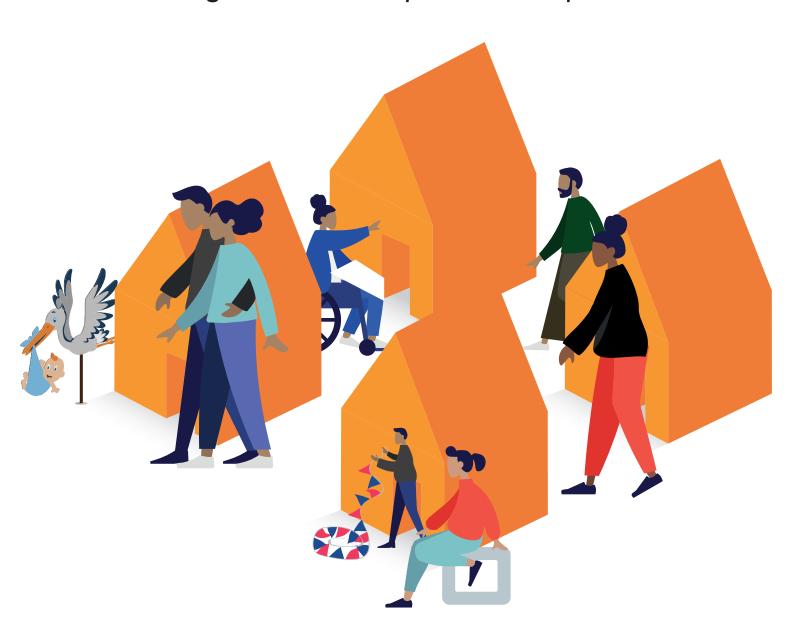
# The NICU Neighbourhood

Creating a low-stress parental experience



Wikke Alphenaar

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Master Thesis By Wikke Alphenaar





# **EXECUTIVE SUMMARY**

When pregnancy is terminated prematurely, from 24 weeks the newborns can be treated at the Intensive Care Neonatology (ICN) at the Amsterdam UMC. At this department also at term babies with severe medical conditions are treated. The parents of the newborn find themselves in an intense, emotional situation. The experiences at the ICN can strongly influence the parental well-being and can even lead to Post Traumatic Stress Disorder (PTSD) (Lefkowitz, Baxt & Evans, 2010). The emotional state of parents during the ICN-hospitalisation can influence the condition of the baby on short and long term (Civic & Holt , 2000; Manning, 2012).

The ICN will be renovated in 2022, the perfect change to create a innovative, top-notch department that distinguishes itself by addressing the parental experience. However, the Amsterdam UMC did not developed a clear strategy or service concept to deal with this emotional parental experience. Therefore understanding how to improve the parental experience in the future department is missing.

Agrawal & Gaur (2016) learned parents identified the stressors being separated from the baby and not being able to take care of their baby caused the highest level of stress. Hassenzahl, Diefenbach & Göritz (2010) described a set of needs that can be used to design for positive experiences. From these needs, autonomy is considered to be the crucial need in the situation of the NICU. Autonomy and the two stressors need to be fulfilled in order the create a lowstress parental experience. For this, the NICU-Need model is created. The model includes three important values: responsibility, security and information. Per value, two needs are identified:

feeling influential and decisive, feeling confident and competent and feeling knowledgeable and reassured. When a design fulfils these needs, a low-stress parental experience can be achieved.

Parents should be supported at arrival, during their stay and when leaving. Therefore a vision is created: the NICU should be organised as a neighbourhood. The specific Single Bed Unit is home, the nearby parents are neighbours and the rest is part of the district. The NICU should be a place where birth can be celebrated and people can feel like a family from day one. The concept should bring tranquility and positivity, give a sense of ownership and be noncompelling and supportive.

A design that contains three different elements was created: The Lamp, the NICU Mailbox and the Writing Wall. The Lamp embodies the ritual of arriving and leaving, and makes parents feel decisive, competent and confident. It is a non-verbal connecting element between parents and informative tool for the medical staff. The NICU Mailbox creates a moment to settle in the SBU and makes the parents feel knowledgeable and reassured by providing them with information and enable them to make social contact in an accessible way. With the Writing Wall, the name of the baby is written on the glass door of the SBU for a higher sense of ownership. Additionally, with markers the wall can be decorated. The ICN should implement a integrated animal theme to make the NICU less clinical, to allow for recognition by parents and create coherence in all elements.

The lamp and the NICU Mailbox are validated with parents. However, to be able to implement the vision, the elements need further development.



# Acknowledgements

This report is the result of my graduation project. An individual project. However, throughout the project a lot of people supported me. I would like to thank everyone who was involved in one way or another. You made it possible to do this project.

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# **GLOSSARY**

The glossary is intended to create consensus about the meaning of various terms in this report.

# **AMC**

(NL: Academisch Medisch Centrum) Academic Medical Centre, located in Amsterdam.

# Amsterdam UMC

(NL: Amsterdam Universitair Medisch Centrum) Amsterdam University Medical Centre, a merger of the AMC and the VUmc.

# Autonomy path

The course of the parental autonomy feeling throughout the entire NICU-route.

# CC

A room where both the newborn as the hospitalised mother can be treated.

# **EKZ**

(NL: Emma Kinderziekenhuis), Emma Children's Hospital, integrated in the AMC.

# **EVV**

(NL: Eerst Verantwoordelijke Verpleegkundige) Primary Responsible Nurse, a nurse that is main responsible for the care of a specific patient.

# FIC

Family Integrated Care, a healthcare approach developed specific for the NICU. The goal of FIC is to integrate families as partners in the care team to stimulate interactions between parent and child and to build parental confidence.

### First-line care

Department where first treatments after diagnosis are given to a patient, often simple treatments, provides first-line care.

### HC

High Care, patients at the HC the care is less intense compared to the IC. However, at the HC neonatology newborns can still need in an (open) incubator and be connected to monitoring equipment.

### IC

Intensive Care, patients at an intensive care department need intensive care day and night. Newborns at the IC neonatology are in an incubator and often need to be ventilated.

### **ICN**

(NL: Intensive Care Neonatologie) Intensive Care Neonatology, a is hospital department specialising in intensive care of ill or premature newborns.

# Incubator

An incubator is a machine used to maintain suitable environmental conditions for a newborn.

# MC

Medium Care, patients at the MC neonatology only rarely need a open incubator. Less equipment is needed compared to the IC and HC.

### Needs

A set of physiological or psychological requirements for well-being.

# **NICU**

(NL: Neonatale Intensive Care Unit) Neonatal Intensive Care Unit, the specific area where newborns are treated at the ICN. Often used to indicate the ICN.

## **NICU-route**

The parental NICU experience from just before hospitalisation until just after discharge.

# **PNC**

(Perinatologisch Centrum) Perinatological Centre, The collaboration between the ICN department and obstetrics department at the AMC.

### **PTSD**

(NL: Posttraumatische Stressstoornis) Posttraumatic Stress Disorder, a psychological disorder that can develop after a person is exposed to a traumatic event.

# Qualities

A set of distinguishing attributes SBU A room where only one patient is treated at the time.

# Second-line care

Care that is provided when initial treatment, first-line care, does have the longed effect.

# Third-line care

Treatment that is given when initial (firstline care) and subsequent (second-line care) treatment doesn't work.

# **Values**

Non-tangible characteristics (such as a principle or quality) that are intrinsically valuable or desirable

### VKC

(NL: Vrouw-Kind Centrum) Woman-Child Centre, the collaborations between woman and child care divisions at both the AMC and VUmc.

# **VUmc**

(NL: Vrije Universiteit Medisch Centrum) Vrije Universiteit Medical Centre, located in Amsterdam

### **WKZ**

(NL: Wilhelmina Kinderziekenhuis) Wilhelmina Children's Hospital, located in Utrecht.





# 1.1 OBJECTIVE

This master thesis is the result of a graduation project for the master Design for Interaction at Delft University of Technology. The aim of this project was to design a concept that improves the parental experience at the Intensive Care Neonatology at the Amsterdam UMC. To achieve this, the project focused on creating a low-stress parental experience. Various researches were done to specify the values and needs that need to be incorporated into the design in order to fulfil the aim. This thesis documents the research process, the findings and the design.

# 1.2 AMSTERDAM UMC STRUCTURE

# 1.2.1 THE AMSTERDAM UMC

The Amsterdam UMC (University Medical Centre) is a merger of two academic hospitals (the Amsterdam Medical Centre (AMC) and the VU Medical Centre (VUmc)). These hospitals joined forces on June 7 2018 and have been managed as one hospital since. The Amsterdam UMC employs 15.000 professionals and treats over 350.000 patients yearly, but besides patient care also focuses on scientific research, education and training. This differentiates an UMC, of which there are seven in the Netherlands, from peripheral hospitals and brings the expertise to treat patients with more complex medical conditions.

# 1.2.2 THE WOMAN-CHILD CENTRE

Despite the merger of AMC and VUmc most of their departments still operate independently. The goal is to merge departments that are in the same division, but distributed on both hospitals. Of the ten divisions that merge the Woman-Child centre (Vrouw-Kindcentrum, VKC) will be the first. The VKC division consists of multiple departments that can be categorised in either care related to children or care related to pregnancy and giving birth. The merger of these departments involves both relocation and reorganisation. Currently the process of merging is in transition phase and should be completed by 2022. When the transition is completed, all third-line medical VKC procedures will be done at location AMC, first- and second-line care will be provided at location VUmc.

At the VKC, the patient and his social environment are key. They provide care based on the best available evidence, the development level and the stage of life of the patient. Decisions are made together with the patient and their family. To ensure this patient & family centred care they have created three main values: Open, Sensitive and Innovative.

# 1.2.3 THE PERINATOLOGICAL CENTRE

During the merger of the VKC departments, a new department is added. This department is called PNC and includes neonatology and the obstetrics healthcare. The obstetrics department takes care of childbirth and prenatal diagnosis for about 3200 deliveries a year. The neonatology department takes care of about 1000 babies yearly.

After the completion of the merger, the PNC will operate at location AMC and the subdivisions will share the same floor. To accommodate both subdivisions, renovations need to take place. To ensure this collaboration will support staff and patients of both obstetrics and neonatology a PNC-building team was set up. This team is for example responsible for improving the floor plans made by the architects. In order to ensure a state-of-the-art VKC and PNC eight ambitions were created. They will focus on Family Integrated Care (FIC), developing Single Bed Units (SBU's), minimise transportation of patients, create sufficient facilities for employees

### 01. THE PROJECT

and visitors, integrate the care of obstetrics and neonatology by using the Couplet Carerooms (CC), create coherence between other VKC departments and the PNC and creating a more homely atmosphere and routing. For more explanation see appendix 1. The PNC-building team created the interior for the CC-room that is going to be built after the renovations. A hospitalised mother and her newborn can be treated here. Also, the team developed the interior of the SBU. In this room only one newborn is going to be treated, so every patient has his own SBU. A SBU reduces audio stimuli and risk on cross infections and therefore contributes to the health of the baby.

# 1.2.4 THE INTENSIVE CARE NEONATOLOGY

Research shows that from 24 weeks of pregnancy the survival rates of pre term babies are significantly higher than before this time (Smith et al., 2018). In the Netherlands newborns are treated when born after 24 weeks as they are considered to be viable (AMC, 2018). Babies born after a pregnancy of less than 28 weeks are extreme premature, after 32 weeks they are considered to be severely premature, up to 37 weeks is premature and after 38 weeks they are born at term.

At the Intensive Care Neonatology (ICN) all newborns from extreme premature to at term babies with severe medical conditions are treated. Common medical conditions that are treated at the NICU are dysmaturity, need for ventilation, difficulties with the heart or blood pressure and birth defects. The ICN is currently located at the VUmc and the AMC. The ICN at the AMC is part of the Emma Kinderziekenhuis (EKZ). From 2022 only the AMC will provide the ICN care as the VUmc will host second and third line care.

# The current department

The current department has three Intensive Care Units (NICU's). Per unit twelve babies can be hospitalised, so multiple babies are treated within one room. The ICN department is often called the NICU as this refers to the specific room where the child is treated. Within each

unit nurses have a stationary desk to oversee all newborns. Each baby has a primary responsible nurse (EVV'er, Eerst Verantwoordelijke Verpleegkundige) to ensure good care. Nurses can easily ask other for assistance because multiple nurses are stationed in the same unit. Doctors visit the unit when a baby is in need, they are not stationed permanently at the NICU.

Parents can visit the unit 24/7, but they can not sleep over. By exception the parental lounge can be used to sleep over when a baby's condition is acute life-threatening. Normally the lounge is used during the day to take a break. When parents visit the NICU they can help with simple nursing tasks. Sometimes parents have family or friends visiting the ICN. Visitors are allowed if they follow the strict hygienic rules and visit the unit in small groups.

# The future department

The future ICN will be located in the AMC and have 32 Single Bed Units, including four twinrooms and two triplet-rooms. The SBU's include all essential medical equipment and a foldaway bed for one parent. Parents are allowed to be 24/7 at the department and sleep over. To facilitate this, bathrooms, a lounge and a living room are present. At the lounge parents can sit and get coffee. The living room is equipped with more facilities and is exclusively for parents. Next to this room there will be a visitors lounge. See appendix 2 for the floor plan.

Because parents are allowed to stay they are likely to spent more time in the SBU then the nurse. Therefore the nurse becomes a visitor of the SBU. This shift of nurses always being present at the NICU to them being only temporarily present at the SBU should not be overlooked. When the parents appropriate the SBU, the interaction between the parents and the medical staff drastically differs regarding the current situation.

The nurses will be stationed at a nurse post and distribute their time between all SBU's. They will have less contact with colleagues while nursing a baby. To reach out for assistance they will use a

pager system. The information transfer between nurse and doctor will happen at the SBU of the discussed newborn.

"Parents
appropriate
the SBU and
see us as an
uninvited
guest. There
is more
aggressive
behaviour in
SBU's"

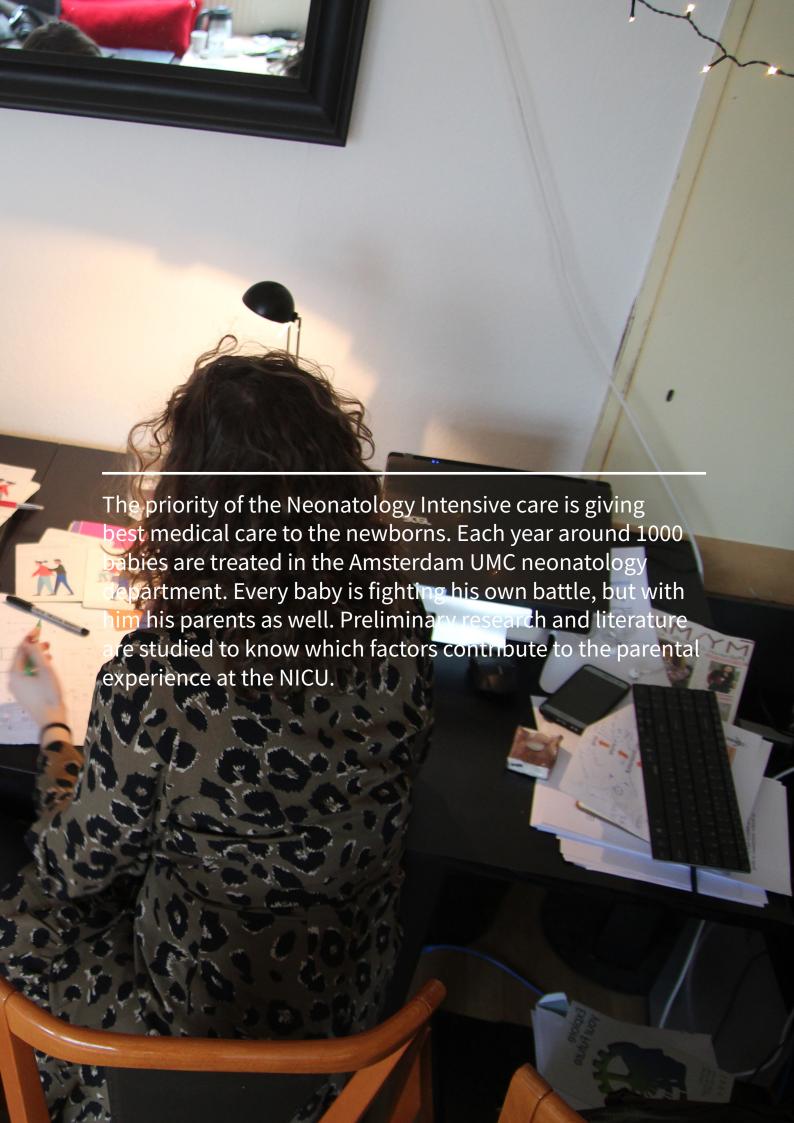
- Nurse at LUMC

# 1.3 RELEVANCE

The SBU's and the CC-rooms are expected to help the Amsterdam UMC realising their ambition to provide FIC, see appendix 1 for more information. While the priority lies at giving the best medical care to newborns, little is known about the parents of the patients. However, the parental experience is important as well. An average stay of a patient is about twelve days, but it can be up to 100 days. During the stay of the baby, the parents visit the department frequently, so this environment has a significant impact on them. Research shows that the emotional state of parents during the ICNhospitalisation can influence the condition of the baby on short and long term (Civic & Holt, 2000; Manning, 2012). The experiences at the ICN can strongly influence the parental well-being and can even lead to Post Traumatic Stress Disorder (PTSD)(Lefkowitz, Baxt & Evans, 2010).

However, the Amsterdam UMC did not developed a clear strategy or service concept to deal with this emotional parental experience. Therefore the people in the organisation lack understanding how to support and improve the parental experience and consequently how FIC can successfully be implemented in the future ICN. Because, although the SBU's enable parents to stay at the department, it does not necessarily means that parents will actually do this. Parents that do sleep over also need a certain incentive in order to successfully implement FIC. The well-being of the parents is crucial in this process.





# 2.1 STRESSORS

Miles, Funk & Carlson (1993) developed the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU). This tool is designed to measure parental perception of stressors that arise from the physical and psychological environment of the NICU. The stressors were divided into Infant Behaviour and Appearance, Parental Role Alteration and Sight and Sound. The category Infant Behaviour and Appearance is purely medical related and lists factors as the breathing pattern and incisions. Sight and Sound includes the noise of the monitors and equipment and other babies among other things. During their study the greatest parental distress was reported for items within the Parental Role Alteration category. This subscale represents factors faced by parents in their role as a parent and their relationship with the baby. The factors of the Parental Role Alteration category are most stressful for both mothers and fathers. (Agrawal & Gaur, 2016). As this category consist out of multiple taking-care sub factors and separation it can be said that parents identified being separated from the baby and not being able to take care of their baby caused the highest level of stress.

The medical care of the professionals can influence the infant behaviour and appearance to a certain level, furthermore only the newborn affects these factors. For the Sight and Sounds category the organisation of the department can play a big role. The SBU's will remove the stress generated by seeing other ill babies and hearing all alarms of the other patients. Also the trend of Silent Alarms will probably in the near future have a positive influence on stress amount in this category. (van Pul, 2015). FIC will have a positive influence on the Parental Role Alteration category as providing care will be more

accessible. However, therefore it needs to be implemented successfully. As the stressors not being able to give care and being separated from the baby prove themselves to be most stressful, addressing these will have a positive impact on the parental well-being. When the parents have a positive experience regarding the ICN, they are more likely to stay at the at the SBU and have energy and incentive to take part in the FIC.

# "You are cast out into a world you did not even know it existed"

- Father of a daughter born at term with heart failures.

# 2.2 STRESS REDUCTION

# 2.2.1 CONSUMER NEEDS

The Amsterdam UMC started, prior to this research, a collaboration with Koos Service Design to investigate the parental experience at the NICU. During the collaboration nurses, doctors, parents with experience at the NICU were interviewed. This resulted in some core values that need to be addressed in order to have a good and satisfactory parental experience. All reviewed values were part of the Elements of Value Pyramid (Almquist, Senior, & Bloch, 2016).

The theory of Almquist et al. (2016) is based on Maslow's theory of human motivation (Maslow, 1943). Maslow created a hierarchy pyramid in which the underlying level of human needs must be met before an individual will have the desire to fulfil the needs in the higher level. See figure 1. The most advanced need in this theory is self-actualisation. When self-actualisation is achieved it is believed that the individual is to be ultimately happy. Almquist et al. (2016) use this theory as a starting point for pinpointing what customers value in a product or service. They described 30 customer values and state that, when optimally combined, these can increase customer loyalty and revenue growth. Customers search for ways to fulfil these needs and are eager to use a product or service that is assumed to help with this.

Because the NICU is not a commercial context the theory is not completely applicable. However, the parents can be seen as a customer of the hospital. They, as customers, are seeking for ways to fulfil those 30 needs.

# 2.2.2 PARENTAL VALUES

The preliminary research shows that the value of stress reduction is the value that is most frequently asked for by the customers. In figure 2 you see the Elements of Value model which illustrates the 30 customer needs. In this illustration the values found during the preliminary research are highlighted. The identified key values for a positive parental experience at the NICU are hope, selfactualisation, stress-reduction, wellness, fun, access, reduce risk, organises, connects, quality, sensory appeal and informs. The values were identified after analysing the interviews. Thereafter, the insights were clustered to see the origin of the need. Figure 2 shows that a lot of the values are linked to one need: stress reduction. This shows the importance of the PSS:NICU(Miles et al., 1993). The need for stress reduction is such an important factor in the parental experience at the NICU that this should be taken into account when developing the department. See appendix 3 for a explanation about all highlighted needs and the connections between them.

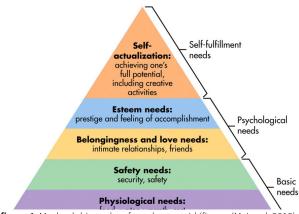


figure 1 Maslow's hierarchy of needs pyramid (figure: (McLeod, 2018)

# **02. PARENTAL EXPERIENCE**



 $\label{figure 2} \textbf{Many of the found values are related to stress reduction}.$ 

### 2.2.3 METAPHOR

To communicate and describe the current parental experience a metaphor was created. See figure 3. This roller coaster metaphor can be roughly divided into three parts.

## Phase 1

The first phase is extremely rough with no time to look around. This is the time when the child is just admitted or still in severe unstable condition.

# Phase 2

The second phase is characterised by longer intervals between the incidents. Parents have some time to notice the environment they are in. This enables parents to be more open for social contact and pay more attention to their surroundings.

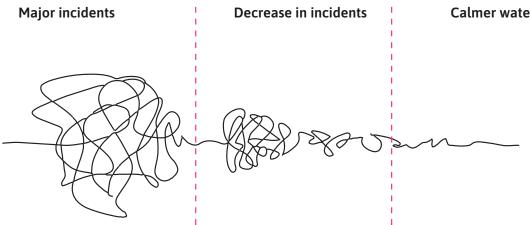
### Phase 3

In the third phase almost no incidents occur and the child is relatively stable. The only loop that is waiting now is the transfer to a peripheral hospital. In this metaphor the hospital can be seen as the builder of the roller coaster rail. The baby's condition determines were the cart is going. Meanwhile, the hospital tries to build the track to keep the cart going and prevent it from falling down.

The emotional contradiction of having a child that needs Intensive Care and the roller coaster ride is interesting. When going for a roller coaster ride you expect it to be fun. However, in this case you have taken a ride in the NICU roller coaster. This is no fun at all, it is exhausting and terrifying. The goal is to leave this horrible roller coaster and continue with the expected fun theme park visit.

# **Start NICU experience**

# Calmer waters



- No control, feeling of total powerlessness
- If the loops are more intense, it leaves less time take some time to 'look around'
- The survival-switch is turned on, everything is a blur.
- Parents try to foresee the coming track and the possible next loops.
- Some more time to look around and allow to experience the outside world.
- The Amsterdam UMC is the most controlled rollercoaster possible, moving causes stress because the seatbelts are getting less tight

Move to local hospital

figure 3 Metaphor was created to communicate parental experience.





# 3.1 DESIGN FOR EXPERIENCE

# 3.1.1 DESIGN AND WELL-BEING

In general products are designed to enhance people's quality of life. How a product enhances the quality of life depends largely on the characteristics and use of the product. Pohlmeyer & Desmet (2017) question if, although design has absolutely contributed in making our lives easier, safer and more pleasurable, design also made our lives more meaningful. That design does not necessarily contribute to our well-being is verified by (Diener & Suh, 1997; Easterlin et al., 2010; Helliwell, Layard & Sachs, 2012). Those researches show that although their material well-being is significantly increased, the happiness ratings on average stayed the same. This suggest that a product which is designed to add value to our life, does not automatically contribute to the quality of life as would be expected. Therefore, when the goal is to enhance the well-being of the parents by focusing on fulfilling the stress reduction need, it is not enough to just try and check the value-boxes in the Elements of Value Pyramid of Almquist et al.(2016).

Multiple studies that researched consumer behaviour confirmed the 'experience recommendation' theory. This theory states that when you buy experiences instead of material items you will become happier. (Nicolao, Irwin & Goodman, 2009; Van Boven & Gilovich, 2003). Vice versa, a design that has the main goal to improve the well-being of people should focus on activities and experiences. This does not mean material objects should be disregarded completely, but it requires a focus on the

activities and experiences objects can provoke (Pohlmeyer & Desmet, 2017).

# 3.1.2 EXPERIENCE DESIGN

To ensure the design creates an experience that addresses the main stressors and therefore improves the well-being of the users it is needed to structure the process in such a way this design for experience is supported. An experience is shaped by the characteristics of the user and those of the product. All actions and processes that are involved, such as physical actions and perceptual and cognitive processes, will contribute to the experience. Moreover, an experience is always influenced by the context in which the interaction with the product takes place (Desmet & Hekker, 2007). The process of design for experience is explained by Hassenzahl et al. (2013) as an approach which places pleasurable and meaningful moments at the centre of all design efforts. Creating a meaningful moment requires understanding of what a positive experience is and how this can be created through activity. Secondly, it should be understood how to mediate the activity that results in the longed experience through design. Where the design can be a physical object as well as a service.

To know what the positive experience is and, more detailed, the activity that is longed in the specific situation research needs to be done. Understanding of the people and the context is essential. For example, the goal to fulfil the need for relatedness can be achieved in many

ways. Depending on the people and the context a handshake might be more appropriate than a hug (Hassenzahl et al., 2013). This is the practice that is part of the activity that creates the experience. This understanding can, for example, develop by observations, interviews and generative sessions. See figure 4 for the levels of experience that should be taken into account by design for experience. A design should support each layer accordingly to be able to create the longed experience.

# Experience Activity Practice Need

figure 4 Levels of experience.

# 3.2 FUNDAMENTAL NEED

Next to Maslow's theory of human motivation (Maslow, 1943) other theories have been developed on human motives, needs and values. Where Almquist et al. (2016) continues with Maslow's work to develop a method to create customer loyalty and revenue growth, Sheldon, Elliot, Kim & Kasser identified a top ten psychological needs that contribute to wellbeing (2001). Continuously this list of needs was narrowed down to fundamental needs as a source for positive experience with interactive products by Hassenzahl, Diefenbach & Göritz (2010). Their study shows that experiences can be classified into groups based on the primary need they fulfil. The needs that could clearly be classified were autonomy, competence, relatedness, popularity, stimulation and security. These needs can be seen as potential sources of positivity because they create a positive affect and therefore contribute to the well-being.

The need for stress reduction proved itself extremely important when analysing the interviews using the Elements of Value Pyramid (Almquist et al, 2016) and reviewing the literature researching the PSS:NICU (Miles et al., 1993, Agrawal & Gaur, 2016). However, a successful design for parental experience at the NICU requires research into which fundamental need is most pressing in this context. Figure 5 shows how these theories contribute to this project. The theory of Maslow together with the more specific theory of Almquist, Senior & Bloch (2016) and the NICU-related research of Miles, Funk & Carlson (1993) help with identifying the unmet needs. This is the principle of this project. Consequently, a suiting approach is needed

to fulfil those identified needs. Therefore the needs that can be used as a source of positive experience as listed by Hassenzahl, Diefenbach & Göritz (2010) are reviewed. This selection of needs is adapted from the list of needs that influence well-being from Sheldon, Elliot, Kim & Kasser (2001). To benefit optimal from these drivers of positivity the Experience Design approach of Hassenzahl et al. (2013) is used.

# **Identify unmet needs Maslow** (1943) **Human Motivation** Theory` Almquist, Senior, & Miles, Funk & **Bloch** (2016) **Carlson (**1993) Elements of Value PSS:NICU, Parental **Pyramid Stressor Scale** Approach to fulfill the needs **Sheldon, Elliot, Kim & Kasser** (2001) Needs that influence well-being Hassenzahl, Diefenbach Hassenzahl et al. (2013) **& Göritz** (2010) **Experience Design** Needs as a source of approach positive experiences Design that meets the needs **GOAL**

figure 5 Literature structure.





# 4.1 FINDING THE FUNDAMENTAL NEED

# 4.1.1 GOAL

A successful design for parental experience requires knowing the fundamental need in the NICU context. The goal of this research is to understand which fundamental need, as described by Sheldon et al. (2001) and adopted by Hassenzahl et al. (2010), is most crucial in the context of the NICU. The fundamental needs that were reviewed are; autonomy, competence, relatedness, popularity, stimulation, and security. In addition to finding the applicable fundamental need, it's relations to the stressors: 'being separated from the baby' and 'not being able to take care of their baby' are investigated. This way it is ensured the fundamental need addresses the key stressors of the NICU situation. The questions that are addressed:

- Which fundamental need is most crucial for parents in the context of the NICU?
- 2. How is this fundamental need related to the stressors being separated from the baby and not being able to take care of their baby?

# **4.1.2 METHOD & TOOLS**

# Observation & preliminary research

To research which fundamental need is crucial for parents at the NICU information was collected by visiting and observing at the NICU at Amsterdam UMC, location AMC & VUmc and additional visiting the MC, HC and IC at the Neonatology department at the Wilhelmina

Kinderziekenhuis (WKZ). Moreover, findings of the preliminary research of the AMC and Koos Service Design provide insight into the entire NICU-route, the NICU experience from just before hospitalisation until just after discharge. These findings are plotted on the road map of the Amsterdam UMC NICU made by Philips Healthcare. For more information, see appendix 4.

# Sensitising booklet & interview

To research the relation between the fundamental need and the stressors interviews were held. Seven parents who currently stay at the NICU and five parents that experienced the NICU more than a year ago were interviewed. Figure 6 and figure 7 show a sensitising booklet. The interviews covered the topics presented in the sensitising booklet the parents received. The topics were structured according to the path of expression (Sanders & Stappers, 2012). During the interview itself the laddering technique was used to gain more detailed knowledge (Reynolds & Gutman, 1988). For more information, see appendix 5.



figure 6 The sensitizing booklet.

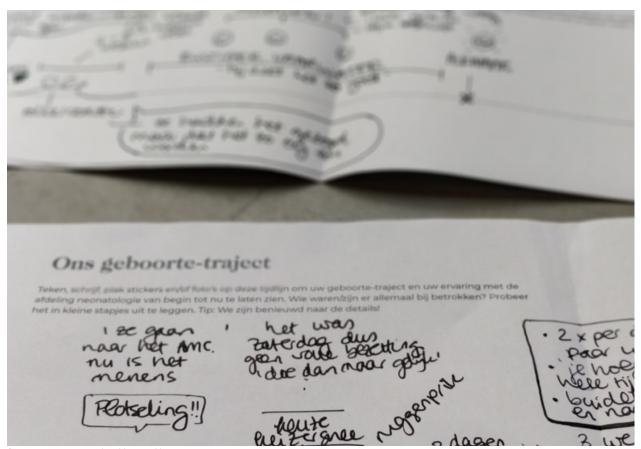


figure 7 A sensitizing booklet used by a participant.

# 4.1.3 KEY FINDINGS

## Autonomy

From the analysis autonomy is considered to be the crucial fundamental need to design for parental experience in the context of the NICU. For reviewing the fundamental needs the definition of autonomy of Hassenzahl et al. (2010) was used: Feeling that you are the cause of your own actions rather than feeling that external forces or pressure are the cause of your action. However, after this analysis the definition is slightly adjusted to optimise the fit for the NICU-environment. Autonomy when referred to in this project is defined as: Feeling that you can be the cause of your own actions without guilt and contribute to the actions of your child rather than feeling that external forces or pressure are the cause of your action.

# Autonomy as umbrella term

The need 'autonomy' can be linked to the

stressors as autonomy section 'feeling that you can contribute to the actions of your child' is clearly related to the stressor of not being able to take care or your child as described in the PSS:NICU tool. This evident relation applies also for the other section: 'feeling that you can be the cause of your own actions without guilt' that is related to the stressor of being separated from your child, also described in the PSS:NICU tool. This way autonomy can be seen as the umbrella term to address the stressors. The clusters created during the analysis of the interviews yielded three main values: responsibility, security, and information. Almost all NICUexperiences can be assigned to one of those three values. Therefore they are important when striving for a positive experience that reduces stress and contributes to the parental wellbeing. Together these values address a common pattern of the autonomy-feeling within the context of the NICU.

During the analysis of the interviews, two pressing needs were defined for all three values. For responsibility the needs 'feeling influential'

and 'feeling decisive' were formulated, security is supported by the needs 'feeling confident' and 'feeling competent' and the information value is subdivided by the needs 'feeling knowledgeable' and 'feeling reassured'. With the needs as subcategories the main value is addressed to a high extent. In this way, when all needs are addressed, the main value that contributes to a positive experience that reduces stress is touched upon. See figure 10 on page 39 for the NICU-Need model that combines all contributing needs.

Responsibility
Influential & decisive

The ability to experience responsibility in a negative or positive way is related to the empowerment of parents to feel like parents. Empowerment is related to the influence of parents on the situation and being trusted and enabled to make decisions (Uhl, Fisher, Docherty,& Brandon, 2013). When parents do not feel decisive they feel like they could create a negative reaction with the child, however if they do feel decisive this contribution to the care strengthens their parental empowerment and therefore their responsibility feeling.

# **Security**Confident & competent

This contributor of autonomy is about the feeling of competence but also about the confidence they have in the healthcare professionals. In addition, the feeling of own competence enhances the confidence in their own parental skills. When parents cannot contribute in the caregiving because of insecurities the parental empowerment is lacking.

## Information

# Knowledgeable & reassured

Parents are eager for information about the condition of their child. With more information they know what to expect and are aware of the situation of the child and consequences of medical and nurturing tasks. In this way they feel more knowledgeable. Any kind of information feels often better than having no clue at all.

Positive information can have a comfortable reassuring effect. This reassurance can help parents with gaining some piece of mind.

The NICU-Need model is essential when designing for a positive, low-stress experience. The needs address the parental need for stress-reduction by taking into account the fundamental need autonomy, that enables to specifically design for experience, and the NICU-specific stressors being separated from the baby and not being able to take care of the baby. Therefore the NICU-Need model touches upon stress-reducing needs that contribute to improving the parental experience at the NICU.

"You feel insecure, vulnerable and dependent"

- Mother of a twin, born with 24 week.

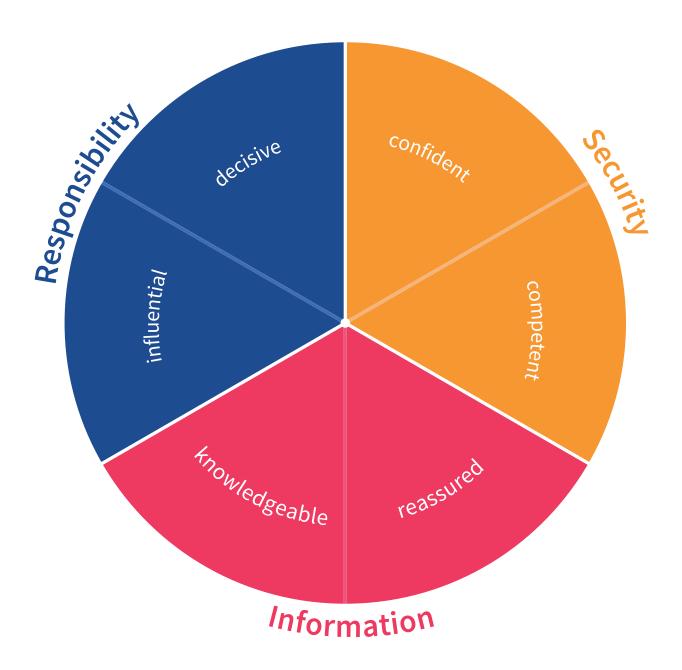


figure 10 The NICU-Need-Model combines all factors that need to be addressed to create a positive, low-stress experience.

# 4.1.4 DISCUSSION

The information that was gained for this research emerged mainly from the data of the twelve interviews. All parents had a different experience regarding the condition and the severity of the outcome of the hospitalisation of their child. Therefore various situations were compared. Parents had experience at the VUmc and AMC and in addition some experienced the Neonatology department in the Leiden University Medical Centre (LUMC), the Zaans Medical Centre (ZMC) and the Groene Hart Hospital (GHZ). Moreover, some parents knew beforehand that they had a chance on premature labour and for some it came unexpected. The medical condition of the baby was in each case very unsettling and alarming for the parents but the manifestation was diverse. For example, the baby suffered from a cardiac arrest just after birth, oxygen deficiency during labour or a harmful infection.

This difference could be alarming as the average of all experiences does not illustrate the common experience. By finding patterns in the current experiences of all participants, as how the first few days at the NICU went or felt, how they experienced the medical setbacks and how they celebrated the progression of their child, a common experience could be found. For example, similar experiences could be found for how parents felt overwhelmed with the sudden loss of autonomy as they were not main responsible for their child, how they all crave for more information and created anxiety for a badnews conversation. It was found that all parents do want to take part in caregiving but can feel restrained or insecure by not feeling authorised or knowledgable.

Understanding this pattern in the current experience enables the designer to design a proper positive experience that contribute to the parental well-being. Because of this pattern the needs in the NICU-Need model could be defined. For example fulfilling the need for responsibility is quite abstract, but with knowledge about the context of the NICU and the situation of holding your baby, the needs feeling influential and decisive are clearly important.

A logical question to arise is if a pattern distilled from all different sources is valid. Hassenzahl et al. (2010) state that a good pattern is foremost plausible and resonates with the designer and that the exact truth is not the most central criterion. This resonation effectuates a feeling of understanding and assertion. If this is the case, it can be used when designing. Hassenzahl et al. (2013) indicates these patterns can be empirically validated.

# 4.2 MANIFESTATION OF AUTONOMY

### 4.2.1 GOAL

In order to make a design that addresses autonomy and the PSS:NICU stressors, it is needed to know how this feeling of autonomy manifest itself during the NICU-route. The goal of this research was to gain more knowledge about the autonomy-feeling of parents with a hospitalised child at the NICU. In this study the course of the autonomy-feeling during the entire NICU-route is composed by parents. Insight into the manifestation of this feeling is essential because the related practices and activities that influences the experience become visible this way. When designing for experience it is crucial to understand the practice and the activities that are at play at moment the need for stress reduction is the highest. The question that is addressed:

# 1. How does autonomy manifest itself during the entire NICU-route?

# 4.2.2 METHOD & TOOLS

To research how the fundamental need manifests itself during the NICU-route generative sessions were done. These sessions help people express feelings and therefore provide latent knowledge (Sleeswijk Visser, Stappers, van der Lugt & Sanders, 2005). In four sessions of an hour, one father and three couples were interviewed. For the generative interviews tools were developed, see appendix 6. The interview started with parents plotting their story on the timeline. This ensured parents were more at ease because the emotional story is told and enables the researcher to empathise with the parents. Next, parents had to identify three positive experiences and three negatives ones. With the timeline in mind they had to plot their feeling of control. Subsequently they had to plot to which extent they felt they were able to be there for their child. During these assignments parents could use ambiguous symbols to strengthen and express their answers.

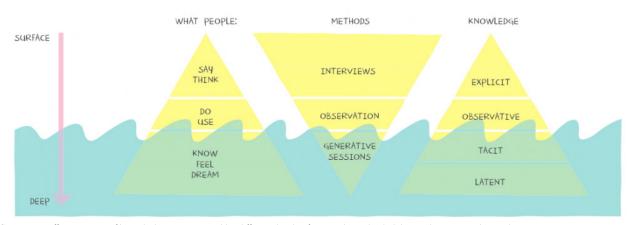


figure 11 Different types of knowledge are retrieved by different kinds of research methods (Sleeswijk Visser et al., 2005).

# 4.2.3 KEY FINDINGS

The course of the autonomy feeling can be roughly divided into three parts:

# First phase

The first important phase is around the time of giving birth. For some women it becomes clear just after birth that the child needs medical attention and this causes a drop in autonomy. It can also be that the hospitalisation was already foreseen but the hassle of the hospitalisation can still lower the autonomy feeling. For some the birth comes totally unexpected and this causes a drop in autonomy as well.

# The second phase

When the child is treated at the NICU it becomes clear that the medical condition is serious. The NICU is serious business. The parents experience a gap in their expectations of becoming a parents and the reality, as described in the roller coaster metaphor. It's not a cozy family gathering to celebrate the birth of their child.

It's the doctors who care for the child and the parents can barely do anything at all. Let alone celebrating happily the birth with friends and family. This realisation of being a bystander causes a major drop in the autonomy feeling.

# Third phase

Step by step this autonomy feeling is regained as the child's condition is improving. However, after the major drop when the child is hospitalised at the NICU, no steady increasing slope is visible. The feeling of control can decline also after admission when the child experiences a medical setback or incident. Only after experiencing something that brings hope, this slope can change into a positive trend. This medical improvement brings more parental responsibility and opportunity to take care of the child. Towards the end of hospitalisation the feeling of control will rise because of the increased responsibility and care giving opportunities.

The phases are illustrated in figure 12.

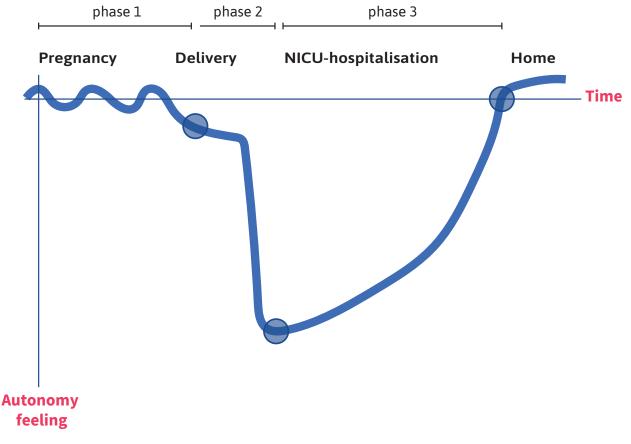


figure 12 Path of the parental autonomy feeling during the entire NICU-route.

### 04. RESEARCH

The second and the third phase are the stages were the extreme drop and the subsequent rise of the autonomy-feeling happen. In order to increase the autonomy-feeling it is desirable to unable this drop or enabling a quick rise. In these stages parents will often visit the NICU.

When the second and third phase are studied more up close a structure in the parental timeline of the NICU can be discovered. This timeline-structure is visible in figure 13. The meta, one-time, timeline is coloured blue. Here, arriving means the first visit after hospitalisation and leaving implies leaving the hospital after discharge. The pink timeline illustrates the sequence of going home and coming back. This will happen every day and in some cases multiple times a day. The orange timeline is the most frequent, this illustrates leaving and arriving at the department. All timelines start with arriving at the NICU, next is the 'stay' phase. This is the time parents stay at the department itself. If parents decide to go home or leave the department for a while this starts with saying goodbye to their child. After this they will leave, and once they are gone and head back to the hospital it all starts over. Leaving the NICU but not the hospital will occur more often because leaving the hospital is more difficult and undesirable for parents. It is considered that with the arrival of the SBU's an extra timeline is added in the parental experience. Next to leaving the hospital and the NICU, also leaving the SBU is an impactful activity.



figure 13 The parental timeline structure.

# 4.2.4 DESIGN DIRECTIONS

Phase 2 and 3 of the autonomy path are important to positively influence the feeling of autonomy and the corresponding needs addressed in the NICU-Need model. It is believed that contributing to the care is more applicable to phase three, whereas phase two is about the realisation of the distance, separation, between the parent and the newborn. A design intervention in phase two could prevent the autonomy drop and an intervention in phase 3 could enable the rise. To address these phases multiple questions are formulated and serve as possible design directions.

parents made. Of course, for each individual the experience is different, but in general a difference between the experience of at term babies and extreme prematures can be found. Mainly because of the duration of stay in the hospital, it takes more time before parents of extreme premature regain all control and have feeling of full autonomy. Because this difference could be recognised thanks to analysing the previous interviews as well, this knowledge is incorporated into the result.

## Prevent the fall

- 1. How could the incubator be a less distant barrier?
- 2. How could you make it comfortable to room-in?
- 3. How could parents be comfortable with leaving their child?

# Enable the rise

- How could parents communicate toward the medical staff what they would like to contribute (in caregiving)
- 5. How could nurses clarify what parents can do to contribute in the caregiving?
- 6. How can parents care for their child (or have the feeling they care) without physical interaction?

# 4.2.4 DISCUSSION

These interviews were done with parents with an at term baby that, due to severe medical condition, was admitted to the NICU. This is an different experience as having a extreme premature child. To put this autonomy-feeling course in perspective the data of the previous interviews (that were conducted with parents from (extreme) premature children) was compared to the statements the at term

# 4.3 IDEATION

## 4.3.1 GOAL

The goal is to create tangible ideas that support the process of arriving, staying or leaving the SBU or the hospital. The ideas mark a new phase in the research where instead of investigating the current situation the longed future experience is designed.

# 4.3.2 METHOD & TOOLS

## **Brainstorm** session

To start the ideation two brainstorm session were organised. Two sessions of two hours with four participants, IDE students, were done. During the session three ideation rounds were done. In each round two of the design direction

questions were handled. After each round, the brainstorm results were discussed.

### Tools

For this brainstorming tools were created to ensure that the participants would understand the context of the NICU and the situation of the parent. A short presentation about the parental experience at the NICU was given and subsequently each participant received an envelope with their name on it with their personal NICU story inside. The participants with a matching NICU situation formed pairs. In each pair one participant had the mission to focus on the first days after hospitalisation, the other had to target the longer term. See appendix 7 for more information.



 $\label{figure 14} \textbf{ Participants ideating on the design direction}.$ 

All material collected during the brainstorm sessions was collected and analysed as well as the recordings were transcribed and analysed

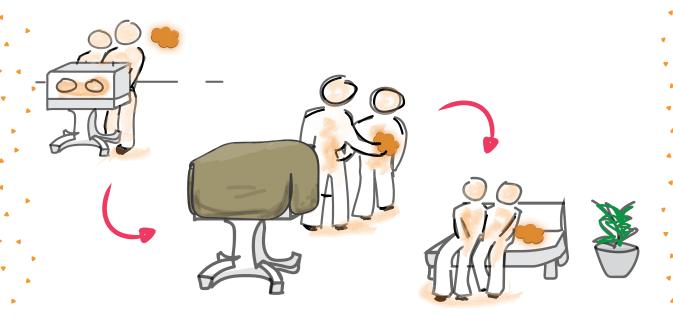
# 4.3.3 KEY FINDINGS

After all materials of the brainstorm session were analysed and processed, nine ideas cards were created. The ideas were roughly developed and visualised. From page 47 to page 55 the ideas are explained and visualised.

# 4.3.4 DISCUSSION

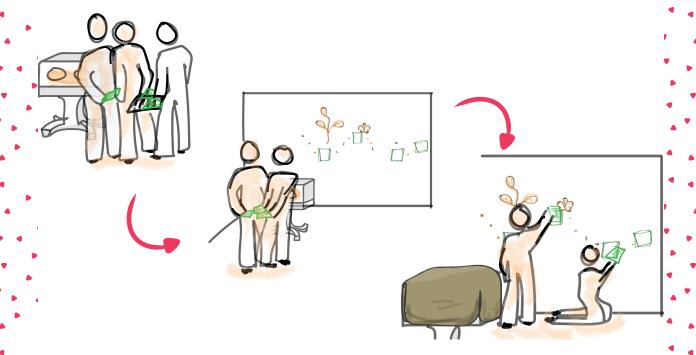
The ideas were created in order to evoke reactions in future interviews. The ideas presented on the cards were not all viable or feasible. However, they did all contain elements that were presumably desired by parents based on the previous studies. Whether parents indicate the idea as desirable or helpful with fulfilling their NICU-Needs (and therefore create a positive experience that reduces stress to contribute to the parental well-being) is at this stage of the design research much more important than the feasibility or viability.

# Wolkje



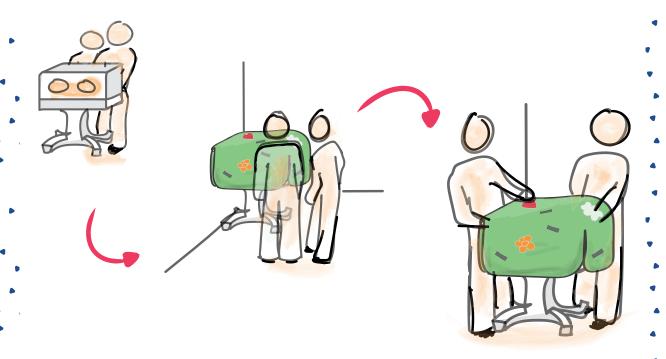
Wolkje is a interactive object that is stationed at the SBU. At the SBU it serves as a kind of nightlight. When parents decide to go home, they can take Wolkje with them. When they are at home, they can have the lamp by their side to feel more connected to their child. The lamp has the same temperature as their child, so they can feel the warmth. Moreover, it lightens up when the baby moves. When parents get back to the NICU they can put Wolkje back in the SBU.

# Information Wall



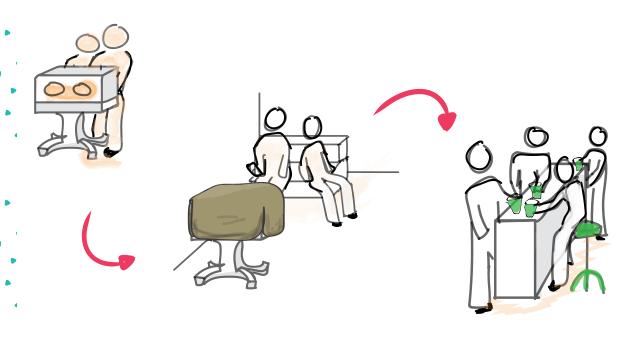
The Information Wall provides the parents with tangible, positive information cards. The doctor or the nurse could give them the cards when they update the parents about the current condition of the baby. The cards can illustrate a picture of their child as well as the milestone cards that are developed by the Vereniging Ouders van Couveusekinderen (VOC; Parents of Preemies Association). After a while a personal storyboard will develop in the room and parents can easily see the progress their baby made.

# Sensing Blanket



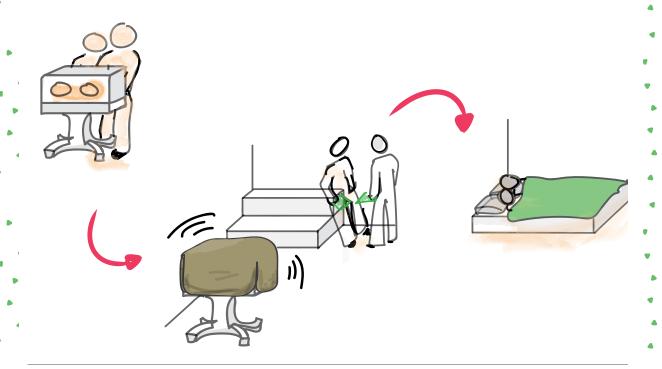
The sensing blanket should replace the current incubator blanket. It enables the parent to have a stronger emotional connection with their child while the incubator is covered to protect the child from light and audio-stimuli. The sensing blanket has three standard figures attached, one that imitates the heartbeat of the child, one where you can feel the breathing pattern and one where you can feel the warmth of the child. It is possible to decorate the blanket by fasten personal illustration to the blanket.

# Coffee Break



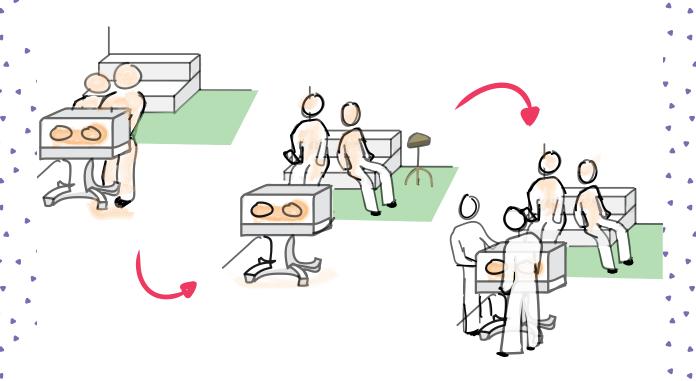
By providing a daily, recurring coffee break parents should feel comfortable to leave the SBU. The break is at the ICN itself, to lower the threshold for parents to participate. Because it is recurring it enables parents to take a social break without losing control as they know when it takes place. Moreover, it is a way to have social interaction with fellow NICU-parents and have a feeling of support.

# Night-mom



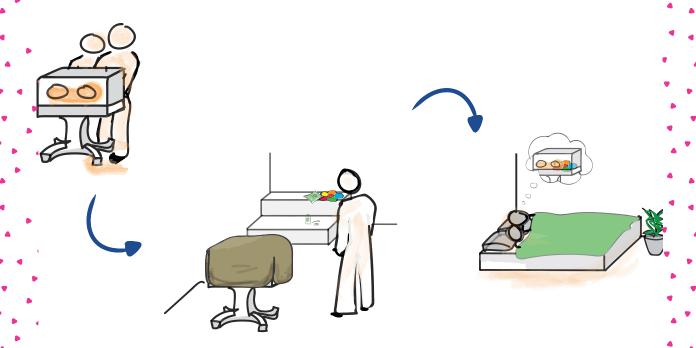
This idea is a designed verbal agreement more as a physical object. When the parent decides to sleep at home, the nurse and the parent have a official moment where they handover their parental tasks. Whatever the parental tasks may be, now the parent knows for sure the nurse pays attention to the child while she/he is at home. It is designed to give the parent piece of mind and let them sleep at home without feeling guilty.

# Parental Zone



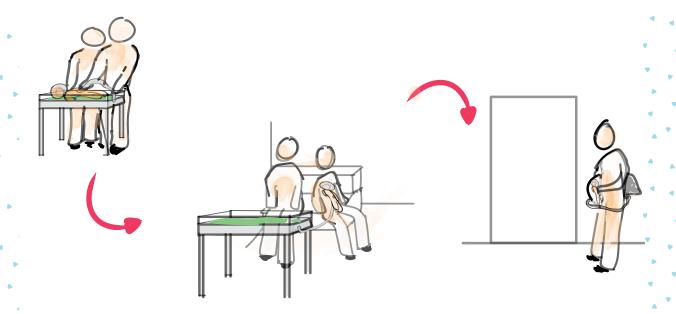
The parental zone should provide the parents with a place that feels like it is theirs. They can sit in this spot while nurses and doctors are treating their child when they are afraid of getting in the way. Moreover, here you can have some personal objects to make the room your own.

# Welcome Package



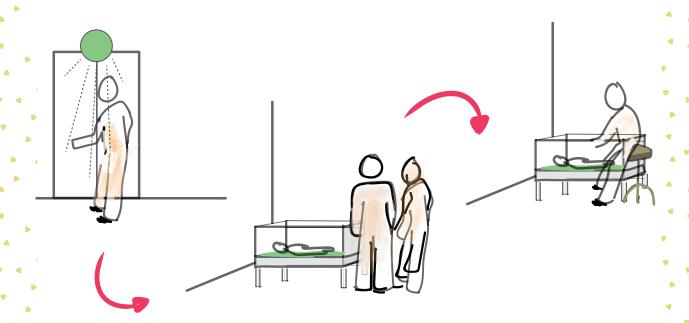
When parents visit the NICU for the first time and enter their SBU, a package with some bathroom amenities will be provided. In this way they feel welcome and supported in sleeping over at the NICU. Additional, a cheerful looking cloth is provided that can be used to absorb scent from the parent. This cloth should kept against the body during stay. It gives the parents a useful feelings. When parents leave, they can put this cloth next to the child. This way they can leave something behind and this can bring them comfort as they know the child still smells their presence.

# **Astronaut Suit**



The NICU astronaut suit is a wearable incubator suit for the newborn. This futuristic idea should help parents to have more control as they are more flexible when they want to be with their child. They can stay at the department but can also choose to take a walk outside.

# Incubator Room



In order to reduce the physical distance between parent and baby, the idea of the incubator room was developed. The child is no longer placed in a incubator as the whole room functions as large version of the machine.

# 4.4 VALIDATION OF IDEAS

# 4.4.1 GOAL

In order to achieve a design that creates a positive experience that reduces stress (caused by not being able to take care of your child and being separated) and therefore contributes to the parental well-being all the needs of the NICU-Need model should be present. The goal in this study is to verify if the ideas generated during the ideation address all needs in the NICU-Need model. The questions that are addressed:

- Do the generated ideas address all needs included in the NICU-need model?
- What are the main idea qualities that contribute in addressing the needs in the NICU-Need model?

# **4.4.2 METHOD & TOOLS**

Four sessions where done with in total five participants. The session took about an hour. To have a fruitful session to evaluate the fit of the ideas regarding the NICU-needs, multiple tools were used.

# Idea cards

To communicate the ideas, the ideas created during the ideation were presented as ideacards to the participants. The cards visualise the ideas and elaborate on the future NICU context with and without the specific design intervention. Each card represents one idea. All nine idea cards were shown. By using these



figure 19 The idea cards communicate the ideas.

cards participants can empathise with the given situation. This allows for fruitful feedback about the developed idea. Figure 19 illustrates how the idea cards were used. See all idea cards in appendix 8.

## **NICU-Need Tool**

The NICU-Need tool is a product of the NICU-Need model that emerged during the research into the relation between the stressors and the fundamental need. This NICU-Need tool is inspired on the Circumplex emotion tool (Desmet, 2007; adapted from Russell, 1980) and the Pick-Mood-tool (Desmet, Vastenburg, & Romero, 2016). The circle embodies autonomy as an umbrella term to address the stressors by taking into account the needs that are at play. In order to review the ideas on their fit with those NICU-needs the circle was slightly adjusted to make it a workable tool. See figure 20 for the NICU-Need tool.



figure 20 The NICU-Need tool is based on the NICU-Need model.

### Use

After participants studied the idea card that explained the situation without a design intervention they received the NICU-Need tool. First they would rate to what extent they believe they experience the needs presented on the tool. Each need was reviewed separately and marked on the circle. The middle of the circle being not experiencing it at all and the edge being experiencing it very much. After all needs were reviewed the participants could read the backside of the card that presented the same situation with design intervention. Subsequently they rated their experience of the needs on the tool as well.

# **Analyse**

When the marks on the circle are connected this results in two surfaces that covers the circle to a certain extent. One surface being their experience in the future department without an intervention, the other one their future experience with design intervention. Because all rated needs are related to the stressors and the fundamental need that needs to be addressed. it is believed that the more the surface covers the circle, the more the idea is able to evoke the longed positive experience that contributes to the well-being of parent at the NICU. Results can be easily compared by reviewing the size of the surface. However, because argumentation of their ratings is key to understand why they experience a need to a certain extent, the tool should not be used without recording and later transcribing the interview.

# Desirability-plot

After all the ideas were ranked according the NICU-Need tool, the participants were asked to place the ideas on a paper that symbolises the desirability of the ideas. The ideas that are placed in the middle are most desirable, the ones on the outer circles are less desirable. This creates an overview of the preference of the participants.

# 4...3 KEY FINDINGS

The data collected with the help of the NICU-

Need tool was visualised in order to get an overview of the results. The ratings for each idea were processed and visualised per participant. This resulted in nine plots per participant in which the ratings for the perceived experience in the future department with and without a design intervention was visible. Moreover, a plot of the average of all scores (separated into two plots with or without design intervention) per idea was created. Figure 22 shows the average result of the idea of the Welcome Package, figure 23 show the idea of an interactive object to take home; 'Wolkje'.

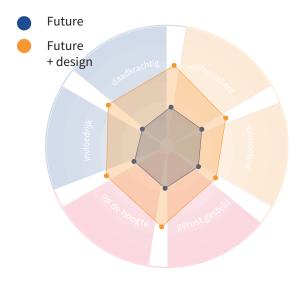


figure 22 Average ratings for the idea Welcome Package.

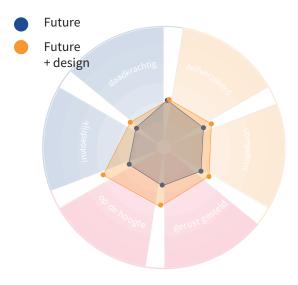


figure 23 Average ratings for the idea Wolkje.

For figure 22 a clear overall increase in the fulfilment of the needs is visible, for figure 23 this

is not the case. In figure 23 the needs that are included in the value information, show a clear improvement, the others hardly show significant changes. For many of the ideas the results were comparable to this. See appendix 9. The needs that address one value (responsibility, security or information) show an improvement, but the needs that represent the other values barely change. This result is undesirable as it is believed all needs need to be addressed in order to fulfil the need of autonomy and positively affect the stressors. Also the desirability-plot in figure 24 did not show significant results. Though, the opinion about the desirability for the ideas Coffee Break and the Welcome Package were less divided and rated more positive.

# Crucial qualities

To understand these results an analysis into the argumentation of the idea ratings was done by reviewing the transcriptions. For each idea positive and negative comments were collected. See appendix figure 37. Those comments were placed in order from negative to positive and the positive underlying elements of each idea were defined. See figure 25. This resulted in an combination of qualities that were not improving the parental experience and qualities that did have a positive effect. The qualities that had an positive impact on the parental experience were distilled.

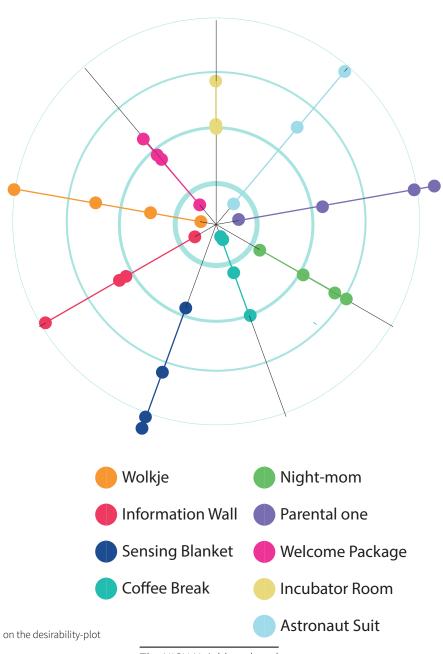
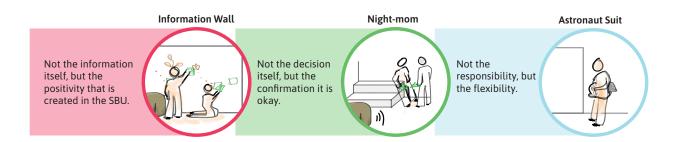


figure 24 Ideas plotted on the desirability-plot

# 04. RESEARCH





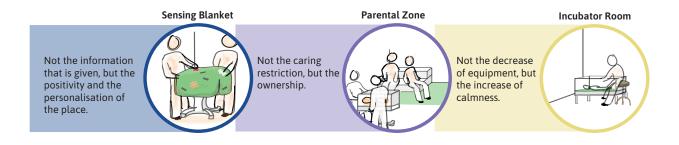


figure 25 Qualities that improved and did not improved the experience listed per idea.

This resulted in five crucial qualities that an idea should foster in order to create a positive experience that contributes to the autonomy-feeling and addresses the stressors. The idea should bring tranquillity, positivity and a sense of ownership and be non-compelling and supportive.

# Integrated design structure

When the ideas are plotted on the NICU-timeline it can be seen that all ideas are relatively isolated, short-term touch points. Remarkable is that the more positively rated ideas, the Welcome Package (pink) and the Night-mom (green), address multiple area's. See figure 26. Not only they address different stages of the timeline, they also cover multiple timelines. They support, for example as seen for the Welcome Package, arriving at the SBU, staying at the NICU and leaving to home. However, only at first visit the Welcome Package addresses the arriving stage. The Night-mom support parents in leaving the SBU and gives a reassured feeling while being away. The other ideas are all addressing only the stay phase or the phase where parents are already at home. Therefore, it is believed that, in order to address all needs of the NICUneed model the idea should cover all three

stages, arriving, staying and leaving and should integrate the multiple timelines of SBU, the NICU and home. Consequently the design should be an integrated design structure that touches upon all phases in the timeline.

## 4.4.4 DISCUSSION

Five participants took part in this research. Each person had a different experience at the NICU and therefore reacted differently on the design ideas. However, because the NICU-Need tool evaluates the fulfilments of the needs that are crucial for reducing the stress, it can be used to see if a design intervention improves the experience. In order to do so the researcher needs to realise it can't be used as an quantitative tool as argumentation is extremely important. Moreover, the difference between the ratings of the situation with or without a design intervention was reviewed per person before creating the average scores. Some persons can have the tendency to rate rather positive and some persons negative. This can be seen when reviewing the individual results. When taking into account those irregularities the results can be processed meaningfully.

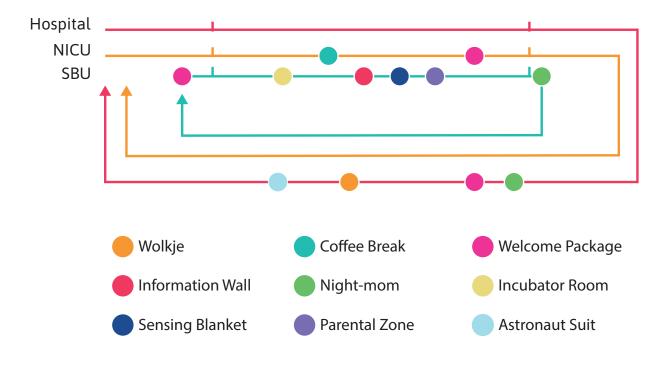
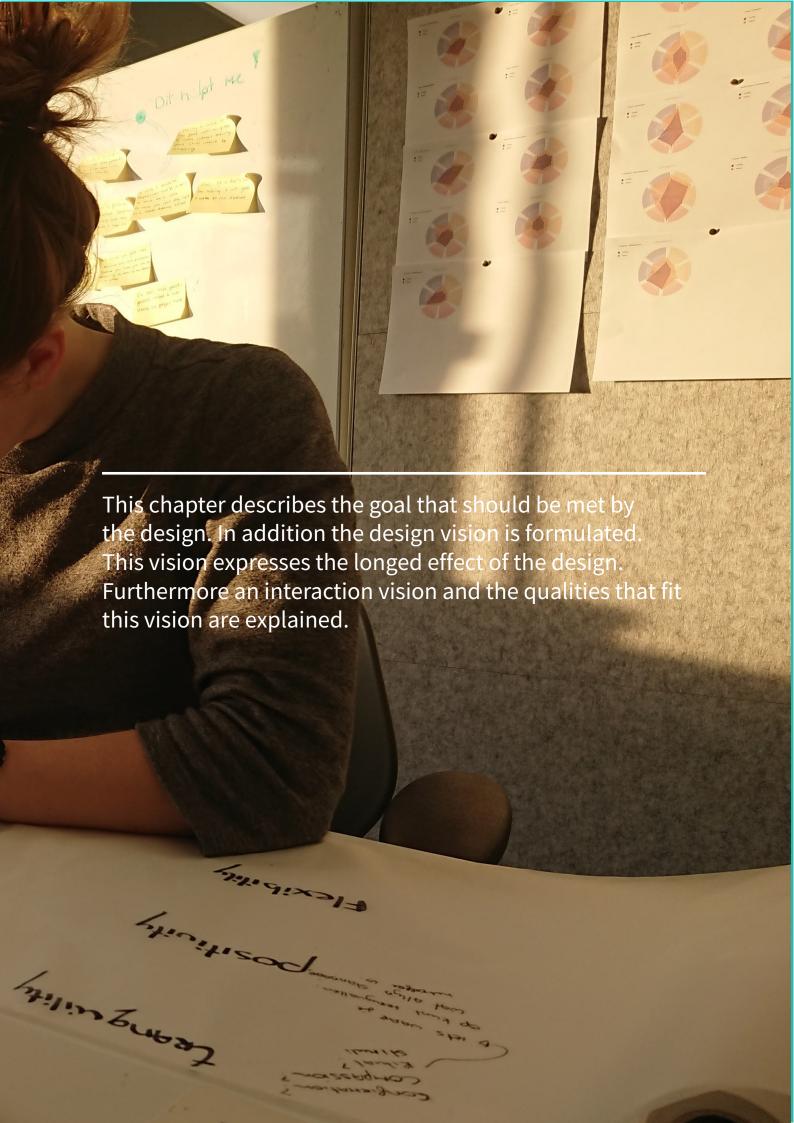


figure 26 The ideas plotted on the NICU-timeline.





# **5.1 DESIGN GOAL**

## **5.1.1 DESIGN GOAL**

The design goal was created after literature research and analysis of preliminary research and was formulated as followed:

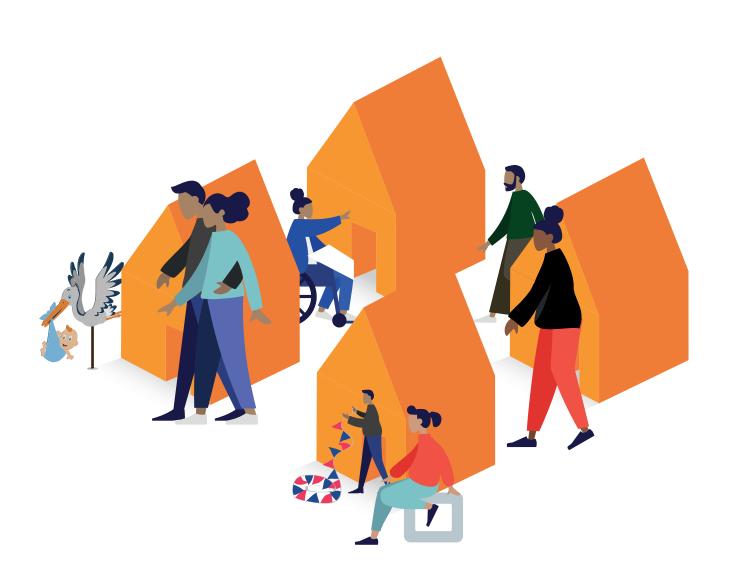
Design for a low-stress parental experience at the NICU by addressing autonomy and the stressors 'not being able to give care' and 'being separated from the baby'.

After the design research the way to address autonomy and the stressors was specified with the NICU-Need model. Those needs should all be addressed in order to design the low-stress parental experience.

It is believed that a positive parental experience that touches upon all needs of the NICU-Need model can be designed when it takes into account all phases of the day-to-day life at the NICU. This includes arriving, staying and leaving the hospital or the SBU. Therefore, it is important that the design is an integral part of the department and not consist out of separate, non-related ideas. This ensures tranquility within the department. Moreover, the department should emanate appropriate positivity and give parents a feeling of ownership regarding the SBU. Parents should be able to feel supported without having the feeling of being obliged to act in a certain way.

# **5.1.2 DESIGN VISION**

Designing for all stages of the day-to-day life at the NICU means designing the stay and experiences within the department. What if this experience is not focused on the NICU but specified on the normal; day-to-day life? With the design I want parents to be able to enjoy and celebrate the birth of their child and feel like a family life from day one. When the design meets the design goal, this vision can become reality.



# 5.2 INTERACTION VISION & QUALITIES

# **5.2.1 GENERAL DEPARTMENT VISION**

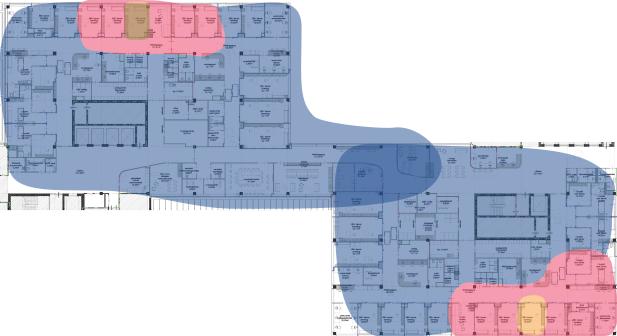
To feel like a family from day one the interaction vision for the department was created. An interaction vision is a metaphor that represents the intended quality of the desired interaction. In this way the known experiences within the situation of the metaphor can be projected onto the current design challenge and new perspectives can arise. The interaction between the parents and the department should feel like a neighbourhood. Where the SBU is your own

home, the SBU's close by are your neighbours in your own street and the more distant rooms are part of streets further down the neighbourhood. This creates different zones of intimacy. When implementing this vision in the structure of the department it can look like figure 27. In figure 28 the SBU is coloured orange, this represent the zone where you should feel at home. Your street is coloured pink and the neighbourhood is blue.



figure 27 The vision: the NICU as neighbourhood.





**figure 28** On the floor plan the houses, street and neighbourhood can be identified.

# **5.2.2 QUALITIES**

During the research five essential qualities were discovered; The idea should bring tranquillity, positivity and a sense of ownership and be noncompelling and supportive. These qualities can be plotted on the floor plan of the department. It becomes visible that the entire department should radiate positivity, tranquillity and feel non-compelling. In addition to those qualities, the more intimate street-zone should give a supportive feeling and the SBU should evoke a sense of ownership. In figure 29 the qualities are visible and related to the department zone via colour.

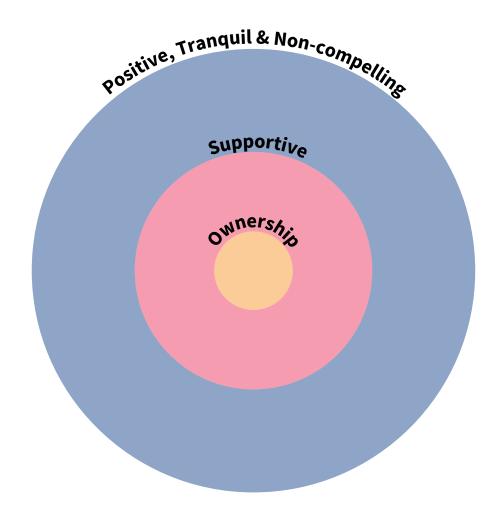


figure 29 Different qualities for different department zones.

"It shouldn't feel like room **4.001** where Allan, Steven and Nick were treated before your own child was born. It feel like your room"

- Mother of a child born with severe birth defects.





# 6.1 FOUNDING THE VISION

To create this integral experience where tranquillity, positivity, a sense of ownership are present and it feels non-compelling and supportive, this neighbourhood vision should be continued in every stage of the timeline. Arriving, staying and leaving need to be addressed. It is considered that the vision should cover these stages for the SBU and the NICU timeline. The hospital timeline does not need to be included as this has less emotional value to the parents. Leaving the hospital is not as difficult as leaving the NICU. Parents need to be supported in staying at the department, therefore designing for the hospital timeline were leaving means going home is less desirable. See figure 30.

should be covered. At this stages the parents should feel ownership and support in a non-compelling way. This is the feeling of a neighbourhood. Designing for the staying phase is important, but can not exist without a intervention that founds the vision at the arriving and leaving phase. Without a street and a home you can not organise neighbourhood activities. Therefore, more knowledge about the arriving and leaving phase should be gained before addressing the stay phase.

In order to create a strong foundation of the vision at first the stages arriving and leaving

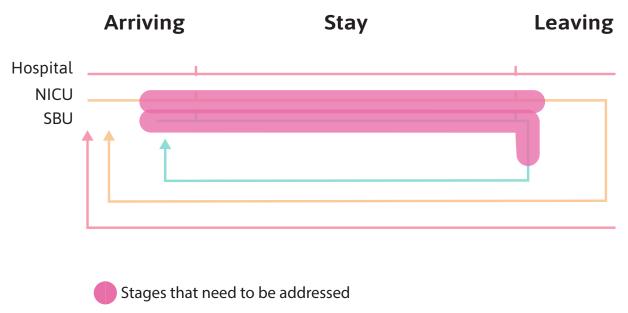


figure 30 Stages of the timeline that need to be addressed.

# 6.2 RITUALS OF ARRIVING AND LEAVING

#### 6.2.1 GOAL

In order to gain more knowledge about the vision in combination with the arriving and leaving stage a research was done. The goal of this study was to identify patterns in behaviour for people arriving at home and leaving home. This to be able to integrate the feeling of being home in the department. The questions that are answered:

Which actions do people perform in order to make themselves self at home? Which actions do people perform when leaving home?

#### **6.2.2 METHOD & TOOLS**

Eight participants contributed to this research by listing their behaviour about leaving and arriving at home in detail. They were asked to make a chronological list of their actions. Those lists were analysed by reviewing all actions and comparing them to each other.

#### 6.2.3 KEY FINDINGS

#### **Arriving**

After the analysis a pattern became visible. Different activities that could be clustered into different stages of arriving became visible. See figure 31 for the identified stages.

At first you have the recognition of your home and the physical act of entering. Those are part of the cluster 'coming home'. For coming home it is important that you have a sense of

ownership and belonging, you recognise the colour of your door or the light next to the door turns on when you approach the entrance. Next, there are a series of actions that are covered by the cluster 'making yourself at home'. Making yourself at home is done by doing some tiny tasks as checking the mail, hanging your coat and turn on the heater. This collection of events is called: 'first-things-first". After this stage people start to settle. Creating their own, comfortable environment by, for example, making a cup of tea and putting on some music. This is called 'Nestling'. Subsequently people enter the 'prepare' stage. In this stage people start anticipating on their future activities. The prepare phase includes actions you do in order to prepare to leave or for a next activity.

#### Leaving

For leaving less significant actions could be discovered. However, participants indicate a lot of the actions they perform during arriving at home they do in reverse order. When the preparation stage is done with attention, leaving will go easier.

The identified stages of coming home, recognition, first-things-first, nestling, preparing and leaving together with the corresponding activities are important to take into account when designing for parental experience at the NICU. See figure 32 for the timeline. When this is translated into the NICU-context while paying attention to the qualities the vision can be implemented successfully.



figure 31 Stages of arriving home.

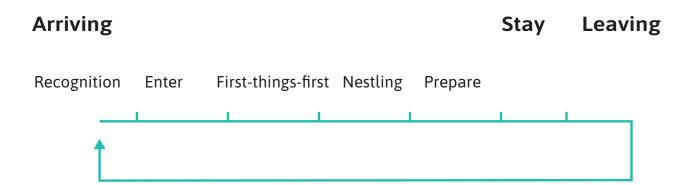


figure 32 Stages of arriving plotted on the timeline.

# 6.3 NICU TRANSLATION CONCEPT

When parents arrive at the NICU they should have the feeling of arriving at their neighbourhood. The different phases of arriving; recognition, first-things-first and preparing should be implemented in the concept. It should radiate a positive, supportive, non-compelling give a sense of ownership to the parents. When people stay, these qualities should maintain present.

A design that contains three different elements was created: The Lamp, the NICU Mailbox and the Writing Wall.

See page 76 to page 82 for a explanation of the ideas.

#### **6.3.1 THE LAMP**

In front of each SBU a interactive lamp will be placed. Just like an outdoor light at home that switches on when you arrive this lamp will acknowledge your presence. This lamp will embody the ritual of arriving and leaving the SBU. Whenever parents arrive at the SBU, they will be welcomed by a message on the interactive screen. Subsequently parents are asked to confirm they are present. This way a feeling of ownership of the SBU is created. This task should be performed every time at arrival and therefore becomes familiar. They feel decisive and competent because they know how it works. The lamp will show presence to NICU neighbours. When looking down the hallway, it is visible if other neighbours are around. This creates a feeling of support and positivity. This non-verbal connecting element supports the parents as they get reminded they are not alone in this. Parents feel belonged without having active social interaction.

When the light switches on, the nurses receive a

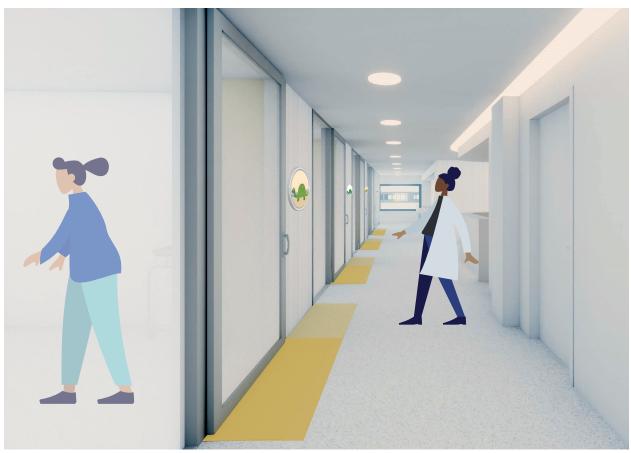
message that the parents are present. This way, the nurses can come by as soon as possible to give an update. For the nurses the lights in the hallway are helpful as well. They can anticipate on entering a occupied or empty room and adjust their behaviour accordingly.

When leaving the department parents will say goodbye to their child. In this situation leaving is much harder than leaving home just to get the groceries. Therefore a parent should be supported in their decision to leave. In order to prevent the parents from feeling helpless and guilty the interactive lamp acts as an confirmation that it is okay to leave. The lamp informs the nurses that the parents are gone. Because parents know the nurses are informed of their leave they feel calm and reassured.

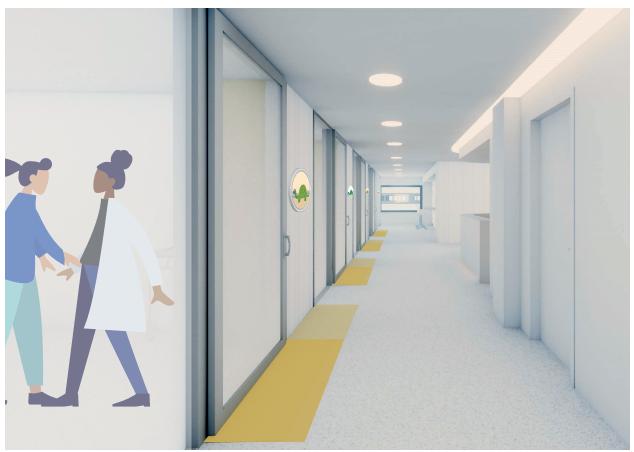
See figure 33, figure 34 and figure 34 for an impression of this idea.



figure 33 When parents enter the NICU they will turn on the lamp.



 $\textbf{figure 34} \ \ \text{The lamp will alert the nurses and show neighbours the parents are present.}$ 



**figure 35** The nurse will check on the parents because of the notification they received.

#### **6.3.2 THE NICU MAILBOX**

The lamp will address the leaving stage and the arrival phases of recognising and entering home. The phases first-things-first, nestling and preparing will be addressed by the NICU Mailbox. When people arrive at home, they have a standard set of activities they perform before settling at ease. First-thing-first before nestling. Therefore, it would be uncomfortable when parents enter the SBU without having an activity to perform before settling for the entire visit. The NICU Mailbox embodies this first-thingsfirst activity. The NICU Mailbox is a tablet that is placed in the SBU. When the tablet is turned on, it gives the parents the option to check the updates, pictures or messages from nurses, that were posted in their personal app while they were away. In the ZorgPunt app, this online diary is already active. Key is to make these new diary

updates easily accessible just by turning on the tablet. It's like finding your mail on the doormat, that needs no effort at all. Moreover, the tablet shows which nurse is taking care of the baby today. This way parents know which visitor they can expect in their SBU. See figure 36, figure 37 and figure 38.



figure 36 Parents can check their NICU-mail on the tablet as a first activity to do when they arrive.



figure 37 The mail shows who is taking care of the baby today.



**figure 38** The app shows new posts of the diary section of the ZorgPunt app.

#### **6.3.3 THE WRITING WALL**

To support the recognition phase of arrival, the Writing Wall should be present at every SBU. A Writing Wall shows the baby's name big on the glass door that is used to enter the SBU. This way, the SBU will have a landmark for recognition from distance. Moreover, it supports the feeling of ownership. The name of the newborn should be written on the glass before parents arrive for the first time. This can be done while nurses prepare the room for the hospitalisation. This way, already at first visit parents feel a connection to the place.

Additionally, it is possible to personalise this glass door with extra drawings. Markers are provided to create an ideal activity for a sibling that pays a visit. While the parents are in the SBU with their newborn, the older child can

entertain itself with personalising the SBU. This contributes to the stay phase of the timeline. In this way the SBU will become a place where all family members are welcome.

See figure 39 and figure 40 for an impression of this idea.



**figure 39** Walking through the hallway where the SBU's are easily recognised thanks to the names on the door.



figure 40 Siblings, or other family members, can decorate the door of their SBU.

#### **6.3.4 INTEGRATED THEME**

Whenever you enter your neighbourhood, you feel at home because you see certain landmarks that feel familiar. The Writing Wall does this for the SBU, specific for the recognition phase of arrival. However, throughout the entire timeline this familiar feeling is desirable. To include this feeling at arrival, staying and leaving, every room has its own theme. This theme is visible on the interactive screen of the lamp, in decorations inside the SBU and on personal lockers in the lounge. This way throughout the whole NICU, parents have their own familiar landmarks that increase the feeling of ownership. It supports the connection between designed elements and creates a coherent, clear and tranquil experience at the department.

Despite the medical difficulties, parents should feel like the NICU is a place where birth can be celebrated. Therefore, the themes are uplifting and childlike. See figure 41.



figure 41 Lockers with the theme to feel connected to the SBU.

# 6.4 FIRST VALIDATION STUDY

#### 6.4.1 GOAL

The goal is to know if this integral design concept within the department is desirable. By evaluating the vision and the general translation this is researched. Moreover, the research was used to decide which element of the concept needs more attention and therefore should be further develop. Questions that are addressed:

- 1. Is the integral design concept, derived from the vision, desirable by parents?
- 2. How are the different elements valued by parents?

#### 6.4.2 METHOD & TOOLS

This study was done with two participants, both mothers of a former NICU-patient. The session took about 45 minutes. The impressions of the concept were shown and subsequently a informal, qualitative interview took place. Next, the different concept elements consisting of the interactive lamp, the NICU Mailbox, the Writing Wall and the general theme were ranked according the NICU-Need tool. Afterwards, the impression of the entire department was ranked. Figure 42 shows the setting of the sessions.



figure 42 The setting of the sessions for the first evaluation study.

#### **6.4.3 KEY FINDINGS**

#### Interactive lamp

The idea of the interactive lamp was received positively as the participants liked to see other parents are present as well.. The participants stated that, in addition to showing their own and seeing the presence of others, they desire a way to ask for social contact. This would contribute to the staying phase as parents otherwise can become isolated in their own SBU. Parents do value social contact with other NICUparents. However, due to the ignorance about the situation of others and their own occupied mind due to the stress, there is a high threshold in making contact. This was already indicated by the Coffee Break intervention from the ideation. So it was recommended to create a noncompelling way of communicating. The simple welcome message that The Lamp can give you was valued. It was believed leaving the department could be supported by the ritual that is created by this lamp. However, when leaving the lamp should not turn off immediately as this feels harsh.

#### The NICU Mailbox

Having a ritual to do when entering the SBU is desirable. Especially the fact that you can see which nurse is taking care of your child was favourably. After the update is read, apps with extra reliable medical information would be a good addition to the tablet. Moreover, a participant stated that neighbourhood activities could be communicated with this tablet as well.

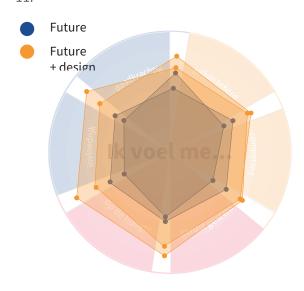
#### The Writing Wall

Recognising the room of your child by having the name written on the door was received positive. This gives not only the feeling of ownership regarding the SBU but also gives the entire hallway a less clinical appearance. The addition of providing markers to draw on the window was perceived as valuable activity to involve family members or other visitors in the NICU visit.

#### General design vision

The participants indicated they had a positive opinion regarding the vision for the future department. In figure 43 the result of the NICU-

Need tool regarding the overall experience of the future department is visible. Blue illustrates the perceived experience of the department without design interventions, orange shows the perceived experience with designs that support the vision. The ratings of both participants are shown. The separate plots are visible in appendix 11.



**figure 43** Both participants rated the overall experience with and without design interventions.

The orange surface covers significantly more of the circle of the NICU-need tool then the blue area. At each need the orange exceeds the blue. This means that every need that is considered to improve the parental experience is addressed positively in the designed vision. Therefore, it can be said that implementation of the interaction vision at the department is desirable for parents.

#### 6.4.4 DISCUSSION

In this research two participant took parts. The two individual tests were slightly different constructed as the development of the elements continued in between the tests. The first interview was analysed and the suggestions were discussed during the second interview. Both participants rated The Lamp and the NICU Mailbox on the NICU-Need tool but only one rated the Writing Wall. This element was discussed briefly with both participants but only one NICU-need tool was filled. Because the interviews were recorded the recordings

of participant one could be compared to the recordings and the filled NICU-need tool of participant two. This allowed for good comparison between both interview. The integrated theme was discussed but only rated for the specific touch point of the lockers in the lounge. Because of unclear explanation if only the specific touch point should be rated or the general integrated theme the participants ranked the NICU-Need tool differently. However, reactions and argumentations could be reviewed because of the recordings.

"My 6 year old daughter really wanted to come and see her brother. **But after 5** minutes at the NICU she was quite done with it"

- Mother of a son born with 25 weeks.

## 6.5 FOCUS

The Writing Wall element is relatively easy to implement as this idea that does not contain new objects or unknown interactions. Therefore, it is considered to be easy to adapt without further detailing. The NICU Mailbox does include new interactions. However, because the information that should be provided is clear and simple and the existing app ZorgPunt can play a important role in including this function, this is also believed to be less relevant to further detail. Considering the participants indicated the interactive lamp as desirable but expressed some concerns as well as recommendations this element is interesting to develop further. Therefore, following this validation research a extra validation research focused on the lamp is done.

# 6.6 DEVELOPING THE CONCEPT

After the first validation study, the lamp was further developed. As indicated, it is desirable to have a non-compelling way of communicating with other NICU-parents besides creating the connected feeling because it is visible who is present. It was decided to include this in the functions of the lamp.

When they show interest, the inner circle will light up as well. See the change in lighting in figure 44. Every time parents check-in, they get the option to show interest by lighting the inner circle. They can change their decision and turn off the light whenever they want. Because this takes no effort it has a low threshold to interact and possibly show interest in social contact.

#### **6.6.1 THE LAMP LIGHTING**

The outer circle of the lamp lights up as parents indicate they are present. After this step, parents get the option to show interest in social contact.



figure 44 The lamp light up after check-in and the inner circle lights up after parents show interest for social interaction.

#### **6.6.2 THE LAMP SCREENS**

The five screens that show the different functions of the lamp are illustrated in figure 45 to figure 49. The welcoming message is illustrated in figure 45. They have the option to check-in with a simple button that shows: `We are here! ´. Next, parents have the option to indicate if they would like to have social contact, if they choose the illustrations with multiple animals the inner light will turn on. If they choose the illustration of the animal reading a book the light will stay off. See figure 46. Parents can understand the image but are not asked specifically if they would like to have contact or not because this can feel judgmental. After parents indicated they are interested in contact the lamp will show information about the daily coffee moment or another event. See figure 47. When parents leave, they will check-out. Those screens are visible in figure 48 and figure 49. In figure 50 the functioning digital prototype is visible.



 $\label{figure 45} \textbf{ The welcoming and check-in screen of the lamp.}$ 



figure 46 Screen that allows parents to show interest for contact.



figure 47 The screen parents get when they are interested in contact.



figure 48 Screen where you indicate you are going away.



figure 49 Screen that is visible after check-out.



**figure 50** A functioning digital prototype for testing.

# 6.7 SECOND VALIDATION STUDY

#### 6.7.1 GOAL

Subsequent to previous validation research and the concept development of the lamp, another study was done. The goal of this study was to evaluate how the social connection function is valued and to know if the lighting indeed is positively received as a non-verbal tool to show presence. Questions that are addressed:

- Does the social connection function match with a low threshold and noncompelling way of searching for social contact with other NICU-parents?
- 2. Does the interaction of checking-in and checking-out make the parents feel more competent and confident?
- 3. Is the lighting valued as a non-verbal connector between parents and to staff?

#### 6.6.2 METHOD & TOOLS

This study was done with two parents. The session took about 45 minutes and it took place at their home. First of all a short introduction was done. After the researcher asked them to role play entering the imaginary SBU where their child was hospitalised. While keeping this situation in mind they were asked to interact with the prototype of The Lamp. Next they were asked to role play leaving the SBU. Subsequently they filled in the NICU-Need tool regarding their interaction with the lamp. The completed NICU-Need tool formed the starting point of a qualitative interview. The concept was also

reviewed shortly by the team captain of the AMC NICU.

#### **6.6.3 KEY FINDINGS**

The participants appreciated the non-verbal connecting element of the lamp. They indicated that they would feel welcomed by the light of other parents. They also stated that they valued the connection it creates with the medical staff while being inside the SBU. It made them less insecure as nurses can see they are around and therefore come over for an update. Although, the screens did not gave the feedback that the nurse was informed as this was only explained verbally by the researcher. The ritual for arriving and leaving that it creates was considered to be helpful to feel decisive and competent. In figure 51 the average of the NICU-Need tool of both participants is visible. The separate plots are visible in appendix 12.



figure 51 The average rating regarding the lamp of both participants.



figure 52 A participant using the NICU-Need tool.

It can be seen that especially the needs decisive, confident and influential received a high ranking. This proves that the interaction with the lamp support parents with fulfilling the needs that influence the security and responsibility value. The information value is rated less high then the others. This is a foreseen outcome as the NICU Mailbox is especially design to addresses this value.

The idea of enabling parents to show they take interest in social interaction with other parents was received positively. However, the current embodiment was not appreciated. The participants stated that when they check-in, their minds are occupied seeing the child. At that moment, there is no real need for social interaction. When looking into the vision this makes sense. Whenever you come home, you first follow the steps of recognition, first-thingsfirst, settling and preparing. In this situation the preparing phase is placed just after recognition, that does not feel right. The current interaction did not feel non-compelling as you have to make the decision before you start your visit. Of course parents are able to switch the light off but this increases effort and can make the parent insecure because of the public display of their change of mood.

#### 6.6.4 DISCUSSION

This research was done with two parents. They provided helpful feedback and their suggestions help to increase the fit with the design vision. However, it would be desirable to present and discuss the prototype with more parents. This way it could be researched if the same feedback is given repeatedly and a pattern could be created. Due to time limits it is decided to analyse this interview thoroughly and with the knowledge of the previous researches in mind take well-considered decisions to incorporate in the final design.

When I arrive to go to my baby, I don't immediately want to think about what I am going to do next. I'm definitely not in for a chat yet.

- Mother of a son born with 34 weeks.





# 7.1 THE NICU NEIGHBOURHOOD

The NICU Neighbourhood is a vision that is supported by three different design elements, The Lamp, The NICU Mailbox and the Writing Wall. The designs that embody the NICU Neighbourhood are all quite simple to enhance feasibility and viability. Moreover, as the design should create a low-stress experience in this emotional setting it should not ask for lots of cognitive effort. Every element has its own focus and own touch point within the parental NICU timeline. All elements together address all the needs of the NICU-Need model and create a

integral experience. See figure 53.

Stand alone the designs also have a valuable contribution to the parental experience, but do not create the integral experience that supports parents at arrival, during stay and when leaving. Each individual element has its own focus on one of the values of the NICU-Need model: responsibility, security or information. The designs can be seen as building blocks that all contribute to, and together create a low-stress parental experience at the NICU.

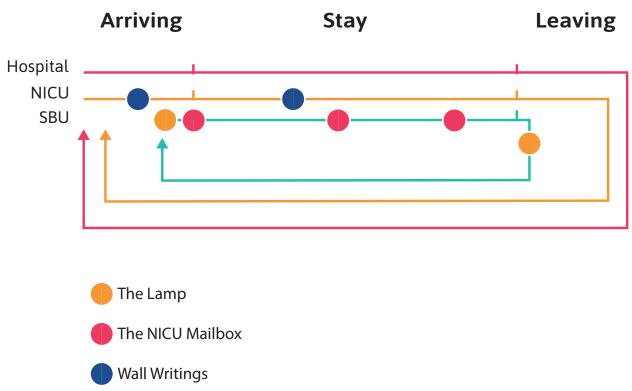


figure 53 The different elements of the NICU Neighbourhood plotted on the NICU timeline.

## 7.2 THE LAMP

The Lamp embodies the ritual of arriving and leaving the SBU. This ritual is a simple task that should be performed every time parents arrive at their SBU. Parents will check-in by touching the screen when the check-in button is showing. This button shows a positive, personal confirmation: 'We are here!'. This ritual ensures parents feel decisive and confident. Because this ritual is repeated every time they arrive at the SBU, the activity will become familiar. This makes parents feel competent because they know how it works. The Lamp in use is visible in figure 54.

After the check-in activity the lamp will show their presence to the NICU neighbours as it lights up. When looking down the hallway it is visible if other neighbours are around. This creates a feeling of support and positivity. This non-verbal connecting element supports parents as they get reminded they are not alone in this. It is a simple but informative tool that enables the parents to show their presence without feeling dependent and needy. Parents feel belonged without having active social interaction.

When the light switches on, the nurses receive a message that the parents are present. This way, the nurses can give an update as soon as possible. The Lamp is also helpful for the staff. They can anticipate on entering an occupied or empty room and adjust their behaviour accordingly.

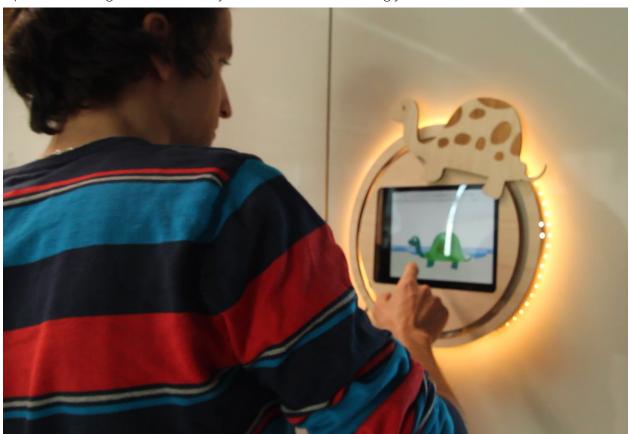


figure 54 The Lamp in use.

#### 7.2.2 PHYSICAL APPEARANCE

The lamp has a positive appearance thanks to the circular shape and the theme-animal that can be attached to the lamp. This accomplishes a non-clinical character and therefore it is clearly not meant for the medical staff. Also, when parents walk towards their SBU, the lamp will ask for their attention by starting to light up the screen when they come close. This stimulates the interaction. See figure 55 for an illustration of The Lamp. When leaving the SBU, parents checkout and get the confirmation it is okay to leave with a simple but positive goodbye. The light will gradually turn off to prevent a harsh feeling. Parents can leave with a calm and reassured feeling as they know it is visible they are not present in the SBU so the nurses know they are the only ones that can check on the baby.

# It is a familiar ritual every time, which makes me feel feels more competent.

- Father of a son born with 34 weeks



 $\label{figure 55} \textbf{ The appearance of the lamp.}$ 

#### **7.2.1 SCREENS**

The lamp welcomes the parents with a message on the screen. The name of the child in the greeting can be edited by the staff members when the newborn is admitted. In this way the message is personalised. This personal greeting creates a feeling of ownership of the SBU. Next, the screen that embodies the check-in activity is displayed. When the button on this screen is pressed, the light will turn on. The next screen informs parents that the nurse is notified about their presence. Moreover, after check-in they are reminded of the daily coffee break. No decision is needed yet, so it is non-compelling. It is just to remind parents it is okay to leave the SBU and make them feel less guilty if they do so. See figure 56 to figure 61 for the different screens.

Scan the QR code to see a video of the functional screens!





figure 56 The welcoming screen.



figure 57 The check-in screen.



figure 58 The confirmation screen.



figure 59 The reminder of the daily coffee break.



figure 60 The check-out screen.



figure 61 The screen after check-out.

## 7.3 THE NICU MAILBOX

The NICU Mailbox creates a moment to settle in the room as it unnaturally to just sit and wait for what is coming as is researched previously. Each room is equipped with a tablet that shows a NICU home screen which provides three options. The third option enables the parent to use the tablet in normal mode, with the familiar home screen with access to internet and apps etc. The other two options are NICU-specific apps.

#### 7.3.1 ZORGPUNT PLUS

ZorgPunt is an, already existing, app that provides the user with reliable information about medical issues and the Amsterdam UMC in general. The idea for the app was conceived by two nurses from the Amsterdam UMC, Nathali Nienhuis-Schiedon and Anita Zijp. The app enables parents to stay informed about the developments of their child 24 hours a day. It includes a diary section where nurses can upload messages and pictures. Parents can upload content as well and, for example, keep track of the weight of their baby. Whenever you are not at the NICU, you still have valuable information at hand. This diary section is secured with a login code that is sent by a nurse. No specific medical data is shared in this app as it is not a replacement for the electronic patient file (Amsterdam UMC, 2019).

To provide an activity that can be done each time the parents enters the SBU the ZorgPunt app is installed on the tablet. The NICU home screen that automatically opens after turning on the tablet will give the option to open ZorgPunt. In addition to the current app, it will be visible when new content is placed in the NICU home screen. This stimulates to check on the updates and have an activity like checking your mail

at home. This update will, next to the pictures and messages, include a overview of the duty nurses and the planned doctor's visit. This way, ZorgPunt ensures parents to know which visitor they can expect in their SBU. Because they have a feeling of ownership regarding the SBU, they should be informed who is coming over at their place in order to feel informed and reassured. See figure 56 to figure 61 for the different screens.

## 7.3 Sealiffle GHAT de to see a video of the functional screens!





figure 62 The NICU home screen with ZorgPunt Plus.

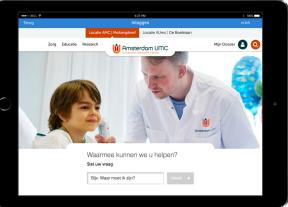


figure 63 The general information on ZorgPunt Plus.



figure 64 The screen where parents can login.



figure 65 The screen after login, presenting the nurses.



figure 66 The screen presenting who the duty doctor is.



figure 67 The screen with diary updates.

After I arrived, I sat still. With closed doors. **Nobody saw if** I was present or not. Should I ask for attention or am I then being too needy? It is nice to have some information at start.

- Mother of a twin born with 28 weeks

The NICU Chat app is also provided in the NICU home screen. This is the social app of the NICU to connect parents in a non-compelling way. With low-threshold and a non-compelling character people can show interest in social activities. In this app there are three options: Parents can show interest for the daily coffee break, start a conversation with an other parent, and when available show interest in extra activities as a VOC-meeting evening.

#### Coffee break

The coffee break section of the app makes it visual and tangible that other parents are interested in having a social break at the lounge. Therefore, it becomes easier to leave the SBU for a while. The parent can sign in and subsequently show interest for the coffee break, but can easily cancel this. This supports them in taking control and does not make them feel guilty when they decide otherwise. By providing the option while the parent is inside the USB, it lowers the threshold to show interest. As described in previous research, parents are at this moment in the nestling or prepare phase, and this is an logical moment to think of activities to do while being present at the NICU. When you show interest it can be seen by other parents, so it is a stimulation to actually go outside the SBU. When you cancel the interest, this will be processed in the app but it will not trigger a notification for the other interested. This makes the change of mood less public and therefore the decision to sign up or cancel will feel safe.

In order to implement this section of the app, the NICU should offer short breaks at the lounge to bring parents together. Those breaks should be organised multiple times a day, for example in the morning and the evening. This ensures that people who are not able to stay all day still have the opportunity to gather. The breaks are announced at the NICU chat app, but will preferably be organised at the same time every day and every week. Consistency will contribute to the tranquillity feeling and enable parents to anticipate on the break. This will make them feel informed. There is no need for medical staff joining this meeting. It is a informal gathering

and the Amsterdam UMC NICU only provides the option to meet at a set time in the lounge. See figure 68 to figure 70 for the different screens.

#### Conversation

Scan the QR code to see a video of the functional screens!





figure 68 The NICU Chat app home screen.

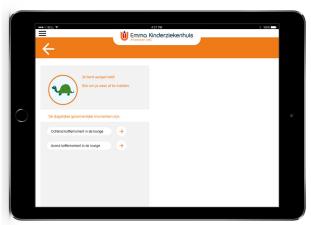


figure 69 See coffee breaks that are organised.

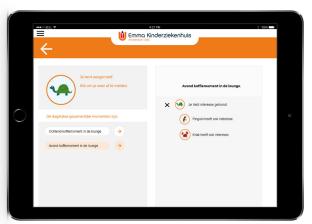


figure 70 See other parents that are interested in the break.

#### **07. FINAL DESIGN**

The conversation section of the NICU Chat app makes it possible to chat with another parent that is present at the NICU. Messages can only be received when a contact request is sent and accepted. This individual chat allows for more contact with people who you feel more connected to. For example, this could be somebody with a child with comparable medical condition. See figure 71 to figure 74 for the different screens.

#### **Events**

Scan the QR code to see a video of the functional screens!



Extra activities can be promoted in this section of the NICU Chat app. These activities can be seen as neighbourhood events and therefore it is valuable to see who is interested to join and to stimulate parents to go. For example, a VOC-meeting at the NICU could be highlighted here.

Scan the QR code to see a video of the functional screens!



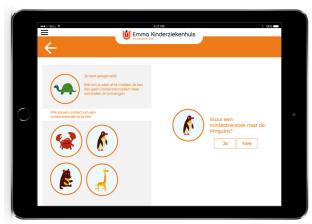


figure 72 See coffee breaks that are organised.

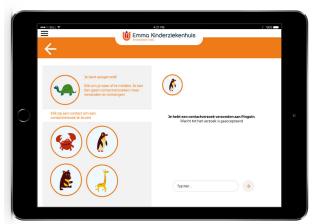


figure 73 See other parents that are interested in the break.



figure 71 The NICU Chat app home screen.

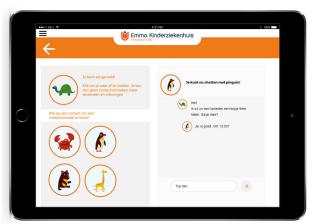


figure 74 See other parents that are interested in the break.

## 7.4 THE WRITING WALL

The personalised message on the glass door of the SBU is a element that creates a stronger feeling of ownership for the parents. When they enter the department, they can see the name of their child and feel connected to that specific SBU. This creates a moment of recognition and makes the parents feel decisive and confident to start their visit at their SBU.

The name of the newborn should be written on the glass before parents arrive for the first time to create a feeling of ownership right from the start. This can be done by nurses while preparing the room for the hospitalisation. It can also be done by the care supporters that support the nurses Additionally, markers are provided to personalise this glass door some more. This can be an ideal activity for a sibling that pays a visit. See figure 75. While the parents are in the SBU with their newborn, the older child can entertain itself with personalising the SBU. In this way the SBU will become a place where all family members are welcome. This supports the vision that parents should be able to start their family from day one at the NICU.



figure 75 Drawing on the Writing Wall.

# 7.5 INTEGRATED THEME

The integrated theme allows for recognition and coherence in the experience of parents. The themes are implemented in each element of the design. Every room has its own animal theme. Parents can not choose which animal they prefer, as it could cause confusion in communication when the room themes switch often or when the same animal is used at more SBU's at once.

The themes provide a positive atmosphere and give the NICU a friendly character. The themes are deliberately designed to look childly. This creates a less clinical feeling and make it feel more like a nursery at home. The NICU becomes a place where birth can be celebrated. The figures of the themes are based on the illustrations of Jamie Oliver Aspinall. The graphic designer is experienced in making children's illustrations that stimulate fantasy (Studiostudio, n.d.). This way, other children visiting the department can be entertained by the graphics while parents have time to sit with their newborn. In figure 76 to figure 79 examples of four themes for the SBU's are shown.



figure 77 Penguin illustration for the animal theme.



figure 78 Bear illustration for the animal theme.



 $\label{figure 76} \textbf{ Turtle illustration for the animal theme.}$ 

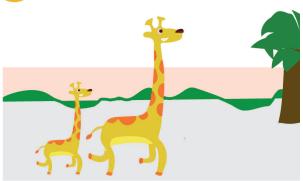
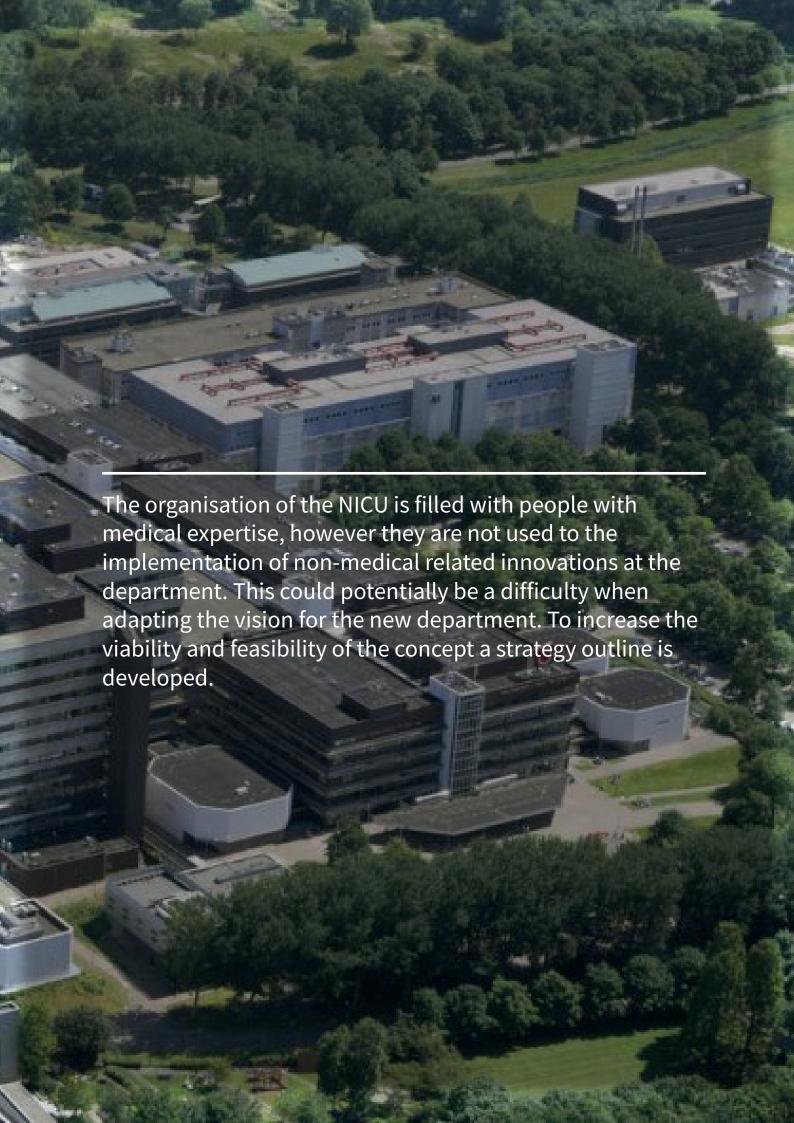


figure 79 Giraffe illustration for the animal theme.

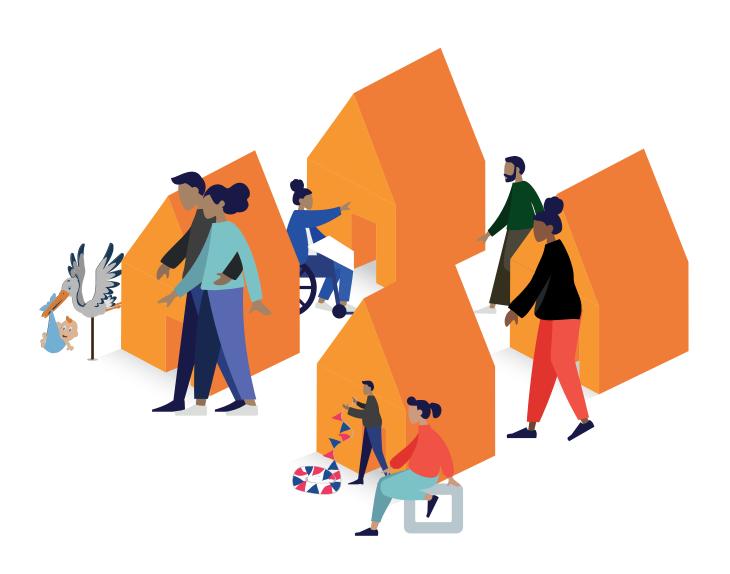




## **FROM THIS**



## **TO THIS**



# 8.1 IMPLEMENTATION TIMELINE

The NICU neighbourhood vision with its associate elements is designed to be implemented after the renovations from the NICU have finished in 2022. The renovation itself is an exciting and demanding project, it could be hard to incorporate the NICU neighbourhood vision together with all other tasks that require attention. However, after the renovation is the perfect time to implement a new vision as medical staff needs to adapt to the new situation anyway. To support the implementation while taking into account the difficulties it might bring, it is recommended to gradually implement the different elements and expand the options when feeling comfortable and confident. Figure 80 shows the recommended timeline for implementation.

#### **8.1.1 BEFORE RENOVATION**

### Rethink organisation of recreational rooms

To incorporate the vision of the NICU Neighbourhood, it is important to understand and implement the different mental zones of intimacy. As seen in figure 81. In the current plans the two lounges, located in each NICU lobe, are only used for a quick, individual, coffee break. The parental living room is situated in the department hallway that connect both lobes. During this project, the different ideas generated during the ideation were discussed with medical professionals. The Coffee Break ides was received positively. The idea was raised to organise these breaks in the shared living room. However, when incorporating the vision successfully this should be reconsidered.

#### Implementation Timeline

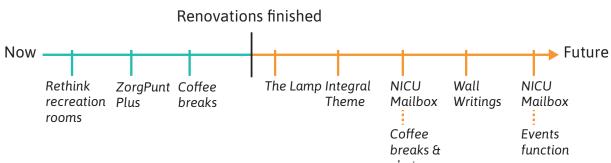


figure 80 The timeline for implementation of the NICU Neigbourhood.

#### Lounge

Going to the lounge should be like leaving your home for a short walk, even without locking the doors. During this walk to go the playground located in your street. To relax a bit you sit down on the bench. The lounge should feel like this local playground. Parents can have a casual but as well a more emotional conversation, just like when a neighbour walks by while you are sitting on the bench at that playground. This interaction vision for the parental lounge incorporates the intimacy of the lounge. It's a place you feel connected to, only familiar people are around and it is okay to have a short or a more extensive conversation with one or more persons. This is the place where the coffee breaks that are presented with the NICU Mailbox should take place.

#### Living room

The living room for parents is situated in the hallway before you enter the closed environment of the SBU's. This living room is shared by parents of both NICU lobes. This living resembles the local supermarket where you recognise most people but are not open to talk to everybody. It's a place where most people move and act individually but sometimes a talk or a short encounter takes place. This is a place where you meet external people, those who are not

part of the neighbourhood. A lunch with family members could take place here.

#### ZorgPunt Plus

The ZorgPunt app is already functional and used by many parents and nurses. Therefore, the step to expand this to ZorgPunt Plus is easy to make. The current app only needs some adjustments to incorporate the information such as the name of the duty nurse and doctor. This schedule is always already available at the team captain of the department, so it only needs further development to include this schedule in the back-end of the app. In the current department the medical staff does not feel like a unexpected visitor like it does with SBU's, but it is still informative and can give parents more feeling of control.

#### Coffee breaks

Scheduling shared coffee breaks can be implemented before the renovation. Although there is no specific shared parental lounge at the AMC it is possible to use the parental living room that is available with reservation for this activity. At the VUmc the shared parental living room is the right place for such coffee breaks. When starting with implementing Zorgpunt Plus and the coffee breaks the parental experience can already be improved before renovations.



figure 81 The NICU lobes are connected in the parental living room.

#### 8.1.2 AFTER RENOVATION

#### Lamp

The interactive lamp is an essential element as this provides the nurses with information and makes the parents feel in decisive and confident. It will make the interaction between staff and parent easier, because parents know they are noticed and ask for less attention. This will support the new work flow of the nurses at the NICU. Moreover, it can support the medical team having overview as the lamp could provide information if a nurse is present in a SBU. Therefore it is recommended to implement directly after the renovations.

**Themes** 

When the first newborns are hospitalised at the renovated NICU, it is desirable to have implemented the themes at every SBU. Integrating a theme will ensure recognition and ownership. Implementing a positive theme is essential to the vision of the NICU neighbourhood as the SBU should feel familiar and non-clinical.

#### The NICU Mailbox

The NICU Mailbox can be placed directly after renovations as this means a tablet should be available in every SBU. Before the renovations, the ZorgPunt Plus, the existing app with the extra information about the duty nurses and doctors can already be developed. Subsequently it can be installed on the NICU Mailbox tablets right from the start. The other functions, the different options in the NICU chat app can be implemented gradually. The coffee break function and the chat should be implemented together. Those functions enhance each other as they make parents feel more connected. The events functions can be implemented later when the department is running smoothly and events are organised.

#### The Writing Wall

The concept of the Writing Wall can be put in motion later but still be up and running when the department is operating. Organising does not take much effort. This element is easily adopted. It does ask for a additional activity from staff members as the name of the child should be written on the wall. The Amsterdam UMC is working together with care supporters and possible with volunteers that could provide this service. When it is decided which person involved will provide the service, it can be implemented easily.

## 8.2 STEPS TO TAKE

Before implementation it is recommended to continue to develop and test the different elements in order to create a fully functional product or service. When all these elements are fully detailed, the implementation can start. Therefore different steps need to be taken.

#### 1. Project group

The PNC bouw has a team that is involved with making decision regarding the new NICU and the interior of it. They are informed of this project. It is key to make and keep them informed and enthusiastic about the concept. It is recommended to set up a subdivision to create internal buy-in to implement the vision and the elements at the new department.

#### 2. Funding

Stichting Emma indicated they are always searching for input about special projects from the different departments of the Emma Kinderziekenhuis (EKZ). The concept can be presented to the management of this charity foundation in order to start the process of funding.

#### 3. Graphical style

The different textual and informative digital elements should all match with the style of the Amsterdam UMC. Dart Group has developed the communication style for the Amsterdam UMC and this is accessible for all employees. They can be approached for advice.

The animal theme should be further developed so that there is an unique animal for every SBU at the same NICU lobe. Decorational style

elements as seasonal change in illustrations could be welcome addition. This way, just as a in a normal neighbourhood, the time of the year is visible in the NICU neighbourhood. The theme elements are currently based on visuals of Jamie Oliver Aspinall, this designer can be contacted through the company Studio-Studio.

To develop fully functional digital products a digital design agency can be contacted. A company like Silo could develop the digital design while paying attention the Amsterdam UMC as brand and taking into account the spatial factors. Another option could be the design agency Panton. This agency is specialised in healthcare projects and can further research and development of the digital and physical elements.

#### 4. Make staff familiar with concept

After developing the elements, employees should be informed about the vision and the elements. The instruction should include providing information how parents can interact with the elements as well as how the staff can update the digital elements to personalise for different parents. This instruction could be done during a workshop where different cases are role played in order to prepare the staff on possible situations. This should be done before all SBU's are equipped with the elements. This way the staff feel confident when parents ask for information and are able to support where necessary.

#### 6. Implement

After instructions the elements can be

#### **08. WHAT'S NEXT?**

implemented following the timeline as discussed in figure 80.

#### 7. Press release

A press release to celebrate that celebrating birth is possible at the NICU of the Amsterdam UMC could be made. As the Amsterdam UMC strives for a top-notch PNC after the renovation, it can be emphasised that this concept is unique. No other hospital had such elements that focus on improving the parental experience. The press release could show the innovative character of the new Amsterdam UMC NICU to others.

#### **08. WHAT'S NEXT?**





# 9.1 YOU NEED TO KNOW THIS

During this project a lot of lessons were learned. Eight takeaways that can be useful for every designer and design graduate student in a hospital setting are described.

#### **Know your context**

When the organisation is as big as the Amsterdam UMC, try to dive into this structure as soon as possible. People will refer to divisions and projects you never heard about, use abbreviations that could mean anything and expect you to know who is currently working on which projects. Start to figure out how departments are linked. Understanding the organisation helps to talk to people on the same level and it shows you understand what is going on. Especially in the medical field it is valuable to learn the abbreviations. Ask people what it means, if you do not, it will not be explained. For them it is completely natural to speak in this way.

#### Network

It is very valuable to know who works for which department. Especially knowing who the decision makers and influencers are of specific departments can be useful. In this way you know who to contact when you want to organise a meeting for example. Contact those people directly and don't be too reactive. Those decision makers have very busy schedules, so if you want their attention you should make some effort.

Moreover, documenting your contacts is incredible valuable for future references. You come across much more knowledgeable if

you can recall who gave the tour or who was present at the meeting. Do not be afraid to ask someone's name and contact information, often they already agreed for a meeting so it is not a surprising question. Write it down immediately because you will not remember it as long as you think. Moreover, if you already know you want to contact the person on short term, ask a phone number. In NICU context this can especially with parents this can feel a bit intruding, but without a phone number you are only obstructing yourself. Email is much more impersonal and easier to ignore.

#### Work flow

Because there is so much to find out and explore, try to focus by thinking in small (personal) deliverables. Of course it is difficult to a certain goal but just make conscious decision why something would be interesting to do, see or visit for your project. Moreover, try to divide it in long-term or short-term relevance, this can help you prioritising activities as well as the analyses of the activity in question.

It is highly recommended to talk to other designers about your project. Not only is it interesting to hear what they think of your work but also the questions and fresh ideas could help regain energy and see new perspectives. Also, it is nice to be in a familiar and more personal atmosphere once in a while. Don't underestimate how important it is that you feel energised and motivated throughout the project. Find activities or workplaces that help you to feel comfortable or inspired.

#### Interviews

When doing interviews, especially on a more emotional topic like the experience at the NICU, make sure you do not want to touch upon a lot of topics. First thing is to let people tell their personal story. For you as interviewer is this often already very rich information and without this introduction it is hard to touch upon other questions or assignments. It is always good to emphasise that you are not an employee of the discussed department. Therefore they do not have to soften their opinion. When discussing outcomes of interviews with other people of the target audience, it could be nice to work with keyword instead of whole sentences. In this way, they can form their own story. This prevents them from being indignant and opens possibilities to validate if they have the same experiences without steering the participants too much.

Generative interviews work great if you want to deepen into the situation and the experiences of your target group. In this case a tool was used with symbols which they could map on their timeline. The illustrations were provided in the paper strokes of the same symbols. So, some preparation was already done, but to use a symbol the participants still needed to use the scissor. This small effort worked great because they were detailing their story about this event while working to get the symbol.

Be flexible. Often interviews will not turn out as planned. Participants will cancel, bring someone (their child for example) or the time and place has to change. Make sure your interviews are well prepared and therefore can adapt to changes and still have valuable results. Also, when time happens to be really limited, make sure you can adapt to this by extracting only the essence of your preparations into the new 'speed' version of your interview.

#### **Participants**

Contacting participants at the NICU was a challenge. In the beginning mostly because it is quite scary to enter a NICU or ask parents randomly at the hallway to participate in the research. However, remember that it is you

that experiences this threshold. If parents have time and energy to participant they will agree to participate and otherwise they will decline. That is not that bad right? Just, do not take the rejections personally.

#### **Professionals**

While working in such a large organisation as the Amsterdam UMC, you will come across a lot of people. If those people are enthusiastic about the project or even expressed they can or would like to help, be aware that you are still the person to take initiative. They have plenty of other things to work on. In addition to this, when reaching out to someone for collaboration or just a small interview, always emphasise their roll in the subject and how they could benefit from your project of intermediate findings. Do this before giving a extensive explanation or making a blunt request.

#### Presentation

It sounds obvious but, when giving an presentation about your project, know who is listening. Doctors and nurses are trained looking for concrete findings and clear and structured solutions. A design project that is working in the fuzzy front end can be confusing. It is in your own interest to keep them believe in your relevance and try to make them understand what you are doing. This can be by making really clear why you use this fuzzy approach, or by translating it to a more structured process for them to identify with the work flow.

#### **Outsiders**

When doing a brainstorm session with others that are not familiar with the hospital context, or even an update meeting with your coach be aware that they do not work on this subject all the time. Always do a recap with people before explaining all the new things. For people who were never involved in your project before, explain it in small steps. First, introduce the context and think back to how little you knew when you started. Having a premature born child of 25 weeks does not sound worrying if you do not realise a normal pregnancy is 40 weeks. 9 months sounds familiar to everyone, but translating it to weeks can be difficult.

# 9.2 PERSONAL REFLECTION

I decided to take the opportunity to graduate at the Amsterdam UMC because I thought the project could be challenging on many levels. And it was. During the project I experienced many ups and downs. Thanks to the interesting and complex context to design for, the NICU, I could be inspired by many different perspectives, all wonderful people who were willing to tell their story and by all possible design directions. This gave boosts of energy. However, because of the emotional charge of the topic once in a while my inspiration and energy blocked. How was I going to be satisfied with my suggested design? The parental experience is never going to be good. Parents do not want to be there. I had to remind myself that the project was about improving the parental experience and that, whatever the final design would be, the insights I gained throughout the project already could be of value during the development of the department.

Next to the emotional charge of the project I had difficulties with finding my way in the large organisation of the Amsterdam UMC. I experienced the Amsterdam UMC as a passionate organisation where everybody contributes to delivering the best care as possible. Working in such a large company taught me some valuable lessons as described in the takeaways. I learned I value a workplace where I can discuss with people and can be inspired by coincidences. This is helpful for in my future projects. I experienced setbacks as not being able to access parental contact information and ideas that did not show the longed results. I noticed I can react well on unforeseen circumstances, and this gave me

confidence in my project approach.

I liked to have the opportunity to take on a individual project. A project where you are the only responsible for the end result. You are the responsible for all that went well and all that went wrong. I think you can learn a lot from this. However, because I am quite a competitive person I sometimes was doubting if I did well enough and how other graduate students were already detailing their ideas and I was doing research over and over again. I can say I am satisfied with my end result. I truly believe in the value of the concept. In the beginning of the project I expected a more detailed end result but because of the complexity of the topic my research phases took longer than expected. I think I made the right choice by further dig into the needs and values of parents. This made me really knowledgeable about the situation of the parents and I am able to express this to the medial staff.

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# 00 APPENDIX

# 1. VKC & PNC AMBITIONS

In order to ensure a state-of-the-art VKC & PNC eight ambitions were created.

#### Family Integrated Care

With Family Integrated Care (FIC), family is the center of care. This includes the mother, partner and the child. When the mother is hospitalized before giving birth, the partner is involved in the treatment as much as possible. Also after delivery both parents are involved in the treatment of their child, just as in normal dayto-day life. If possible, the caregiving activities extend the normal diaper changings, but also involve parents with more medical related tasks as giving tube feeding and provide assistance with nursing tasks. With more complex activities there should always be a professional to supervise and coach. The FIC is not only applicable to parents but also to other family members or even close friends. Parents will be stimulated to participate in the caregiving, but it will not be mandatory. The choice is theirs. Parents are free contribute more or less in the caregiving whenever they want. However more study is needed on this subject, studies show that Family Integrated Care within Neonatology could lead to less stress for parents, longer breastfeeding, less incident, better grow and a shorter hospitalization of the child (Liu et al., 2007).

#### Single Bed Units

The essence of a Single Bed Unit (SBU) the newborn and the parents are together as much as possible and are nursed in their own room. The most important advantages of nursing in a private room are better hygiene resulting in

a reduction of infection changes, more privacy for the parents and child, better bonding between parents and child, and a faster recovery with shortening of the hospital stay (AMC, 2016). A SBU Is in line with the concept of FIC. Participating in care can only be properly done if parents have the opportunity to be near their baby at all times.

#### Minimize movements of patients

Moving a sick child is stressful and therefore undesirable situation that must be kept to a minimum. This applies both to moving patients between hospitals and within the hospital. In order to prevent the moving the sick newborn (postnatal transfer) to another third-line center, the ambition is to create sufficient capacity. To prevent movements within the Amsterdam UMC NICU setting, work is done as much as possible with one interior and the same equipment. This means that the fixed (building) facilities does not differ between IC and post IC / HC care. Only because of mobile equipment the levels of care in a room can be distinguished. Therefor, newborns do not need to be moved when their need in level of care changes.

#### PNC-facilities and working environment

Within the PNC all facilities that enable FIC and minimize the patient movements should be available. Also the ambitions in the fields of research and education should be supported. Besides the focus on care in the SBU's, there also should be sufficient facilities to enable the stay of the parents (a good sleeping place, TV, Internet etc.) But also sanitary, lounges and a place to get food should be provided at the

PNC. Also the working environment for the professionals has to be optimal. To keep an overview of the patients in the SBU's, the aim is to include transparent sight lines and a lob-shaped structure of the room layout. Besides, there are sufficient facilities such as a coffee room, flex workstations, and consultation rooms. For the night shifts sufficient sleeping places and sanitary should be available

## Far-reaching integration perinatology and neonatology

All steps within the health care process care of the VKC will be accommodated within one single department (PNC) at one location. Real physical integration is realized with the Coupled Care rooms (CC). In this room, the care of mother and child will be covered. This will also create a stronger connection between the health care professionals of perinatology and neonatology, because they share the responsibility for the CC patients.

## Integration of PNC with the VKC department and facilities

Within the PNC, care for pregnant women, mothers and newborns is within one department and at one location stationed. There are other departments and facilities that closely connected to the PNC. It is important that the balance and coherence between those departments and within the whole VKC are taken into account before detailing the structure of the PNC department.

#### Atmosphere and appearance new PNC

The new PNC has almost an homely atmosphere where calmness and reduction of stimuli (light and audio) are important components. This should by in proper balance with the

necessary facilities to deliver efficient and safe care. Therefore, medical equipment should be as much as possible out of sight but easily accessible for healthcare providers. The lights have to be dimmed but sufficient for medical interventions. The atmosphere of the PNC should match as good as possible with the new EKZ. This creates a continuum in the environment when a patient is transferred to other departments of the EKZ.

## Routing for parents / family / visitors and health care professionals

To create peace at the department, the patient is approached through different walking routes by parents / family / visit and by health care professionals. For healthcare professionals, the new PNC ensures a safe, ergonomic and sustainable work environment in which the employee can work well and healthily.

## 2.FLOORPLAN





# 3.VALUE PYRAMID PRELIMINARY RESEARCH

The interviews that were done during the preliminary research resulted in distillation of twelve values that play a role in the experience of the parents at the NICU. The values that were found:

#### Hope

Provide something to feel optimistic

#### **Self-actualization**

Help parents feel like they are becoming a good parent

#### Stress-reduction

Help parents to reduce their stress level during the NICU-route

#### Wellbeing

Improve the mental and physical condition of the parent

#### Distraction

Have a positive, appropriate distraction for parents during their stay at the NICU.

#### Quality

Provide the best medical care

#### Information

Offer reliable information in time

#### Risk-reduction

Try to reduce the risks for children at the NICU Sensory Stimuli – Minimize the negative sensory stimuli.

#### Organisation

Have a structured organization for parents that stay at the NICU.

#### Access

Give parents freedom and the feeling of access at the NICU.

#### Connection

Be aware of parents that totally exclude themselves for others.

With being Hope, Self-actualization, Stress-reduction, Quality, Information and access as most pressing ones. The values were linked to create an overview of which value in influencing the other, see figure 2.

These relations were found while clustering of all data received from the interviews, see figure 1 for the clustering process.

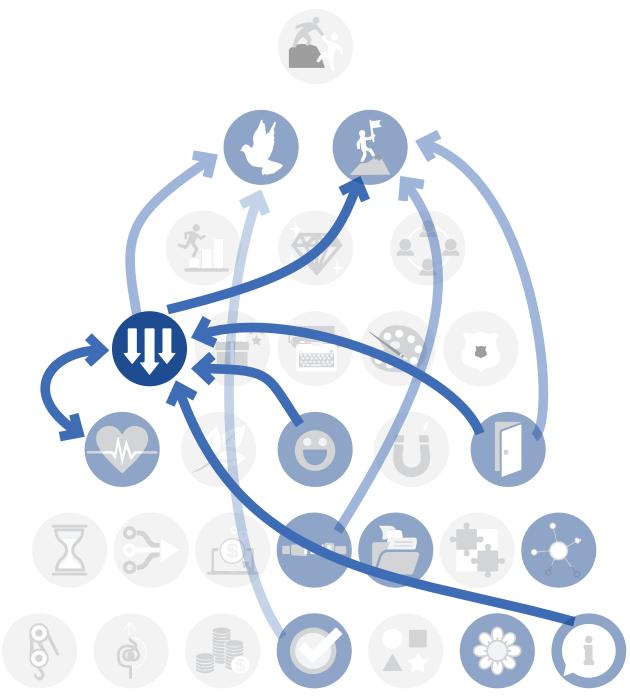
Hope is extremely important. Parents find strength from having hope the condition of their child is improving. On the contrary, a medical setback is an impactful negative experience. The value hope is related to their need of fear/stress reduction and their need for quality and risk reduction. The fear/stress reduction value is associated with the value of connection, amusement and their need of taking care of their own wellbeing. Connection is about finding support and comfort with their partners, family and friends. However, it is discovered that most people only find comfort with their most inner social circle. Later in the hospitalization process, their social circle can expand a little.

#### **00. APPENDIX**

Many people stated that they don't feel the need to socialize with their fellow-sufferers at the department. However, people indicated when a moment of contact did happen, they enjoyed it. The values amusement and the care for their wellbeing are both about finding relaxation and distraction. Another important is their self-actualization of being a parent and caring for the baby. Parents of a newborn are often insecure and especially in the NICU environment they are a bit afraid to do harm to their child. They long for caring for the baby, but medical restrictions are holding them back. Moreover, organizational matters as room access and involvement of the nurses and physical access to their child contribute to this need of feeling like a 'normal' parent. Last, parents want to have clear and detailed information about the medical condition of their child but also about the planning of their process. For example, when are they going to be transferred to a regional hospital? The informed and prepared feeling can give them some ease.



**figure 1** Clustering the data from the interviews.



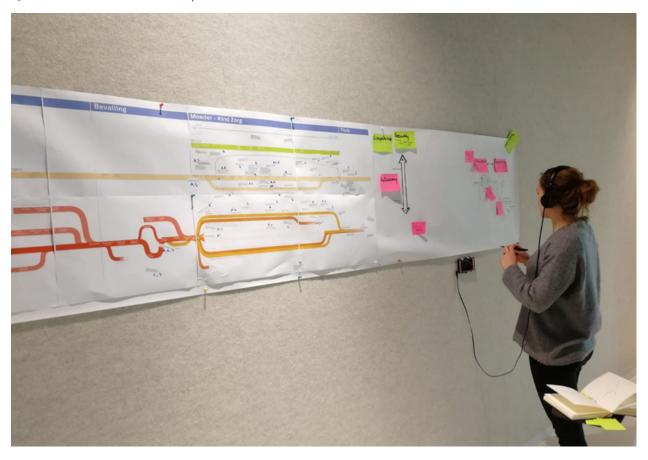
**figure 2** Many of the found values are related to stress reduction.

## 4. NICU ROADMAP

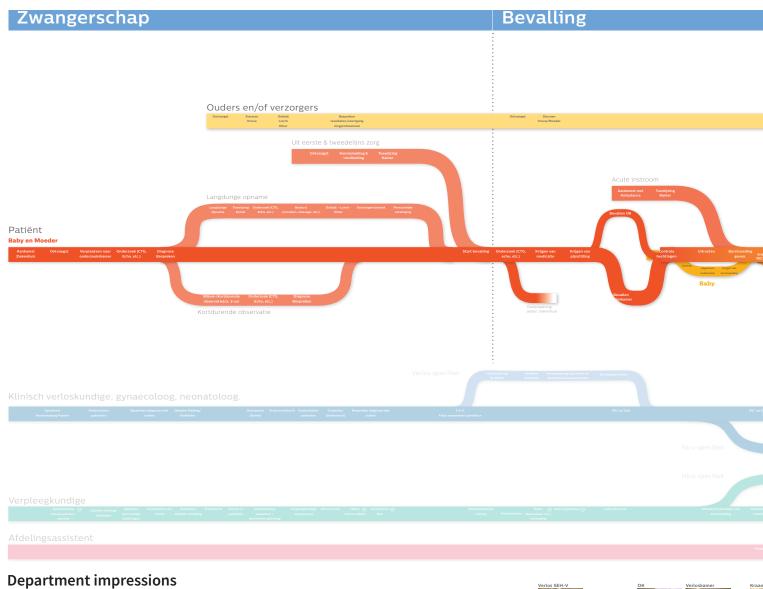
The roadmap that was created by Philips
Healthcare was used to plot all findings
of preliminary research, interviews, and
observations. This roadmap illustrates different
experience flows of people at the NICU.
Visitors, parents & caretakers, patients, medical
specialists (clinical obstetricians, gynecologists,
and neonatologists), nurses and the department
assistant. For this research only the experience
flows of the parents, the patient and the visitors
are taken into account.

This specified part of the roadmap was printed and hanged onto the wall. This way the researcher was able to create an overview. Quotes from interviews were placed on the

part of the timeline that they were referring to. Subsequently, the quote was compared with the definitions of the fundamental needs as described by Sheldon et al. (2001). The most applicable need was then marked on the quote. Consequently, after all insights were plotted on this roadmap and had a mark of the applicable fundamental need, it could easily be seen which need was most present at the NICU.



#### **00. APPENDIX**







#### **Personas**





Nick en Damian

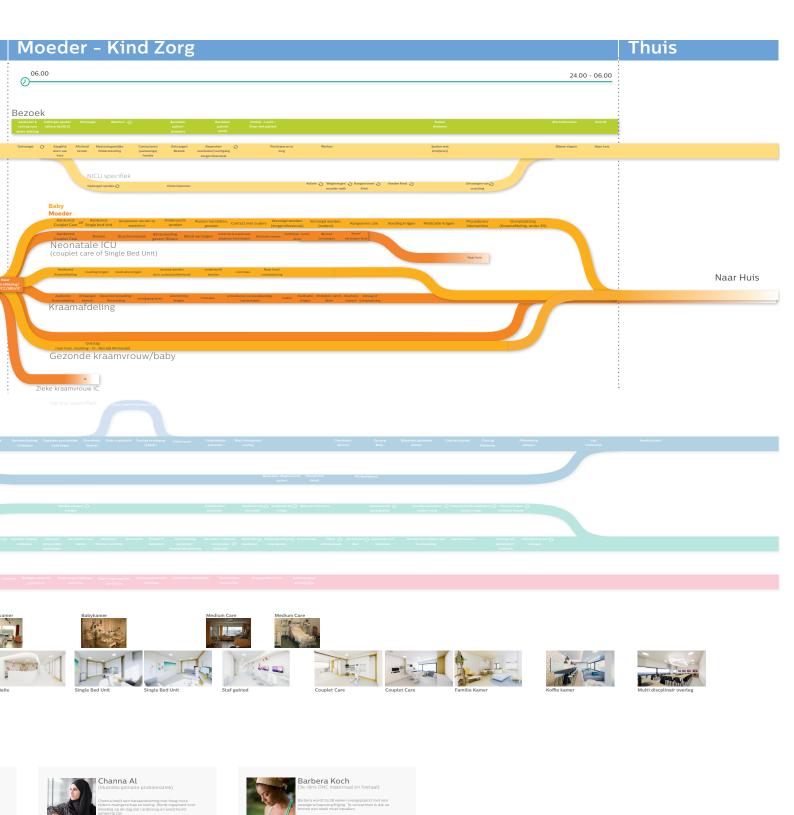


Esmer Bekdamirova





#### **00. APPENDIX**



# 5. INTERVIEW WITH SENSITIZING BOOKLET

A sensitizing booklet combined with an interview were used to gain insight into the parental experience. Later the findings were analyzed during clustering activities together with both Koos Service Design as Amsterdam UMC.

#### 3.1 SENSITIZING BOOKLET

The booklets were structured to let the participants tell their personal story step by step. This way the participants could explain their situation and the corresponding needs and emotions. Before starting this research



Ik, mijn baby & het ziekenhuis

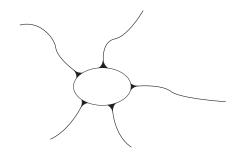
#### Ons geboorte-traject

Teken, schrijf, plak stickers en/of foto's op deze tijdlijn om uw geboorte-traject en uw ervaring met de afdeling neonatologie van begin tot nu te laten zien. Wie waren/zijn er allemaal bij betrokken? Probeer het in kleine stapjes uit te leggen. Tip: We zijn benieuwd naar de details!

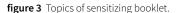
the booklet was reviewed by the head nurse of the AMC and consequently, adjustments were made. The number of questions was limited to decrease the pressure on the parents and increase the willingness of participation. The topics presented in the booklet are structured according to the path of expression (Sanders & Stappers, 2012). See topics in figure 3. Distributing the booklets previously to the interviews was discouraged by the head nurse due to the lack of a clear course of the situation of the parents. Therefore, the booklets were handed out during the interview and filled in together with the researcher.

#### Wat mij kan helpen

Maak een schets, plak afbeeldingen of beschrijf wat u allemaal kunt helpen rondom uw ervaring met de afdeling neonatologie.



Plak de groene stickers op de tijdlijn om aan te geven op welke momenten u zich het prettigst voelde. Plak de rode stickers om aan te geven waar u zich minder prettig voelde.



#### 3.2 INTERVIEW

Because the booklets could not be filled in prior the interview it was decided to do this during the interview itself. Together with pre-described some topic areas the interview was conducted. The main part of the interview was constructing their NICU-route and their corresponding experiences.. The chronological timeline made it possible to mark positive and negative experiences. During the interview, the laddering technique was used to gain in-depth insight into the emotions of the parents.

#### Participant recruitment

The recruitment of the participants was done at the NICU of both location AMC as VUmc. The parents were asked to participate in the research at the parental lounge. With permission from the head nurse, the researcher could also enter the unit to ask parents to participate because only little parents use the parental lounge. When entering the unit all hygienic procedures should be followed as wearing a hygienic coat. This can be intimidating. Moreover, a volunteer of the VOC (Vereniging van Ouders van Couveusekinderen; Association for Parents of Incubator children) was able to bring the researcher into contact with more parents that experienced the NICU some time ago. This was done because it was noticed that parents that are currently on the NICU have difficulties with expressing themselves. In total 7 parents of babies currently hospitalized at the NICU were interviewed, at 5 parents that experienced this more than a year ago.

#### Procedure

After parents indicated they were willing to participant they could schedule their preferable time. The parents were interviewed in a meeting room next to the NICU. This was done in order to keep them close to their baby and therefore lower the threshold to participate. The interview took about one hour. The former NICU-parents were contacted by telephone and email. Those NICU-parents were scheduled in a meeting room away from the NICU. During all interviews, the booklet was filled in by the participant, and the researcher was making notes.

#### **Analysis**

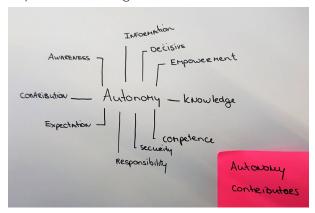
The analysis of the interviews was done by looking into the booklets and the notes of the researcher. This data was processed and clusters per stressor from all insights were made When the clusters of both stressors were compared three recurring themes were discovered: Security, Information and

responsibility.





When looking into the collected quotes with the three categories in mind, for each one two important subcategories could be found.



# 6. GENERATIVE SESSION

#### **3.1 TOOLS**

For during the generative interview some assignments were developed. The interview started of with parents plotting their story on the timeline. After they had to identify three positive experiences and three negatives ones. With the timeline of their story in mind, they had to plot their feeling of control in the next assignment. Subsequently, they had to plot to which extent they felt they were able to be there for their child. Those three different assignments ar visible in X.

During these assignments parents could use ambiguous symbols to strengthen and express their answers. The nine different symbols are visible in X. In order to stimulate the participants to use the symbols they were printed and precut on a strip of paper. The participant only had to cut to separate one from the many. By doing so, they had time to deliberately choose for a specific symbol and were encourage to tell why this one was applicable.

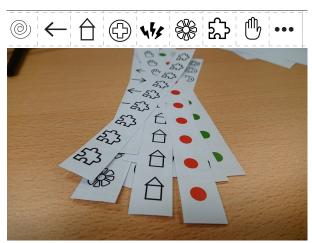
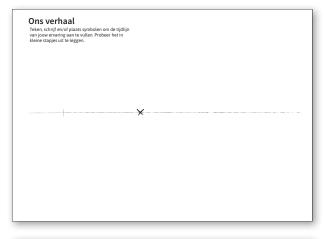
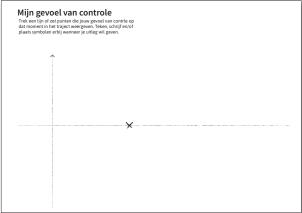


figure 4 Different ambiguous symbols used for the generative session





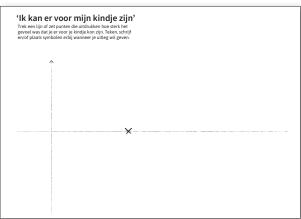


figure 5 The three different assignments of the generative session

#### 3.2 THE SESSION

#### Participant requirement

This research is focussed on the entire NICU-route which includes the hospitalization time of the child, until the moment of discharged and going home as a family. Therefore it was required that the participants were parents from children that were already discharged from the hospital. Moreover, it was learned in previous research that parents currently at the NICU have more difficulty with expressing their emotions and thoughts.

#### Participant recruitment

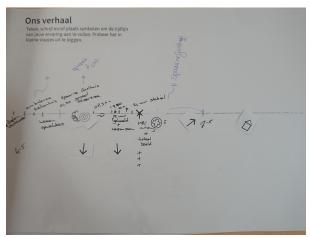
Due to privacy legislation, contact information of the parents could not be provided by the Amsterdam UMC. However, at a evaluation meeting for parents at the VUmc neonatology department, it was possible to personally ask parents for their information and consequently ask them to participant in the research. Seven parents gave their information and showed interest in participating. Four couples eventually were interviewed.

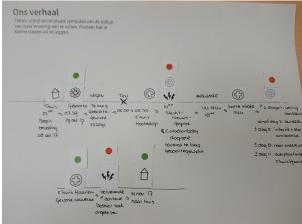
#### Procedure

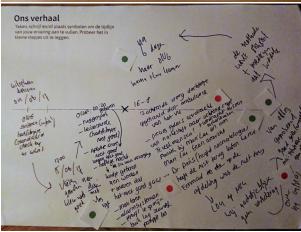
After obtaining contact information, parents received an email where the research was explained in more detail. They could choose a date & time slot. It was suggested to do the interview at their homes to prevent hassle with a babysitter and therefore lower the threshold to participate. Two interviews were done at the VUmc, two interviews were done at their homes. The interview took about one hour and was recorded and later transcribed for analysis.

#### **Analysis**

The analysis of the interviews was done by comparing the three assignments from and by reviewing the transcripts. Quotes of the interviews, as well as the insights gathered during the feedback meeting, were collected and analysed. The findings of the autonomycourse were compared with statements made previously by parents. From this, three important phases could be identified. See figure 6, figure 7 and figure 8 for the finished participant







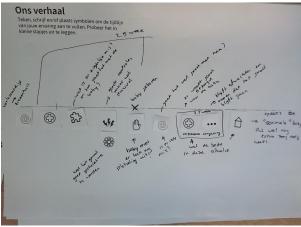
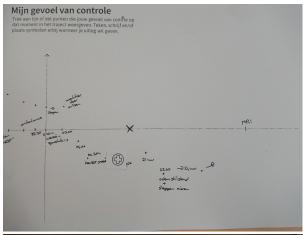
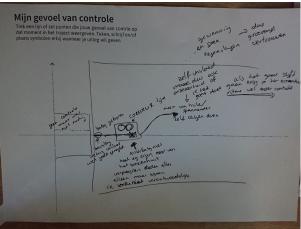
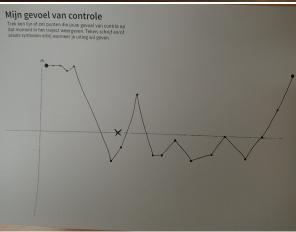


figure 6 The first assignment completed by parents







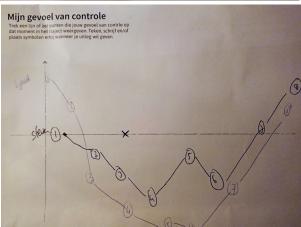
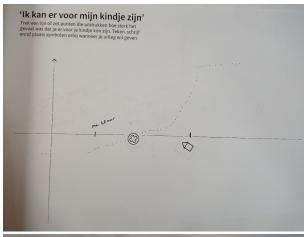
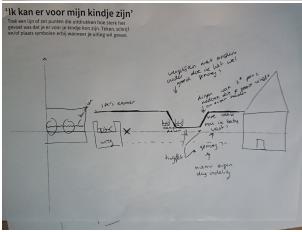


figure 7 The second assignment completed by parents

"He is 6 months old now, but if you ask me if I feel in control about his medical condition, no, I'm still scared to relive it again."





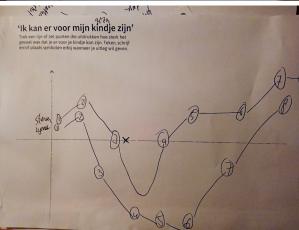




figure 8 The third assignment completed by parents

# "You simply lose a certain ability to think logically. You are a mess of emotions."

# 7.BRAINSTORM SESSION

To start the ideation two brainstorm session were organized. Two sessions of two hours with four participants, IDE students, were done. During the session, three ideation rounds were done. In each round two of the design direction questions were handled. After each round, the brainstorm results were discussed with the entire group.

#### **4.1 PRESENTATION**

The session started with a short introduction presentation about the NICU process. This was to ensure the participants understood the context of the NICU and to let them empathize with the parents. See the presentation in figure 9.

#### 4.2 PERSONAL STORY & MISSION

Subsequently, each participant received an envelope with their name on it with their personal NICU story inside. This story was about their imaginative pregnancy and one story described the experience of having an extreme premature and the other story described the experience of having an at term baby with a severe medical condition. With four participants this created two pairs. The extreme premature parents and the at term parents. In each pair one had the mission to focus on the first days after hospitalization, the other had the focus on the longer term. The longer term for the at term parents was around day 12, for the extreme premature around day 70. See the materials that were inside the envelop in figure 10.



Soms gaat de zwangerschap of bevalling niet zo als gepland.



figure 9 A couple of slides from the brainstorm presentation

#### **00.** APPENDIX



**figure 10** Personal story and brainstorm mission in envelop

## 8. IDEA CARDS

After all materials of the brainstorm session were analyzed and processed ideation cards were created. In total nine different ideas were roughly developed and presented on those cards. The cards elaborate the future NICU context equipped with single bed unit's with and without the specific design intervention. In figure 11 till figure 19 all ideas are presented.

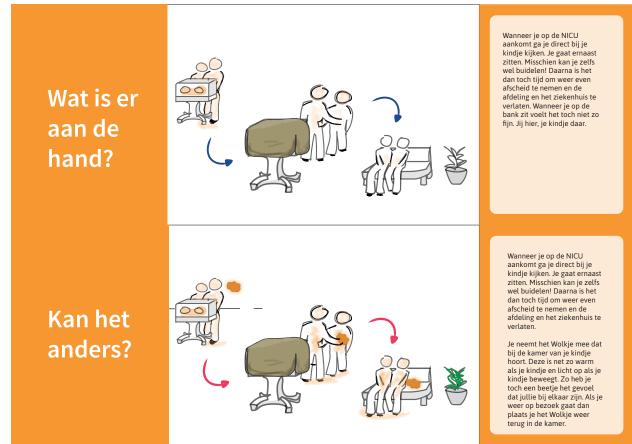
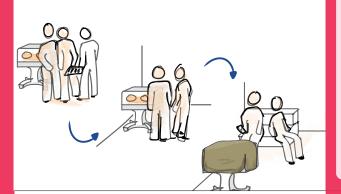


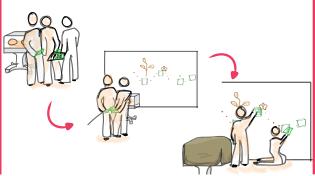
figure 11 Concept cards report appendix.ai

# Wat is er aan de hand?



Je bent op de NICU bij je kindje. De verpleegkundige komt langs en vertet je over wat er allemaal is gebeurd afgelopen nacht. Als je kindje een rustige nacht heeft gehad is dat erg fijn. Helemaal fijn als blijkt dat hij weer een stapje heeft gezet in de goede richting! Toch zijn er ook minder fijne nieuwtjes en als de verpleegkundige weg gaat ga je malen. Dingen opzoeken op Google maakt soms alleen maar bang, maar toch doe je het.

## Kan het anders?

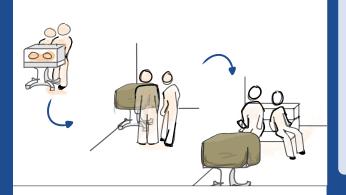


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De verpleegkundige heeft je een leuk fotootje gegeven van je kind en een bijzonder mijlpaalkaartje. Deze kan je op de muur plaatsen in jullie kamer. Zo denk je vooral aan de fijne momenten!

figure 12 Concept cards report appendix.ai: 2

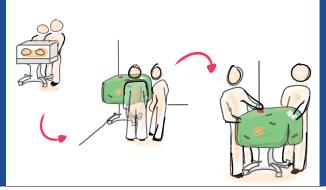
## Wat is er aan de hand?



Wanneer je op de NICU aankomt ga je direct bij je kindje kijken. Je gaat ernaast zitten. Misschien kan je zelfs wel buidelen! Na een tijdje moet het verduisterende doek weer over de couveuse heen, te veel licht is niet goed voor je kindje.

Nu ben je nog wel bij je kindje, maar je kan hem/haar niet meer zien. Het voelt niet zo fijn dat je geen contact meer hebt. Toch blijf je op de

# Kan het anders?



Wanneer je op de NICU aankomt ga je direct bij je kindje kijken. Je gaat ernaast zitten. Misschien kan je zelfs wel buidelen! Na een tijdje moet het verduisterende doek weer over de couveuse heen, te veel licht is niet goed voor ie kindie.

Hoewel je je kindje niet meer kan zien, kan je op het doek voelen hoe het met je kindje gaat. Het hartje bootst de hartslag na, het wolkje de ademhaling en het bloemetje de temperatuur. Zo ben je toch een beetje verbonden Er kunnen ook eigen vormpjes voor de versiering op worden geplakt.

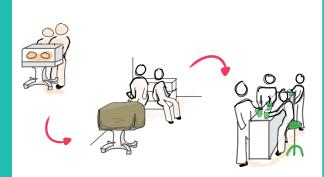
figure 13 Concept cards report appendix.ai

## Wat is er aan de hand?



Je bent op de NICU bij je kindje. Je kindje heeft veel rust nodig dus je kan niet de hele tijd het doek van de couveuse afhouden of je kindje aanraken. Na een tijdje doe je het doek er weer op. Nu je niks te doen hebt ga je malen. Je wilt eventjes je hoofd leegmaken, maar je wilt eigenlijk je kindje niet alleen achterlaten op de kamer. Toch zou het fijn zijn om even wat energie te krijgen, maar je weet niet zo goed hoe. Je gaat maar weer even naar je kindje kilven

# Kan het anders?

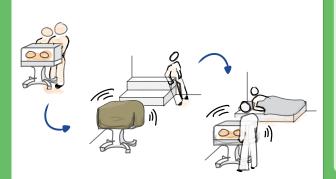


Je bent op de NICU bij je kindje. Je kindje heeft veel rust nodig dus je kan niet de hele tijd het doek van de couveuse afhouden of je kindje aanraken. Na een tijdje doe je het doek er weer op. Nu je niks te doen hebt ga je malen. Je zit in je eentje op de kamer en bent door al het gedoe zelf ook uitgeput.

Over een kwartiertje is het dagelijkse koffie-moment. Hoewel je moe bent besluit je toch even te gaan. De ouders van de kamer naast je zijn er ook! Toch fijn om ze even te spreken hoe het met hun en hun kindje gaat maar ook gewoon over koetjes en kalfjes.

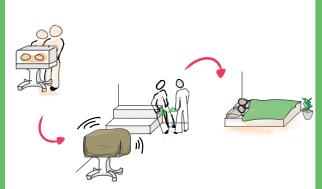
figure 15 Concept cards report appendix.ai: 2

# Wat is er aan de hand?



Je bent bijna de hele dag bij je kindje op de NICU. De alarmen gaan steeds af omdat je kindje nog niet stabiel is, maar het gaat al wel beter dan eerst! Je bent erg moe en klapt het bed uit op de kamer. Het lijkt je fijn om zo dichtbij je kindje te kunnen slapen. 's nachts gaan de alarmen echter door en de verpleegkundigen komen ook geregeld binnen. De volgende ochtend klap je het bed weer op, maar uitgerust ben je niet. Om je kindje weer bij te staan schraap je toch je energie bij elkaar.

# Kan het anders?



Je bent bijna de hele dag bij je kindje op de NICU. De alarmen gaan steeds af Omdat je kindje nog niet stabiel is, maar het gaat al wel beter dan eerst! Je bent erg moe. Dan komt de verpleegkundige die vanavond de Nachtmama/papa is binnen. Je kan haar dingen meegeven over hoe het vandaag ging met je kindje. Jullie spreken af dat ze vannacht tijdens de voedingsronde een fotootje zal sturen. Zo weet je dat er vannacht iemand extra goed op jouw kindje let en kan jij naar huis om lekker in je eigen bed te slapen.

figure 14 Concept cards report appendix.ai

#### **00. APPENDIX**

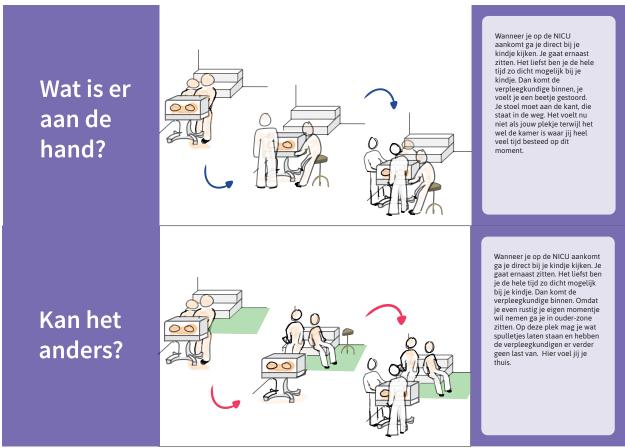


figure 17 Concept cards report appendix.ai: 2

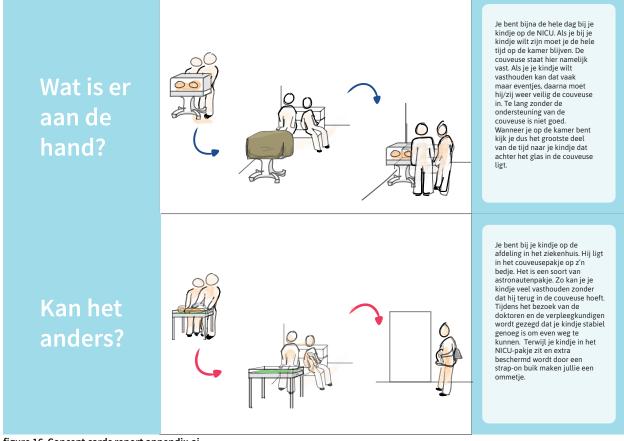
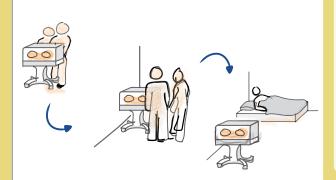


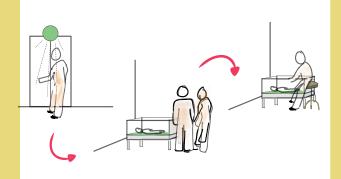
figure 16 Concept cards report appendix.ai

# Wat is er aan de hand?



Wanneer je op de NICU bent, ben je dichtbij je kindje maar nog steeds voel je afstand. Je kindje ligt namelijk in de couveuse, een enorm apparaat met veel piepjes en een soort cocon om je kindje in warm te houden. Hierdoor zit er altijd een barriëre tussen jou en je kind. Dit geeft een vervelend gevoel.

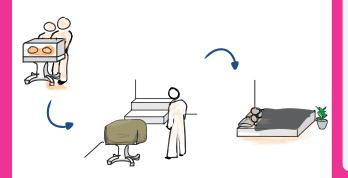
# Kan het anders?



Wanneer je op de NICU komt ga je naar jullie kamer. Voordat je binnenkomt ga je langs een desinfecterende zone en ga je sluisdeuren door. Dan kom je in een grote couveuseruimte terecht. Je zit nu dus eigenlijk samen met je kindje IN de couveuse. Zo verdwijnen de barriëres en het technische apparaat waar je kindje in ligt, dit wordt allemaal aangestuurd via de sensoren in de kamer. Ook de piepjes hoor je niet meer in de kamer, maar die krijgen de doktoren en verpleegkundigen natuurlijk wel doorgestuurd. Zo is het eigenlijk een soort van huiskamer.

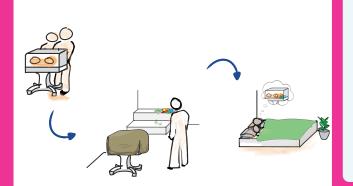
figure 19 Concept cards report appendix.ai: 2

# Wat is er aan de hand?



Als je kindje net is opgenomen op de NICU kom je in een grote onbekende chaos terecht. Je wordt naar jullie eigen kamertje gebracht waar je kindje al ligt en is aangesloten op alle apparatuur. Er staat een bank en de verpleegkundige vertelt dat je die kunt uitklappen om te blijven slapen. Het is maar voor één persoon, dus je partner kan helaas niet blijven. Je besluit toch samen thuis te gaan slapen zodat je wat meer steun aan elkaar hebt, maar je hebt geen fijn gevoel bij het achterlaten van je kind.

# Kan het anders?



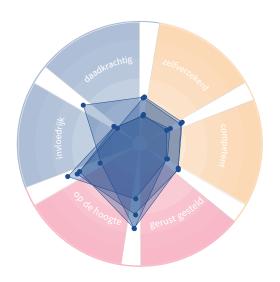
Als je kindje net is opgenomen op de NICU kom je in een grote onbekende chaos terecht. Je wordt naar jullie eigen kamertje gebracht waar je kindje al ligt en is aangesloten op alle apparatuur. De verpleegkundige vertelt dat je kunt blijven slapen. Je ziet dat er een welkomspakketje voor je klaar ligt. Het zijn de basis overnachtigsspullen als een tandenborstel en een zeepje. Ook zie je een bloem liggen van een zacht materiaal. Er word uitgelegd dat dit jouw geur kan absoberen. Als je dan besluit thuis te slapen kan je dit bij je kindje leggen. Zo ben je ook als je er niet bent toch een beetje bij

figure 18 Concept cards report appendix.ai

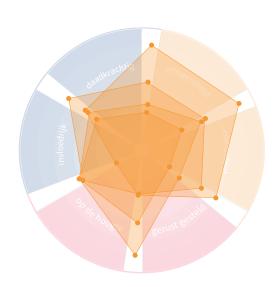
# 9. VALIDATION PLOTS

During the validation of the ideas on the idea cards the NICU-Need-model was used. For each idea the combined plots of all participants are visible in this chapter.

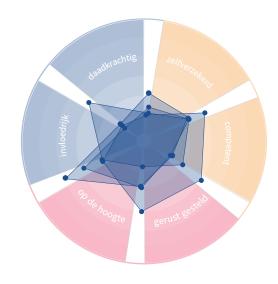
### Incubator-room without interventions



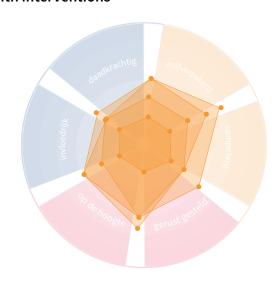
#### with interventions



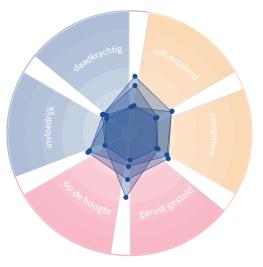
### Parental-zone without interventions



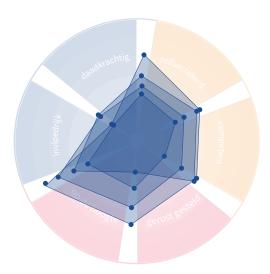
#### with interventions



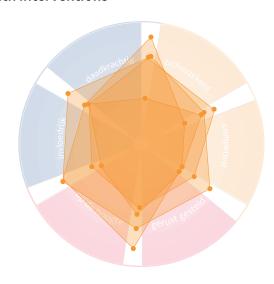
# Welcome package without interventions



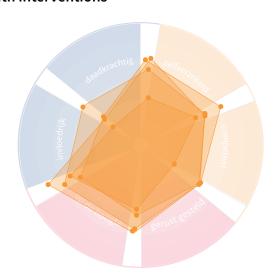
#### Information-wall without interventions



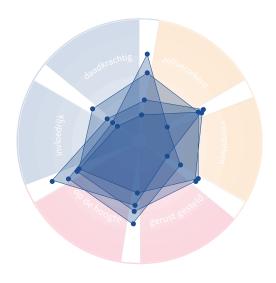
with interventions



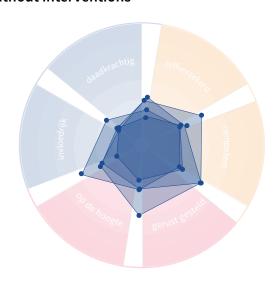
with interventions



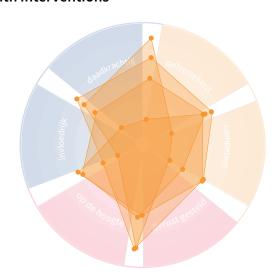
# Night mom without interventions



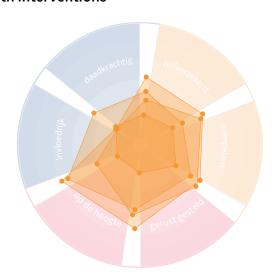
## Incubator blanket without interventions



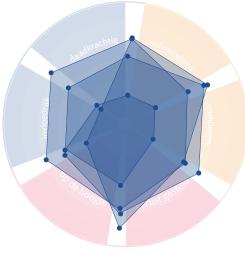
#### with interventions

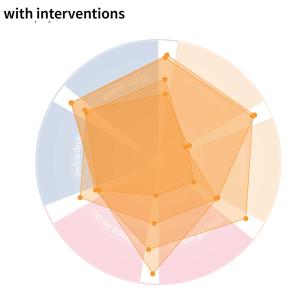


#### with interventions

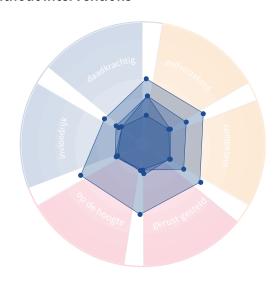


Astronaut suit without interventions

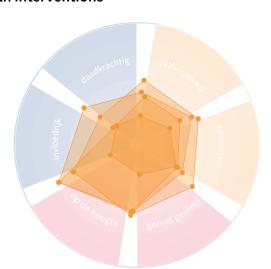




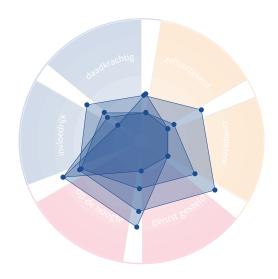
Wolkje without interventions



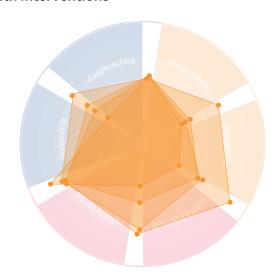
with interventions



# **Coffee moment** without interventions



#### with interventions



# **10.CRUCIAL QUALITIES**

The crucial concept qualities were identified during analysis of the argumentation of the idea ratings was done by reviewing the transcriptions. This resulted in five qualities that a idea should foster. The idea should bring tranquility, positivity and a sense of ownership and be noncompulsory and supportive.

The transcriptions were analysed and for each idea positive and negative comments were collected. Next, a ranking of those comments was made. The ranking was based on how the comments indicated if the idea would improve their NICU experience or not. The comments were placed from negative, 'This is bothering me', to positive, 'is helps me'. See figure 20. Subsequently the comments that were ranked positive were compared to the negatives ones. This resulted in an combination of qualities that were not improving the parental experience and qualities that did have a positive effect. This is visible in page 31. The qualities that had a positive impact were distilled, see figure 21.



figure 20 Comments ranked from negative to positive.

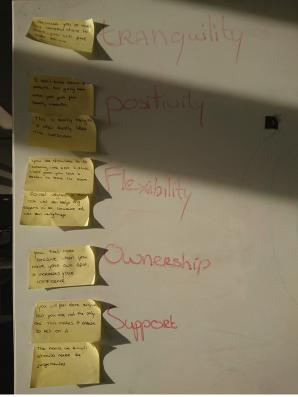
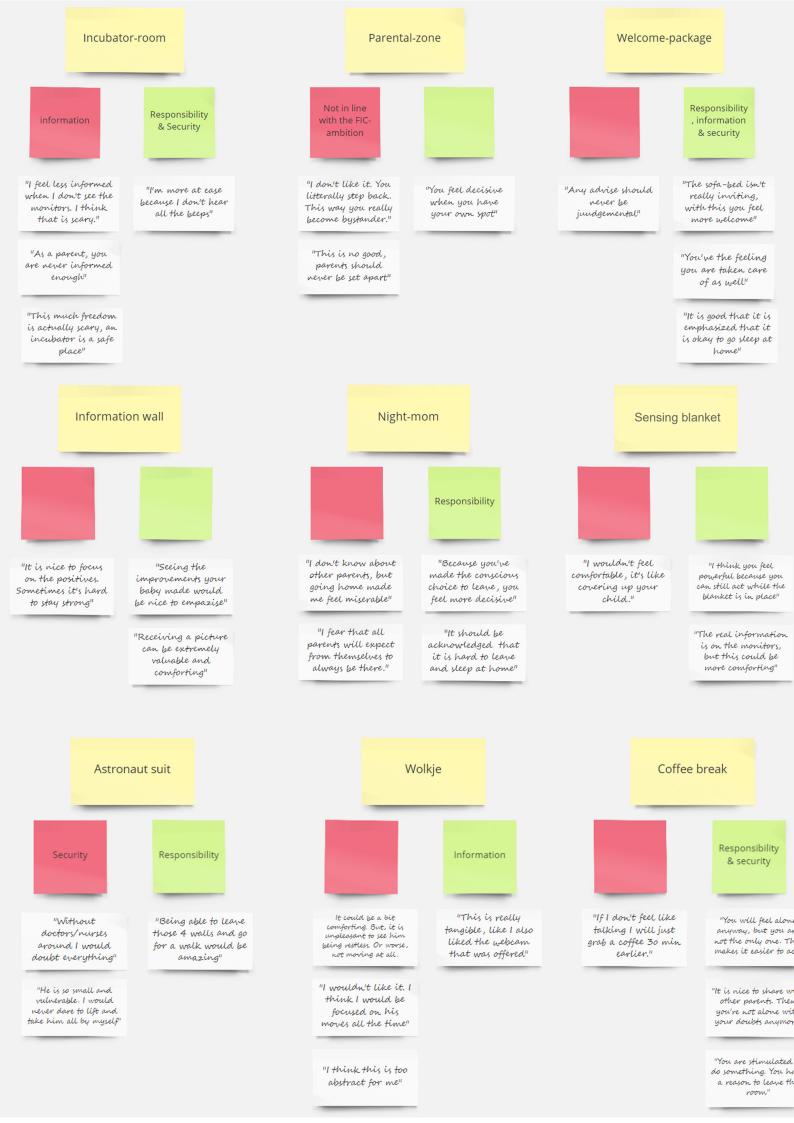


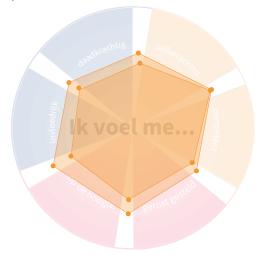
figure 21 The positive qualities.



# 11.FIRST DESIGN **VALIDATION PLOTS**

During the first validation of the elements of the NICU neighbourhood the NICU-Need tool is used. For each element the plots of the participants are visible in this chapter.

#### Lamp



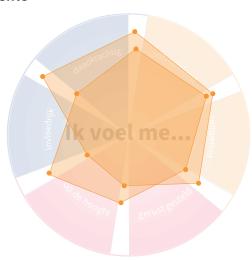
#### **Writing Wall**



#### **NICU-Mail**

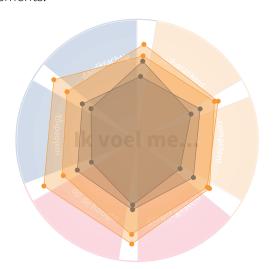


#### Theme



#### **00. APPENDIX**

**General experience.**In blue the experience without interventions, orange the experience with the designed elements.



# 12. SECOND DESIGN VALIDATION PLOTS

During the second validation the NICU neighbourhood the NICU-Need tool is used. Only the lamp is studied now.

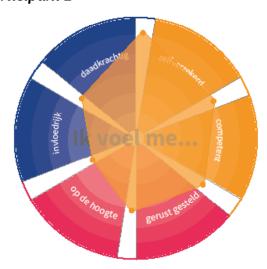
#### Participant 1



#### Combined



#### Participant 2



#### **00. APPENDIX**