## **CareTunes for Families**:

Connecting ICU Patients and Their Families through Music

Graduation Thesis by Chen Chou

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## **CareTunes for Families**:

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## **Executive Summary**

CareTunes for Families is a product-service system that connects Intensive Care Unit (ICU) patients and their families through music.

Families of ICU patients often experience distress and anxiety. They have the need for information, closeness, assurance, hope, control, and the need to support the patient. These emotional and social needs point to a need for stronger connection/connectedness, especially when the family is outside the hospital. In addition, the families experience many negative emotions such as uncertainty, worry, guilt, fear of loss, etc.

Meanwhile, music is a powerful way to communicate emotions and meanings; it has the quality to fulfill the family's social needs, emotional needs, and need for information at the same time.

Therefore, the project aims to increase the connectedness for the families through music, and to bring them more positivity.

A series of literature research and qualitative user research was carried out. The design also went through several iterations, inspired by insights gathered from user tests and interviews with experts. The final design of CareTunes for Families includes service design, user experience design, and music design.

The design facilitates a meaningful connection between patients and families by transferring the patient's mental activities and emotions through music streaming or music messages to the family. The music streaming enhances the sense of close presence of the patient, and the music messages enhance the feeling of intimacy and assurance, and reduces the sense of guilt. The product also enables the family to support the patient by sending back voice messages.

The music in the design is automatically generated by the system. It comprises a theme melody of the patient, increasing intimacy and connectedness, and multiple other tracks which are connected to different data sources such as heart rate, brain waves and movements, creating variations in the music and a sense of realism.

Moreover, the product gives the family the control in ending the music as an act of closure at the end of the service. The user evaluation of the design validates that the experience and the music together can indeed create connectedness and enhance positive emotions such as calmness, hope, and acceptance.

The project leads to the following conclusions: (1) Music presents an advantage in building connectedness through an emotional experience and is unfitted to present technical information. (2) The experience is very personal. (3) Streaming and messaging can both cater to the families' needs respectively. (4) A two-way connection that also supports the patient may be needed. (5) Positivity in music is important. (6) Multi-dimensional composition can bring more life to the music. (7) The music should be predictable. (8) The selected data source for the music should have (humanized) meanings.

While the project focuses on the families, the product is expected to benefit other stakeholders as well. It is recommended for future research to involve the nurse and the patient, and a greater diversity of the families. Then, explorations can be carried out concerning how the design can be implemented from the strategic and technical point of view.



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# Chapter 1 Introducing the project

In this chapter, the problem definition, project context and approach used in the project are introduced.

## 1.1 Introduction

The project "CareTunes for Families" derives from the CareTunes project of the TU Delft Critical Alarms Lab.

The Critical Alarms Lab studies and designs for alarms and soundscapes in medical environments, and the CareTunes projects make use of monitored data in the Intensive Care Unit (ICU) and turn them into sound and music. The initial CareTunes project aims to turn the ICU patients' vital signs into certain musical sounds to replace the original alarms, whereas CareTunes for Families aims to use music to connect families and ICU patients.

ICU patients are hospitalized patients who are in life-threatening situations and require advanced care and constant monitoring, as their condition may change at any time.

Families of ICU patients often experience distress and anxiety; their psychological, emotional, and social needs are not always met, and one of the reasons behind this is the lack of connectedness. Connectedness is also one of the important human needs according to Maslow's hierarchy of needs [1]. A new way of connecting the families and patients can be designed to improve this situation. Therefore, CareTunes for Families aims to improve connectedness and thereby offer psychological support for the families.

One thing to note is that, the project started in spring 2020, during the global crisis of the outbreak of COVID-19. While this places unprecedented challenges in the process, such as limitations in human-involved research, this project has also become especially relevant to the situation of the time.

## **1.2 Problem Definition**

A project brief was formulated at the beginning of the project.

### **Problem Definition**

The families of ICU patients often experience distress and anxiety. Most of the families' needs are related to assurance, closeness, and information, which points to a demand for a stronger patient-family connection and connectedness. However, barriers such as difficulties in communication and limitations in caring for the patient hinder this connection. Therefore, the connectedness between the family and the patient needs to be improved.



**Figure 1.1.** Main stakeholder: the ICU patient' family. (Credit: Intermountain Medical Center)

### Assignment

Within the scope of CareTunes, the project aims to explore how music can improve the connectedness between families and patients in the ICU. The design outcome is expected to build up a new way for connecting, while catering to the psychological, emotional, and social needs of the family, and using music's unique qualities. The outcome involves service design, user experience design, and music design.

## **1.3 Project Context**

The project context is studied through literature research, and offers an overview of the project stakeholders, their journeys, and their relationships.

### Journey in the ICU

People are admitted to the ICU when they are in a life-threatening situation, usually after a planned surgery or in an emergency. Special equipment is used to monitor, support, and/or take over a patient's body functions. ICU patients often require much rest, and some may be sedated, such as patients on mechanical ventilators.

The average ICU length of stay is around 3.3 days [2]. However, it is influenced by several factors, such as the type of disease or surgery. For example, the average length of stay of COVID-19 patients is estimated to be around 7-8 days at the time of the project [3].

Figure 1.2 shows the stakeholders' actions, which are summarized from literature review of medical studies [4,5,6], including the four stages the family may go through according to Jamerson [5], and insights obtained from interviews with families and nurses.

The final design of this project intends be introduced to the family by nurses in the information seeking stage, and be used from that moment on.



Figure 1.2. Simplified patient journey map.

### Stakeholders and their relationships

The target user of this project is the families of ICU patients. However, the project also involves the patient and the nurse as stakeholders (see figure 1.3), and intends to benefit them as well as the families.

#### **Family-Patient**

Families of ICU patients play an important role in supporting the patient, including psychological and social support, and decision-making, as the patients are often unresponsive [7,8]. However, their support may be hindered by stress and anxiety [9].

#### **Family-Nurse**

ICU nurses are responsible for communicating with the families about the condition of the patient, and they play a crucial role in helping families manage their anxiety and cope with the situation [7]. However, nurses may experience difficulties in comforting and supporting the families [10], while families can also be a potential source of stress for nurses and other care providers [9].

Therefore, providing emotional, psychological and social support for the families can not only benefit the family, but also the patient and the nurses.



Figure 1.3. Summary of relationships among the main stakeholders.

## 1.4 Approach

The graph below shows the approach and activities throughout the project. The approach of iterative design is used, and research is continued throughout the process.





Defining the scope of CareTunes for Families

#### Activities:

- Observation study at Erasmus MC
- Exploratary desk research



Understanding the context and finding design opportunities

#### Activities:

- Context study by literature review and interviews
- Literature review and desk research on connectedness, emotions, and sound design



Determining the intended qualities of CareTunes for Families

#### Activities:

- Shaping a design goal and interaction vision for design conceptualization



Exploring the possibilities of music composition and delivery

#### Activities:

- Brainstorming and idea merging
- Design conceptualization: generating three design concepts
- Design iteration and rapid prototyping

#### Design cycle 2.1 2.2 2.3

Ch. 5

#### CareFunes for families - Mockup Test Concept A: Background - Listerling to the music while doing other tasks Press later to the piece of music while reading the following article, and stop when the music exist. (1) Press agroups the following in the running for the press Model and the stop of the stop of the music Model and the stop of the running for the press (2) Press age in the stop of the running for the stop.

Ch. 4

## Choosing a direction for further design iteration

#### Activities:

- Setting up research questions and the user test
- User testing
- Quantitave and qualitative data analysis
- Shaping the next design conceptualization strategy



Reshaping the service, user experience, and music

#### Activities:

- Continued design iteration
- Interview with former ICU nurse
- Interview with design for end of life expert Professor Marieke Sonneveld



Ch. 6

Detailing the final design of CareTunes for Families

#### Activities:

- Detailing in service design, user experience design, user interface design, and music and sound design



Ch. 7-8

## Evaluating and reflecting on the design

#### Activities:

- Evaluation done by user tests
- Reflection on possible further improvement of the design

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# **Chapter 2** Exploring the target user: A closer look into the families

This chapter includes the research targeted to the user, which is conducted through literature review and interviews. The goal of the research is to understand the needs, challenges, and experiences of the target user.

## 2.1 Research Method

The research on the families was done mainly through literature review of studies in the medical field and interviews with families of former ICU patients. Meanwhile, user tests done throughout the project also offered validations and new insights about the research on the families.

### **Research direction**

#### To understand the families

As the target user of the project is the families of ICU patients, research into their emotions, needs and experiences was conducted so that the design can be well suited to their journey and corresponds to their demand and state of mind.

#### Related to connection or connectedness

As the project focuses on the connectedness between families and patients, the research analysis also puts emphasis on information related to connection or the feeling of connectedness. For example, the emotional needs and social needs are more deeply explored, whereas the physical comfort of the family in the hospital is not discussed.

It is later found that many of the families' needs are indeed related to staying connected to the patient in one way or another, as shown in figure 2.1. Details will be explained later in the chapter.

#### Experience outside the hospital

The research circles around the project context, where the family is outside the hospital. However, their interactions with the patients in the hospital are also taken into account as they are a part of their connections.

### Literature review

A number of studies in the medical field are analyzed according to the following research questions:

- Why are families important in the context of ICU?

- What do ICU patients experience?
- What do ICU patient families experience?
- What are the needs of ICU patient families?

- What are the challenges encountered by ICU patient families?

- What is the current relationship among families, patients, nurses?

The results can be found in Chapter 1 and 2.

### Interviews and user tests

Three semi-structured interview session were conducted with family members of former ICU patients, based on the following research questions:

- What is the journey gone through by the patient families?
- Which connectedness elements are lacking in the ICU context?
- What value can music bring to the context?

The interview questions and results can be found in Appendix B.

In the chapter, participants one, two, and three of the interviews are quoted as P1, P2, P3.

The user tests will be further explained in chapter 4 and 7.



**Figure 2.1.** An overview of the close relationship between connectedness and the families' needs and emotions. Details will be further explained in this chapter. (The needs are categorized based on Vervaeghe's study [1], but they are reinterpreted and altered according to the research results of this project.)

## 2.2 Characteristics of the Families

The characteristics of the families related to the project are summarized to paint a fuller picture of the target group. The study is done by literature review of relevant medical research, together with insights obtained from interviews and user tests at later stages of the project.

### Facing uncertainty

#### Meeting many uncertainties

Uncertainty is commonly met at the ICU. The uncertainty of whether or not a patient will get better can trouble their family constantly, and can become a major source of stress [2,3].

P1: "[I thought about] how long it would take, if there are any more risks, would everything go well..."

#### Staying vigilant throughout the ICU stay

The fact that the condition of a patient can change in a sudden adds to the feeling of uncertainty. The interviews show that, regardless of the condition of the patient being good or critical, the families would always stay vigilant.

#### A loss of control and a need to seek it

Uncertainty is linked with the loss of control and can cause a sense of helplessness [1]. While the family does not have control over the patient's medical condition, they would try different means to gain a sense of control, such as searching for more information [1]. While reducing the uncertainty of an ICU patient's condition may require advancement in the medical field, it is possible to address the family's feeling of uncertainty through design, such as increasing connection between families and patients to fulfill the need of staying vigilant and receiving more information, and giving the family a more active role in the journey to generate a sense of control.

### Facing changes in life

#### **Role alteration**

A family member may find themselves becoming the caregiver of the patient (in the sense being responsible for visiting the patient, communicating with the doctors and nurses, decision making, etc.).

#### Life goes on, with guilt or longing

As mentioned above, the family might feel a greater urge or sense of responsibility to care for their loved one. However, the family still needs to maintain their work and life, meaning they cannot always be at the side of their loved one in the ICU. Therefore, it is possible for the family to feel a sense of guilt or to long for more contact.

Increasing connectedness in the family's daily life in a nondisruptive manner can be a way to help them adapt to their new role and to reduce their sense of guilt or longing.

### **Experiencing various emotions**

The family of an ICU patient might experience emotions such as shock, denial, anger, despair, guilt, fear of loss, and stress caused by anxiety, uncertainty, and psychological preoccupations [1,2]. The patient's condition also plays a big role in triggering the family's emotions. Figure 2.3 and 2.3 summarize the emotions families may experience throughout the journey.

The various emotions and personalities of family members may result in a variety of interpretations or motivations when using the product, which should be taken into account when designing.



**Figure 2.2.** Development of emotions of the family throughout the journey. The emotions are summarized from literature research [1,4,5] and interview insights. Due to differences in patient conditions and personalities of family members, the emotions in the figure are only examples to illustrate a general picture of the situation.



**Figure 2.3.** Negative emotions that may be experienced by the families with quotes from interviews and user tests. To reduce these negative emotions, one can aim to enhance relevant positive emotions through design.

## 2.3 The Needs of the Families

As the design will be targeted toward families, it is important to understand their needs, so that the design can be applied accordingly. The needs are summarized from literature review and validated during the interviews with former family members of ICU patients (see Appendix B).

### **Selection of needs**

The Critical Care Family Needs Inventory (CCFNI) developed by Molter [6] has been used in numerous medical studies. It includes the need for information, assurance, proximity, comfort and support. Burr et al. [7] indicated two other major needs: the need to protect and the need to provide reassurance and support to the patient. Furthermore, there exists also the need for control, which stems from uncertainty and helplessness, and the need for hope [1,8].

The needs for information, assurance, closeness, hope, control, and the need to support (and care for) the patient are selected to be explored further in CareTunes for Families due to their emotional and social nature, which is closely related to connectedness. These needs have also been stressed upon during the interviews with family members of former ICU patients.

Figure 2.4 summarizes a selection of needs of the families, summarized from literature [1,2,3,7,8,9].

### Links among needs and emotions

Many of the families' needs resonate with the emotions they experience as discussed in Chapter 2.2, and the different needs can also affect one another.

### (Non-medical) Information can be a source of assurance and reduces uncertainty

Although the need for information itself is regarded as a cognitive need, it is closely linked to assurance and control, as it is sought by families to reduce uncertainty [1]. However, the top information needs require medical personnel to fulfill, such as the need to know the expected outcome and how the patient is being treated. These kinds of specific information are often provided by doctors, while nurses provide general information (e.g. the care the patient receives, and the knowledge about the unit and equipment) [1,3].

## Insufficient or unclear information can raise anxiety

According to the insights gained from the interviews and user tests (see Chapter 4), once information is provided, the family would want to search for more until they feel sufficient, or else they could experience distress or anxiety.

Medical information, such as the health status and the condition of the patient, should be provided by doctors and nurses. However, non-medical information can be provided to meet the families' needs and to serve as a bridge for connection. The way to provide this information should also be cautiously designed so that it would not raise additional need for information.

## Caring interactions provide comfort and help allay fears [9]

For the families, the patient takes precedence, and caring or interacting with the patient allow them to feel that they are doing some good [1]. The caring interactions do not need to be professional; a participant from the interviews expressed that they would regularly read newspapers to their mother when she was hospitalized.



#### Figure 2.4. Needs of the families and their relationship.

\*The need for proximity in the CCFNI stresses on being physically close to the patient, while CareTunes for Families focuses on the emotional aspect of closeness.

## 2.4 Conclusion

- Offering information can reduce uncertainty. However, specific medical information should be provided by medical personnel.
- A way for the product to be easily accessible and usable in the family's daily life can be designed to reduce their sense of guilt.
- Negative emotions such as uncertainty, worry, fear of loss, guilt, shock and denial should be reduced, and the design should avoid evoking them further.
- Positive emotions such as assurance, hope, calmness, comfort, and acceptance should be enhanced.
- The design should aim to meet the need for closeness, assurance, control, hope, and the need to support.
- The design may involve active participation from the family's part to give them an opportunity to support their loved one.

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# **Chapter 3** Exploring the core of the design: Connectedness and music

This chapter explores knowledge in social connectedness and music. The goal is to be inspired on how to design to enhance connectedness and how to design with sound and music.

## 3.1 The Value of Connection and Connectedness

The project aims to increase the both connection and connectedness between the family and the patient. However, connectedness involves not only the act of connecting but also the user experience (e.g. how the family feels). Therefore, a stronger emphasis is put on "connectedness".

### What does connectedness mean?

Philips-Salimi, Haase, and Kooken [1] concluded a broad definition to "connectedness" in the patient-provider relationship from literature studies as such:

"In social relationships, connectedness is the degree to which a person perceives that he/she has a **close**, **intimate**, **meaningful and significant** relationship with another person or group of people. This perception is characterized by **positive expressions that are both received and reciprocated**, either by the person or between people, through affective and consistent social interactions."

Insights collected from the interviews and user tests (see Chapter 2, 4, and 7) also resonate with this definition. Based on this definition and the user insights, this chapter discusses the importance of connectedness for families of ICU patients and its attributes which can be enhanced in the project context.

# How does connectedness meet the families' needs?

When the family is outside the ICU, many of their needs cannot be met in the same way as when they are in the ICU with their loved one. For example, they cannot see and care for the them. In this case, enhanced connection and connectedness can be helpful in fulfilling their needs (see figure 3.1).

#### A close and caring connection

The families' social needs (see figure 2.4) -the need for closeness and the need to support -- are in line with two of the seven attributes\* of connectedness identified by Philips-Salimi et al. [1]: intimacy and caring.

*Intimacy*: A feeling of closeness or having a unique bond with another person.

*Caring*: Being affectionate towards others and experiencing warmth from them.

#### A meaningful relationship

Building connectedness is also about building "a meaningful relationship". From a practical point of view, the families tend to continue to search for meanings in every contact or piece of information related to their loved one in the ICU. This has been pointed out both in previous studies [2] and in the user tests (see Chapter 4). From a psychological point of view, the family would see more value in a new way of contact with the patient if they find it meaningful, according to the user tests (see Chapter 4).

## Consistent social interactions: staying in touch

The need for "consistent social interactions" in the above-mentioned definition is reflected in the families' need to receive up-to-date and consistent information from or about the patient.

Receiving sufficient information can also decrease the feeling of uncertainty and increase the feeling of assurance and control [2].

\*The seven attributes are: intimacy, sense of belonging, caring, empathy, respect, trust and reciprocity [1].

#### **Positive expressions**

Positivity is important in the connection between family and patient, as the perception of connectedness is characterized by positive expressions, as mentioned in the definition above. The user tests (see Chapter 4) also show that families feel more intimate and connected to the patient when their experience of the contact is more positive.

Therefore, evoking positive emotions (such as calmness, assurance, hope, acceptance, etc. as shown in figure 2.3) not only benefits the families' state of mind, but can also improve connectedness (see figure 3.1).



**Figure 3.1.** Examples on how connectedness can affect the families regarding their needs and negative emotions highlighted in this project.

## 3.2 Building Connectedness through Social Cues

A way to build connectedness is through social cues. Because the patient may not be in a fit state to communicate with the family, as they may be sedated, resting a lot, or in delirium, increasing their social presence to their family can be a way to build connectedness.

## Receiving and sending subtle social cues

The sense of feeling close to another does not necessarily have to derive from physical proximity, but can also be evoked from the social presence in one's mind [3].

Subtle social cues contribute to the social well-being and sense of social connectedness of people [4]. They include:

*Phatic cues*: Communication that serves a social function, such as a simple greeting message.

Awareness cues: Awareness systems based on the automatic communication of data, such as seeing the status of a loved one being online.

One thing to note is that, a phatic cue may not foster more feelings of connectedness if it is considered insincere and with little meaning, such as the Facebook Poke. On the other hand, sending phatic cues has a strong impact on the feeling of closeness for the sender [4].

### A spectrum of social interactions

Using a spectrum of social interactions, varying in richness, content, and level of intention in design can also add to the feeling of connectedness [4]. The interviews and user tests with the families also show that different levels of social interactions are suitable for different levels of need for connectedness, which may differ from person to person or change throughout their journey (see Chapter 4 and 7).

The social cues are later incorporated in the design of CareTunes for Families. Awareness cues in the form of patient-generated music streaming are used to create the social presence of the patient. Phatic cues are sent to the families in the form of musical messages. These will be further explained in Chapter 4 and 6.

## 3.3 The Value of Music

Music can add value to the connection between the families and patients in a unique and powerful way, and its characteristics can be embodied in the design.

# Communicating meanings and emotions at the same time

Music is a powerful way to communicate emotions and meanings; it also exerts physical and behavioral effects [5].

With the power to express meaning, it is possible to use music to pass on information about the patient to the family.

Music can also be used to enhance or reduce positive or negative emotions, or simply to regulate levels of arousal [6].

Therefore, music has the quality to fulfill the family's social needs, emotional needs, and need for information at the same time.

Details on how music communicates information and influences music are explored further in the chapter.

### A natural & familiar presentation

Some objects may have a more natural representation in sound [7]. Bly [8] stated that:

"Because perception of sound is different than visual perception, sound can offer a different intuitive view of the information it presents."

In the evaluation of CareTunes for Families (see Chapter 7), families also expressed that the use of music increases the intimacy and connectedness between them and the patient, because the image of their loved one lying in an ICU bed, or any text that represent their state, can actually feel more distant and unfamiliar than music, to which they are able to attach meanings that resonates with the personality of their loved one or their own state of mind.

## 3.4 Communicating Information with Music

Research into music communication and Sonic Interaction Design (SID) offered guidance for designing music to communicate information.

### Presenting relative information

Sound is better suited to display relative data than absolute data with high precision [7].

Therefore, if music is used to display everchanging information, it is not necessary, nor aesthetically pleasing, for the music to change precisely with every detail of the data it translates. Instead, information can be classified first before being used as input for the music.

### Freedom in interpretation

The musical communication is not only about the music providing information, but also about people interpreting the music. Factors that may affect musical communication include musical features, situations and contexts, and individual preferences and knowledge [9]. Therefore, the meaning of the music may not be fixed, but rather changeable as fluids within certain boundaries, in relation to the listener's experience [10].

This room for imagination and interpretation can have its advantages and disadvantages,

as later found in the user tests (see Chapter 4 and 7). The advantage is that it allows the listener -- or in this case, the family -- to give meanings to the music, which makes the experience more intimate as they are often based on the family's or the patient's past memories. It also allows the family to see past the image of their hospitalized loved one, which may seem distant and unfamiliar, and instead picture their state of mind or their thoughts and emotions in a more beautiful or humanized way.

The disadvantage is that the listener's individual preferences or emotions can greatly influence their perceptions of the music's meaning, making it difficult to design accurately for an intended effect using music.

One can conclude that, the strength of music communication lies in its ability to facilitate the listener to perceive information in a humanized or even spiritual way. Therefore, it is advisable that the music design in the project context takes on a more emotional approach.

## 3.5 Influencing Emotions through Music

Literature research into music therapy, music aesthetics and music theory was conducted to help develop a strategy to influence emotions through music.

### Multiple ways to induce emotion

Justin and Västfjäll [11] concluded six mechanisms through which music listening may induce emotions: (1) brain stem reflexes (e.g. arousal feelings when hearing sudden, loud, dissonant sounds) (2) evaluative conditioning (memory of music stimulus paired with other positive or negative stimuli), (3) emotional contagion, (4) visual imagery, (5) episodic memory (relating music with a past event), and (6) musical expectancy (e.g. surprise caused by changes).

The music design of CareTunes for Families focuses on emotional contagion and visual imagery. Emotional contagion is used to reduce negative emotions and evoke positive emotions of the family, and visual imagery is used to communicate the state of the patient to the family.

In addition, as "calmness" is one of the emotions to be enhanced (see Chapter 2), sudden changes in the music are avoided to prevent causing surprises or sudden emotional arousal. Instead, the transitions in music are designed to be gradual.

### **Emotional contagion**

Emotional contagion is defined by Koelsch [12] as such:

"The process by which an individual perceives an emotional expression and then copies this expression internally via mirroring processing in terms of motor expression and physiological arousal."

Examples in using music to cause emotional contagion include the use of different timbres. For example, the timbre of string instruments has a higher emotional quality due to its voice-like characteristic [6]. While the strings are able to evoke more longing, sadness and tenderness, the piano can evoke more joy [13].

### Reducing anxiety by music

Music may reduce anxiety by making people attuned to its melodies and harmonies, or project their own frozen emotions and unconscious images onto the music. The amplitude and frequency of the vibratory stimuli also evoke psychophysiological responses [14]. Lee et al. [14] concluded that the characteristics of anxiety-reducing music include:

"Simple repetitive rhythms, predictable dynamics, low pitch, slow tempos, the consonance of harmony, a lack of percussive instrumentals and vocal timbres."

However, there has been no consistent agreement on the type of music, and people's musical preferences remain one of the most important factors in the effect of music [14].

#### **Evoking positive emotions**

Musical keys and chords can convey different emotions. To enhance the positivity in the families' experience, chords associated with positive emotions or harmony, such as the sixth, seventh, added ninth chords [15,16,17] and the pentatonic scale [18] are selected for music design in the first cycle of design, and their effects on the listeners/families are evaluated in the user test. It is later found out that major keys are desirable on the whole, for the exception of the sixth chord, as its ambiguity has different effects on different people, some positive, some negative (see Chapter 4).

## **3.5 Conclusion**

### **Designing for connectedness**

- Several aspects of connectedness can be designed: enhancing intimacy and closeness, building a meaningful relationship, enabling families to stay in touch consistently.
- The design may give the family an opportunity to be more active in supporting their loved one.
- Positivity in the experience should be enhanced.
- The design can make use of social cues such as phatic cues (e.g. online messaging) and awareness cues on a spectrum of different interactions.

### **Designing with music**

- The design can classify the collected data first into a number of levels, before displaying them through music.
- The design should be cautious about the range of possible interpretations of the music by the families.
- The design can make use of emotional contagion, and involve string instruments.
- The transition that takes place when the music changes should be smooth.
- The following characteristics are suited to be included in the music: simple repetitive rhythms, predictable dynamics, low pitch, slow tempos, the consonance of harmony, and a lack of percussive instrumentals.
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# **Chapter 4** Design cycle 1: Designing the Music

Based on the insights obtained from the research stage, the first round of design ideation was carried out. The goal is to create diverging concepts and mockups to test out different possibilities in the user test that follows.

# 4.1 Design Method

The design cycle 1 is aimed for divergence. It starts with determining a design goal and interaction vision, then a series of design conceptualization methods are used, such as brainstorming and rapid prototyping. The cycle ends with the first round of user testing and analysis.

### Determining the design goal

A design goal and interaction vision were formed at the beginning of the design cycle to serve as a basis for further design development. The goal and vision are formed based on the project brief and the insights gained from the research phase.

# Brainstorming and idea merging

Research insights were clustered to generate "How Might We" questions [1] for brainstorming, such as:

How might we...

- ... provide assurance and hope?
- ... provide the feeling of intimacy?
- ... provide information through music?
- ... reduce stress/anxiety?
- ... reduce powerlessness?
- ... reduce the fear of loss?
- ... make the design appealing for families?
- ... make the design appealing for nurses?

The ideas generated from the brainstorming session were divided and merged into three diverging design concepts so that the different ideas can all be evaluated in the user tests.

## Rapid prototyping and user testing

The three design concepts were refined and went through rapid prototyping. The user experience was designed with storyboards, and the music with Garageband. In design cycle 1, more design iterations are done in the area of music design.

The three refined concepts were then tested to see which elements could be extracted to be further developed and converged in design cycle 2.

1. IDEO.org. (n.d.). How Might We. Design Kit. Retrieved July 26, 2020, from https://www.designkit.org/methods/3

# 4.2 Design Goal and Interaction Vision

A design goal is formulated at the beginning of design cycle 1, as well as an interaction vision [2] that aims to inspire the qualities of the design.

# **Design goal**

To enhance the connectedness between families and ICU patients using music, while reducing the family's negative emotions.

## Interaction vision

**Stargazing** (as illustrated in figure 4.1).

Characteristics	Affordances		
Patience	Room for imagination		
Connectedness	Ability to see the light of the stars despite the distance		
Calmness	Peaceful and consistent environment		
Acceptance	Acknowledgement of human's limitation in the vastness of the universe		



Figure 4.1. Interaction vision: stargazing.

2. Pasman, G., Boess, S., & Desmet, P. (2011). Interaction vision: expressing and identifying the qualities of user-product interactions. In DS 69: Proceedings of E&PDE 2011, the 13th International Conference on Engineering and Product Design Education, London, UK, 08.-09.09. 2011.

# 4.3 Design Concepts

At the end of the first round of design conceptualization, three concepts that contained different design elements are refined and prototyped to be tested. The playlist of the concept music can be accessed at the following link: https://soundcloud.com/chen-chou-614743749/sets/caretunes-for-families-design-cycle-1-first-user-test-music-samples/s-HZmw0AzDg4k

# Concept A: Background music for work or other activities

### Design concept

The interface is continuously **streaming website** that the family can access at any time. The music transforms the patient's **heartbeat into random harmonious notes**, and is to be listened to as a background for work or other activities.

### Music style

- Harmonious notes combined randomly using the pentatonic scale
- Plain, steady and less dynamic
- The pitch slowly changes within a small range
- Slow tempo

### **Musical features**

- Main instrument: guzheng
- Key/Chord: D / pentatonic scale (presenting harmony)
- A subtle artificial background that represents the heartbeat indistinctly







Figure 4.3. Concept A music. (The yellow line indicates the main melody of the music.)

# Concept B: Music for the mind to focus on

### Design concept

The interface is a continuously **streaming website** that can be accessed at any time. The music is generated based on the patient's heart rate, and subtly mimics the **waves of the vital signs** and the **breathing** of the patient. The music is designed for people to focus their mind on (when alone or with others). The website also includes **visuals that show the condition** of the patient in a simple way.

### Music style

- Neutral tone and tempo

- The pitch goes up and down repeatedly within a range

### **Musical features**

- Main instrument: harp and an artificial background sound that imitates the heartbeat distinctly

- Key/Chord: D6 (presenting warmth and ambiguity)



Open the APP

Play the music and listen

Check the visual information if in doubt

Figure 4.4. Concept B use scenario.



Figure 4.5. Concept B music (to be repeated once).

Figure 4.6. Concept B visual image.

# Concept C: Short message to receive and collect everyday

#### Design concept

Automated messages are sent to the family through an APP or an existing messaging APP with a short piece of music. The music puts emphasis on the **positivity or negativity of the patient's condition**. The family can choose to save the music, which is accompanied by a short animation indicating the music message being saved.

### Music style

- Higher pitch and cleaner notes (with soft background sounds)

- A more joyful tone

### **Musical features**

- Main instrument: harp

- Key/Chord: Dmaj7/9 (softness, serenity, with some steeliness)









Receive a notification

Click on the notification or open the APP to play the music message

Collect the music message each day

Figure 4.7. Concept C use scenario.



Figure 4.8. Concept C music.



**Figure 4.9.** User test mockup using an existing messaging APP

# 4.4 User Test Setup

The first round of user tests involves testing with the three concepts. The goal is to gain feedback on different aspects of the design and to come up with a design strategy for the design cycle 2.

### User test scope

The user test aims to cover the social needs, emotional needs and cognitive needs of the family. While this cycle focuses more on the design of music, different use scenarios are also incorporated into the user tests. Therefore, insights are gained regarding both aspects of the design: the user experience/context of use and the music composition.

Research questions are formulated before setting up the user test as follows:

- What is the most suitable context of use for CareTunes for Families?
- What kind of music (pitch, chord) is best suited for this experience?
- Which families' needs are satisfied and which are not, and why?
- What information do people retrieve from the music?
- What emotions are evoked through the music?
- What emotions are evoked through the interaction?
- Can visuals enhance the experience?

### Method

The user tests take place online, using online forms and video calling applications. The test lasts for one hour per session (see figure 4.10). The participants are asked to test out all three design concepts (A, B, and C), and to fill out a questionnaire and answer related questions after each concept. At the end of the session, an interview is conducted to compare the three concepts and to discuss the overall experience of the product. The user test script can be found in Appendix C.

# **Participants**

The user tests involve six young adult participants with mixed genders, including people with and without related experience. The participant details and their feedback can be found in Appendix D.



Figure 4.10. Procedure of the user test.

### **Data collection**

The data collection methods in the user test includes questionnaires and interviews. The interview questions are formulated based on the research questions, and can be found in the user test script in Appendix C. The questionnaire contains three scales, exploring different aspects of the design, and are listed as follows.

### Scale A: Connectedness and needs fulfillment

A modified AttrakDiff scale [3] (ranging from -3 to 3) is used to determine if the design has met the families' needs, and if the designed music and interface can communicate information effectively.

#### Scale B: Emotional influence (STAI-6)

The 6-item State-Trait Anxiety Inventory (STAI) scale [5] is used to evaluate if the families' negative emotions can be reduced by the design.

#### Scale C: Emotional influence (musical qualities)

Several emotional qualities of musical chords [4] which are more relevant to the project context are selected to evaluate if the designed music can achieve emotional contagion on a 7-point scale.

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# 4.5 Questionnaire Results

The results come from the survey questionnaires filled out by the participants after testing each concept. The scores are averaged. The questionnaire focuses more on the musical aspect of the concepts; however, the participants' perception of music was also affected by other elements of the concepts.

# Connectedness and needs fulfillment (Scale A)

### I feel... (to the loved one)

Disconnected - Connected Distant - Intimate Doubtful - Assured Faraway - Close Hopeless - Hopeful Passive - Active



Incomprehensible - Comprehensible Complex - Simple

Confusing - Clear

### The product is...

Unpleasant - Pleasant Repelling - Appealing



1



# Emotional influence (Scale B&C)

# I feel calm. I feel relaxed. I feel content. I feel tense. I feel upset. I feel worried.

How do you feel?



Not at all Somewhat Moderately Very much SO so

### What does the music express?



# 4.6 Insights on Music Design

The results come from the analysis of the questionnaires and the interviews. Participants one to six are quoted as P1 to P6. More detailed results can be found in Appendix D.

## The feeling of connectedness

# The feeling of connectedness is related to the pleasantness of the music

Concept C in general makes people feel more connected to their loved one. This is related to the joy and contentment it evokes through its major key and bright melody.

# Familiarity of the music style is related to the feeling of connectedness

Familiarity is important in how much people feel connected or intimate. People may feel more connected if the music style relates to their loved one or themselves. For example, some people are unaccustomed to the pentatonic scale in concept A, as it reminds them of traditional Asian music, and therefore find the experience less intimate.

P4 felt distant when listening to concept A because it felt Asian, and they were not attached to this music style. "I will feel more connected if it is the style of the patient."

P5: "I like the music [in concept C] because it feels closer to the type of music I listen to."

# Intimacy can be evoked from music with more "life"

It appears that music with more details and "up and downs" instead of being plain can better enhance the feeling of intimacy. It is possible that music with more "life" can present a person more strongly, thus increasing the feeling of intimacy.

P4 expressed that the feeling of intimacy evoked by concept B was stronger than concept A, because concept A was "calm and plain", while concept B had more elements "with buzzing and details".

## **Evoking positive emotions**

# Music combining joy and tenderness makes people feel calmer an more relaxed

A joyful piece of music (like concept C) seems to make people feel calmer and more relaxed than a slow piece of music with no strong emotions (like concept A). A piece of music that expresses tenderness (like concept A) can make people feel calm and relaxed, but more so if people find the music "happy-flavored". P3: "I like the music, because of the slow tempo, which is good for relaxing. [...] It is happy flavored, and not boring and slow for sleep."

P1: "[Concept C] is pleasant and appealing [...]. It seems to involve more joy, but not energetic, in a good way."

### Sinister feelings can be evoked by the six chord, low background noise, and instability in the melody

The music in concept B is considered to express sadness strongly, and makes people feel more tense, worried, doubtful, and hopeless. This may be due to:

(1) the use of the sixth chord, which has the nature of ambiguity,

(2) a low "noise" in the background,

(3) less stable melody.

P6: "I feel doubtful because there is a low buzz which feels sinister, like something bad is going to happen."

P3: "The music is not stable. I feel 'something is about to happen.' "

#### Heavier sounds can evoke insecurity

Although no percussion instrument was used in the composition of the music samples, sounds that send out a stronger beat can still make people uneasy (see also Chapter 7).

P5: "It felt insecure during a certain sound when it felt like a punctuation."

The tenderness in music may not be enough to make the families feel connected and relaxed; the music should also express joy subtly, and brighter and softer melodies with more details are preferred. The music should also be universal.

### **Communicating meanings**

# Sounds similar to heartbeats can arouse worry

Presenting the heartbeat of the patient directly through the tempo of the music can make people worry about changes in the patient's condition. For example, the background sound of concept B arouses doubts and anxiety when people interpret it as heartbeat. P5: "I feel doubtful and worried because of the echo [in concept B] which sometimes stays longer, so I will wonder what happened."

### Families might relate the music to the consciousness and movements of the patient

Music that has more ups and downs (as in concept B) can give people the image that the patient is conscious or moving, while music that is plainer (as in concept A) can be interpreted that the patient is sleeping.

P4: "The patient [in concept B] might be conscious. They are active and moving around, and awake, while [concept A] feels like sleeping.

# Music with more dimensions brings more life to the representation of the patient

The music in concept B has more ups and downs as it mimics breathing, and it has more layers. This can expand the room of imagination and can bring more life into the representation of the patient.

P2: "[Concept A] feels more linear, and [concept B] feels like a flower blossoming.

It feels more dynamic, more playful and vivid. More images jump out."

#### Complexity can evoke confusion

Music with more layers or elements (as in concept B) can evoke confusion as the listener try to interpret it due to its complexity.

P4: "[Concept B] feels complex because there are more elements, so it feels more confusing."

### Families may find the music more meaningful when related to the patient's emotions

People find it meaningful when the music is related to emotions, instead of a way to monitor the patient, which can make the families tense and worried.

The music should not become a way to monitor the patient, such as using the tempo to represent heartbeat. Instead, it can present the patient's consciousness, emotions, and/or movements, with music that has more dimensions and therefore more life.

# 4.7 Insights on Experience Design

The results come from the interviews of the user test. Participants one to six are quoted as P1 to P6. More detailed results can be found in Appendix D.

# **Context of use**

#### Music streaming as background music

Some people find that listening to CareTunes for Families as background music of their daily activities enables them to continue their lives uninterrupted while feeling more assured. However, others find it distracting because they would want to focus on the music in order to stay vigilant.

P5: "I was focusing on my things and [the music] makes me want to turn back."

The desire to listen to CareTunes for Families as background music is also related to the pleasantness of the music.

P1: "[Concept A] is more pleasant and [therefore] useful because I can experience it more in my life."

#### Music streaming for the mind to focus on

If the music is not comforting, focusing on the music for a long time may create more worries as people concentrate their entire mind on the situation. P1: "By focusing on the music [in concept B] itself, it is all I have in my mind. It was one full minute thinking about that situation, so I feel connected but worried. However, if it is as relaxing as [concept A], it would be easier to focus on."

### Music in the form of a message

A music message may reduce uncertainty as it presents the moment and does not concern the future.

P6: "It is clear because it is now presenting a moment, so there is no doubt of 'Is it going to change?' It is given to me so it is what it is. [...] I was able to accept the situation. There is a beginning and an end."

There is no significant difference in people's feelings between the two contexts of music streaming: listening to it as a background or focusing on it. What matters most is the pleasantness and the meaning of the music. It appears that, when participants are told that the music translates the patient's "vital signs", the meaning of the music becomes worrisome.

# Preference for streaming or messaging can change throughout the journey

The family's preference between streaming and regular messaging can change throughout the patient's stay in the ICU, depending on the patient's condition and the family's state of mind.

P2 expressed that they would want more messages right after the patient's admission to the ICU, but not so much after the stay becomes long-term, because then they will feel more alright. "Maybe I can request it to be a message or continuous music. I want to have control."

### Messaging creates distinct touchpoints

A message may create a more distinct touchpoint than a streaming website, and may even be regarded as a reminder to check in on the patient. People may also want to share the music with other family members.

P3: "Live streaming is nice, but I will not stream the whole day. Maybe I can receive [the message] at lunchtime when I am free, so that I would have the time to put my attention in it, because it is important to know how they are doing."

#### Intimacy can be evoked by receiving messages on phone

Receiving the music on the phone can enhance the feeling of intimacy due to its portability, and even more so when people need to hold the phone close to their ears to listen.

P3: "I like the idea of receiving in my phone. A phone is something I can just have with me."

P6: "I definitely feel more intimate because I was holding my phone to my ear, so it feels like the message is really for me."

Music streaming and messaging both has their qualities. However, people might be more in touch with the messaging service.

# Connectedness and the families' needs

#### Intimacy can be evoked from personal messages

Receiving personal messages (in messaging applications), enhances the feeling of intimacy as they are directed to the receiver.

P3 felt intimacy because as they opened their phone, they saw "there is an automated message to 'me'."

P2 felt messaging was a "more direct way of interacting with the person."

#### Continuous music as a continuous presence

Continuous music may enhance the feeling of presence of a loved one.

P2 expressed that the continuous stream of music was like a representative of their loved one, enabling them to feel them.

# Music creates stronger feeling of closeness without added visual information

Visuals elements indicating the condition of the patient may create the feeling of distance, while music itself creates the feeling of closeness.

P6: "[The visual] was not so personal, but more technical, like checking the status light of the central heating system. [...] The visual helps me to detach as it is turning the person into a 'number', while [the music] is completely about the feelings."

# Doubt about own interpretation of music generates additional need for assurance and control

People may have doubts about their own interpretation of the music, creating uncertainty, and may continue searching for cues or information to ensure themselves.

P2: "I keep wondering how it works. It would be nice to know so that I would trust it more." "I have nothing to compare with. I want information to know what to expect: what means 'bad'." People would also continue to search for meanings in the music.

P6: "When a new sound appears, I wonder what it means."

#### People may worry that something bad could happen when listening to the streaming of the loved one's condition

When people relate the music to the (medical) condition of their loved one, they can become worried and want to continue to listen in order to maintain vigilance, especially if the music is live-streaming.

P3 was worried that if the heartbeat slows down, the music would change.

P4 had doubts and concern when listening to auto-generated music as they expected something to happen.

As the meaning of music depends heavily on the interpretation of the listener, it seems unsuitable to provide information that hints at the condition of the patient or any other information that may cause the family to doubt themselves. In addition, technical information can remind the family of the uncertainty of the situation, creating the feeling of distance and the need for more assurance. On the contrast, music is suitable at presenting feelings and transferring the presence of a loved one, fulfilling the families' need for closeness and assurance.

#### A need for caring actions

Being sent a message can make people feel more passive, and the ability to save the music does not make people feel more active, either. Many feel the need to be more involved or giving, such as sending encouragement or their own music. However, people may only feel the need to send back the message if there is someone to respond to it.

P4 found [the messaging service in C] more interactive, and expected that they can send something back.

A way to send back a certain form of message that can be received by the patient can be designed to fulfill the family's need to support.

# 4.8 Conclusion

## About the generation of music

- Positivity in the chords can be more powerful than tenderness in meeting people's emotional needs and enhancing connectedness.
- Music with more details may enhance the feeling of intimacy, paint a fuller picture of the patient, and present more "life".
- The way of presenting the patient (through vital signs) should be more subtle.
- Familiarity in music is important for the feeling of connectedness and intimacy, so the style music should be more universal.
- Compared to seeing the music as a channel to present the vital signs of the patient, families are not as worried when they interpret the music as a way to show the consciousness, emotion, or movement of the patient.

### About the context of use

- Personal messages can be an important channel for the design.
- Whether the music is suitable for being a background or not depends more heavily on personal preferences, so it can be left free for the families to decide how they want to listen to it.
- The family's preference between streaming and messaging can change throughout the patient's stay in the ICU, depending on their condition. Therefore, both can be an option for the families to choose.

### About the families' needs

- Music streaming can evoke a sense of presence of the patient.
- People feel the need to take action in the process, which could be achieved by allowing them to reply the message in a meaningful way.
- Visual information is unnecessary.
- The design should avoid giving hints on the patient's medical condition to eliminate their doubts and worries.



# **Chapter 5** Design cycle 2: Designing the service

The design cycle 2 started with ideating with the insights obtained from the user test. The design concept went through three small round of iterations, being optimized each time with inspirations from an interview with expert.

# 5.1 Design Method and Iterative Process

The design cycle 2 is aimed for convergence and concept refinement. It started with determining the design strategy, then went through several rounds of iterations, inspired by interviews with experts.

### Determining the design strategy

From the insights obtained from design cycle 1, a few design directions are determined as a starting point for design cycle 2 as follows.

# Having both streaming and messaging options

The service of music streaming and messaging will both be included in the design.

#### Sending personal music messages

An automated messenger will be one of the main features in the design.

# Presenting the patient with music in a more humanized way

New data sources for generating the music will be included, and the music will present the patient in a more humanized way (e.g. showing if they are sleeping or awake, if they are moving, etc.), instead of in a technical way (e.g. directly presenting the vital signs).

# Enabling the families to send back messages to be received by their loved one:

The families will have the option to send back messages, such as voice recordings.

# **Expert interviewing & Iterations**

In design cycle 2, more design iterations are done in the area service and experience design. A big part of the iterations is based on the interview results with experts in the medical field and the design end-of-life field. The iterative process is shown in figure 5.1.

The music is also redesigned, and evaluated together with the user experience at the end of design cycle 2 (see Chapter 7).





# 5.2 Early Ideas of Design Cycle 2

The ideas focused on designing the form of the product-service system, finding a way to stream the music without evoking worries, and presenting the patient in an ideal way.

### A chatbot as the main interface

An APP with a chatbot (see figure 5.2) as the main interface was designed for the families to receive music messages. The music messages were designed as phatic social cues (see Chapter 3) to enhance the connectedness between families and patients.

#### Sending back voice messages

The family can use the chatbot to send voice messages to their loved one, similar to how people send voice messages via common messaging APPs.

#### Indicating end of the service

After the nurse informs the family about the discharge, transfer or death of the patient, the APP stops updating, the music streaming stops, and its functions are disabled. The chatbot also sends a message indicating the end of the service. Meanwhile, the family can still access the message history, if they want to listen to the music messages again.

This way of ending the service was later found to be quite abrupt and not meeting the families' emotions and needs, and was therefore redesigned.

### **Delayed music streaming**

To reduce families' worries and fear of loss when listening to the live-streaming of the music, the music was designed to be delayed for a period of time before broadcasting to the families, so if there is any news regarding changes in the patient's condition, the family would hear from the medical personnel first, before hearing changes in the music.

One possibility is to update the music in the APP's playlist at regular intervals (e.g. every three hours), and each piece of music will only be added to the playlist once it is completed (as shown in figure 5.3). If the condition of a patient becomes alarmingly critical and the data become significantly irregular, the nurses will have the power to halt the generation of music in process, and contact the family first.







Figure 5.3. Mockup of the music playlist.

It was later found out during the interviews with experts that families would not want to have the music delayed. Therefore, this idea was discarded, and the focus was shifted to how up-to-date information can be provided without evoking negative feelings.

### Multi-track music composition

Multiple tracks of music or sounds generated from different data sources were combined together to compose a representation of the patient (as shown in figure 5.4). This representation illustrates the state of the patient not in a medical way, but more as a human-being, as the heart rate data no longer dominates the melody and tempo of the music, but presents the changes in the patient's emotions or movements in a subtle way using added tracks. Beside the internal state, the external environment the patient is in is also presented, including the time of day and the weather. The music tracks are automatically generated in the same major key, and the environmental sounds are ready-made.

A flaw in the design is that the music tracks sounded quite random as the tunes were automatically generated, and their meanings were not very clear to the listener. Therefore, the music composition was further designed.

The environmental sounds representing the weather and time of day were later replaced with other data sources because of their relatively weak relevance to the state of the patient. For example, the sleeping pattern of an ICU patient may not follow the time of day like common people.



**Figure 5.4.** Example of the music and the data sources of the tracks. The music can be accessed at the following link: <u>https://soundcloud.com/chen-chou-614743749/caretunes-for-families-design-cycle-2-early-ideas-music-sample/s-6Sy4RsVvueL</u>

# 5.3 Insights from the Nurse's Perspective

An interview with a former ICU nurse was carried out after design iteration 2.1. The interviewee gave their opinion on the design concept at that time, and provided knowledges of the ICU system in the Netherlands. The quotes are written between quotation marks.

### Information to present

### Selection of vital signs

Showing the family many parameters of the vital signs in the music is unnecessary, as it could be: (1) complicated for the family to understand, (2) confusing as different parameters may change in different directions.

In addition, it is important to consider the characteristics of the parameters when designing. For example, heart rate is the most volatile, and blood pressure is more stable.

#### Possible data sources

Possible data sources to generate the music that can be obtained in the ICU include:

- Voices and sounds in the room as long as they are not alarming.

- Brain waves.
- Movements (e.g. twitches in sleep).

- Vital signs (e.g. heart rate, blood pressure, oxygen saturation).

- etc.

Combining several vital signs to present the patient is not necessary nor practical. Instead, data such as brain waves can be used to present the patient's consciousness and sleep stages. Unalarming environmental sounds of the ICU can also be an addition to consider.

## Delivery of the music

#### Delay of the music may not be appreciated

Delaying the streaming of the music may not be an appropriate way to avoid arousing fear of loss, because receiving real-time information is a priority for the families.

#### Music messages can offer great comfort

Even short music messages would already offer great comfort to the families, as *"it is much more than they have now"*, especially during the coronavirus crisis, where many families cannot visit the patient and the communication between hospital and family depends on video calls.

### End of the journey

If the patient is going to be transferred, the family will usually be informed directly when they are visiting, but in some cases, they might arrive at the ICU and be told to go to another ward. If the patient's situation becomes critical, the families will normally be informed directly and asked to go to the ICU quickly, but if the patient is to be resuscitated, the process might take quite some time, even all day.

Many different scenarios may happen at the end of the ICU journey, and in different orders. Therefore, the end-of-service design should aim to be universally applicable.

### Sending back voice messages

For the patients, it is not certain yet if the family's voice can be heard by a sedated person, but sometimes there is a clear response. However, for the families, merely talking to the patient would already be comforting. "It would be very comforting for the family and the patient, especially the family."

# 5.4 Insights from the End-of-Life Perspective

An interview with Dr. Marieke Sonneveld, an expert and professor in design for end-of-life, was carried out after iteration 2.2. Although only a part of the ICU patients ends in death in the ICU, it is still important to consider the scenario.

### **Prolonged existence**

To the families, the patients do not just disappear and leave their lives when they pass away. Firstly, social death\* can happen after physical death. For example, to many families, the patient only passes away after the medical personnel informs them so. Secondly, the families would need to go through a transition before accepting the death of their loved one, and stopping the music directly after the patient passes away or after the family is informed of the patient's death can be too harsh and abrupt.

As the project's target group is the families, and as the project focuses building connection rather than passing on technical information, it would be more appropriate for the design to face end-of-life situations from the perspective of social death instead of physical death. It is therefore decided in later design that the service and the connection it builds should be ended according to the families' state of mind, instead of the physical death of the patient.

### Overcoming the fear of loss

The early ideas of cycle 2 include delaying the streaming of the music to avoid the families' fear of loss. However, this reduces the value of streaming as the patient's sense of presence might be lost. In addition, it does not fundamentally solve the problem because it can be challenged by the complexity of the different end-of-life situations. Therefore, the music streaming would be of most value to the family if it is live.

The music streaming should remain live, while other solutions should be found to reduce the families' worries and fear of loss.

### A need for closure and a ritual

The family needs to have a sense of closure (on a spiritual level) when the patient passes away. Usually, this involves some kind of gesture or ritual, such as saying "goodbye" or "thank you". The design should be sensitive and modest in this situation, as it is very personal.

A possible design that respects this personal situation and meets the families' need for closure is to let the families take control in ending the service.

\*The term "social death" is used to describe "the ways in which someone is treated as if they were dead or non-existent". It can happen before and after physical death, and is related to the loss of social connectedness [1].

<sup>1.</sup> Borgstrom, E. (2017). Social death. QJM: An International Journal of Medicine, 110(1), 5-7.

# 5.5 Design Changes after Iterations

At the end of design cycle 2, while some early ideas were kept and developed, a few major changes also took place in both service and music design in iteration 2.3. The complete final design is explained in Chapter 6.

### Chatbot and live streaming

The chatbot service is kept to send and receive music messages and voice messages, while another interface is designed to access live-streaming of the music.

### New data and new description

Data such as heart rate, brain waves, and unalarming environmental sounds are included in the new design. The patient's mind activities, emotions and movements are presented in the music, and the description of the music is refined: the families will no longer be informed that the music presents the "vital signs" of their loved one.

### The patient's theme

a new music track is added to the music composition as the core of the music: the theme of the patient. The theme of the patient is a ready-made melody that represents the patient themselves; it can be regarded as their spirit or their identity. The music will now be generated based on the theme/spirit/identity of the patient, and change according to their mind and movement, more similar to how people perceive fellow human-beings.

This theme is expected to (1) give more meaning to the music by symbolizing the patient as the tune can be recognized by the families\*, (2) enhance the connectedness between families and patients by creating a unique and intimate bond, and (3) to be in line with the families' state of mind as the theme will continue to play on even if the other data sources are cut off, like the patient's existence in their heart.

### A final ritual and closure

#### Taking initiative to end the service

The power to end the streaming service is given to the family. After the data from monitoring devices are cut off, the theme of the patient would continue to be streamed, until the family decides to end the music as a ritual for closure.

### A retrospective music piece

As the family ends the streaming, the APP will create a mashup of music pieces selected throughout the patient's stay in the ICU for the family to take away.

\*Desmet [2] listed six sources of how emotions can be evoked in human-product interactions. One of the sources is the "meaning" of the object, and it involves evoking emotions about the user's loved one. In this case, the product can become a symbol of the loved one.

<sup>2.</sup> Desmet, P. M. (2012). Faces of product pleasure: 25 positive emotions in human-product interactions. International Journal of design, 6(2).



# Chapter 6 Final design

This chapter explains the final design of CareTunes for Families after the two design cycles. The final design is a product-service system that connects ICU patients and families by translating the patient's monitored data through music. It includes service design, user experience design, and music design.

# 6.1 Core Values and Main Features

The core values guide the direction of the design, and are embodied in both user experience and music design, as can be seen in the main features.



# A meaningful connection

# Providing meaningful information through music

CareTunes for Families transfers the patient's mind activities and emotions to the family through music, which changes accordingly. These are not medical information that may evoke uncertainty, worry, or the feeling of distance, but information that brings meaning into human interactions, and that the family would care about.

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}		

### An intimate experience

### The theme of the patient

The theme melody of the patient lies in the core of the generated music. It enhances the intimacy of this music connection by symbolizing the patient and hence creating a unique bond between them and the family.

### Personal messages and portal

Pieces of music are sent as personal messages by an automated messenger to the family. The music streaming can also be listened to from an APP on the family's phone. The entire experience is kept personal between the family and the patient.

### A continuous connection

#### Live-streaming music

The sense of presence of the patient is enhanced by the live-streaming music, bringing the patient closer to the family. The streaming can also be seen as a social awareness cue: the family would know that the music -- and hence the presence of their loved one -- is always there, within reach.

#### Music that goes on

Like their presence in the family's heart, the patient's theme melody will continue to play on, regardless of the result of the treatment, until the family decides to end the service.



### Enhanced assurance & control

#### **Regular music messages**

Music messages are sent regularly each day, according to the family's preferences. This can, on the one hand, bring a sense of certainty into the uncertain situation and hence a sense of control, and, on the other hand, increase the feeling of assurance as the family can "check on" their loved one regularly, which can also reduce the sense of guilt. In addition, the messages can be seen as a social phatic cue, increasing social connectedness.



### **Positive emotions**

#### Calmness, hope, acceptance, connectedness

The music is calming, soothing, and evokes the feeling of hope and acceptance. This can not only reduce the family's negative emotions such as uncertainty and worry, but also increase the feeling of connectedness.

In addition, due to how the music is generated, the music will not show dissonance or become alarming if the data becomes unstable.

At the end of the patient's stay in the ICU, the family takes the initiative to end the service and receives a retrospective piece of music, creating a sense of closure and acceptance when facing discharge, transfer, or death.

## A way to support

#### Sending voice messages

Making use of this new channel of connection, CareTunes for Families allows families to send voice messages to the patient, and provides suggestions that encourage positive talks. The family can fulfill their need to support the patient, while feeling comforted themselves, and it is also possible that the patient can hear the message and find it comforting.

# 6.2 Service Design and User Journey

The service blueprint (see figure 6.1) shows the customer journey together with the interactions among stakeholders and services relevant to the design. Details will be explained further in the chapter.

### **User journey**

#### Product introduction and gaining access

CareTunes for Families is introduced to the family at the beginning of the patient's admission to the ICU, together with other information provided by the nurse. Upon the family's agreement, the patient's monitored data is transferred to the cloud, and connected to an individual account. The family is provided with the login credentials, and is then able to access the music generated by the patient through this account using the CareTunes for Families APP as a portal.

#### First use

After downloading the APP and logging in, the family can follow a short tutorial of the product. The tutorial explains how the music is generated, and guides the family through their first use of the product, as well as initial settings such as how the patient is referred. The tutorial is facilitated by the CareTunes Messenger chatbot.

#### Everyday use

The patient's data is continuously transferred to the cloud and generates music that is sent to the family. Throughout the patient's stay in the ICU, the family is free to receive music messages at their preferred times every day, to access the live-streaming music, and to send voice messages to the patient.

#### End of use and after

At the end of the patient's stay in the ICU, meaning they might be discharged, transferred, or dead, the patient's monitored data would be cut off (while the theme melody remains). The APP would stop sending and receiving messages, and would kindly ask the family if they wish to end the music streaming, which is up to the faily to decide.

Once the family ends the music, the APP would generate a small piece of retrospective music piece which is a music mashup from the highlights of the journey. The family can access this piece of music as well as the previous music messages after the service ends. For example, they can share it with their recovered loved one.

## **Stakeholder interactions**

### Family - Patient

The family could listen to the music generated by the patient's monitored data through the cloud, and send back voice messages.

The interaction between the family and the patient inside the hospital during visiting times is not included in the design scope.

#### **Nurse - Family**

CareTunes for Families aims to involve actions from the nurses in the service as little as possible to avoid increasing their workloads. Therefore, the main touchpoints of CareTunes for Families for the nurses are the introduction of the product at the beginning of the journey and the stopping of the messaging service at the end of use.

#### **Nurse - Patient**

If the family sends a voice message to the patient, the nurse would be best positioned to play it to the patient. However, this concept has not yet been validated in user research.

### Data transfer

The data generated from the monitoring devices are sent to the cloud and the music generation is processed there. It keeps the streaming of the music, processes the messages, and generates a retrospective piece of music at the end of the service.



Figure 6.1. Service blueprint including user journey.

	Everyday use			End of use		>	After the end of use
		  ₫ゥ 			0	4	
	Music Messages: The family can receive music messages at set times.	<b>Music Streaming:</b> The family can listen to the live streaming of the music.	Sending Voice Messages: The family can send or reply with voice messages.	The theme remains but the variations stop, the messaging service stops, and the APP asks the family if they want to stop the music.	The family decides to stop the music.	The APP generates a retrospective piece of music.	The family can still access the message history.
-			The nurse plays the voice messages to the patient if needed.	The nurse informs the family about the discharge, transfer or death of the patient, and stops the messaging service.			
· · · · · · · · · · · · · · · · · · ·	The patient can be active ing on their condition.	e or sedated depend-	The patient can listen to the voice messages.	The patient is discharged, transferred or passes away.			
rar	nslates them into music, wh	iich is sent to the APP.		The cloud stops translating the data into musical variations and alerts the nurse to stop the messaging service.			
:0	the cloud.			The monitoring devices stop sending data.			

# 6.3 User Experience Design and Scenarios

The design of the user experience includes the start of use, everyday use (including messaging, streaming, sending messages), and the end of use.

## First use of the APP

The CareTunes Messenger leads the family through a simple tutorial and explanation of the product, and initial settings.

# Explanation with simple but clear wording to avoid unnecessary worries

The CareTunes Messenger first explains how the music is generated, stating that it is generated based on the patient's theme, and changes according to their mind activities, emotions, and movements, and pointing out explicitly that the music does not represent any medical information.

### Enhancing intimacy with familiar name

In the first use, the CareTunes Messenger asks the family if they want to change how the patient is called in further messages, to give the family an opportunity to personalize the experience and to increase intimacy. A message is sent first to serve as a demonstration of how future messages will look like, so that the family can know how they want to change the way the patient is called.




### **Receiving messages daily**

Each CareTunes message will last for 20 to 30 seconds, and is captured from the streaming music 30 seconds prior to sending the message, cut according to the beginning and end of the bar.

The CareTunes messages are sent three times a day by default during break times (breakfast, lunch and dinner time), to offer assurance as well as avoid disturbance. However, the family can set the time to their preferences.

The music is referred to as "Tunes".

#### Enhancing intimacy and social connectedness with personal messages

The message is designed to be sent like a personal message, increasing the feeling of intimacy and social connectedness as it is similar to a phatic cue.



Figure 6.3. Receiving a message.

#### **Music streaming**

The music is streamed live, and can be accessed anytime.

The streaming is easy to access and simple to use. The focus of the product is on the audio, so the visuals are designed to be as simple as possible to avoid distraction.

#### Enhancing connection by symbolization

The picture can be changed to a picture of the patient to increase intimacy and the feeling of social connection.



Figure 6.4. Listening to streaming.

### Sending voice messages

The family can send a voice message using the CareTunes messenger by simply clicking on the recording button.

#### Facilitating positive support and encouragement

The messenger will give some suggestions to the family about what they can say in order to support the patient in a positive way, such as sharing happy memories [1].



1. Visiting a patient in the ICU. (n.d.). The Australian & New Zealand Intensive Care Foundation. Retrieved August 9, 2020, from https://www.intensivecarefoundation. org.au/visiting-a-patient-in-the-icu/



#### End of use

The music will not entirely stop when the patient is discharged or passes away. The theme of the patient will continue to play, while the variations stop.

#### The sense of control and acceptance

The family can stop the music when they feel ready, instead of being surprised by an abrupt stop. A retrospective piece of music -- an approximately three-minute\* music mashup of the highlights throughout the journey -- will be generated to serve as a memory for the family and to bring a sense of closure.

#### Continued connectedness after end of use

Families can still access previous musical messages. Patients who are discharged and sent home can also listen to their own music.



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\*The length of the music is similar to the average length of a modern-day song.

Figure 6.6. A choice to end the music and the generation of a retrospective piece of music.

# 6.4 Music Design

The music design includes the generation and composition of the music, and principles that the automatic generation system follows.

### **Characteristics**

#### **Abstract expressions**

Due to the limitations of technology in deriving higher levels of meanings from the monitored data (e.g. thoughts and emotions), and the needed room for interpretation of the music by the families, the music is designed to express meanings in a more abstract way.

#### Major key and soothing style

The music is composed in major keys to ensure positivity remains in the experience.

The style of the music is soothing and it aims to evoke calmness, assurance and peace of mind. The tempo is relatively slow, the theme is repetitive, the melody is light, the dynamics are stable, dissonance is avoided, and no heavy percussion instruments are used.

#### **Smooth transition**

The transition between different parts of the music is gradual and smooth. Tracks are added or removed by slowly fading in and out.

### Composition

#### Theme melody of the patient

A list of themes is composed beforehand and stored in the database. Upon the patient's admission, they will be connected to a theme melody, which will represent the patient and serve as a basis for future music generation. It is repeated throughout the patient's stay in the ICU.

It is later found out in the user evaluation that the family might want to select the theme, so that the patient can be better represented, as it serves as a symbol of the patient.

#### Layering multiple tracks

Multiple tracks are layered upon the theme to represent the mind activities, emotions or emotional arousals, and movements of the patient, creating variations in the music, as shown in figure 6.7. Data generated from the monitoring devices in the ICU determines which track is added or how the music changes, according to the data mapping principles shown in table 6.1. All the variations will fall into the same key of the theme.

#### **Background layers**

Background layers are added to make the music sound fuller. Two of the background tracks are automatically generated to give the music more diversity, so as to enhance the feeling that the music is progressing together with the patient. They consist of random notes from a major chord within an octave of a lower pitch than the main melody. For example, if the key is D major, the notes could be randomly selected from D2, F#2, A2, and D3.

#### Future possibility: environmental sounds

An additional track of unalarming environmental sounds of the ICU can be added to the music according to the family's preference. Nevertheless, how to select and adjust the ICU environmental sounds requires additional study that is outside the scope of this project. Therefore, environmental sounds are not added to the final design.

However, the sound of people talking in the hospital are included in the user evaluation as environmental sounds to provide certain insights in this area.

#### **Data Mapping**

#### Selection of data sources

The data sources are selected according to information would better increase the sense of connectedness, and what the families would be likely to interpret or imagine, according to the first user test results in Chapter 4. This information includes the patient's emotions, state of consciousness, and activities. Therefore, heart rate, brain waves, and movements serve as data sources for the music variations [1,2,3].

Heart rate and brain waves are data that are on a spectrum. For example, a normal resting heart rate for adults ranges from 60 to 100 beats per minute (though some ICU patient's heart rate can be higher due to increased metabolic rate [4]), and brainwaves are defined by electroencephalography (EEG) frequency: alpha wave (8-13Hz), theta wave (3-7Hz), etc. [2] Therefore, they are divided into levels when being presented in the music.

#### A mixture of meanings

Although the data sources are separate, they usually affect one another, often in a complex manner, and cannot be distinctly separated to represent respective meanings. For example, when a person starts exercising, their heart rate and movements would increase. Nevertheless, an increase in heart rate does not necessarily mean a person is exercising; it can also signify and emotional arousal such as stress or excitement, as hear rate. Heart rate and brain waves also change according to a person falling asleep or waking up.

#### **Limitations and alternatives**

While heart rate is always monitored, continuous EEG monitoring is yet uncommon and still being developed in the context of ICU [5]. Motion sensors are not a standard equipment in the ICU, either. Nevertheless, this project included these data sources as a design vision for the ideal situation. If it is to be implemented without EEG and motion monitoring devices, alternatives can be considered, such as using heart rate to present the state of consciousness and physical activities. However, this may not have the same effect as using brain waves, because families might relate thoughts and emotions more to the brain, and regard the heart to have a more "biological" meaning, according to the user evaluation (see Chapter 7). It is also possible to eliminate the presentation of physical activities and focus on presenting psychological activities.

Meanwhile, this also points to one of the advantages of having multiple tracks of music in the design: it allows different ICUs to customize the music according to their resources and expertise.

#### **Principles**

The data derived from the monitoring devices should not be constantly changing to avoid evoking the feeling of instability and hence uncertainty. Therefore, the data is updated at regular intervals (e.g. every five minutes).

In addition, if any track is to be added or removed from the music, it needs to follow the bars of the music and wait for the right moment to come in.

Data source	Meaning	Levels	Track	Characteristics	Variations
Pre-composed theme melodies	Symbol/Spirit of the patient	-	Track A	Stable melody, neutral pitch and tempo	Personalized choice from a list
Heart rate	Emotions, sleep and wakefulness, physical activities, etc [1,4].	Divided into 3 levels from minimum to maximum	Track B	Quicker and more diverse notes	An added track with 3 levels of loudness
Brain waves (EEG)	Mind/Psychological activites and state of consciousness	Beta waves: alert wakefulness Alpha waves: relaxed wakefulness Theta waves: drowsiness, light sleep Delta waves: deep sleep [2,3]	All music tracks	-	4 levels of pitch/key and tempo
Motion sensor / Heart rate	Physical activities	-	Track C1, C2	Crisp sounds with or- naments	Added when triggered
Pre-composed and au- tomatically generated background music	Background	-	Track D1, D2, D3	Low pitch, slow tempo, soft and quiet	Following the theme
Pre-recorded nature sounds (e.g. bird sounds)	Relaxed wakefulness	-	Track E	Lively, soft	Added when triggered by alpha brain waves

 Table 6.1. Possibilities of the data-mapping in the design.



**Figure 6.7.** The multiple tracks that build the music together. The tracks are marked according to table 6.1. The music can be accessed at the following link: https://soundcloud.com/chen-chou-614743749/caretunes-for-families-final-design-music-sample/s-59pV7veOp45

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# Chapter 7 Design evaluation

The final design is evaluated in a second round of user test. The user evaluation validates if the design meets the design goal and the needs of the families, and provides knowledge on how the families may use the product in real life.

# 7.1 User Test Setup

The second round of user tests involves testing both the service and music aspect of the final design. The goal is to evaluate the final design and to provide future recommendations.

### User test scope

The user test aims to cover the connection between the family and the patient, the needs of the family, the user experience and context of use, and the music design.

Research questions are formulated before setting up the user test as follows:

#### Building connection and meeting the needs:

- Does the design enhance connectedness between families and patients?
- Does the design reduce the feeling uncertainty?
- Does the design increase the feeling of intimacy?
- Does the design enhance positive emotions (e.g. assurance, hope, calmness)?
- Can the family use the product without additional worry or fear (of loss)?

#### Context of use:

- When will the family listen to the streaming? How long would they listen to it?
- When is the best time to send a message?

#### Music design:

- Can the music express what it is meant to express? How does the family interpret the music?
- Should the music include environmental sounds?
- Does the music enhance positive emotions (e.g. assurance, hope, calmness)?
- How does the family feel about the end of the service?

### Method

The user tests take place online, using online forms and video calling applications. The research is divided into two interview sessions (see figure 7.1).

### First session: music design and meeting the needs

The first session focuses on music design and meeting the needs. It lasts for 45 minutes, including an introduction, the first part of user test, and instructions for the second part of user test. In the first part of user test, the participants are asked to listen to four 30-second pieces of music, and after each piece of music they are asked to answer a short questionnaire and a few interview questions. The questionnaire consists of a simple scoring system for the participants to rate their emotions on a bipolar seven-point scale. The interview questions that follow provides understanding on the reason behind the scoring and the participant's interpretation of the music.

#### Testing the prototype for 2-3 days

At the end of the first session, the participants are introduced with the prototype that involves user interaction in real-life context. They are asked to role-play and test out the prototype in the following 48 hours, during which they will receive several 30-second music messages and are able to request access to the live-streaming if they want to.

#### Second session: context of use and meeting the needs

The second session focuses on the context of use and meeting the families' needs. In a semi-structured interview, the participants answer questions about their experience in using the prototype. The user test script can be found in Appendix E.

#### **Participants**

The user tests involve two young adult participants, who have formerly been a close family member of an ICU patient\*.

Because there exist potential risks to evoke emotional stress and negative memories of the participants during the study, precautions are taken to protect them. The participants are informed of the potential risks at the beginning of the study, and are ensured that they can refuse to answer any question and/or withdraw from the research at any time, without having to give a reason. The researcher also pays extra attention to the participants' mental state and emotions.

### **Data collection**

The data collection methods in the user test includes questionnaires and interviews. The interview questions are formulated based on the research questions, and the questionnaire contains a modified AttrakDiff scale (ranging from -3 to 3) that evaluates if the design is able to meet the families' needs.



Figure 7.1. Procedure of the user test.

\*One of the participants' family member was in the hospice at the time of the user test.

# 7.2 Music for Testing

Four music samples were created for the user test to evaluate the effect of the music style and composition method. The participants tested the samples in different orders.

#### **Music samples**

The music samples derive from the music in the final design. They are variations of the same piece of music, meaning they are generated by the same patient, showing their different states. To reduce the variables and distractions in the user test, the music composition is simplified, by using track B to present a general arousal of mind and emotional activeness of the patient.

#### Description of the music samples

Music A shows the patient when they are awake, with no physical activities.

Music B shows the patient asleep with some small movements.

Music C shows the transition when the patient wakes up, where track B slowly fades in.

Music D is added to preliminarily test the effect of including environmental sounds in the music. Real sounds in the ICU are not used as they would need to be specially edited so as not to sound alarming. Instead, the sound of people talking in the hospital is used.





Sample	Track	Α	В	<b>C1</b>	C2	D1	D2	D3	Е	Environ.	Link to playlist
Music A		Х	Х			Х	Х	Х			
Music B		Х		Х	Х	Х	Х	Х			https://soundcloud.com/chen- chou-614743749/sets/caretunes-for-
Music C		Х	Х	Х	Х	Х	Х	Х	Х		tamilies-evaluation-second-user-test- music-samples/s-mIU5197PZ2J
Music D		Х				Х	Х	Х		Х	

 Table 7.1. Tracks used in each sample.

# 7.3 Interaction Prototype for Testing

The user test is focused on testing the interaction of messaging and streaming. Therefore, a substitute messaging APP is used as the media.

### **Automated messages**

The researcher acts like an automated system that sends out music messages at certain times of the day using a messaging APP (as shown in figure 7.4).

### **Music streaming**

YouTube was used as a platform for live streaming the music in the user test. The participant can click in the link provided in the above-mentioned messaging APP to listen to the music if they want to.



Figure 7.4. Automated messages (left: first use; right: everyday use).

# 7.4 Results on Music Design

The insights on music design gained from the first session of the user test are listed below. Participants one and two are quoted as P1 and P2.

#### Imagination far beyond the ICU

# Families may think of images far removed from the ICU when listening to the generated music

One of the powers of music is that it can evoke visual imagery in the listener's mind (see Chapter 3). This phenomenon is also seen amongst the participants in the user test. However, the scenes or images that pop up in their minds may not be related to the context of ICU. For example, they would not think of their loved one lying on a hospital bed; instead, they would think of scenes involving their loved one lying on the grass or wandering in the streets, or a conductor conducting an orchestra, etc.

Despite being detached from reality, these scenes are closely connected to the patient; either the patient can be inside the scene, or the scene represents their state of mind. These scenes are also deeply connected to the listeners' past memories, such as a cartoon they watched when they were little. P1: "[Music A] feels like she is peacefully lying on a field of grass. [...] It looks like scenes from 'The story of Perrine'."

These results are quite different from the results of the first user test (see Chapter 4), where the families constantly picture the state of their loved one in the ICU. This may be due to the newly designed music composition and user interaction, where families are no longer informed that the music is generated based on the patients' vital signs, but instead comprises the patient's theme melody and their brain and heart activities.

### The mental images evoked by the music reflect the family's perception of the condition of the patient

The images evoked by the music in the families' mind have a lot to do with how they perceive the condition of the patient, for example if they feel that the patient may be recovering or about to pass away. However, if the music is soothing (like music sample A), it could make the latter situation more peaceful and positive despite its sadness, which enables the family to accept the situation more easily. P1: "It feels like she is dead but very peaceful. [...] I know she was almost dying, so I thought of a coffin. But it is a 'nice death', like following a light and smiling."

P2: "I felt uncertain because [music B] sounds like he is wandering in the streets, and does not know where to go."

### The family may be guided to imagine what their loved one feels or wants to tell them

The family may imagine what the patient feels or want to tell them, guided by the music and their perception of the patient's personality.

P2: "At least the patient's state of mind is optimistic, so I felt hopeful."

The fact that the families are able to see their loved ones in a different, or even a more personal and beautiful scene than the ICU is encouraging, because they are being deeply connected beyond the stress of the physical world, which is well suited to the project context where the connection happens outside the hospital and no additional (medical) information can be obtained to satisfy their need for information and assurance (see Chapter 2). These scenes ensure intimacy in the connection, as they involve the family's perception of the patient and their own past memories. They may also trigger the families to reflect on how the patient might feel, think, or want to express. Once the families are guided to a positive direction by the music, they would be able to accept the situation more easily, and acceptance is one of the positive emotions the design wishes to evoke (see Chapter 2).

### The way the music is generated reduces the families' tendency to analyze the music

Unlike in the first user test (see Chapter 4), the participants seem to be less inclined to analyze the (medical) meanings behind different tracks of the music.

P1: "The atmosphere is good, and I would not analyze the music carefully. I would not worry if anything bad happens."

This corresponds with the goal to reduce the families' worries, fear, and need for vigilance when listening to the generated music.

### Generation of the music

#### Families find the music more related to emotions, which is regarded to be related to brain waves\*

The families relate the music more to emotion than monitored data, and they find it reasonable and believable to use brain waves and heart rate to generate the music. However, brain waves seem to provide more abundant information to the families as brain is regarded to generate thoughts and emotions, while heart is regarded to be more related to the biological state of a person.

P1: "Anything the person generates is 'real'. Heart represents the sign of life, but brain waves bring in emotions."

The music generated in this way can also enhance the feeling of assurance.

P1: "The brain-waves-generated music makes me assured."

## Families need to know how the music is generated to be assured

Despite the emotional touch, the families still want to know what kind of sources generates the music. It concerns whether the music is "real" or not. In addition, when there is much positivity in the music, it can also raise the feeling of doubting the situation.

P1: "I was curious what produces the music. I wonder what 'good' means in her context [...] For [music A], I thought: 'How can the situation be this good?'"

P2: "[What concerns me is] how the information is transformed. I would think of its accuracy, but in the moment, I quite enjoyed it."

It is important to let the family know how the music is generated. At the beginning of the user tests, the participants are given the information similar to the explanation given in the APP, but a more complete explanation may be needed in the CareTunes messenger tutorial.

\*The relation between brain waves and emotions is still stiudied in the medical field. This project does not claim to present emotions through brain waves, but merely shows that people might relate brain waves to emotions.

#### **Evoking emotions**

### The music on the whole is able to enhance intended positive emotions

The music pieces (including music samples A, C, and D) have succeeded in enhancing positive emotions, such as assurance, hope and calmness (see figure 7.5).

P2: "[Music A] sounds calm. It feels quite good. He is not recovering, but i wouldn't feel very sad because the emotion can be controlled."

P2: "I feel assured because the chords [in music C] are brighter. [...] Because of the tempo it feels happier, [...] like he is recovering, and not so lonely and bored.

P2: "I feel calm because the pace [in music B] is slow and not anxious. [...] I could face it and accept it, because I feel calm. C'est la vie. [...] This is positive for me."

Only music sample B (which represents a patient sleeping) does not evoke many positive emotions. This is due to the low pitch, slow tempo, and heavy background sounds. One thing to note is that, the background track sounded like heavy beats in user testing for Participant 1 due to file compression, hence the stronger sense of negativity.

P2: "I feel hopeless because the sound [in music B] is low and uncertain. It also feels random."

### Sounds of nature can bring liveliness and hope

Sounds like bird chirping can bring liveliness and hope into the music. They also make people imagine outdoor sceneries or activities.

P1: "The bird sounds are like birds flying in the distance. It feels more released."

P2: "The lively (bird) sounds sounded like he is close to recovering."

The designed music has succeeded in evoking intended positive emotions, but how the music sounds during less active phases (e.g. when the patient is sleeping) should be further designed to sound more assuring and hopeful. One way to brighten up the music is to include sounds of nature.

#### **Music composition**

# The multiple music tracks with different characteristics help construct multi-dimensional scenes or stories

The construction of the scenes or stories in the family's mind is completed and enriched with every track of music. For example, the background sounds and the theme may sound like the background and foreground of the scene, and the appearance of special sounds may represent a new character or event.

P1: "I thought of the meadow because of the light and crisp sounds [in music A]. [...] The foreground is lively with flowers and birds, and the background is steady. [...] There are also big waves which feel like the wind."

P2: "The 'ding dong' [bell] sounds [in music A] are like external stimulations, such as meeting a passerby or a cute dog [on the street], and the background sounds describe his feelings."

As intended, the bell sounds in the music are seen to be related to external stimulations.

### Environmental sounds of the ICU can have very different effects on different people

Incorporating environmental sounds of the ICU in the music brings the family closer to reality. Some people find this assuring, others feel more worried and in need for more information.

P2: "I would think that, if I hear the [environmental] sounds, I should also be able to see videos. [...] Music feels more artistic; if there are environmental sounds, sensibility would become rationality. I would wonder if the situation is worsening, and become more worried."

P1: "The environment sounds offer a feeling of reality. They make me feel that there are people nearby working to take care of her. It is also my personal preference to listen to environmental sounds. [...] The sounds of the machines give me a sense of assurance. The picture is complete."

Due to the significant difference in people's preferences, environmental sounds can be made optional for the families to turn on or off in future design.



- Music A: awake
- Music B: asleep with movements
- Music C: waking up
- Music D: asleep with environmental sounds

**Figure 7.5.** Averaged result of how music sample A, B, C, and D scored on the scale for emotions.

# 7.5 Results on Service and Experience Design

The insights on service and experience design gained from the second session of the user test are listed below.

### Context of use

## Messages are opened during the family's personal free time

The participants opened the music messages during their free time, such as during meal times or in the evening. Some would also prefer to listen to the music when they are able to immerse themselves calmly in the experience.

# The urge to listen to live streaming can be triggered upon receiving messages, depending on the person

Some people may be satisfied by only receiving messages, some would want to listen to the music longer after listening to a music message. In both cases, automated messaging is an important touchpoint.

P1: "Push notification is not bad, because I would not want to keep listening to live streaming. [...] I did not feel the need to keep confirming."

P2: "After I listened to the 30-second music message, it did not feel satisfied, so I opened the streaming to fulfill the need." How the music messages are sent now seem to work for the families, three times a day during their free time. Live streaming is also needed by certain groups of people if they find the music messages not enough.

### Meeting the needs

# The need for connectedness and other emotional needs are fulfilled

The families' need for connectedness, assurance, and hope are fulfilled by the experience as well as the music. The presence of the patient is also enhanced. In addition, the families are able to remain calm and positive (see figure 7.6).

Several features were pointed out to be of help: the music being generated from the patient themselves, the positivity in the music, the immersive quality of music, and the around-the-clock accessibility.

P1: "Many 30-to-40-year-olds can be busy, [...] and in this way they can feel that their mother is there. [...] It is helpful." P1: "[The experience] feels intimate because it is generated from the person, so it is real. I feel connected, which also makes me feel assured. I feel hopeful because it feels like the situation is alright, and it is possible for the person to recover. I feel calm because the music is calm."

P2: "[The experience] feels intimate because music and sound are more immersive. If it is text then it would feel distant. I feel assured because it sounds good, and because I could listen to it anytime. [...] I felt hopeful and calm because of the music itself and the atmosphere."

The design is particularly meaningful for families in long-distance relationships, as the time difference enhances difficulty in accessing information, and the family is not able to visit the patient at all.

P2: "I would want to use it. Because at that time I was in [another country] while my family is in [my home country]. I could only receive messages from the family group chat. I would wait till midnight to check the messages, and I was always waiting fruitlessly, because I did not want to disturb other family members. [The product] helps in the long distance context."

#### The sense of guilt can be reduced by checking the music messages

Checking the music messages makes families feel connected despite not being able to take care of their loved one, thus reducing the sense of guilt.

P1: "I can confirm her state when I am eating, and my sense of guilt will be reduced, which may emerge once I am not taking care of her. Now we are still connected, which is good."

## Negative emotions such as worry and fear of loss are not evoked

Both participants did not voice out any concern about the patient's condition worsening.

P1: "I had no concerns because if anything bad happens, the doctor will notify us. If I am busy then I would even think less about it." The design has successfully benefitted the families with enhanced connectedness, assurance, hope, and calmness. This connection also reduced their sense of guilt, and did not evoke additional negative emotions. Moreover, it is particularly meaningful in the context of long-distance family relationships.

#### Choosing the theme can increase symbolization and intimacy

People would want to choose the theme of the patient because it can better represent the patient, and creates a stronger connection between them. However, some would also think that being gifted with a ready-chosen theme is also quite beautiful.

P1: "If I have the choices, I would want to try all of them. I think it is positive because it enhances the connection. If I cannot choose, it is also positive, as it is like a gift life gives you, and it is for us to accept it. There's beauty in randomization."

P2: "I would want to choose, because the family would know better of his personality."



**Figure 7.6.** Averaged result of how the overall user experience scored on the scale for emotions.

#### End of use

### Families would like to end the service themselves

The power to end the service or the music themselves provides a sense of control for the families.

P1: "It is a nice design, because I cannot decide whether or not to stop their life, but I can decide whether ot not to stop the music. [...] Some part of them are still in the world. I like it."

#### Some may want to end the service rightaway, others may want to let the music play on

People's actions differ a lot when it comes to ending the service and the music. Some may want to end the service right away after the end of the journey because it does not make sense for them to continue playing when the patient has already passed away; others may want to let the music play on because it is seen as the last piece of thing or memory that is left on this world by the patient. P1: "I am very moved. I really feel it when talking about ending the music ourselves. I think I will never stop it. [...] If I could not come out of it, I will let it continue to play, maybe even after 5 years, because it is the last thing she produced, the last thing she left on this world."

P2: "I would want it to stop, and if I want to listen again I could go back to listen offline [past messages]. Streaming gives a feeling of being in public, and I don't know if his soul would want it. I prefer offline memories."

This difference may be related to "social death" of the patient.

P1: "Maybe because we did not live together, so after 5-6 years, emotion-wise I still do not consider her dead."

## The retrospective music mashup generated in the end is much appreciated

Families appreciate how the APP would generate a retrospective piece of music at the end of the service. P1: "The APP needs to inform me first that it will generate the mashup for me, or I will want to always keep it, and not stop it.

P2: "It would be useful in making memorial videos, with very personal music of different versions and styles (meaning the different states in streaming, like waking up or sleeping), for sad or happy parts of the video."

#### Preserving memory in music

Some may find that the music can trigger memories in a positive way.

P1: "The memory of her will have elements of music in it. [...] Even if they will not recover, I still feel consoled. [...] The memories are positive. As music can trigger emotion, memories will be triggered.

# 7.6 Conclusion

### About meeting the needs

- Both the user experience design and music design of CareTunes for Families have been proven to be able to satisfy the need for connectedness and other emotional needs, such as calmness, assurance, hope, of the families. The sense of guilt can also be reduced.
- The new narrative of the product and the music composition is able to avoid additional worry, fear, or need for vigilance.
- The product can be particularly useful in the context of long-distance family relationships.
- Families might want to choose the theme of the patient.
- Families would like to end the service themselves, but it depends on the person if they want to end it right away, or let the music play on.
- A retrospective piece of music generated at the end of the service can provide a sense of closure.

### About the context of use

- Families prefer to listen to the music in their free time.
- The urge to listen to live streaming can be triggered upon receiving messages.

#### About music design

- Although the music translates the state of the patient, it is possible that the family would think have a even greater imagination than how the patient is doing.
- Families find the music more related to emotions.
- The family would want to know how the music is generated. More in-depth explanation may be needed.
- Sounds of nature can bring liveliness and hope.
- The multiple music tracks with different characteristics help construct multi-dimensional scenes or stories.
- Sounds with different characteristics than the main theme can be related to external stimulations.
- Environmental sounds of the ICU can have very different effects on different people, and can be made optional for the families to turn on or off in future design.



# **Chapter 8** Conclusion and Future recommendation

This chapter concludes the learnings from this project, and offers recommendations for future study or design development.

# 8.1 Conclusion on Design

Conclusions on experience, interaction, and music design are drawn from the design process, the user tests and the interviews.

#### Experience & interaction design

#### Emotional and not technical

Music easily evokes emotions, and offers great freedom in interpretation. This presents an advantage in building connectedness (as it is more related to the families' social and emotional needs), but is not suited to present technical information. This should be taken into account when designing the user experience or service, so as not to cause additional uncertainty or confusion.

For example, how the product is presented and explained to the families can already make a big difference in how the family perceives and analyzes the music. Another example is that, if other technical information is added to the interface and presented together with the music, it can create the feeling of distance, and reduce the effect caused by the music alone.

#### A personal experience

Connectedness can be reinforced by the feeling of intimacy, and therefore making the experience personal can be a way to increase connectedness, such as sending personal music messages and giving the patient a theme melody.

On the other hand, the design should also be sensitive about this, because even when it is not intended by the design, the experience could still become very personal for the families. For example, when the family associate the music with the patient's brain activities, they might start interpreting the patient's emotions, thoughts, or even what the patient would want to tell them.

In addition, music can be powerful in evoking memories. If the patient passes away, the music might be tied with the family's last memories about them. Therefore, the end of service should also be carefully designed to maintain a positive personal experience, such as letting the family take initiative in ending the music when they are ready.

### Streaming and messaging can both cater to the families' needs respectively

Although music streaming seems to be a direct way to build strong connections between families and patients, people may not find it necessary, especially for those who are busy in life. Some people may like to listen to the music longer to immerse themselves in the music, while others only need a few messages a day to gain assurance. This also depends on the severity of the situation.

#### A two-way connection

Although receiving the music is comforting for the families, the families' priority is still the well-being of the patient. Social connectedness is also associated with caring and reciprocity. Therefore, a way to send back support can be considered in the design, such as sending back voice messages, which can also potentially benefit the patient. However, this still needs further validation.

#### **Music design**

#### **Encouraging positive interpretation**

One should be cautious when designing with music for the families of ICU patients, because they could easily be in a negative mood, which could greatly influence their interpretation of the music. Therefore, positivity is greatly needed in the music to avoid unintended negative interpretations. When there is enough positivity in the music, the family could then be more prone to accept the situation peacefully even when the situation is not getting better. Positivity in the experience can also increase the feeling of connectedness.

#### Bringing life with multiple layers

Music that is plain can be less lively and seem to hold less information. Whereas music with more dimensions, including foreground and background, different instrument and sounds, and different variations, can make the music feel more real and lively, and encourage more imagination and reflections.

#### Predictable music to avoid uncertainty

Uncertainty is a commonly encountered problem in the context of the ICU. Uncertainty in music can also evoke worries. Therefore, although the music is generated automatically, it still needs to be predictable. For example, having a theme melody in the music is one way to achieve this.

One basic principle is that, when translating different data into music, they should always be harmonious and change reasonably.

#### Data that have (humanized) meanings

Brain waves seem to make the families feel more connected as they represent their mind. If the design is to be implemented using other data sources, the selection of data should take this emotional aspect into account.

# 8.2 Design Implementation

This project focuses on early explorations of design possibilities of the product and their impact on the target group. Therefore, CareTunes for Families needs further design development before it can be implemented. Below are some general ideas on implementation that can be considered in future design development.

#### **Practical issues**

This project is focused on exploring the possibilities of connecting ICU patients and their families through music, as this is a new subject that has not been commonly practiced yet. Therefore, the design concept is more ideal and inspirational than practical. Here are some examples of practical issues that need to be considered in future implementation.

#### Access of data

Currently, brain waves and movements are still not commonly monitored in the ICU. However, alternatives can be found as long as they are meaningful to the families.

#### **Configuration of data**

Some data may need to be configured before it is translated to music, or it can also be regularly reconfigured for accuracy if necessary. For example, while data like brain waves may not differ that much from person to person, the difference in the heart rate amongst ICU patients might be greater.

#### Data privacy

The privacy of the patient's data should be treated carefully. Consent might be needed from the families or the patient themselves.

# Fitting into the socio-technical system of the ICU

#### Involvement of the nurses

Being one of the main stakeholders of the product-service system, how they interact with the product, or how they interact with the families with the product being used, should be further designed.

## Connecting the product to the monitoring devices

This project has provided the principles, but not yet explored the technical aspect on how the data can be retrieved from the monitoring devices and how they can be translated into music. This would require further engineering design.

## 8.3 Conclusion and Recommendation on Research

Limitations of this project and recommendations for future research or design validation are suggested below.

#### Limitations of the study

#### Representation of the target group

This project included families of former ICU patients in the user research, but did not include families of current ICU patients. In addition, the participants of the user tests are all from the same age group: young adults between 20-30 years old. Therefore, their feedback may only represent a certain group of the population. One reason behind this is that there are limited resources from the hospitals and user research restrictions at the time of the study, and participants cannot be recruited through from ICU, and need to be tech-savvy to some extent to participate in online testing. Therefore, the research results and the design would need further validation from a more diverse group of participants.

#### Long-term effect of listening to the music

In this project, the user evaluation lasts no longer than three days. The effect of using the product for a longer term if a patient is to stay in the ICU for more days is not yet validated.

### Possible future research directions

#### Service design

The service design may need to be further developed, especially on the user journey of the nurses. For example, how to minimize the additional workload, how the product can bring most value to the nurses (e.g. less workload in taking care of the families), etc.

#### Sending voice messages

The design of recording and sending voice messages is not yet validated with the families and the patients, and this feature alone would need its own study.

#### Prototyping with real data

This project offers insights on how the user experience and music might be like in the context of CareTunes for Families. The next step would be prototyping with real data and adjusting the design according to the new research results.

#### **Environmental sounds**

Environmental sounds can benefit certain groups of people. However, they need to be unalarming, as their purpose is to assure the family the patient is being well cared for. The environmental sounds used in the user evaluation can only mimic the effect, and this will need further design and evaluation.

#### Choosing the theme of the patient

Though not included in the final design, the possible feature of enabling the families to choose the theme of the patient themselves is discussed in the user evaluation. The results are positive, and so it could also be considered in further design development.





# A. Original Project Brief



Procedural Checks - IDE Master Graduation	<b>Ťu</b> Delft
APPROVAL PROJECT BRIEF To be filled in by the chair of the supervisory team.	
chair <u>Elif Ozcan Vieira</u> date <u>28 - 02 - 2020</u> signatu	
CHECK STUDY PROGRESS To be filled in by the SSC E&SA (Shared Service Center, Education & Student Affairs), after approv The study progress will be checked for a 2nd time just before the green light meeting.	val of the project brief by the Chair.
Master electives no. of EC accumulated in total: <u>iU</u> EC <u>YES</u> Of which, taking the conditional requirements into account, can be part of the exam programme <u>IU</u> EC <u>NO</u> m	all 1 <sup>st</sup> year master courses passed
List of electives obtained before the third semester without approval of the BoE	
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FORMAL APPROVAL GRADUATION PROJECT To be filled in by the Board of Examiners of IDE TU Delft. Please check the supervisory team and s Next, please assess, (dis)approve and sign this Project Brief, by using the criteria below.	study the parts of the brief marked $^{**}$ .
Does the project fit within the (MSc)-programme of the student (taking into account, if described, the activities done next to the obligatory MSc specific courses)?     Is the level of the project challenging enough for a	VED NOT APPROVED
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IDE TU Delft - E&SA Department /// Graduation project brief & study overview /// 2018-01 v30 Initials & Name <u>C. CHOU</u> Student number	Page 2 of 7 4825527
Title of Project CareTunes: connecting ICU patients and their families through music	^ · ·

#### Personal Project Brief - IDE Master Graduation

**TU**Delft

#### CareTunes: connecting ICU patients and their families through music project title

Please state the title of your graduation project (above) and the start date and end date (below). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

start date 18 - 02 - 2020

<u>22 - 07 - 2020</u> end date

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The project focuses on using music to optimize the connection between Intensive Care Unit (ICU) patients and their families (and informal caregivers).

The main stakeholders of this project are ICU patients and their family members. ICU patients are hospitalized patients who are in life-threatening situations—due to being seriously ill or having surgery—and require advanced care and constant monitoring, as their condition may change at any point in time. Some stay in the ICU for a few days, others for months, while some may deteriorate there.

Family members of ICU patients play an important role in supporting the patient, including psychological support, social support and decision-waiking. Meanwhile, they themselves also need to be well supported from the emotional and psychological aspect, as they often experience distress and anxiety due to the admission of their relative into the ICU, and are in need of reassurance, closeness, and information. These kinds of support are usually provided by ICU nurses, who are responsible for communicating with the families. However, the families psychological needs are not always met. Therefore, a new way of connecting the families and the patients can be developed to improve this situation.

The TU Delft Critical Alarms Lab (CAL) presents an opportunity for this design intervention. The lab's previous project CareTunes was developed to turn the ICU patients' vital signs (including heart rate, blood pressure, and oxygen level in blood) into certain musical sounds to replace the original alarms. Although CareTunes was originally targeted toward ICU nurses, the concept of turning vital signs into music can benefit the families as a new form of connection with the patients. Therefore, this project will build on CareTunes was needed to the context of establishing connectedness between families and patients.

The Critical Alarms Lab is also in collaboration with the Erasmus MC, providing the opportunity to study the context of the project. Although the patients cannot be directly accessed, it is possible to get in touch with patient organizations.

Other limitations of this project include the restrictions of conducting research in the critical environment, the conditions of the patients (who can be sedated or unconscious), the privacy of patient data, etc.

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 Initials & Name
 C.
 CHOU
 Student number 4825527

 Title of Project
 CareTunes:connecting ICU patients and their families through music
 The student number 4825527

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introduction (continued): space for images



image / figure 1: ICU patients' family values connection with the patient.



image / figure 2: \_\_\_\_ICU patients' vital signs are constantly monitored.

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Initials & Name	С,	CHOU	Student number	4825527
Title of Project	CareTu	nes: connecting	ICU patients and their families through music	

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**TU**Delft

### PROBLEM DEFINITION \*\*

The family of ICU patients often experiences distress and anxiety as their loved ones are admitted to the ICU and are in a life-threatening situation. Most of the families' needs are related to reassurance and closeness, as well as obtaining honest, up-to-date and understandable information. These needs point to a demand for a stronger patient-family connection. As families play an important role in supporting patients, providing emotional and psychological support for the family members can be benefit both the family and the patient.

While the family longs for connection with the patient, there exist many barriers that hinder this connection, such as difficulty in communication, hospital visit time limit, etc. Most of the times, the family and the patient are separated, breaking the original connection between them. However, social connection is a basic human need, and connectedness is related to the feeling of safety. Therefore, the connectedness between the family and the patient should be improved.

One thing to note is that, in the given context, it is possible that a patient's condition might deteriorate, and the effect of this kind of event on the families should be taken into consideration.

Solution of a sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in 'problem definition'. Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance a product a product-service combination, a strategy illustrated through product or product service combination ideas, ..., In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

Qualitative and literature research on ICU patients' families will be conducted to understand their needs and concerns. The research insights will be used to create a music-related design that aims to improve the ICU patient-family connection.

Within the scope of CareTunes, the project aims to explore how music can improve the connectedness of families with the patients in the ICU. It will use music as a starting point and include it as a property for a product/service/system that enhances feeling of connectedness. The design outcome is expected to build up a new way of connecting, while catering to the psychological and emotional needs of the family, such as reassurance, closeness, and honest and understandable information.

A patient's vital signs can constantly indicate their condition, and will be used as the basis of this new connection. Through design, the patient's vital signs will be turned into music—also know as "organized sound"—and be made available for the family. Therefore, the design will focus on how the family receives and interacts with the music, and how the music makes sense in the context.

The design will also make use of music's strengths and characteristics; for example, music has the ability to evoke emotions or feelings, such as calmness, warmth, comfort, etc., which is well-suited for the goal of the project.

This project follows the Medisign specialization. Therefore, the research and design outcome will stay closely within the medical and healthcare context.

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Include a Gant Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should it within the given net time of 30 EG – 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.

start date <u>18 - 2 - 2020</u>

<u>22 - 7 - 2020</u> end date



The project consists of research and design, and will go through iterative cycles of design, evaluation, and redesign.

The first phase is the research and analysis phase, during which literature and desk research will be conducted, and a few interviews and observation are expected. The research will be focused on analyzing the context of these. The targets for desired user experience quilties. Relevant design requirements will be formulated at the end of this phase.

The second phase is the conceptualizing phase, during which initial design ideas and concepts will be formed. This is a diverging phase, so there should be multiple diverse concepts. The concepts will be turned into low fidelity mock-ups, which enable testing for user experience and interaction. The feedback received from the tests will be analyzed and used as insights for the next phase. Real users will be recruited as participants, and more in-depth research into the users and stakeholders will be conducted simultaneously. A design strategy will be formulated at the end of this phase, which will be discussed together with the test results during the mid-term meeting.

The third phase is the design detailing and evaluation phase, during which the a more concrete redesign concept will be formed, and turned into a experiential-quality prototype for user testing. A detailed user test setup will also be designed to create a realistic experience along the prototype. Real users are also expected to be recruited, and the evaluation results will be used as insights for the final design, which will be discussed during the green-light meeting.

The fourth phase of the project will be used for final design detailing, report/thesis completing, and presentation and showcase preparation.

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#### Personal Project Brief - IDE Master Graduation

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#### Design for Interaction:

Lesgin non increased. I want to gain more experiences and skills in researching from the human aspect, while gaining more knowledge in human behavioral sciences, and to be able to conceptualize the research findings into new products or services, which are able to both answer the research questions and be valuable for the market.

#### Medisign:

I want to gain more experiences and knowledge in medical and healthcare design, while not only considering the patient, but also taking the viewpoint from other stakeholders, such as the family of the patient. I also want to learn process reactions with grow everyonic morner stakenolders, such as the family of the patient. Lalso want to how to take the whole socio-technical system into consideration in the design process, which is important in Medisign.

#### Sound design:

experience and interaction, what kind of possibilities sound design provides, and how to best make use of my musical background in the sound design field.

#### Digital design:

Firstly, I want to gain more knowledge in technology, and more skills in prototyping with digital tools. Secondly, I want to learn how to involve the technical or digital knowledge from the very beginning of a design project, to serve as an inspiration and to open up more possibilities.

#### Project management:

I want to gain the ability to manage projects independently, and as the leader of a project.

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# **B. Interview with Family Members of Former ICU Patients**

### Semi-structured interview guide

#### About context and journey:

- Why was [the patient] admitted to the ICU?

- Were you the main person, or one of the main people, in your family to take care of [the patient] while they were in the ICU?

- If not, then to what extent were you involved in the situation?

- Can you tell me briefly the process you went through, as a family member, from [the patient]'s admission to discharge?

- How often did you visit [the patient] in the  $\ensuremath{\mathsf{ICU?}}$ 

- How stressed were you about the situation from a scale of one to five (one being not stressed at all, and five being very stressed and anxious)? Why?

#### About connectedness:

- When you were outside the hospital, what were your main thoughts, or worries, about [the patient]? Why?

- When and where did these thoughts usually occur to you?

- Please listen to the following statement: "Factors such as limited visiting time and the condition of the patient hinder the physical and emotional connectedness between the ICU patient and their family." Do you agree or disagree? Why?

- What do you think are missing in this connection/connectedness?

- Do you think this lack of connectedness with [the patient] had increased your stress or other negative emotions? Why or why not?

- How did you maintain your connectedness with [the patient]?

- How would you imagine an ideal improvement of connectedness? For example, receiving information more often, or increasing the feeling of company, etc.

#### About music:

- How often do you listen to music?

- If you could listen to [the patient's] condition through music at any time, any place; for example, if [the patient's] vital signs are turned into music and you can listen to it real-time at home, could you imagine in which way it could benefit you or your family? Or do you think it wouldn't be useful or helpful at all? Why or why not?
# Interview result codebook

Theme	Description	Examples
Thoughts and worries	Families wonder about the duration, risk and outcome of the treatment.	"How long it would take, if there are any more risks, would everything go well" (P1)
		"Will he suddenly get better? or will he suddenly pass away?" (P3)
	Families would constantly think of the patient,	"All the time, I think of" (P2)
	most so in their free time.	"When I was free from work. [] During work I was more focused on work." (P3)
	Families want to support the patient.	"I was thinking about how to help, who to contact, what to do, how to manage time, and about arranging visits." (P2)
	Families cares about the patient and hope the situation would improve.	"I cared about her. I wondered if she became better and hoped that her situation could improve" (P2)
Emotions	Families may feel stressed at first but will feel less stressed once they understand the situation	"I felt stressed in the ER, but was more relieved in the ICU, because in the ER I was the main caregiver, [] and I did not understand the situation." (P2)
	and the medical personnels take over.	"At the beginning I was very stressed, because I did not understand the situation at all. Then after listening to the doctor's explanation, I was less stressed." (P3)
	If the patient's condition becomes stable, the family would feel relieved with only a little worry.	"I was not very stressed because she can be treated, but there was still the possi- bility that something could go wrong." (P2)
		"I did not worry much outside the hospital, because there is nothing I can do about the situation."(P2)

Theme	Description	Examples
	Information can be a great source of assurance.	"The information I received were the most essential and needed information, and nothing else. There was little information and time, but it was clear, which low- ered my stress level. The information was also positive, so I did not worry much; but if it was negative, then I would worry more." (P2)
	Families are still on constant alert even if the situation is turning good.	"I was also on constant alert, in fear of anything bad that might happen." (P2)
	Uncertainty evokes anxiety and powerlessness.	"If the situation is uncertain, I would feel the most anxious, and would feel lost." (P2)
	Unoptimistic situation evokes sadness.	"If the situation is deteriorating, I would be thinking what the next step would be, and my emotion would be sad instead of anxious." (P2)
		"Yes, they were quite direct. [] I was sad but not anxious." (P3)
Needs and connected- ness	Families would accompany and touch the patient as a way to connect.	"By being with her, touching her." (P1)
	Families would want to be close to the patient.	"My mom was almost always at the hospital despite not being able to be in the ward." (P3)
	Families would want to take care of the patient but they need to maintain their life and work.	"At the beginning I could take leave more often, but then later I still need to go back on track." (P3)
	The feeling of company could improve connect- edness.	{How would you imagine an ideal improvement of connectedness?) "The feeling of company." (P3)

Theme	Description	Examples
	Description   Families would want more to support the patient than being supported.   The uncertainty of the situation greatly influences the family's needs.   Information is important in maintaining connection.   Families see it as a way of receiving information.   Music can help in both information and emotion.   If the music presents vital signs, it can make people more anxious.	"There was no need for company." (P1)
	than being supported.	"Emotion was not that important, because in my case, rationality overcame all sensibility, as I was constantly thinking what I could do. I was part of the team in helping her get better." (P1)
	The uncertainty of the situation greatly influenc- es the family's needs.	"It was fine to only receive the information that are needed. There was no need to keep watching her, and it was not possible to do anything. However, if she was not getting better, [] I would want to keep watching if there are any changes in the situation, and I would not get assured until I see a good result. It would be more like the situation in the ER, where the situation was uncertain. Uncertainty is a very important factor." (P2)
	Information is important in maintaining connec- tion.	"When there was no information, and I could not see him, I felt worried, because I could not know what was the current situation, though even if I knew, there was nothing I could do about it." (P3)
Music to connect	Families see it as a way of receiving information.	"It would be an interesting method of getting information." (P1)
	Music can help in both information and emotion.	"It could benefit in stabilizing my mood. It is like reading information from statisti- cal reports, and the anxiety could be lowered after receiving information." (P2)
	If the music presents vital signs, it can make peo- ple more anxious.	"I think it would increase the feeling of restlessness, because what if it is always stable, then suddenly becomes rapid? I would not know what to do. But if it is always stable, then it is a benefit." (P3)

# C. First User Test Script (see Chapter 4)

# **Background Interview**

How often do you listen to music? Is it a habit of yours? When do you listen to music? Are you a current or former ICU patient's close relative?

# **Concept A**

The music is generated by the patient's heartbeat and broadcasted to you. It indicates the patient's condition.

Please listen to this piece of music while reading the following article, and stop when the music ends.

One thing to note is that, reading the article serves as a simulation of what could be a task of your daily work. Therefore, please read it in the way that you usually do at work.

### Interview questions:

What do you think the condition of the patient is?

What messages did you get from the music? Did you like the music? Why or why not? Were you distracted while you were reading the article?

# Concept B

The music is generated by the patient's heartbeat and broadcasted to you. It indicates the patient's condition.

Please listen to this piece of music, and stop when the music ends.

You can look at this image as an added channel of information.

### Interview questions:

What do you think the condition of the patient is?

What messages did you get from the music? Did you like the music? Why or why not? Did the visual help? Do you think the visual is necessary?

# Concept C

The music is generated by the patient's heartbeat and is sent as a short message to you each day. It indicates the patient's condition. The researcher will send you a message on your phone and please follow further instructions indicated by the messages.

## Interview questions:

What do you think the condition of the patient is?

What messages did you get from the music? Did you like the music? Why or why not? Would you want to send back a message? Would you want to save the message?

## **Overall Interview**

If you would to choose one of the three products to use, which would you choose? How would you rank the products and why?

Which differences do you think the visual elements bring to the experience? Why?

How would you rank the three concepts? Why?

Could you think of any other preferred way to communicate this information?

## Questionnaire

#### 1. You feel... (to the loved one)

		-3	-2	-1	0	1	2	3
1	Disconnected - Connected							
2	Distant - Intimate							
3	Doubtful - Assured							
4	Faraway - Close							
5	Hopeless - Hopeful							
6	Passive - Active							

#### 2. The (audio) information provided is...

		-3	-2	-1	0	1	2	3
1	Incomprehensible - Comprehensible							
2	Complex - Simple							
3	Confusing - Clear							

#### 3. The product is...

		-3	-2	-1	0	1	2	3
1	Unpleasant - Pleasant							
2	Repelling - Appealing							

### A. STAI-6 (State-Trait Anxiety Inventory) (How do you feel?)

		Not at all	Somewhat	Moderately so	Very much so
1	l feel calm.				
2	I feel tense.				
3	I feel upset.				
4	I feel relaxed.				
5	I feel content.				
6	I feel worried.				

#### B. Emotions conveyed by music (What does the music express?)

		1	2	3	4	5	6	7
1	Longing							
2	Sadness							
3	Expectancy							
4	Joy							
5	Tenderness							

# D. First User Test Interview Results (see Chapter 4)

# Participants

	Related experiences	Music listening habit
P1	Both his grandmothers were in the ICU a couple of years ago, and a close friend of a grandmother a couple of weeks ago.	Daily: while working and studying, and sometimes before go- ing to sleep and during shower.
P2	None, but her sister almost went into the ICU once in another country.	Daily: during morning shower (podcast), working, working out, and for relaxing.
P3	None.	Daily: 30 min. radio after waking up, and music is on the whole day when at home (morning and night: chill music; afternoon: happy and energetic music).
P4	None.	Five days a week (when working on projects), 5-8 hours a day.
Р5	A grandmother was in the ICU once.	Daily, mostly in the evening, and not while working. Also when feeling a bit stressed. Sometimes in the morning to wake up.
P6	A cousin was in the ICU once, an passed away in the same day.	Almost everyday, usually while working (sometimes as back- ground, sometimes as foreground). Sometimes during shower, doing dishes, or for the music itself).

|--|

Theme	Sub-theme	Description	Examples
Project context	Music streaming as a	The nature of the music can enable it to be an undistracting background, but some	"I was not distracted. It was a background, ambience sound. I would look for the playlist." (P1)
	background	und may find it very distracting because of the meaning it represents.	P5 had the desire to ensure. "I was focusing on my things and it makes me want to turn back and look at them."
		Being a background music can enable people to continue their lives uninterrupt-	"I can listen to [A] during day-to-day activities, so it does not seem like your life stops. It also helps you go on with your life while feeling more assured." (P1)
		ed.	"If I want to continuously monitor I would use [A] or [B]; they don't stop me from doing my own things." (P2)
		People's preference of the music being a background may be related to the pleas- antness of the music, but being a back- ground may also distract people from the unpleasantness of the music.	"[A] is more pleasant and useful because I can experience it more in my life." (P1)
			"I was reading the article so I did not focus too much on the music, but when I play it again, it becomes more suppressed." (P5)
		People may want to change the music af- ter a while.	"I would want to change the music." (P2)
	Music streaming to be focused on	Focusing on the music for a long time may create more worries as people concentrate their entire mind on the situation (especial- ly if the music is not comforting).	"By focusing on the music [in B] itself, it is all I have in my mind. It was one full minute thinking about that situation. So I feel connected but worried. However if it is as relaxing as concept A, it would be easier to focus on." (P1)

Theme	Sub-theme	Description	Examples
	Music as a message	The nature of the music can enable it to be an undistracting background, but some	"It is clear because it is now presenting a moment, so there is no doubt of 'Is it going to change?' It is given to me so it is what it is." (P6)
		may find it very distracting because of the meaning it represents.	"I was able to accept the situation. There is a beginning and an end [in C]." (P6)
	Overall	People's preference between stream- ing and regular messaging can change throughout the patient's stay in the ICU, depending on their condition.	P2 expressed that they would want more messages right after the admission, but not so much after the situation gets long-term, because then they will feel more alright. "Maybe I can request it to be a message or constant music. I want to have control."
			"If the patient needs more intense care, I prefer streaming." (P5)
		Continuous monitoring/streaming may	"Continuously monitoring feels a bit anxious." (P2)
		evoke anxiety.	"[C] is a better way to cope with the situation. It is good for the mental health to accept it instead of going to check it every 10 minutes. The constant music can worsen [the mental health]." (P6)
	Touchpoint of the design	People automatically relate music to a time of day.	"[C] feels like something to receive in the mornings. It is a nice way to start the day, as I might wake up worried. It also has a "Good morning" chime. It feels like you are waking up at the same time as the loved one at home." (P1)
			"[A] feels like a good way to start the morning, or to listen to before sleeping." (2)

Theme	Sub-theme	Description	Examples				
Project	Music .	A message may be have a more distinct	"Maybe I would not visit the website [of A and B]." (P3)				
context	streaming as a background	touchpoint than a streaming website.	"I don't think if I'm at home I will find the time to click on [the website]. But when I want to listen I can click, so it's also good." (P5)				
			"Live streaming is nice, but I will not stream the whole day. Maybe I can receive at lunchtime (when I am free), so I have the time to put my attention in it, because it is important to know how they are doing." (P3)				
			"The message [in C] is clear, and I am not looking for more. I understand it is no useful to listen to it all day. A snippet is good and I can move on with my day." (P				
		A message may be regarded as a remind- er.	"[C] reminds you to check the status. [A and B] do not remind you to listen to the tune from the patient." (P5)				
	Channel of the design	Receiving the music on the phone may enhance the feeling of intimacy due to its	"I like the idea of receiving in my phone. A phone is something I can just have with me." (P3)				
		portability and the need to holding the phone close to the ear to listen.	"I definitely feel more intimate because I was holding my phone to my ear, so it feels like the message is really for me." (P6)				
		People may want to share the music in family group chats.	"People would like to know the progress, as I have experienced when my grand- mother was in the ICU, the group chat is on every hour." (P4)				
		People may want to access the music via a music platform they already use.	P5 expressed that the music can be integrated in Spotify for people who use it a lot, as a specific channel.				

Theme	Sub-theme	Description	Examples				
Connect-	Need for caring	People may feel the need to be more in-	"I cannot produce anything back like 'We are here for you." (P1)				
edness		volved/giving, such as sending encourage- ment or interact in the same way	"I wish I can also send my vital signs to them, or both our vital signs can join, so that I can be part of an actor in the experience, instead of just receiving." (P1)				
			P2 felt excluded and wanted to be a part of the action.				
			P2 wondered if their loved one could listen to their state as well.				
			P2 would like to send back a message by video call or text.				
			P6 would like to send love and encouragement,				
		People may only feel the need to send back the message if there is someone to respond it.	"I would not want to send back a message because I feel [C] is just for you to receive." (P1)				
			"If it is sent by my family member I might want to respond in the same way. If it is generated randomly then I will only receive it." (P3)				
			"Receiving is enough. Because who would read it if I send back?" (P6)				
	Feeling of intimacy	Personal messages (in messaging APPs) make people feel more intimate.	P1 enjoyed using Whatsapp to receive the message, because it feels more per- sonal, and adds the feeling of intimacy as Whatsapp is used by people close to them.				
			P3 feels intimacy because as they open their phone, they see there is an automated message to "me."				
			P2 felt C was a more direct way of interacting with the person.				

Theme	Sub-theme	Description	Examples			
		Music with more details may enhance the feeling of intimacy.	P4 expressed that the feeling of intimacy evoked by B was stronger than A, be- cause A was calm and plain, while B had more elements with buzzing and details.			
		Receiving the music on the phone may en- hance the feeling of intimacy.	"I definitely feel more intimate because I was holding my phone to my ear, so it feels like the message is really for me." (P6)			
	Feeling of connectedness	The feeling of connectedness might be evoked through both positive and nega- tive emotions.	P4 feels connected when a message was positive and clear, indicating that some- thing is going well. P5 feels connected as they pay more attention when they feel worried.			
Families' needs	Need for closeness	Continuous music may enable people more to feel the presence of a loved one.	P2 expressed that the continuous stream of music was like a representativ their loved one, enabling them to feel them. P1 expressed that the music in C went on for too long, and did not feel li			
		People may feel distant when there is un- certainty.	message. Instead, it felt more human like the vital signs. "I felt distant because I was watching the image, and music is not stable. I feel 'something is about to happen.' It is calm but there is something worrying." (P3)			

Theme	Sub-theme	Description	Examples				
		People may feel distant when there is un- certainty.	"[B] was not so personal, but more technical, like checking the status light of the central heating system." (P6)				
			"I feel distant and far away because of this screen that I have. I feel unattached because you can distance yourself from the situation." (P6)				
			P6 expressed that visuals and music did not go together. "The visual [in B] helps me to detach as it is turning the person into a 'number', while [C] is completely about the feelings."				
	Need to Be support fee	Being sent a message can make people feel more passive, and people may expect	P4 found C more interactive, and expected if they can send something back, like a Line (messaging APP) official account.				
		the messaging to be more interactive.	"Because the message is sent to me instead of me checking it, it feels more pas- sive." (P6)				
		People may want to ask questions in nega- tive situations.	"If it is negative then I want to send a message to ask what happened." (P5)				
		Saving the music does not make people feel more active.					

Theme	Sub-theme	Description	Examples				
Project context	Need for control	People may have doubts about their own interpretation of the music, creating uncer-	P2 wanted to know what the music/rhythm actually mean. "I have nothing to compare with. I want information to know what to expect [what means 'bad']."				
		tainty.	P3 felt they might misinterpret the music.				
		People may worry that something bad	P3 was worried that if the heartbeat slows down, the music would change.				
		could happen when listening to the streaming of the loved one's condition.	P4 had doubts and concern when listening to something auto-generated as they expected something to happen.				
			"When I am listening, I am waiting for something to happen, so it creates a nection for me to want to check all the time. I don't know if it is worse or bet (P6)				
	Need for assurance	Visuals can be helpful for assurance when people have doubts about the music.	"I feel a bit calmer because the visuals are doing a lot." "The music arises a ques- tion and the visual gives an answer." (P6)				
			"It is one more layer of assurance." (P1)				
			"[B] reassures me with an image, so what I'm listening is being confirmed." (P:				
Presenta- tion of in- formation	Music as an information source	People may have doubts about the trust- worthiness of the vital sign information provided by the music when it is not very clear.	"I keep wondering how it works. It would be nice to know [how it works] so that I would trust it more. (I did not hear heartbeat rhythm, so I think it might not be related to it, so it could be false.)" (P2)				
		When music represents crucial information, people may want to continue searching for cues to ensure themselves	"When a new sound appears I wonder what it means." "The music [in A] is giving all the information, so I was searching for cues." (P6)				

Theme	Sub-theme	Description	Examples				
	Meaning of the music	Although heartbeat-generated music can represent the patient, presenting the heartbeat directly through the tempo may worry people.	P1 worried if the music was going to slow down or go faster, and expressed that using tempo to present the heartbeat/condition felt too literal.				
		People may find it meaningful when the music is more related to emotions.	"It feels meaningful if it is more related to emotions and not as a way to monitor." (P1)				
	Visual elements	Visuals are not necessary when the music is clear.	P1 expressed that visual was not necessary. "[A] has only audio and overall fe more coherent and focused. So no other channels is needed."				
			"Visual is not really necessary, because there are not so much information conveyed." (P4)				
		Visual and audio perceptions may interrupt	"When listening I forget to look at the text [on the visual]." (P5)				
		each other.	P6 did not listen to the music that well when the visual gave assurance.				
			"The music did not match the visual. I couldn't as easily draw an image of the person [in B]." (P1)				
	Other channels of receiving information	Regarding the patient's information, peo- ple may want to know a lot more than what can be offered by music.	P4 would like to see a very simple bar chart (e.g. index number of unconscious- ness), and wanted to know if their loved one was getting better or not with quan- tified data. "I would like to know as much as possible."				
			"I would prefer a nurse to call me everyday at a certain time and tell me about the condition. I can also ask questions." (P6)				

Theme	Sub-theme	Description	Examples			
Music character- istics	Dynamics and layers	More dynamics and layers/elements in the music can feel more lively, but can also evoke unstable feelings.	P2 liked B more because it felt rippled and round. "[A] feels more linear, and [B] feels like a flower blossoming. It feels more dynamic, more playful and vivid. More images jump out."			
			P4 expressed that the low frequency noise in the background in B brought more difference, so it felt doubtful and not so secure.			
		Music that is more similar to heartbeat may evoke worries.	"I feel doubtful and worried because of the echo (from the drum) which some- times stays longer, so I will wonder what happened. (The background sound of the drum sounds like heartbeat.)" (P5)			
		Information-wise, people may prefer sim- pler dynamics.	"I prefer [A] to [B] because it is clear instead of complex." (P5)			
			"The pauses are sometimes shorter or longer, and I question: 'Is it how it's sup- posed to be? Are they alright?'" (P6)			
			"It feels complex because there are more elements, so it feels more confusing." (P4)			
		People may like music with more elements when it paints the picture of the situation.	"What I really loved was that I felt like almost every element of the context is there [in C]: suspense, sadness, joy" (P6)			
		People may relate the dynamics in the mu- sic to the (concious) state of the patient.	"The patient [in B] might be conscious. They are active and moving around, and awake, while [A] feels like sleeping." (P4)			

Theme	Sub-theme	Description	Examples			
	Music style	Familiarity is important in how much peo- ple feel connected or intimate.	P4 felt distant when listening to A because it felt Asian, and they were not at- tached to this music style. "I will feel more connected if it is the style of the loved one."			
			P5 felt [B] was intimate the bass was like a water drop, which felt familiar, and ap- peared sequentially.			
			"I like the music [in C] because it feels closer to the type of music I listen to." (P5)			
			"The music [in A] sounds like a normal thing that I listen to in the morning." (P2)			
		People feel relaxed because of the slow tempo and "happy-flovered" chord.	"I like the music, because of the slow tempo (which is good for relaxing). I prefer slow paced music. It is happy flavored, and not boring and slow for sleep." (P3)			
		The negativity and uncertainty mainly comes from the low and complex back-	"I feel doubtful because there is a low buzz which feels sinister, like something bad is going to happen." (P6)			
		ground layer and the ambiguous (sixth) chord and instability.	"It sounds a bit ominous, and not super stable. I feel anxious, and need to be ready for something to happen." (P1)			
			"I felt a little bit depressed because of the uncertainty [in concept A]. There is tenderness because overall it felt quite soft and gentle." (P5)			
		People find a piece of music more pleas- ant because of the lighter tone and joyful	"[Concept C] is pleasant and appealing because the music is more cheerful. It seems to involve more joy, but not energetic (in a good way)." (P1)			
		chord, and the softness/tenderness is im- portant.	"I don't want something too dashing." (P2)			
			"[Concept C] is more light and joyful." (P3)			
			"It felt insecure during a certain sound when it felt like a punctuation." (P5)			

# E. Second User Test Script (see Chapter 7)

## Introduction

Welcome to the user test of CareTunes for Families. This project explores the possibility of building a new kind of connection between the families of Intensive Care Unit (ICU) patients and their loved ones at the hospital. As there are limitations in visiting a patient in the ICU, and as the patient might be sedated or unconscious, this new design aims to allow the families to connect remotely with their loved one through music, when they are outside the hospital. Each patient has a main theme, and the music changes according to the patient's mind and movements.

## User test explanation

In this user test, we will evaluate the design from two aspects: the music itself and the overall experience. Today we will first have an half-hour interview to evaluate the music, then you will experience the design for approximately three days, which will not take you much time, and after that we will have a second half-hour interview to evaluate the experience.

## **Background questions**

Can you first tell me your gender and age? Have you ever had any relevant experiences in having any close relative in the ICU? Who is/was the relative? What is/was the cause (and how did it end)? What is/was your experience (back then)? How do/did you feel?

# Music testing 1 - presenting the patient

### Introduction

You are about to hear 3 pieces of music. The pieces are simulations of music being generated from patients in the ICU. And in this case, I would like to ask you to picture one of your loved ones is in the ICU, and that this music is generated from them. The music will consist of a main theme of your loved one, and will change according to their mind and movements. And now please listen to the music, and I will ask you some questions afterwards.

### Interview questions after each sample

Can you explain the reasons behind the questionnaire scores?

How do you interprete the music?

What do you think this music tells you about your loved one?

## **Role-playing setup**

That was the end of the first part of the user test. Next, we will be testing the overall experience of using the service. The service would eventually be provided through and APP, but for the user test, we can simply use existing APPs to simulate the experience.

In order to create a realistic and immersive experience, we will need to do some role-playing throughout the test. I will be playing the service system, and you will be the family member of a patient in the ICU, so first, we need to determine who the patient is. Do you feel comfortable picturing your [relative in the ICU] in the scenarios throughout the user test? Or do you wish to picture another family member of yours?

Whom would you feel comfortable picturing in the scenarios throughout the user test? For example, your grandparents, parents or spouse.

And what is [his/her] last name? You can give me [his/her] real last name or a made-up name.

It is possible that the thought of your [relative] in a critical situation might cause you some stress during the user test. If you at any point feel that it is too much, please let me know.

## **Prototype introduction**

Imagine you have come to the hospital after learning about the admission, and the nurse has just explained the situation of your [relative] to you, who is sedated at the moment. The nurse has introduced you to the Care-Tunes for Families service, and this is the first message you receive from the system.

### After first use of prototype

In the final product, there will be an in-built live-streaming channel. However, due to the limitations of the user test, we will use the YouTube streaming platform. Therefore, several links will be provided, and you can click on the links to listen to the streaming for long periods of time.

You will receive one or two messages each day from today to our next interview, I would like to ask you to listen to them for the purpose of the research. And if you want to, you can also listen to the streaming.

# Final interview after prototype testing

### Introduction

Welcome to the final interview. I would like to thank you for testing out the experience, and I here are some questions about how you find the experience.

### Interview questions:

When do you think was the best time to receive a message?

Did you listen to the streaming? If yes, when and how long did you listen to it?

Why did you want to listen to the streaming?

Regarding the overall experience, can you fill out the following survey?

Were there any concerns when you were using the service?

What differences do you think the product would make?

Please imagine that after the patient's discharge/transfer/death, you are able end the music yourself when you want to. How do you feel about it?

If the APP would provide you with a 3 minutes long mashup of pieces of musi throughout the journey, would you want to keep it?

Would you like to be able to choose the theme?

## Questionnaire

### Questionnaire for the music samples in the first session.

	-3	-2	-1	0	1	2	3	
uncertain								assured
hopeless								hopeful
worried								calm

### Questionnaire for the overall experience in the second session.

	-3	-2	-1	0	1	2	3	
distant								intimate
uncertain								assured
hopeless								hopeful
worried								calm

