle der ønsker det ihvertfald.
Synes godt om · Svar · 1 · 19. november kl. 15:56

Brian Lindahl Og fantastisk initiativ Jonas
Synes godt om · Svar · 2 · 19. november kl. 16:19

June Staun Søndergaard Jeg er rigtig ked af at høre dit tab Det gør mig rigtig ondt at høre! Jeg synes det er et rigtig godt intiativ Jeg bor dog i Vejle så jeg er lidt langt væk
Synes godt om · Svar · 19. november kl. 16:10

Anne Birkenfeldt Hansen Hej Jonas.
Det er da en skøn idé.
Hvordan har du tænkt dig det skal forgå ?
Synes godt om · Svar · 19. november kl. 16:54

Jonas Berg Bonde Hej Anna, Det afhænger af antallet. Jeg er vant til at holde større arrangementer, men det er mere i ehvervs-regi, så dette vil være en lidt mere intim størrelse, med lidt at drikke, snaks, godbidder. jeg vil arrangerer nogle nemme spil/lege som alle k... Se mere
Synes godt om · Svar · 2 · 19. november kl. 17:06

Ingelise Baltzersen Rigtig fin idé. Og du har så meget ret, at pårørende står på sidelinjen
Synes godt om · Svar · 1 · 19. november kl. 17:41

Iben Vinther Hej Jonas!
Synes godt om · Svar · 19. november kl. 18:19

Iben Vinther jeg synes det er et rigtigt godt initiativ du tager. Jeg har selv været igennem et 4 årigt Cancer forløb og er overlevet takket være en Professor i Tyskland. Jeg ved hvor hårdt det er, at være den der for en Cancer diagnose hvor man går i en overlevels... Se mere

SUPPORT GROUP RELATIVES / PEER TO PEER NETWORK.

This concept was also pretotyped with the help of social media groups. A post was made where we invited relatives to a dinner with activities. We had a success criteria of 10 participants.

- A big amount of positive feedback and interest was shown
- Both patients and relatives responded well to our claim that relatives were often overlooked in regards to support from professionals, they supported this claim and came with similar stories in the comment section.
- Many people showed interest by either commenting, “liking” or responding positively to the post.
- No one signed up, however.
- Four days later we informed that the dinner was canceled due to not enough participants.

The pretotype was successful, we identified that there was an interest in the service. Many people had questions about how exactly the dinner would proceed. However the success criteria of the “service need” were not met. When looking back we think the pretotype should have been even more clearly defined to limit questions and confusions, as well as fixing a date and location. However interest was shown, and many people supported the idea.

CONCLUSION

The process of testing the pretotypes gave us insights into all of the concepts. All in all, there wasn't any concrete negative feedback for any of the concepts. The Support Groups and The Terminal Guide received the most attention, and involvement from the users. The other concepts received positive feedback but not as much attention.

We learned that the need for the services is there, but depending on what palliative stage the patient is, the need will differ. We saw that the need for information is generally largest in the early stages of the palliative care, this is supported by our initial research that indicated patients and relatives were overwhelmed during this stage, and that many things are happening which is why the need for being on top of the process is larger. The Support Groups or Peer to Peer Network were something people needed in the later stages of the palliative care, while The Caregiver Buddy Network was somewhere in the middle and overlapping towards the end.

After a discussion we compared the concepts, the feedback and the knowledge from our problem statement, which of these solutions would be an active part of solving it, or at least improving the situation. We feel that The Caregiver Buddy Network was something that will have the biggest effect on helping the patients to die at their home. The reasoning for this decision is that by freeing up time for the family members, relatives can use more time to focus on the patients, thus increasing their well being. By securing the patients to have a good home service which will work as an extension to the help offered by the municipality, it will enable the patients to die at their private homes. Moreover, it will help the relatives with their daily chores, which will make their situation more manageable.

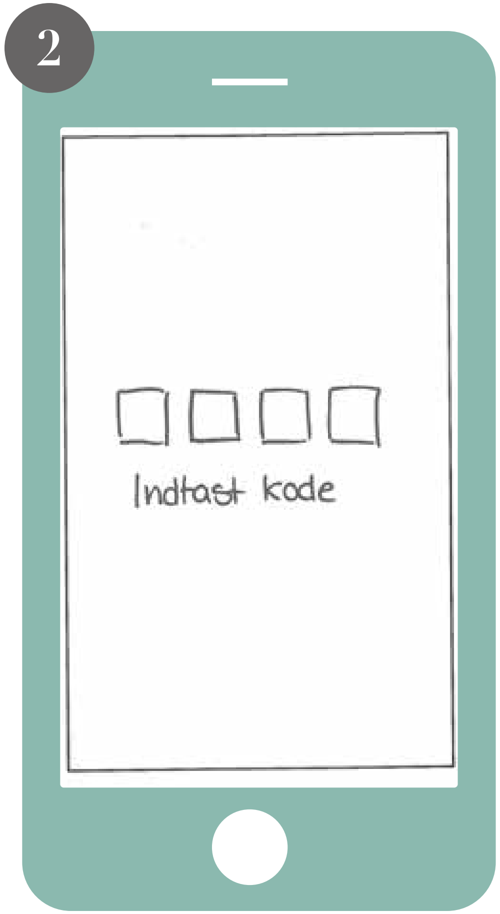
OUR SOLUTION

Image: Wireframing

CONCEPT DESCRIPTION WITH WIREFRAMES, SERVICE BLUEPRINTING, SERVICE ECOLOGY

We decided that The Caregiver-Buddy Network is the most suitable concept to build upon. Considering all of the findings we have gathered, this is the solution that we will enable the terminally ill patients to die at their homes by taking some of the burden off of their relatives. The following chapter will include the description of our solution supported by wireframes of the application, as well as the service blueprint.

THE SERVICE FROM A RELATIVE PERSPECTIVE

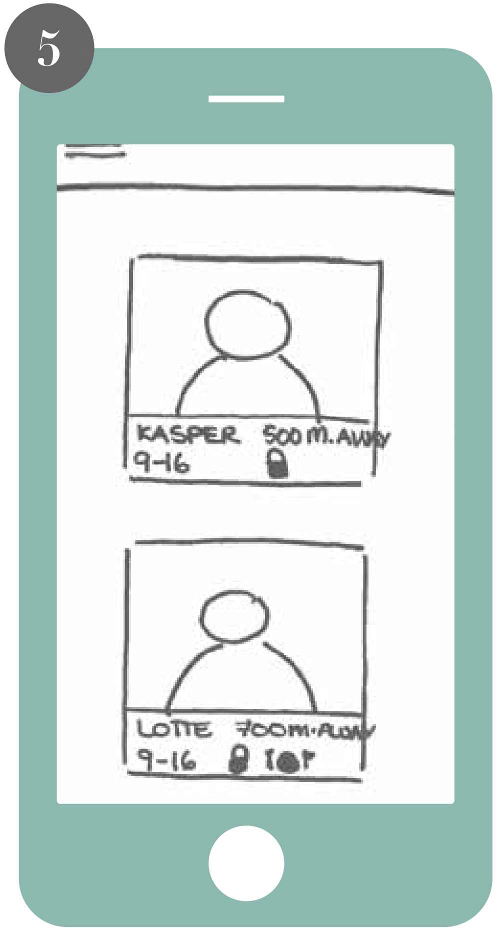


WIREFRAME 1 & 2

A unique code and username are given to a relative of a terminal patient by a doctor. After downloading the application, the relative must first enter the unique username and code.

WIREFRAME 3

The patient is presented to a screen where they have the possibility to take a picture and fill in their address.



WIREFRAME 4

They can browse and choose through the different tasks which the volunteers can help them with. When a task is chosen it changes its color.

WIREFRAME 5

After they choose the task they need help with, they are redirected to the volunteers' list. They can browse through the list and click on the different profiles for more information.

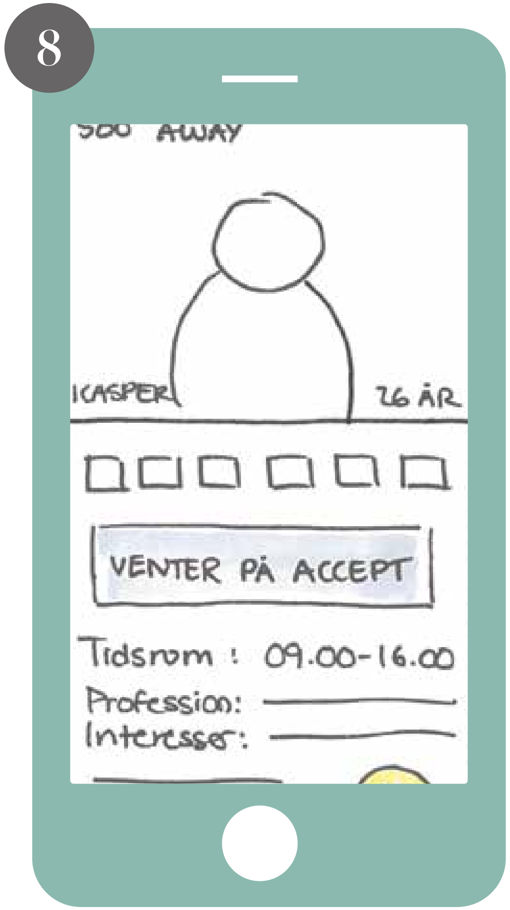
WIREFRAME 6

If a profile is clicked they can see much more information about the volunteer such as: when the volunteer is available, their interests, etc. This is where they can see how active the volunteer has been from the badges he/she has gathered. They can also ask for help here by pressing the button "**Ask for help**".

WIREFRAME 7

When a relative choses to ask a volunteer for help they should fill in details for the task they need help with such as: the day, time, and its duration. After all of it is entered, the relative finalizes it by pressing the "**Spørg for hjælp**" button.

8



WIREFRAME 8

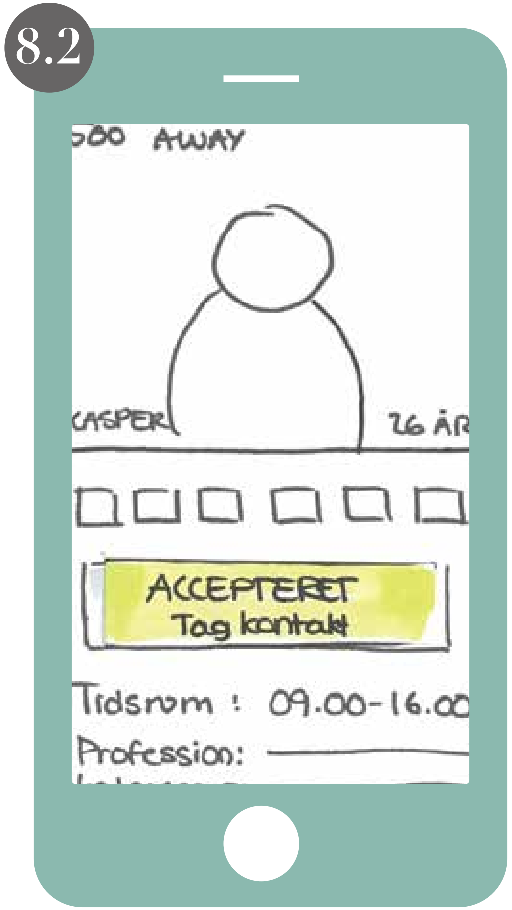
The relative is redirected to a screen where they have to wait for the volunteer to either accept or decline.

8.1

WIREFRAME 8.1 DECLINE

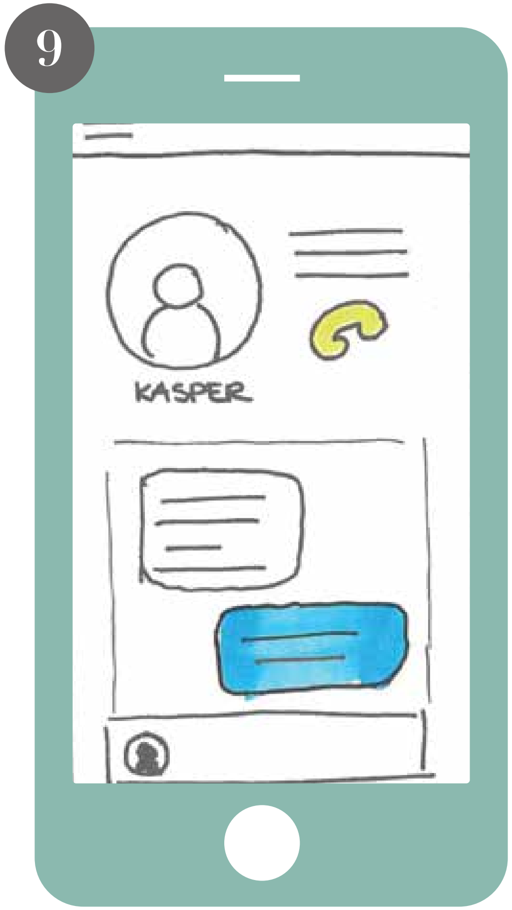
If the volunteer declines, the relative is redirected back to the volunteers' list where they can choose another volunteer and receive help.

8.2



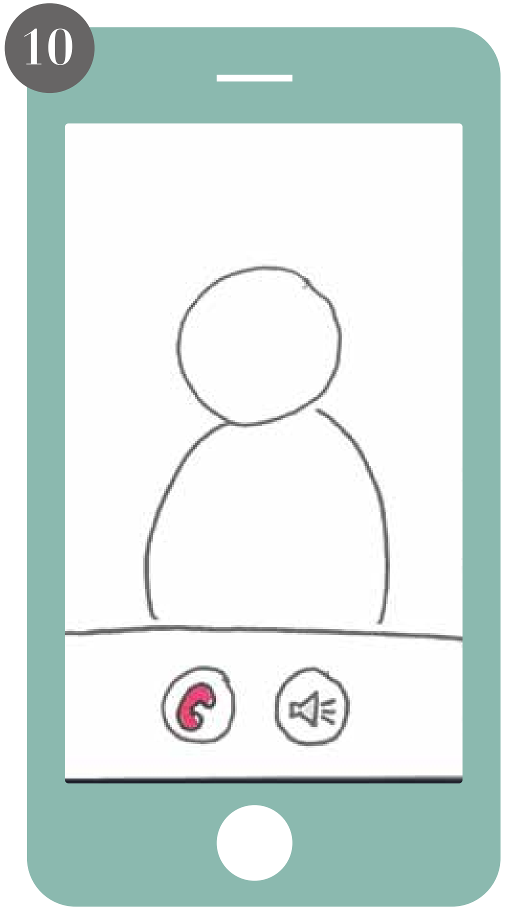
WIREFRAME 8.2 ACCEPT

When a volunteer accepts to help, a communication screen opens where they can have a private conversation and exchange additional information.



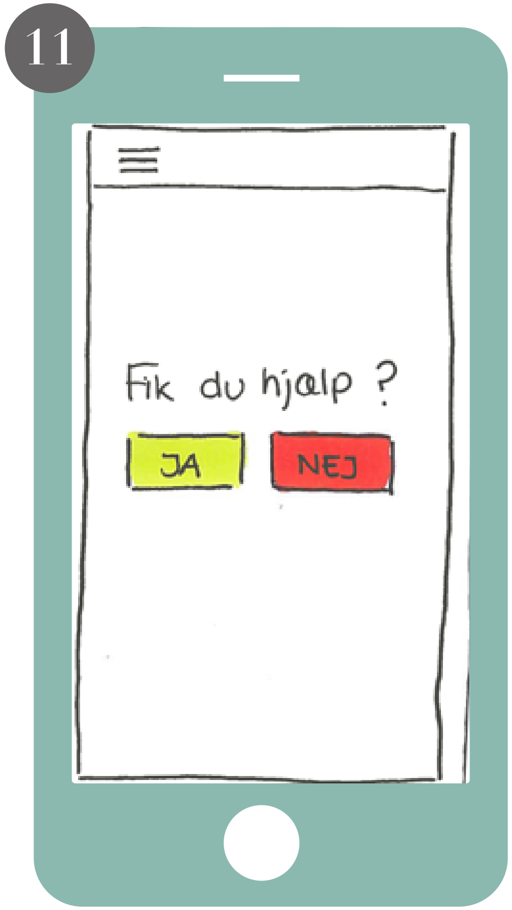
WIREFRAME 9

A chat window where both users can have a private chat.



WIREFRAME 10

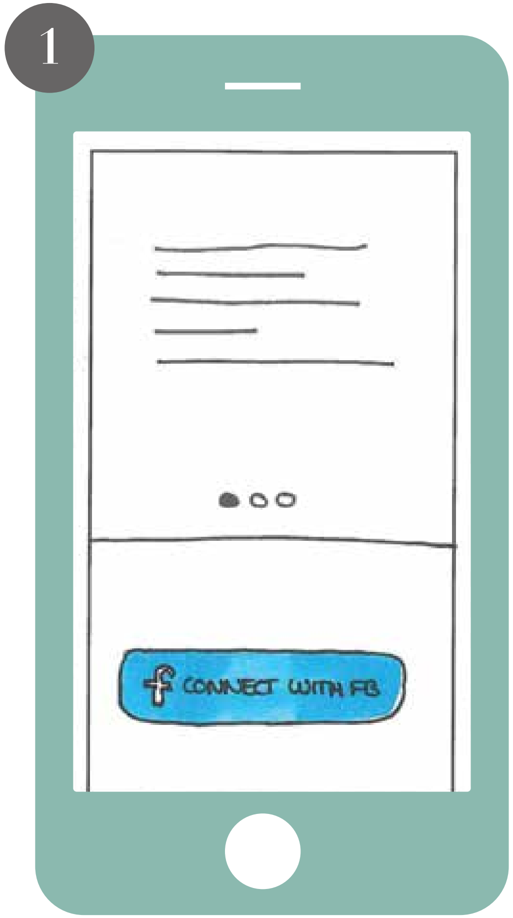
A feature that allows the relative to call the volunteer in the application.



WIREFRAME 11

After the volunteer has finished a task, an automatic notification is sent to the relative. It has the aim to understand if they have gotten the promised help. They should simply press '**Ja**' or '**Nej**'.

THE SERVICE FROM A VOLUNTEER'S PERSPECTIVE

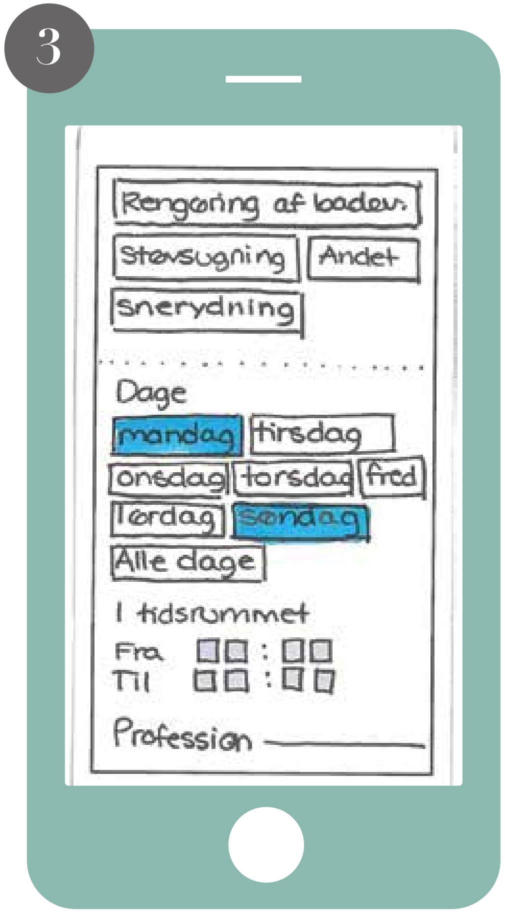


WIREFRAME 1

After downloading the application a volunteer has the choice to connect with their Facebook profile or with a personal email.

WIREFRAME 2

They are then redirected to a screen where they should fill in their information profile. There is an option for adding a picture. All the tasks they can help with are also on the same screen. When a task is being chosen it changes color.



WIREFRAME 3

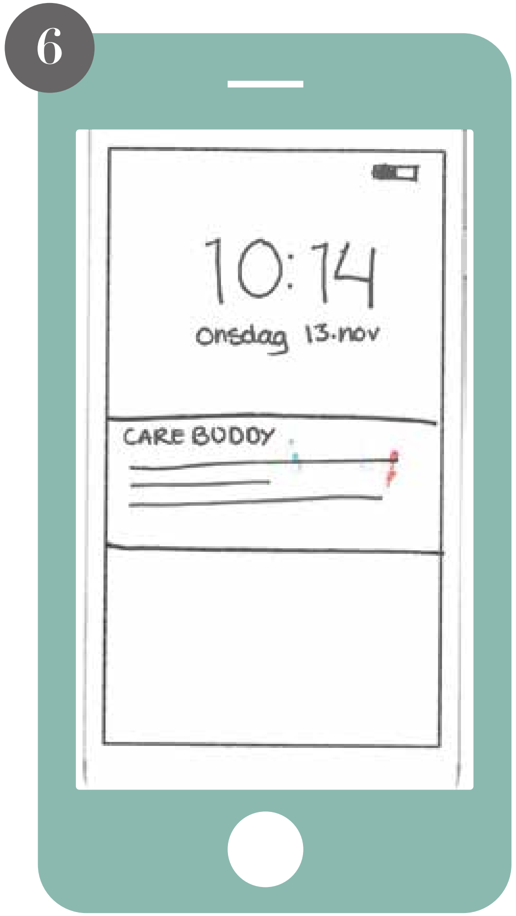
This wireframe is a continuum of **Wireframe 2.** It allows the volunteer to choose the days and time of their availability.

WIREFRAME 4

The volunteer can add more personal information to their profile and confirm its activation. There are also two buttons which allow them to be shown as active volunteer after three hours or not active. They can always return to this screen and change the settings.

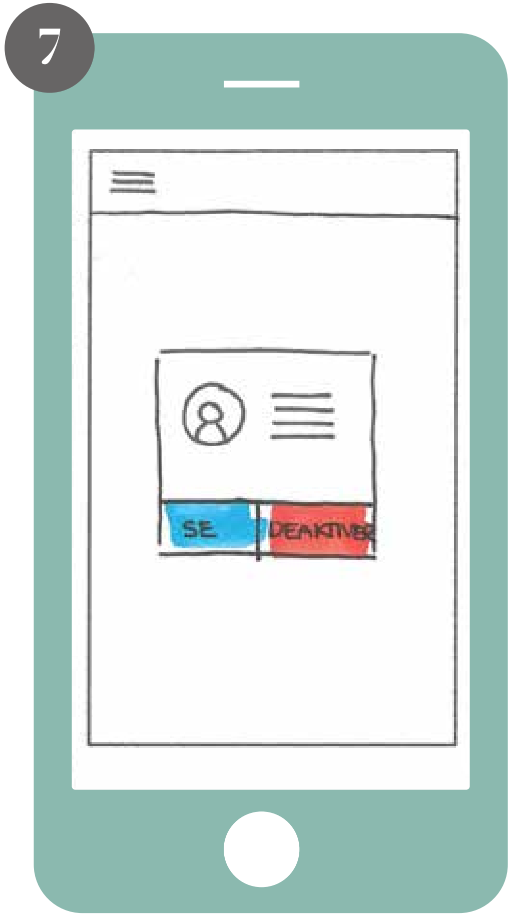
WIREFRAME 5

When a profile is active meaning that the volunteer is available to accept tasks from relatives, they can change their location. This enables them to choose only task that are close to their location.



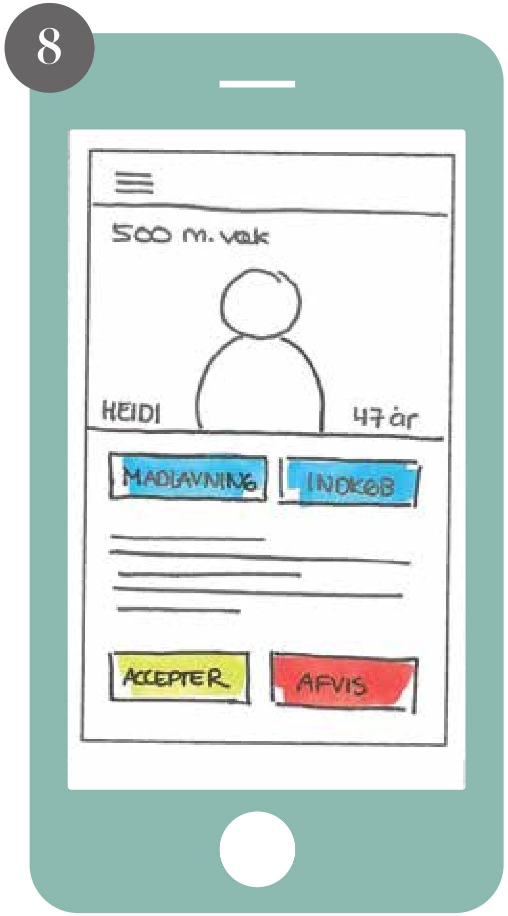
WIREFRAME 6

When a relative needs help with a task that the volunteer has chosen to help with, they will receive an automatic notification on their phone's home screen.



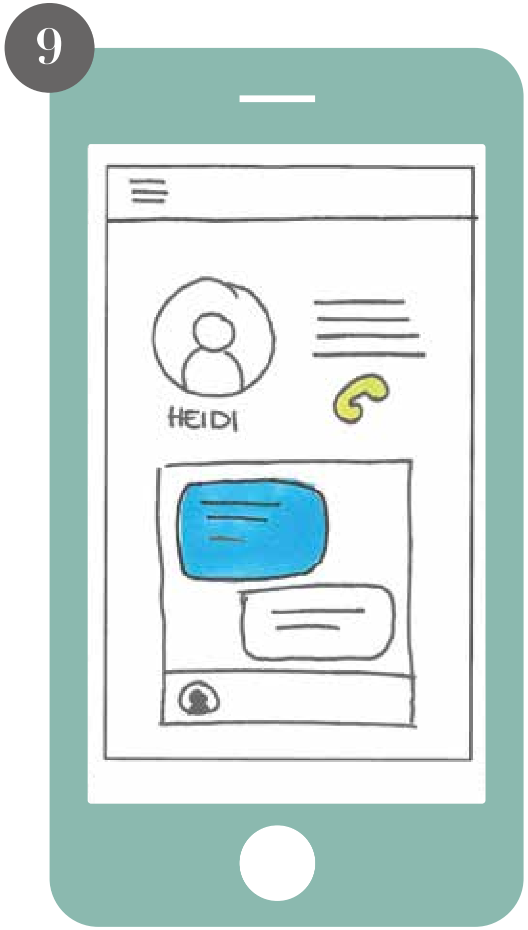
WIREFRAME 7

The volunteer has the option to either see more details about the task or decline it.



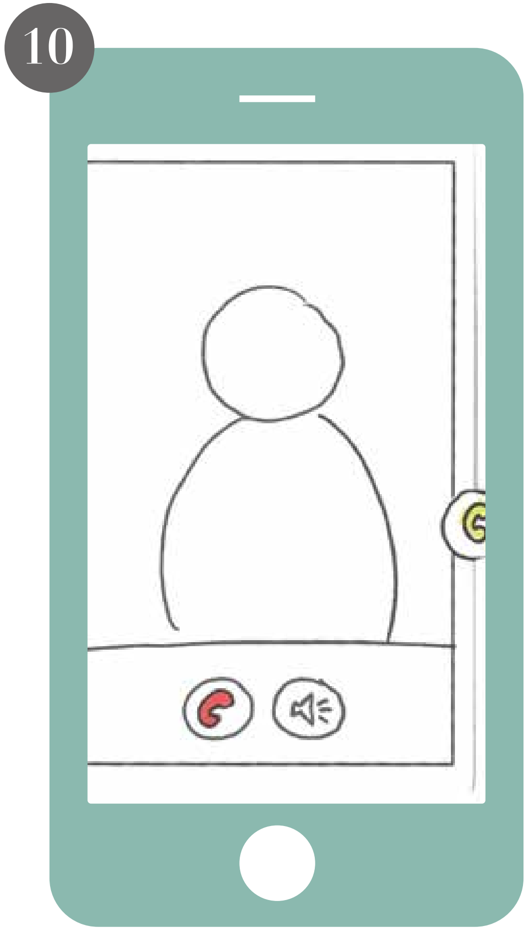
WIREFRAME 8

When they press the button **'Se'** they are redirected to this screen where all details are available, as well as the relative's profile. This is where they can choose to either help or decline.



WIREFRAME 9

If chosen to help, they are presented to a communication window, where they can have a private conversation with the relative.



WIREFRAME 10

This screen allows them to have a personal calls with the relative within the app.

WIREFRAME 11

After the volunteer has finished with the task and has left the relative, they receive a notification saying thank you for their help.

BLUEPRINT OF THE CURRENT SERVICE

Blueprints have their use in many other disciplines than service design. They have their roots and use in disciplines and approaches such as business management, organisational structure, interaction and experience design as well as systems and process mapping (Polaine et al, 2009). Polaine describes service design blueprinting as, "the mapping out of a service journey identifying the processes that constitute the service, isolating possible fail points and establishing the time frame for the journey". The idea was pioneered by G. Lynn Shostack in the early 1980s as a way to plan the cost and revenue associated with operating a service (Polaine, Løvlie, Reason, 2013). From these the most important aspects were time in the form of customer experience and the line of visibility, which according to Polaine, Løvlie and Reason (2013) should be everything that the customer experiences, since bad smell or loud noises can easily worsen an experience. A service blueprint can be summed as being a map of the user journey, the touch points of the services and the backstage processes, which are the processes behind the line of visibility (Polaine, Løvlie, Reason, 2013).

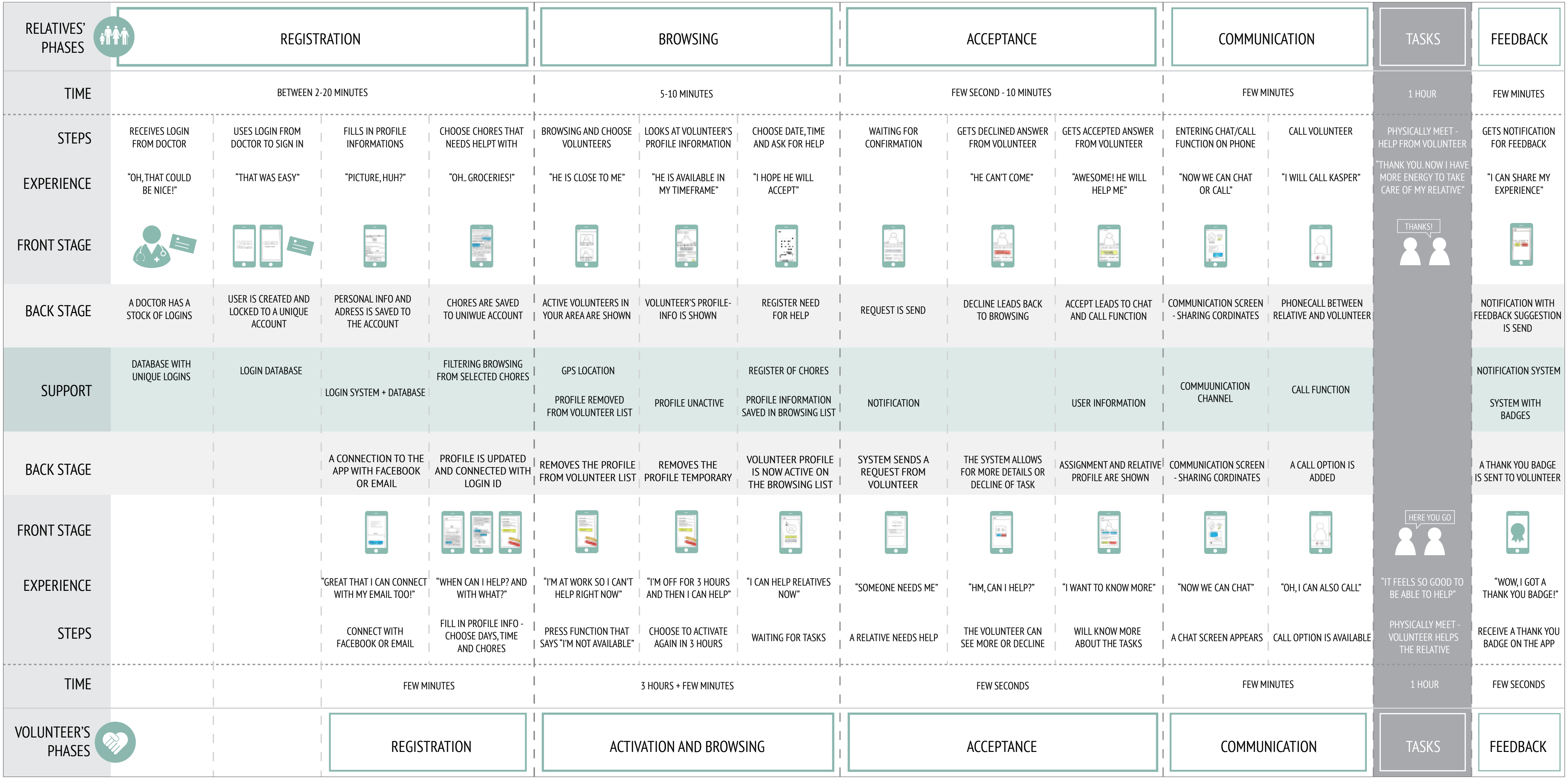
CARE BUDDY NETWORK'S BLUEPRINT

We have in our project used blueprinting to represent the new service concept. It took us a lot of time to research blueprinting properly to not just understand how it works, but if it will benefit our process. From concluding that it could be the method to help us map out the service with all its touchpoints meticulously, we were now only missing a starting point of a How. All the blueprints that are shown in books such as Service Design: From Insight to Implementation by Polaine, Løvlie & Reason do not have more than one focus point. We do this with both the relative and the volunteer in the focus at the same time.

Our initial plan was to create two blueprints that were representing the service from the two different perspectives. But by recommendation from our supervisor we were introduced to a blueprint for a bike sharing service done by an older class of students of Service Systems Design. The example of this blueprint inspired us to create our a new one that was very much alike, and still using the general recommendations of how to create a good blueprint by Polaine et al (2009). We have added time, as well as representing the customer experience in each step.

The blueprint of The Buddy Caregiver Network is based around phases. On the top of the blueprint the relatives phases are shown, and at the bottom the phases of the volunteers. They follow almost the same steps, but the timeframes can be very different. The phases they have to go from are the registration, browsing, acceptance, communication, tasks and feedback. The only difference between the actors' phases is that: the volunteer who goes through an activation phase where they enter the browsing phase by being the one who can be browsed for. For each phase there is a time estimation that gives an understanding of the expected time for each step. These time frames vary between a few seconds to a few minutes to sometimes several hours. For each step there is a small explanation of what happens, the expected experience for the user, a visual explanation of what happens, whether done by physical interaction or wireframe. What happens in the backstage and what support processes are required for the service to function correctly is also written down and taken into consideration at every step. The step of the physical interaction between the two actors where the tasks is being fulfilled is marked clearly, combining the two sides of the blueprint entirely.

CARE BUDDY NETWORK'S BLUEPRINT



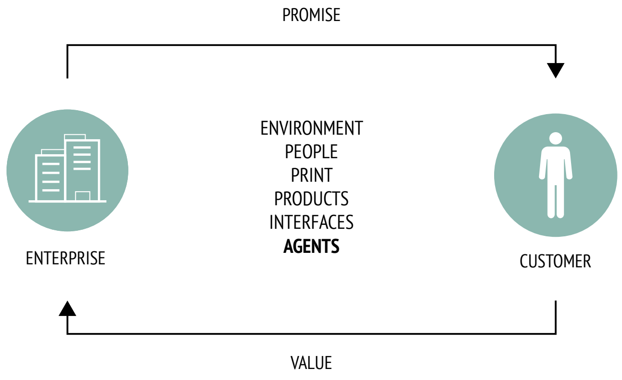
RELATIVES' PHASES	REGISTRATION				BROWSING			ACCEPTANCE			COMMUNICATION		TASKS	FEEDBACK
TIME	BETWEEN 2-20 MINUTES				5-10 MINUTES			FEW SECOND - 10 MINUTES			FEW MINUTES		1 HOUR	FEW MINUTES
STEPS	RECEIVES LOGIN FROM DOCTOR	USES LOGIN FROM DOCTOR TO SIGN IN	FILLS IN PROFILE INFORMATIONS	CHOOSE CHORES THAT NEEDS HELPT WITH	BROWSING AND CHOOSE VOLUNTEERS	LOOKS AT VOLUNTEER'S PROFILE INFORMATION	CHOOSE DATE, TIME AND ASK FOR HELP	WAITING FOR CONFIRMATION	GETS DECLINED ANSWER FROM VOLUNTEER	GETS ACCEPTED ANSWER FROM VOLUNTEER	ENTERING CHAT/CALL FUNCTION ON PHONE	CALL VOLUNTEER	PHYSICALLY MEET - HELP FROM VOLUNTEER	GETS NOTIFICATION FOR FEEDBACK
EXPERIENCE	"OH, THAT COULD BE NICE!"	"THAT WAS EASY"	"PICTURE, HUH?"	"OH.. GROCERIES!"	"HE IS CLOSE TO ME"	"HE IS AVAILABLE IN MY TIMEFRAME"	"I HOPE HE WILL ACCEPT"		"HE CAN'T COME"	"AWESOME! HE WILL HELP ME"	"NOW WE CAN CHAT OR CALL"	"I WILL CALL KASPER"	"THANK YOU. NOW I HAVE MORE ENERGY TO TAKE CARE OF MY RELATIVE"	"I CAN SHARE MY EXPERIENCE"
FRONT STAGE														
BACK STAGE	A DOCTOR HAS A STOCK OF LOGINS	USER IS CREATED AND LOCKED TO A UNIQUE ACCOUNT	PERSONAL INFO AND ADRESS IS SAVED TO THE ACCOUNT	CHORES ARE SAVED TO UNIWUE ACCOUNT	ACTIVE VOLUNTEERS IN YOUR AREA ARE SHOWN	VOLUNTEER'S PROFILE-INFO IS SHOWN	REGISTER NEED FOR HELP	REQUEST IS SEND	DECLINE LEADS BACK TO BROWSING	ACCEPT LEADS TO CHAT AND CALL FUNCTION	COMMUNICATION SCREEN - SHARING CORDINATES	PHONECALL BETWEEN RELATIVE AND VOLUNTEER		NOTIFICATION WITH FEEDBACK SUGGESTION IS SEND
SUPPORT	DATABASE WITH UNIQUE LOGINS	LOGIN DATABASE	LOGIN SYSTEM + DATABASE	FILTERING BROWSING FROM SELECTED CHORES	GPS LOCATION PROFILE REMOVED FROM VOLUNTEER LIST	PROFILE UNACTIVE	REGISTER OF CHORES PROFILE INFORMATION SAVED IN BROWSING LIST	NOTIFICATION		USER INFORMATION	COMMUUNICATION CHANNEL	CALL FUNCTION		NOTIFICATION SYSTEM SYSTEM WITH BADGES
BACK STAGE			A CONNECTION TO THE APP WITH FACEBOOK OR EMAIL	PROFILE IS UPDATED AND CONNECTED WITH LOGIN ID	REMOVES THE PROFILE FROM VOLUNTEER LIST	REMOVES THE PROFILE TEMPORARY	VOLUNTEER PROFILE IS NOW ACTIVE ON THE BROWSING LIST	SYSTEM SENDS A REQUEST FROM VOLUNTEER	THE SYSTEM ALLOWS FOR MORE DETAILS OR DECLINE OF TASK	ASSIGNMENT AND RELATIVE PROFILE ARE SHOWN	COMMUNICATION SCREEN - SHARING CORDINATES	A CALL OPTION IS ADDED		A THANK YOU BADGE IS SENT TO VOLUNTEER
FRONT STAGE														
EXPERIENCE			"GREAT THAT I CAN CONNECT WITH MY EMAIL TOO!"	"WHEN CAN I HELP? AND WITH WHAT?"	"I'M AT WORK SO I CAN'T HELP RIGHT NOW"	"I'M OFF FOR 3 HOURS AND THEN I CAN HELP"	"I CAN HELP RELATIVES NOW"	"SOMEONE NEEDS ME"	"HM, CAN I HELP?"	"I WANT TO KNOW MORE"	"NOW WE CAN CHAT"	"OH, I CAN ALSO CALL"	"IT FEELS SO GOOD TO BE ABLE TO HELP"	"WOW, I GOT A THANK YOU BADGE!"
STEPS			CONNECT WITH FACEBOOK OR EMAIL	FILL IN PROFILE INFO - CHOOSE DAYS, TIME AND CHORES	PRESS FUNCTION THAT SAYS "I'M NOT AVAILABLE"	CHOOSE TO ACTIVATE AGAIN IN 3 HOURS	WAITING FOR TASKS	A RELATIVE NEEDS HELP	THE VOLUNTEER CAN SEE MORE OR DECLINE	WILL KNOW MORE ABOUT THE TASKS	A CHAT SCREEN APPEARS	CALL OPTION IS AVAILABLE	PHYSICALLY MEET - VOLUNTEER HELPS THE RELATIVE	RECEIVE A THANK YOU BADGE ON THE APP
TIME			FEW MINUTES		3 HOURS + FEW MINUTES			FEW SECONDS			FEW MINUTES		1 HOUR	FEW SECONDS
VOLUNTEER'S PHASES			REGISTRATION		ACTIVATION AND BROWSING			ACCEPTANCE			COMMUNICATION		TASKS	FEEDBACK

Illustration: Blueprint

SERVICE ECOLOGY MAP

To get a sense of the context a service is operating within, a service ecology was created. It can be used as a method to map this context and its stakeholders. Services are usually operating in a context that is very complex. A service ecology can thereby assist the designer in giving him a bird's-eye view of the ecosystem that a service exists within.

Polaine, Løvlie & Reason describes this as a diagram of all actors affected by a service and their relationships, displayed in a systematic manner (Polaine, Løvlie & Reason, 2013). They continue with describing these actors as being the enterprise that makes a promise to the customer (or the service user), and the agents who deliver that promise through different channels, and the customers who return value back to the enterprise. They conclude that a: *"healthy ecology is one in which everyone benefits, rather than having the value flow in one direction only."* (Polaine, Løvlie & Reason, 2013) This is visualised in the illustration below, which also can be found in the book Service Design: From Insight To Implementation.



The enterprise itself does therefore not deliver experiences and utility to people. However, these are provided by agents who are in direct contact with the customer (or the service user) through channels such as touch points like an application. The role of the enterprise is to deliver the tools and infrastructure that agents need to deliver a good service experience (Polaine, Løvlie & Reason, 2013).

THE CARE BUDDY NETWORK'S SERVICE ECOLOGY

To understand what context our services concept will be constructed within, we have used service ecology map to visualize all stakeholders and the relationships between them. We plan on using this overview of the services context to better understand the service, as well as where to position it in the world amongst other similar services. We also plan on the ecology itself to be a tool that will support our service proposition in representing it as a supportive service for the municipalities existing systems around end-of-life care.

Our service ecology is based upon the concept of The Caregiver Buddy Network. Its starting point is the enterprise that is through a virtual agent, an application, and it facilitates communication through two kinds of users, volunteers and relatives. The users create a relationship between them with tasks and assistance. These two are mutually beneficial through the satisfaction of helping for the volunteer, and an easier and more manageable everyday for the relatives. The facilitation of this relationship is initially done through the application that is provided by the enterprise.

Through the assistance the relatives will have a more manageable everyday life which will allow them to have a greater focus on the patient they are taking care of. This greater focus has the potential of easing the work of the homecare and healthcare professionals, which will thereby let the municipality and regions save money or improve the quality of care, they provide. It is through this value that we believe that the municipality is interested in cooperating with the enterprise and support the service financially. We consider the use of digital channels such as Facebook for example which will help us create a potential network of volunteers who are interested in assisting relatives in need. Furthermore we will take on the advantage of the users already existing connection with these channels, and the possibility of targeting them with ad campaigns which will have the aim to reach the citizens interested in volunteering as well.

CARE BUDDY NETWORK'S SERVICE ECOLOGY

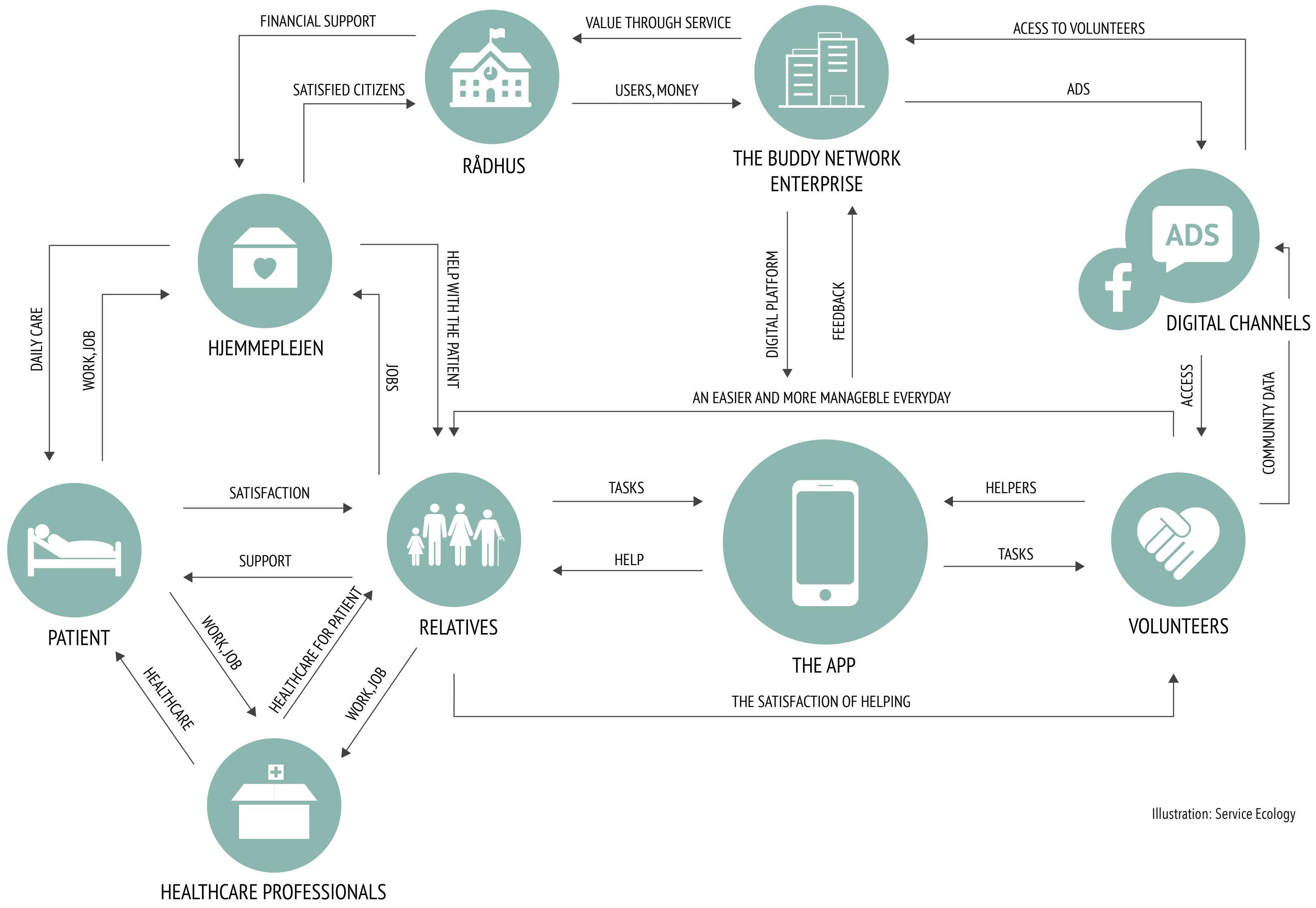


Illustration: Service Ecology

PROTOTYPE & TEST

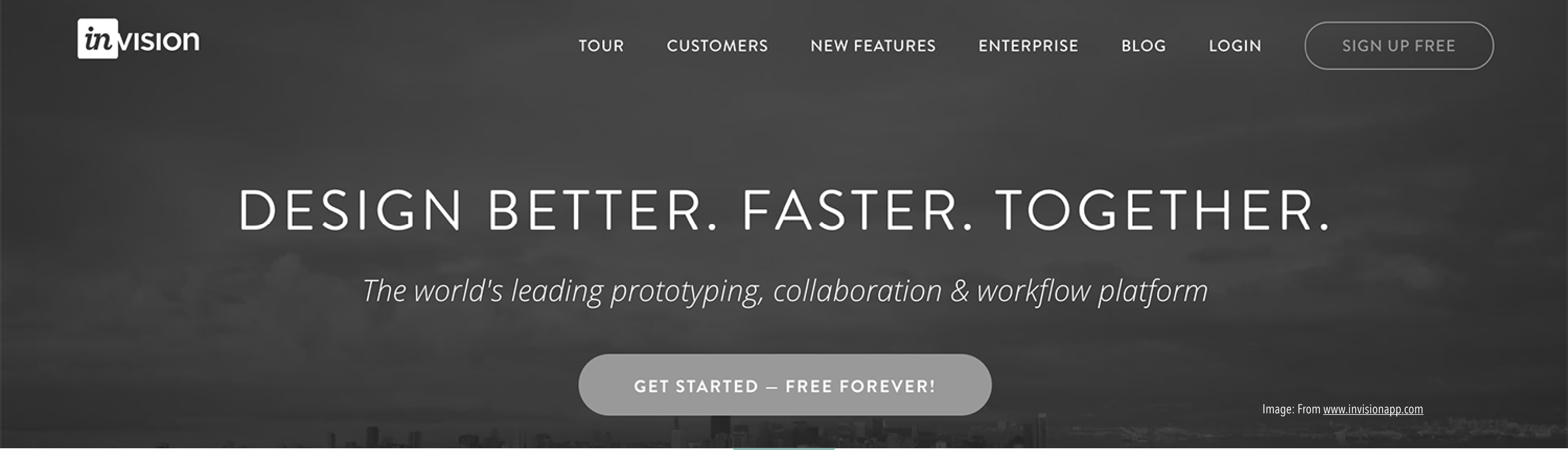


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Image: From www.invisionapp.com

PROTOTYPE, TESTING

"Service Prototype" (https://goo.gl/qzulOL) is a tool that is used to test how a user interacts with a service. The user interaction with the service is observed and gives valuable insights into "how" the user uses the service. In our case the "service prototype" is created with the help of a digital software to imitate specific functions, visuals and/or other options that are available to the user and which we wish to include in the actual service.

Prototyping is a good way of getting valuable knowledge in a cheaper and faster way than creating the "real thing". By prototyping we are able to identify what works and what doesn't. We can among other things, test specific areas of the service with a user and see if the results are as intended. As a result we can correct and improve errors or other unintended functions in an early phase of the overall service production process.

By creating prototypes, we also achieve another critical factor; which is securing a common "problem view" of what and how our service should work, this is something Meinel et al. (2014, pp. 99) stresses the importance of. Prototyping is not only good for the user-designer relationship, but it is also a powerful communication tool that helps secure a common understanding of where we wish to go within the "Design team" itself, it is a good way of sharing knowledge and securing that the point you wish to make gets across in a more intuitive way.

THE CAREGIVER BUDDY NETWORK'S PROTOTYPE

For the prototype we decided to make a phone application with the help of Invision (https://goo.gl/dZJtOh) which is an online software that allowed us to build a functioning and very realistic application. We used the already created wireframes, which are representing the different design and functionalities available in the application. This was used, as mentioned in the "method section" to secure a common understanding within the group. Afterwards a more user-friendly and test-friendly service prototype was made using Invision (https://goo.gl/dZJtOh). The prototype can roughly be separated into an "interface prototype" than an actual "service prototype", because the service behind is not actually available to be tested.

TESTING THE INTERFACE PROTOTYPE

BEFORE STARTING WITH THE TESTING OF THE PROTOTYPE WE DECIDED ON THE FOLLOWING OBJECTIVES:

- Identify if there are any parts of the current prototype that need to be redesigned or changed.
- Observe how easy to use the prototype is, and if there is a need to simplify specific functions.
- Evaluate how the application works as a touchpoint for the service behind it.
- Receive feedback from the test subjects

HOW DO WE PLAN ON REACHING THESE OBJECTIVES?

DURATION: 15-25 MINUTES

We will introduce the project and its goal, after that a brief conversation with the participant will follow in order to understand more who the are. It is very important to understand what was important for them and how their process of caring for a terminal patient was.

DURATION: 5-10 MINUTES

We will explain to the participant how the test will be conducted, meaning which the limitations of the application are, and how the test subject should proceed when reaching these "dead end" situations. We will assure them that nothing they do is wrong and there is no "correct" or "incorrect" way of using the application, all we wish to do is to identify how it works and how it can be improved.

MOST IMPORTANTLY WE WILL ASK THAT THE USER VOICES THEIR THOUGHTS BEFORE AND WHILE USING THE PROTOYPE:

- What they see and how they understand it.
- If they wish to press something, what they expect to happen upon pressing a specific button (before they press it)
- Reflect on what the result was and if this was what they expected.

DURATION: 5 MINUTES

After these instructions the user will be able to use the the application without any guidance or help. meanwhile we will observe, and take notes of any confusions, delays or problems that in any way can slow or misdirects the participant.

DURATION: 5 MINUTES

We will be very open when it come to answer questions or any other requests. These questions will be noted down exactly what area the questions refer to, as well as what they are.

These will be used as our guidelines, and it will be followed to where it still adds value but always be open for what the participant says, even if they are drifting a bit away. Because the test is a "think out loud-test" we are prepared for participants that don't respond well to this, in those cases we might ask questions to make the participant talk about what they are thinking during the process. Experiences from interviews show that sometimes valuable information is actually gained in those cases where the participant drifts away and brings new insights into the interview or in this case "test" we might not otherwise have thought of.

Based on the feedback and the information gained from these initial tests we will add changes that might improve the application. In the ideal situation you will go back and forth between prototyping and testing, this can be done until either you run out of resources such as time, money or even patience. However throughout this prototype and test process, the prototype will often become more and more complex slowly becoming a close replication the final product and at this stage the next "prototype" can be considered the large scale implementation.

TESTING THE PROTOTYPE WITH KATRINE, A RELATIVE

During our test of The Caregiver Buddy Network application we planned to investigate the specific touch points of the app and the service itself. We wanted to look into the specific touchpoint that the application as well as feedback on the overall service in relation to the other touchpoints, such as getting access to the application as well as the "home" touchpoint.

For this first test, we got a contact through a Facebook post with a relative Katrine, that had been the main caregiver for now, her deceased father. She has been receiving financial support, so she could take care of him.

Katrine was introduced to the service of The Caregiver Buddy Network. She was told about the application and how it was thought out to belong in the service. We then presented her with a rough description of the different touch points together with the home visit of the volunteer and how she would get access to the application through the municipality or a doctor.

She was asked to think out loud when she was using the application so we could understand her thinking process. She had no troubles navigating throughout the application but believed that she would prefer the application "upside-down". Katrine believed that she would rather create a task and let a volunteer choose her, instead of her having the ability to choose the volunteer. To this she added that while she was taking care of her father, most of the help she need was very instantaneous and she needed someone within an hour. This she believed was rooted in her not living with her father while she was taking care of him.

She was very fond of getting access to the application through the municipality or the doctor. She had thought of this herself meanwhile going through the application, and was afraid that people not in a need would take advantage of the service if it was not moderated.

In the discussion of the service in general afterwards, she requested a greater focus on the social part. Her experience with the terminal care system shows that her father needed someone to talk with. She has good experience with the home care who were taking care of most of the daily help such as cleaning. And while there still were some things she would have needed help with, such as groceries and running errands. She had missed help especially in the areas of someone sitting down 20 minutes, just to talk with her father.

While she had these specific problems and needs, she had found out that they were a lot different from municipality to municipality. The differences she experienced the last 2 weeks of her father's life, where he had to move to another municipality in order to be able to stay at his ex-wife's, which was in inner Copenhagen. Here the municipality had a bigger focus of the social aspects of caring than in the municipality of Kalundborg, where he had lived throughout most of his disease.

Overall she believed The Caregiver Buddy Network would be of much help to relatives, who are caring of their terminal family members.

TESTING THE PROTOTYPE WITH MILLE, A RELATIVE

We got in contact with Mille through our network and she is a relative to a terminally ill patient. This test was done at AAU campus, Friday the 2nd of December and took about 45 minutes. The participant gave us good input about what we could do to improve the concept.

At first we presented our concept shortly to the user so she could better understand what it is about.

We opened the Invisionapp on a smartphone, so Mille could interact with it. We asked her to go through each step and think out loud if any thoughts or questions came to her mind. That way we could interpret if she understood how to use the application, if she was satisfied with the information given or if she thought the application was easy to navigate.

She thought that the concept is better to focus on, as she thinks the "Terminal Guide" (other concept we considered first to work with) would be too much. It would be hard to handle, as there would be too much information at one place and difficult to comprehend at this fragile stage where people are. Mille would never have the time or energy to read though a whole guide at this point. So her opinion was that The Caregiver Buddy Network concept is better and more useful to work with.

Mille said that mutual trust is crucial for this to work. If she wanted someone to come to help with certain tasks at her home, she would need to know something about the person in advance. She sees as an invasion to one's privacy to have a random person come to their home. If someone is supposed to come and help the relative and the patient, is should be someone that they could get to know a little more about before they come.

According to her we focus too much on the practical side with the help we want to provide. From her own experience she would rather have needed an extra pair of ears and eyes, like duplication of herself. She felt these practical tasks, such as doing grocery shopping, run errands, cooking and other tasks at home was something she easily could do by herself. And to let a stranger to do her laundry would absolutely cross her privacy boundaries.

Furthermore, MIle said that we should focus more on the human contact, rather only these practical tasks, as she thinks it would be more helpful. She came up with examples such as the need for someone escorting the patient to the doctors meetings and listen to the doctor from an objective perspective. Another example was to go and check on the patient at home when the relative is prevented to do that. The third example was that sometimes the patients and relatives just need someone to talk to. So some sort of companionship would be more preferable rather than someone who could perform the practical chores at one's home.

If people decide that they want to be a part of this progress and become a volunteer, they should be engaged and make a commitment. There should be a minimum of 24 hours deadline for people to notify if they can't come.

Patients and relatives are both in a very vulnerable stage at this point, so they don't have the vitality to get to know new people constantly. They prefer familiar faces and especially at this stage when they are still processing the notion about the terminal diagnosis. It is too much to deal with sudden change of people coming in and out of their home at this delicate stage. Therefore it would be preferable that the volunteers commit to a specific period of time, and would stick to the same patients to avoid inconvenience.

Mille said that even though this is unpaid job for the volunteers, they should know after some time if this is really what they want to do. They should get some kind of reward after some time to motivate them pursuing volunteering. The participant mentioned we could also think of the financial aspect of this concept.

She would have been willing to pay for a service like that when she was taking care of her mother. Mille said there could be a monthly subscription to the service, standard and one that gives access to more than the standard subscription.

The basic or standard subscription could cover these practical tasks and the other could cover the more human contact/escort/companion assistance.

> *"Your concept is overall very good, you should go to Løvens Hule (DR)"* - Mille

When the participant scrolled through the application interactions, her comments were:

- "You should have a more distinct design for your application".
- "I like that the profiles have pictures to show who they are".
- "The chores, which relatives can chose from are very practical, not so much focus on the human contact".
- "What is this? (She did not quite understand what the badge represented). You should add rating system, just like Trustpilot".
- "I would like to pay about 150-200 kr per month for that extra security to be able to get good, trustworthy people to chose from".
- "You should focus more on the financial aspect in the long run".
- "You should make it as a requirement in your application that the relatives rates the volunteers after each time".
- "To expand this concept, you should apply for some grants and financial aids".
- "Your concept is overall very good, you should go to Løvens Hule (DR)".
- "What creates dependence in business is what keeps the customers within your company. You should focus on the mutual respect aspect".
- "If you have a paid positions, you can have signed contracts that enables more stability and security".

KEY FINDINGS

- A rating system is needed in order to show trustworthiness.
- Too much focus on practical tasks. Should focus more on human contact and more of a companion/escort service as well.
- There should be a binding period so the volunteers would be more committed, and to prevent overflow of new people constantly entering the homes of the relatives and patients at this fragile stage of their lives.

There must be taken under consideration that it is very individual what kind of help suits each person. The input we got from both participants reflects their own experience from being a relative and primary care giver to a patient in the terminal phase.

Last but not least, it is important to note that we only tested the prototype once, we went back and prototyped based on the results and then we began designing this product. Ideally, we should have tested it once more to identify if the new changes made caused new problems we did not anticipate.

DISCUSSION AND REFLECTIONS ABOUT THE PROJECT PROCESS

DISCUSSION AND REFLECTIONS ABOUT THE PROJECT PROCESS

LEARNING GOALS

In the very beginning of the project we sat learning goals for ourselves. Goals, which we expected would help with focusing our efforts during the process. These were based around our strive to improve skills, knowledge and competences both as individuals and together as a group. These goals are the following:

- Understand how a Service System works from a holistic point of view
- To get a better understanding of how to use and apply different methods and tools that are available, both as a service designer but also within sensitive research topics
- To understand and solve the problems among different actors within the healthcare sector.
- Acquire experience with writing academics papers in a group.

The discussion on our process is affected very much by our initial point of view, but also additional failure points we have had during the process.

We felt we achieved these goals throughout this report, after working on this project we got an insight in to the health sector as a service system as well as the "sub" systems of the health sector as an organization, we got an understanding of how to approach topics as sensitive as this and we saw that there can be huge requirements to a service being trustworthy especially with users such as ours, they require extra security and do not want to take unnecessary "risks". The Danish healthcare sector is complex and even after working with this project intensively for the past semester, we still do not fully understand every detail. There are many sub services that are offered to patients and no easy way to access this information, for us and for patients involved in a cancer disease course, there is a need to gather relevant information and to increase the clearness of the communication among actors.

CHANGES TO PROBLEM FORMULATION

After a while working on the project we were informed from CHC that they have formulated the initial problem formulation in cooperation with Rønne Hospital. This problem formulation was framed in consideration of how to increase the number of patients to die at their private home.

To change the initial perspective, we framed the question in how we started might consider what is the best for all the actors involved, and not just fixing the very specific problem of decreasing the number of the people dying in hospitals. During the course of the project, new frames created new discussions that ended in changes to our perspective. By this we changed our problem formulation together with new perspectives of the situation.

After the conducted research we moved our attention towards the relatives of the patients. The relatives became a very important focus point and we decided to create a service that includes them as the primary actor, however keeping in mind that if we affect them positively this will reflect onto the patient.

All these changes took a lot of effort groupwise, which is normal to happen when there are five people with different opinions in a group. On the positive side, it was clear throughout the process when a new frame was introduced that changed our perspective, since this was often done in relation to long discussions. The changes to the problem formulation have also helped us understand the different actors in the end-of-life care, since we have had frames that took the perspective of more or less all the important stakeholders.

METHODS, TOOLS AND HOW THINGS CAN GO SOUTH

In our design program and in the early phases of this process we had an understanding among the group on how to proceed and with what methods. But since none of us had properly experienced a service design process before, we were aware that problems could occur.

The stakeholders map helped us a lot to understand who the stakeholders are and which ones should be contacted for interviews, as well as creating a bird's-eye perspective to be a starting point for us in this very sensitive project. User journeys and personas helped us throughout the process and allowed us to gain knowledge about the stakeholders. A user journey helped us reveal the existing system process, which identified exact problems and gathered all the fragments into a whole. In the end of the process, the service ecology and the blueprint uncovered the specifics of our new service that needed to be focused upon in order to complete it.

Personas have changed a lot during our process. We have created new and removed other personas as the process developed. The personas have helped us very much retain the important aspects of who we are designing for. To understand if we were missing a kind of users in the project we used a cross parameter map to understand if there were any gaps into the stakeholders' insights. We never had much success with this, and because of the bad experience with it at this time, we did not try to reuse it later in the process in situations where it might has been useful. From a small discussion we had, we came to the conclusion that the bad experience was initially caused by our bad understanding of when to use it and how.

We have also reflected upon our use of service ecology and blueprinting, which we understood were done too late. The blueprint might has revealed problems in the existing service earlier and maybe even showed problems that weren't uncovered with the research.

INTERVIEWS - HARD TO GET BY PATIENTS

We had an expectation that the interviews with all stakeholders in this sensitive theme would turn out to be a problem, especially interviews with the patients and relatives, since we considered them most sensitive. From the beginning we hoped that by using the snowball effect we would reach the patients, however we did not have success with this method. The professionals were not willing to refer us to relatives or patients and we have not been able to get in contact with them even with the help of our acquaintances. The relatives were also not giving us access to the patients, either because they were too ill and weak, or they were simply not interested in facilitating this contact. The solution to this could be to have had a cooperation with a hospital from the beginning of the process, which might have helped with these contacts. Moreover, we could have prepared ourselves better, for example not to continue with the project before proper interviews were planned, however this could have been difficult considering the timeframe of the whole project. The whole problem seemed remarkable, since all the nurses and most of relatives we talked to, said that the patients were bored and would love to talk about their illness and about their situation.

INFORMATION GATHERING FROM DIFFERENT PERSPECTIVES

The interview process showed us a distorted image of the situation, because of not being able to get equally information from all stakeholders. We expected that our process would have been very different if we had been able to get access to terminal patients from the beginning to the end, and not through the relatives and the experts' interviews.

The information we did gather from the health professionals and the relatives was really good. It showed clearly what they believed was the problem. It also showed the confusion between the stakeholders that Trine Brogaard has concluded in her Phd, that all the different stakeholders believed different people had the responsibility for the entire process.

We gained information from Trine Brogaard's Phd through desktop research. All this information was really useful, but we had to wary of where all the information came from, since much of the research was from North America, as well as rest of Europe. We were afraid from the beginning that there would be too many differences between the Danish system and others. Therefore, we would not use desktop research that was not based on the Danish healthcare system. A decision like this should have been taken earlier in the process, before we had read through it all. Even though it is not used directly in the project, we are sure it has affected our process.

There has been a lot of changes to the terminal care in the last 20 years. This is something we should have taken into consideration. Many of the palliative teams were not implemented into the healthcare sector more than five to six years ago.

Both in what desktop research we used as well as the relatives we were in contact with could have been looked upon. Since we had had a hard time including relatives to in the process, we decided it would be best to include them, and meanwhile be critical over the information.

Overall the mix of the quantitative and qualitative information gave us a holistic overview of the situation. This is our conclusion, even though we believe our process would have gained more information and perspective with interviews with patients.

EMPATHISING WITH PATIENTS

With this sensitive theme we have had troubles emphasizing properly with the patients, since none of us have ever been in the situation, which is in contra to many other situations, where you can experience them. In this case however, with terminal care is not something we could just do. It is also very hard to imagine what the experience truly is. We see a problem in this, and we had to rely on interviews and desktop research for our design process entirely.

ETHICAL ISSUE DURING PRETOTYPING PHASE

We had a discussion on the ethics of using pretotyping in a topic like this, as well as in general. With this being a school project, we felt that there is a limit as to "how far you can go" with pretotyping. We would not feel overly comfortable with troubling terminally ill patients, and "selling" a project that doesn't exist, while knowing this project is during our first semester where we are still only developing and are still learning how to apply many of the methods in this field. This is also the main reason of our pretotyping method being limited a bit, as in we would not require a "payment" to prove that the participant was willing to use the service that still doesn't exist. Still our method of pretotyping might have been going to far? We "infiltrated" support groups for cancer patients, making posts "selling" our idea as if it existed and some felt this was "trespassing". They used these groups to seek comfort, not to buy into ideas or concepts. (Appendix 4)

WORKSHOPS AND PRODUCTIVITY

To help us align our understanding of the information we gathered a workshop, and another one to begin with the ideation phase. Both of these workshops turned out very good, having a simple structure, with a clear goal and using a few tools to get through them. Both days we did workshops, we progressed a lot. The only negative experience we had with the workshops was our own inexperience with the same. We could most likely have done the same workshop in much shorter time and done additional ones on different times throughout the project, if we had more experience with both workshops and service design. Another problem we had with the workshops was that they ended up monotonous in their design and execution. We imagine that next time we do a workshop we will be able to use different methods and have more control over how long time is required to manage the different methods.

CREATING THE SERVICE

From the second workshop we created a couple of ideas to go on with. For validating these ideas we planned on pretotyping them. Based upon a discussion of the ethical concerns of using pretotyping in such a sensitive area as terminal care, we decided to try it. From our pretotype testing we had mostly positive experiences, but not surprisingly found out that the ideas had only been validated and not tested in a way that would show the best concept. The feedback we got was only through sign ups to the different services and comments on social media groups.

We felt that we were missing a customer or relative that could inform us what they prefered. The comments showed us that all ideas were interesting during the different stages of terminal care, but we chose to go with the one we expected could help the relatives the most in their daily life.

We found it very hard to prototype a service entirely. Our plan was to test the different touchpoints we had created in the new service concept and thereby cover the service. We found it impossible to properly test all the touchpoints, especially because we believe that the most important thing in a service are the relations between the touch points. By testing only a touchpoint at a time this would not be taken into consideration.

TESTING THE SERVICE

The testing was very eventful, both in consideration to feedback to our service concept as well as other things in relation to the project. The participants in the testing had several comments and recommendations to the prototype, that were missing for it to be perfect. They had remarks in relation to the prototype and requested for the service to focus more on the emotional aspects, e.g. a visitor that would come to talk with them or the patient about both, life in general and deeper conversations topics such as existence and death.

We were very confused to where we misunderstood our stakeholders' needs. We believe it happened to be around the pretotyping phase, and with the testing it was obvious that pretotypes only validate the idea, and do not rate it in any way in relation to other ideas. For this we would still need a discussion with a relative about what would be needed the most. Around the pretotyping phase we had a discussion with a relative. It was 20 years ago she had to take care of a patient and we suspected that this might have caused her to see the terminal care differently that it is today, both in changes in the terminal care but also in her memory. It also stresses that early prototypes are very important to remove early failures from the process and service.

On the service concept, we had a hard time prototyping the different phases properly. We were not able to meet a relative within a current terminal care where we could test the physical touchpoint and were thereby forced to only test the application's touch points. Even If we had the possibility of testing all touch points there would still have been a risk that something could go wrong, since there might be fail points in relations between the touch points. This is in relation to the participants in the testing not experiencing the whole service.

We feel that we have accomplished a lot by testing the application's touch points and we gained new information, even though it changed a lot. We would have wished to prototype the things properly but without access to any relatives taking care of terminal patients who were willing to test the physical touch point we had to test only the ones we could. We imagine that there might be problems in relation to the relationship between the physical world and the application which could have shown during the testing of the physical touch point, if we had been able to do it.

CONCLUSION

CONCLUSION

When designing a service within an area as sensitive as terminal care, it is very important to get a hold on the real user, in our case relatives to terminally ill patients and the terminally ill patients themselves. We have used several channels to get in contact with the terminal patients, but we didn't have success in having a personal conversation with them. However, we were able to get in touch with several relatives to patients whom had passed away. Unfortunately, there was only one person currently having a terminal ill relative, who was found through our personal network and was willing to participate.

What we learned and what should be noted for future designers is how difficult it actually was to establish this contact, there are huge trust requirements and the people involved have a very large emotional investment prior to being part of interviews or the design process. To be able to understand the user and truly benefit from their participation one should first identify users that are willing to be part of an entire design phase, and not only during specific stages such as the interviews and testing. This will improve the final product, with knowledge from full participation of the user. It is thereby possible to dig properly into the test stages and see the direct impact, on different participants. Another major benefit is in identifying how the needs of the users might change or if they change at all throughout the process. It is difficult to compare the needs of users who have already been through the process and the needs of users who are currently in the process, because of the impact of the emotional "factor". It should be taken into consideration when designing that the actual needs might not be the same, for a user reflecting back compared to a user being in the process. The knowledge gained from users reflecting, back on what "would" have been nice is equally important, but this knowledge should be used with that in mind.

Our initial problem statement:

> "HOW TO REDUCE THE NUMBER OF TERMINALLY CHRONICALLY ILL PATIENTS DYING IN HOSPITALS BY 5%?"

... was used as a guiding star throughout the entire process, even though it was changed several times. We might have changed our focus to help and take relatives into consideration, but the overall goal was still somehow to grant the wish of patients wanting to die in their own home. Based on the desk research, qualitative interviews, workshops among others, we reached the final problemstatment:

> HOW MIGHT WE IMPROVE THE SUPPORT AND INCREASE THE FOCUS ON RELATIVES WITHIN PALLIATIVE CARE OF TERMINAL PATIENTS?

We concluded that the best way to reduce the number of patients dying in hospitals was to move the primary focus on the relatives and take some of the burden they have when caring for the patient, because the requirements for caring for a terminal patient are tough and many relatives can't manage the burden. By freeing up time with a service as the Caregiver Buddy Network, we expect it will help the relatives. However, our prototype test showed that the two relatives would have wanted more emotional support than help with physical tasks. Even though we felt we were taking the four key points of palliative care into account (spiritual, social, mental, physical) we might have focused more on some than others. The test also showed the participants felt very vulnerable about the idea of inviting "strangers" into their home, again the trust requirement was a key factor of the success of this service, one participant felt the service should provide an extra set of eyes and ears, the volunteer should be able to attend meetings with relatives. This shows the amount of trust the relative is actually asking for.

We ended up creating the Caregiver Buddy Network, a service that will let the relatives get in touch with volunteers. However the results of testing the wireframe prototype indicated that the service might not be the thing that the relatives needed the most. They expressed a need for a more fiduciary and long-lasting relationshipship where they would be able to chat and get in touch with other relatives, who had been through the process or currently is in it.

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APPENDIX

APPENDIX 1: WHO FULL DEFINITION OF PALLIATIVE CARE

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including be reavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

APPENDIX 2: QUALITATIVE INTERVIEWS

APPENDIX 2.1. EXPERT INTERVIEW 16.10.2016 - GP HENRI GOLDSTEIN, GYNECOLOGIST AND FORMER DOCTOR AT SANKT LUKAS STIFTELSEN: Henri Goldstein has more than 30 years of experience within the healthcare sector. He works as a GP and it was a happy coincidence that he has been working as a doctor in Sankt Lukas Hospice during his career. He gave very interesting information from his experience in the field which was useful for us in the creation of our personas. This time we prepared an introduction about our education and goal with this interview. We met Goldstein in his apartment in Frederiksberg.

KEY-FINDINGS:

During the interview we quickly noticed an emphatic and well experienced man with a lot of great stories gathered from his experience. He has a strong policy when it comes to end-of-life care: "The person who tries to predict death has not understood anything." [...] "I will never take away hope from the patient. I will always try to tell stories about people surviving the disease." [...] "I remember operating a woman with ovarian cancer. I could not remove it all. I told her two sons that she could get chemotherapy that would remove the rest. I knew that the chemo would not remove it, but maybe she could live for some years more, then there was no reason to tell otherwise so early in the process. That's important." (H. Goldstein, Doctor, October 16, 2016).

According to Goldstein, it is often not possible to predict death. People in the healthcare sector make mistakes, and that's nature. "It is often quite difficult to send people home and say: "you are going to die within 4 days. Do you want to lay in your own bed?" (H. Goldstein, Doctor, October 16, 2016).

A terminal period can be either very long or very short period of time. "I've experienced a woman hospitalized in hospice for 9 months - that was too long, I would say." [...] "I've met a patient at 79 years old who got cervical cancer and died within 3 weeks." (H. Goldstein, Doctor, October 16, 2016).

When Goldstein was a doctor at Sankt Lukas Hospice his daily work life was about visiting all patients and talking with them. That could take a whole day. This work routine differs a lot from other clinical experiences he has had. "I decided that I would try to work in a hospice before I retired. This is the lowest prestigeful position within the healthcare sector but I felt that it was my duty. It is the last part of life that's the most difficult part. It was my goal to make that part easier for some." (H. Goldstein, Doctor, October 16, 2016).

A terminal process can be very different from patient to patient, but that day when a patient gets a terminal diagnose, that patient's life has changed completely. "I remember a 41 years old man who cried every night. His wife and two kids visited him and it was a big issue if the kids should visit or not. The kids will get an experience that can be hard to forget later in life. You need to talk to the relatives to find out if they can manage it." (H. Goldstein, Doctor, October 16, 2016)

When a terminal diagnosed patient gets home for home-hospice, a palliative team will come to visit the patient. When the palliative team is not there, the patient will be taken care of by the danish home care (Hjemmeplejen) and relatives. Who asks the patients of where they prefer to die differs. They often get close to someone who they will talk to about it. "It is often the person they're used to talk to. It can be the priest, the doctor or the nurse. It's about trust." [...] "If you have asked them once, I don't think you will ask again. They can of course say something themselves." (H. Goldstein, Doctor, October 16, 2016)

We asked Goldstein why he thinks patients are dying in hospitals and not in their own homes if that's where they want to die. "I don't think the relatives can manage a home hospice and I believe that patients come to hospitals in the end because of an emergency situation and die from it there." [...] "It is really tough for a husband or a wife to take care of a relative at home." (H. Goldstein, Doctor, October 16, 2016)

The palliative system is a big issue between hospitals and municipalities. "If the hospitals can not do anymore for the patient - then the patient is the municipalities' responsibility." (H. Goldstein, Doctor, October 16, 2016)

APPENFIX 2.2. EXPERT INTERVIEW 25.10.2016 - PRIEST KARSTEN THOMSEN, BISPEBJERG HOSPITAL: We went to Bispebjerg Hospital to meet with the hospital priest, Karsten Thomsen. The interview went great and we gained a better knowledge about his role and daily routines as a hospital priest. He also provided us with some interesting stories gathered from his experience within the field which have helped us to get a broader perspective and greater insight in the terminally ill patients.

Key-findings: Karsten has 14 years of experience as a priest and 8 years working in hospitals. He is working within three different areas: patients, relatives and employees. He is working in the church sometimes, but he is mostly at the hospital. "My job is all about talking." [...] "People don't go to the priest. I have to go to them." [...] "I'm walking around the different departments in the hospitals. Sometimes I go outside visiting the terminally ill patients at their homes." (K. Thomsen, Priest, October 25, 2016)

Karsten is also talking and hosting group meetings with relatives. Sometimes he's burying patients that he is close to and who have asked him to do it. Patients often feel security in talking with the priest instead of other clinical employees, such as doctors or psychologists. "Most of the people know that I'm not that kind of a guy who tries to convert souls to have the same opinion as me. People can use us for many things." [...] "Most people think it is easier to talk to the priest." [...] "A psychologist is a part of the "white uniform" who has to report the conversation and who has a goal with the conversation. I don't. I just want to know what the person wants to talk about." (K. Thomsen, Priest, October 25, 2016)

Most of the people that Karsten talks to are 40+ years old. It can be people with any religious opinions. When Karsten is talking with patients the conversations are often dealing with relations or the life in general. "I talk about life after death daily with the patients. We talk about mistakes in life, our relations. The people near us - boyfriends/girlfriends, siblings, parents, friends." [...] "We talk about what the meaning with life is. What is the meaning now? What is the meaning, when I have to die?" [...] "I can for example ask questions such as "do you have a family?", "how do you feel about your cancer?" or "did you consider that you might die from this?"." (K. Thomsen, Priest, October 25, 2016)

The period of time that Karsten is in contact with the patients is very different from patient to patient. It can happen a few times or it can happen during 3 or 6 months. Karsten is very touched by his work and the people he is in contact with and he sees it as a strength. "We cry a lot together. I'm crying with the patients. It is difficult not to." (K. Thomsen, Priest, October 25, 2016) Sometimes he is clearing out his own thoughts to specialists, priests at supervisions himself.

Karsten believes that the clinical staff are life prolonging too much. "They are not good at talking with the patients and relatives about ending treatments to give the patient peace." [...] "Hope doesn't have to mean "more days". Hope can be other things such as good days, hope for days without pain, about spending time with relatives while being in a stable condition." [...] "If we can't cure we must comfort and support, but our system is not build upon that." [...] "The palliative care is lacking in that context." (K. Thomsen, Priest, October 25, 2016)

Most of the people who want to die at home end up dying at the hospitals. Karsten thinks it has something to do with the relatives. "The reason for people dying in hospitals and not at home has something to with that it is care heavy. It can be difficult for an elderly to take care of a relative and make a daily life work with shopping and nursing." (K. Thomsen, Priest, October 25, 2016)

APPENDIX 3: REDESIGNED PERSONAS

APPENDIX 3.1 SONJA

SONJA / PATIENT

“I havn’t had one bad experience in my life.”

AGE	75
OCCUPATION	Retired
STATUS	Husband
KIDS	3 kids
LIVES IN	Gentofte
DIAGNOSED	Ovary Cancer
TERMINALLY	2nd phase
LOCATION	The Hospital
ARCHETYPE	The optimistic

NEEDS

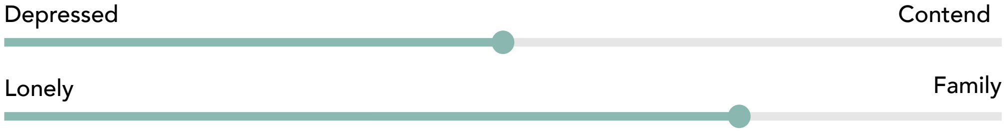
- Talk with a priest
- To be with her family
- Have her everyday routine back
- Pain relief

ABOUT SONJA

Sonja is a 75 years old former secretary with a husband and 3 grown up kids. She is a succesful elderly woman with no adversity in her life besides this terminally diagnose that seems like the worst thing ever happened to her. She hides her feelings and seems contend during her disease. She misses her dog a lot and she’s often thinking about missing out on bridge every tuesday night with her friends. She is diagnosed with overy cancer and she is terminal in 2nd phase laying in the local Hospital.

SCENARIO

”I found out that I had cancer in my ovaries when I was my regular gynecological check. After I turned 50, I have only been summoned to gynecological check every 5 years. I had noticed that I had bleeded a bit during toilet visits up to the check, but I had didn’t thought it was necessary to go to my doctor before I nevertheless had to meet up for the regular check. When she examined me, I could sense that the doctor did not think it looked quite good, but she took some samples and I had to wait a few days to receive the response. My doctor called me and asked me if I had time to come by, and she suggested that I took my husband with me. At the interview we were told that I had ovary cancer, and it unfortunately seems that it could well spread. My doctor gave me some information about my future treatment, but asked me to show up for another consultation at Gentofte Hospital, where I received more information.”



LOTTE / PATIENT

“I wanted to see and experience my grandchildren”

AGE	58
OCCUPATION	Pedagogue
STATUS	Single
KIDS	1 son in Germany
LIVES IN	Sydhavnen
DIAGNOSED	Lung Cancer
TERMINALLY	2nd phase
LOCATION	At home
ARCHETYPE	The lonely one

NEEDS

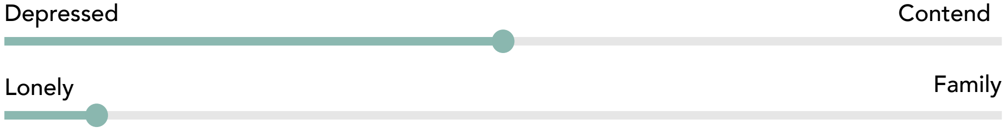
- Cigarettes
- To keep herself busy
- For her son to come home
- Professional visitations
- Pain relief

ABOUT LOTTE

Lotte on 58 is a pedagogue and now at home for palliative treatment because of her terminally condition. She lives in Sydhavnen where she has been most of her time alone due to her son lives in Germany, and where her sister is now taking care of her. Lotte is a DIY type who enjoy making patchwork and she reads a lot of books. She finds joy in smoking cigarettes although it’s not making her situation less difficult. Lotte is afraid that she will die alone and she wish for her son to come home.

SCENARIO

”It all started with a flu that would not go away. I went with cough for several weeks after. At one point I thought that it stopped, but it came back again really quickly. My voice was hoarse and when my son sometimes called from Germany he always said that I should go to the doctor. I had a little difficulty breathing sometimes, but I assumed it was because of the flu and the cough that would not go away. I did actually try with all kinds of non-prescription medicines. I ended up going to my doctor. She took a lung function test, which unfortunately was not so good. I had of course also smoked for many years. She referred me to another doctor who would took some scans of my lungs. A week later she called me up and asked if I had someone to be with for the rest of the day, due to she had really bad news. I immediately thought of my son in Germany. He could not so simply get here. My sister is so busy, so I felt so bad about having to saddle her with my problems. ”You have lung cancer”, my doctor said. And the rest of the day I was crying and texting with my son.”



KARSTEN / PATIENT

"I wish I had learned how to cook"

AGE	82
OCCUPATION	Retired
STATUS	Wife
KIDS	No kids
LIVES IN	Frederiksberg
DIAGNOSED	Brain Cancer
TERMINALLY	3rd phase
LOCATION	Hospice
ARCHETYPE	Pieceful one

NEEDS

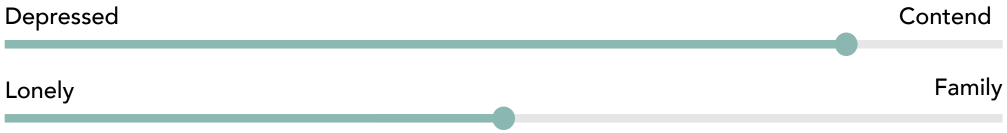
- Quality time with his wife
- To say goodbye to his colleagues and the football team
- Pain relief
- Cooking lessons

ABOUT KARSTEN

Karsten has always been a very active and social man during his 82 years. With no kids to raise, he has had great enjoy in being a foodball coatch and doing other humanitary work. Besides football and swimmingclasses, he has been working as a GP in the Frederiksberg Municipality. Due to his doctor experience, he also has great knowledge in his own condition. That's also why he is very contend about his terminally diagnose, although he would have wished that he'd learned to cook.

SCENARIO

"It all happened very quickly. My wife and I were visiting some friends on a summer evening for barbecue and beer in their garden. I drove the car as my wife does not drive anymore. In the car on the way I become very dizzy suddenly. The car wobble slightly from side to side until I finally get hold of the drive. My wife was scared, but I assured her that everything was fine. We drove 20 minutes more, and the situation played out again. This time I got a violent headache and had to stop the car. I was not quite consciousness, but my wife seems scared and she called our friends for help. They came running, and we drove together to the nearest hospital. I was still a little beside myself when we arrive at the hospital, but I had already made 1000 thoughts about what could have happened. I was almost well aware of what this meant. Either I had had a blood clot or maybe a knot or cyst was in the way up there. The examinations at the hospital showed that there was a knot in my brain unfortunately."



ERIK / PATIENT

“I miss my friends in the bar Stubben”

AGE	62
OCCUPATION	Unemployed
STATUS	Divorced
KIDS	5
LIVES IN	Sydhavnen
DIAGNOSED	Throat Cancer
TERMINALLY	1st phase
LOCATION	Hospital
ARCHETYPE	Alcoholic

NEEDS

- Wants to end his days with a beer in his hand
- He needs relieve from cigarettes
- Misses socialize
- He has Troubles being ouside his comfort zone

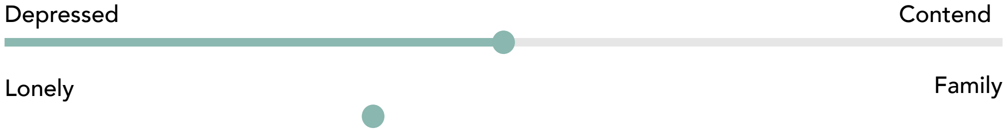
ABOUT ERIK

Erik is an older man. He has worked hard through life as a construction workerm but is now unemployed. He only has one year left before he can retire. In his life he has moved a lot because of different jobs and relationships. He has been married several times and has 5 kids with 3 different women. He enjoys being social in his daily life. Which normally amounts to him visiting the local bare Stubben. He is diagnosed with throat cancer which gives troubles in his daily life, since the treatment does not allow him to smoke as much as he normally does.

SCENARIO

”I has had daily troubles with swallowing for the last couple of weeks. Like most days I had been sitting at my table in Stubben doing casual conversation with Hans at the next table. We were talking about an old dancing bar that was popular around the time I met my first wife. Heidi the bartender yelled at me because I had started coughing yet again. The coughing was provoked by my trying unsuccesfully trying to swallow my beer. She commanded me to go visit the doctor immediately.

My doctor Michael looked at my swollen tonsils and neck. He quickly told me that I needed to go to the Hospital to get them properly checked. Two weeks after having been examined at the Hospital, my doctor Michael called me. He asked me to come by so we can discuss the results of the examination. he calmly explained the situation to me. I has throat cancer. It could be treated but alreadt now it was aggressive and the risk of cancer spreading was high.”



MIKKEL / PATIENT

"Why? And what's going to happen?"

AGE	19
OCCUPATION	High School
STATUS	Single
KIDS	0
LIVES IN	Hvidovre
DIAGNOSED	Leukemia
TERMINALLY	2nd phase
LOCATION	Home
ARCHETYPE	The teenager

NEEDS

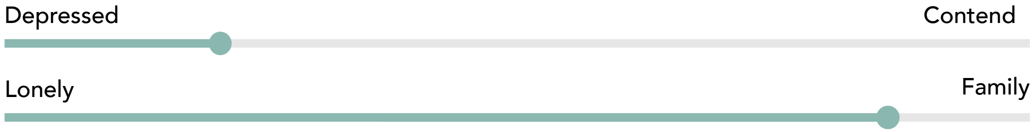
- Only wants to talk with his friends on good days.
- Problems coming to terms with his disease, need spiritual guidance.
- He is confused about his role between child and adult.

ABOUT MIKKEL

Mikkel is a 19 year old high school student. He enjoys school, even though he's a regular high school student trying to act like he hates it. He lives at home with his parent and a younger sister. He spent his sparetime with playing soccer twice a week and a game in the weekend. He always enjoys spending time with the family dog, a brown labradoodle called Choco as well as playing video games such as DOTA with his friends in the evening. He is afraid of being sick, and throughly confused with this period in his life. He is only just getting used to this process of growing up. He is having a hard time coming to term with his disease and switches between trying to take everything upon himself as an adult, and just laying down and seek solace in his family as a child.

SCENARIO

"I was sitting in classes. It was a Danish class about Johannes V. Jensen and his stories. I had been feeling sick throughout the morning, but nothing that I thought was enough for skipping classes. I have been sweating throughout the night and felt really weak, the weakness just continued increasing through the day. Just before lunch I could not take it anymore, I grabbed my bag and skipped classes for the rest of the day, to get home and lay in my bed. I had been laying in my bed, trying to sleep for several hours when my mom came home from work. For the last two hours i had had an increasing pain in my bones. When she heard what was wrong with me, she immediately wanted me to get dressed so we could drive to the hospital. Before half an hour had passed I was sitting in front of a doctor at the emergency entrance to the hospital. The doctor was listening to me explaining my symptoms. When I finished, she took a blood test to find out what was wrong. Until then I would be admitted to the hospital, to be able to keep track of what happened. 3 days later, she was back with the results. I had been giving pain medications to take the top of the discomfort my pains were giving me. I had leukemia. She calmly explained to me what would happen from now on."



BRIAN / PATIENT

"I feel like the whole world is against me"

AGE	41
OCCUPATION	Mechanic
STATUS	Wife
KIDS	2 kids
LIVES IN	Amager
DIAGNOSED	Bowel Cancer
TERMINALLY	3rd phase
LOCATION	The Hospice
ARCHETYPE	The depressed

NEEDS

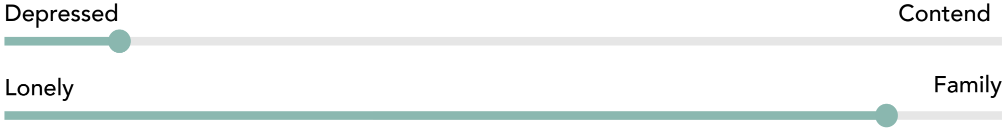
- Comfort
- Want to talk with somebody
- To see his kids
- Pain relief

ABOUT BRIAN

Brian is a Mechanic from Amager who enjoy fixing his car, cruising around and enjoying the nature. Brian is in the Hospice but he has difficulties finding piece with his terminally diagnose, and he cries every night in his room. His wife and 2 small kids visits him every day, but they can't find piece in the situation and cries a lot.

SCENARIO

"I regret that I did not listen more to my wife and went to the doctor sooner than I did. Had I gone to the doctor before the cancer may not spread as it does now. It is hard to say. Perhaps it would be the same. I was going with stomach pains for a long time. Sometimes the pain was so bad that I stayed home from work. My wife said to me several times that I should go to the doctor, but I was convinced that it was nothing special. I have often experienced the same bloating and discomfort and I have often just associated it with something I've eaten. Now I must learn to live with that I can not be healed. That's sad. My wife convienced me to go to the doctor, and the doctor took me very seriously due to I had walked around with the pain for long. He asked if I was bleeding when I went to the toilet, but I havn't notised. I had lost a little weight, but I also had such little desire for food when I had these stomach pains. Quickly I was referred to a screening study where they unfortunately found bowel cancer. It all went so fast."



APPENDIX 4: MESSEGE RECEIVED DURING PRETOTYPE PHASE

Marie Klarskov 11/28, 10:37pm

Det var så lidt - må jeg lige give jer et lille råd med på vejen? Ideen om at lade terminale patienter dø hjemme er efter min mening noget romantiseret - i den sidste tid er der virkelig mange ting man har brug for at bruge tid på ... Som pårørende... Mens tiden bliver mindre og mindre - hvis man passer sin pårørende hjemme kommer du omvendt til at bruge mere og mere tid på pleje jo nærmere på slutningen du kommer altså det stik modsatte af hvad alle har brug for. Jeg er SÅ taknemmelig for at jeg fik lov til udelukkende at være pårørende den sidste tid, at min far bevarede noget selvbestemmelse og værdighed til det allersidste på grund af noget virkelig fantastisk personale omkring os.

Sidst men ikke mindst - det forum du har skrevet på bruges normalt udelukkende af pårørende og efterladte som lufter tanker, tvivl og frustrationer ... Det er ikke for at være "sur kælling" 😉 men det føles ret grænseoverskridende når der så dukker en "salgstale" op det sted hvor man kan sige alle de ting man ikke kan sige til sin familie, venner eller omverden... Du bevæger dig ind på et mega sårbart område med folk der er i dyb krise - det kræver en meget øm håndtering. Ja undskyld det er ikke for at blande mig i hvordan I indhenter jeres empiri - blot et godt råd. Held og lykke med projektet.