Prevention of Sudden Infant Death Syndrome

eHealth intervention design to support the current health promotion and education about SIDS:
human centered contextual inquiry and value specification

Master Thesis

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This master thesis is written to finish my master Health Sciences at the University of Twente. In this master I followed the track of 'human centered eHealth and healthcare services design'. I chose this topic due to my great interest in the child healthcare and the use of eHealth interventions in the healthcare. I have experienced this period as a journey. It was an interesting and challenging period. Particularly, to translate the information from the research participants in an eHealth intervention that could be of added value. I am grateful to all people who have helped me to complete this journey. Beside the ups, this journey had also its downs, which helped me to see my own strong qualities and to develop my weaker side.

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ABSTRACT

Background: Sudden Infant Death Syndrome (SIDS) is the sudden unexpected death of a seemingly healthy child older than one week but younger than one year of age, usually during sleep, that cannot be explained after a postmortem evaluation. The most important modifiable risk factors are stomach sleeping, smoking, use of wrong equipment in bed such as soft bedding, and parental bed sharing. Currently, the incidence of SIDS is very low in The Netherlands and the idea can be assumed by parents that prevention is no longer necessary or due to reduced awareness of cot death, risky behaviors will be performed again in the care of their infant. The aim of this study is to examine whether and how an eHealth intervention can be used to support the current health education about SIDS by understanding the perception of the end-users concerning the current health education. The research question is: *What are the experiences and expectations of prospective parents, parents with an infant between 0 and 12 months old, and healthcare professionals with the current health education about SIDS and towards health education support to prevent SIDS through an eHealth intervention?*

Methods: The study is executed according to the CeHRes roadmap, the first two phases contextual inquiry and the value specification are followed. A qualitative study through semi-structured interviews was performed with primary end-users (N=10), namely (prospective) parents (N=1) and parents with an infant between 0 and 12 months old (N=9), and secondary end-users (N=7), namely a youth healthcare physician (N=1), youth healthcare nurses (N=2), maternity nurses (N=2) and midwives (N=2). The interviews were inductive and deductive coded in Atlas.ti. Subsequently, from the interview the expected added values concerning a possible eHealth intervention were determined and translated into requirements by using the approach of Van Velsen. The persona descriptions of the primary end-users are developed by using the approach of Le Rouge.

Results: The barriers that parents are currently facing are: too late provided information about SIDS, generalized health education, insufficient / lack of detailed information and unattractiveness.
Their needs of the parents concerning the current way of health education are easy to understand, detailed/relevant health education, provided in a more attractive and personalized way, without replacing the current health education. The healthcare professionals perceived language and cultural differences as important barriers in the current health education. Unattractive and anxiety provoking health education were also mentioned as barriers. The healthcare professionals indicated that the cultural and language barriers should be solved, besides they needed visual and non-verbal health education. The expectations from an eHealth intervention are formulated as values. The values of parents concerning an eHealth are that is should be easy to understand, easy to use and affordable. Furthermore it should be able to raise more awareness/increase the knowledge of the users. The health education provided by an eHealth should also be personalized and provide relevant and detailed

information. The values of the healthcare professionals correspond with the values of the parents. They mentioned that the eHealth should also stimulate empowerment, improve patient-professional communication, and be easy to integrate into their current work routine. From these values, 16 requirements are formulated. Subsequently, three initial personas descriptions are designed, based on the interview. The personas were differing in the motivation and domain specific knowledge of the primary end-users.

Conclusion: Taking the needs and values of the primary and secondary end-users into account, it can be concluded that eHealth technology could meet the needs of the end-users, solve certain perceived barriers and fit into the current way of health education as a supportive tool. There seems to be space for blended care in which an eHealth intervention could support the current way of health education about SIDS. Possible interventions could be mHealth or an e-Learning module. However, to conclude this, further research verifying the results needs to be performed.

Key words: *Sudden Infant Death Syndrome (SIDS), cot death, eHealth, CeHRes roadmap, Human Centered Design*

ABBREVIATIONS:

SIDS: Sudden Infant Death Syndrome

ICD: International Classification of Diseases and Related Health Problems

CBS: Dutch Central Bureau of Statistics

CeHRes: Center for eHealth Research & Disease management

HCD: Human Centered Design

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1. INTRODUCTION

Hereafter you can find the introduction for this study, followed by a supporting comprehensive background information about SIDS, the risk factors of SIDS, the health care providers involved in the health education about SIDS, the health education campaigns about SIDS in The Netherlands and the behavior of parents.

SUDDEN INFANT DEATH SYNDROME

"On Sunday February 10 2015, I woke up late by myself after a long time. I was used to hearing my 10-month-old sturdy, strong and healthy little man, Ashler, crying for food, playing with his teddy bear or laughing early in the mornings, trying to call me. His voice was my daily alarm clock. Not this morning. Even before I went into his room, I knew something was wrong. I crept into his room, hoping he was still sleeping or just waiting for me bringing his bottle. As soon as I saw him, his face flat into the mattress, I felt panic wash over me, followed by pain, shock, hysteria... As my hoping changed into begging, I gently pulled him back: his face was a deep, mottled blue. He was as cold and solid as ice, his eyes closed for ever. In minutes, our home became a crime scene. Friends, family, the police and paramedics arrived. The moment when they carried my son away, will stay with me forever, as will the guilt that I never held him one last time, before they took him from his home."

– Nina, Ashler's mother

A child's death is the most painful experience for parents and the worst experience is probably the unexpected and unexplainable death of a healthy baby. Sudden Infant Death Syndrome (SIDS) is the term to describe cot death or crib death, which is *"the sudden unexpected death of a seemingly healthy child older than one week but younger than one year of age, usually during sleep, that cannot be explained after a postmortem evaluation including autopsy, a thorough clinical history and death scene investigation"* [1-3]. This definition is based on the International Classification of Diseases and Related Health Problems (ICD-10, code R95), which is used internationally [4]. The Pediatric Association of the Netherlands defines SIDS as *"the sudden and unexpected death of an infant younger than two years of age"*, because 15% of all infants who die because of SIDS in The Netherlands are dying in the period between one year and two years of age [4]. In this study the definition of SIDS based on the ICD-10 will be used, because the Dutch Central Bureau of Statistics (CBS) uses the ICD-10 definition as well and therefore registers only SIDS cases between 7 days and 1 year of age [4]. The incidence rates of SIDS are very low in The Netherlands. In 2000, 25 cases between 1 week and 1 year of age in total were registered as cot death in one year. In 2010, there were 17, and in 2015 only 7 cases [5,6]. Experts attribute the achievement in low incidence in The Netherlands entirely due to the early effort on prevention.

RISK FACTORS

Even though the sudden death of an infant has long been considered as one of the most mysterious events in medicine [7], recent advances in medical research show us that babies who die of SIDS may not be as healthy as we once thought [8]. Researchers now belief that some infants who die of SIDS are born with brain abnormalities or defects, resulting in babies who may be especially vulnerable to both internal and external influences [9].

After the first recognition of the risk factor that sleeping in the prone position was associated with SIDS, attention turned to factors that might trigger infant's death in this position [10]. One of the most important factors scientists have uncovered that could be the cause of SIDS is an abnormality in the brainstem of SIDS victims that makes them vulnerable to sudden, unexpected death [11]. These abnormalities are found in the part of the brain that controls the bodily (vital) functions[12]. Brain defects alone could not be enough to cause a SIDS death [12]. Research showed that other events must also occur for an infant to die from SIDS [12]. Together with the discovered internal and external risk factors and certain circumstances, the Triple Risk Model has been conceptualized [13]. The best known Triple Risk Model (figure 1) is presented by Filiano and Kinney in 1994 [14], that presents three elements that can interact with each other and cause SIDS [8,13]. According to this model, the likelihood of SIDS is higher when all three elements combine [12, 8].

Figure 1. The Triple Risk Model by Filiano and Kinney [15]
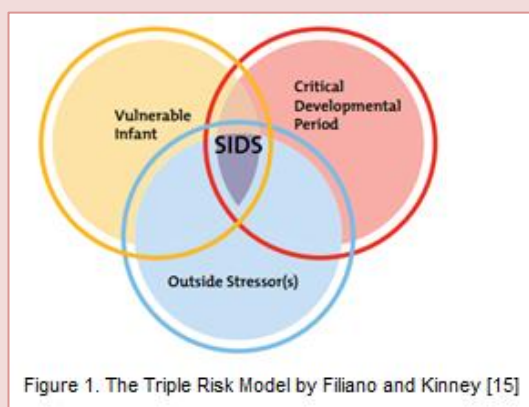
The first element of the model is the critical development period, which is the first six months of life where the baby is growing and developing very rapidly, which can make an infant's system become unstable [8,12]. The second element represents a vulnerable infant with an underlying abnormality in an area of the brainstem that controls respiration, heart rate, temperature, arousal from sleep and other major bodily functions [8,11]. Oxygen deficiency or rise of carbon dioxide in the blood, or over- and under heating, might not trigger the functions in the insufficiently developed brainstem of the infant to breathe air deeply or faster or start sweating to loose heat [8,12,11]. These circumstances may happen when babies sleep prone and the air becomes trapped in bedding. The third element involves outside or environmental challenges which a normal infant can easily overcome and survive, but that an already vulnerable infant might not [8,12]. Those outside challenges are the risk factors, such as tobacco exposure, prone sleeping, soft bedding, bed sharing (table 1A), which alone do not cause death for healthy infants, but could trigger a sudden, unexpected death in a vulnerable infant [8,12]. Normally, babies are able to sense these circumstances and their brain will make them wake up, change their

heartbeat or breathing, but if the baby is already vulnerable because of brain defects, these protective triggers might be missing [12].

The risk factors can be divided in modifiable, which are the behavioral risk factors, and non-modifiable factors. Table 1A summarizes the non-modifiable and modifiable risk factors and table 1B the protective factors for SIDS [15 - 19]. These protective factors are intended as recommendations. Even though, there is no certain way to prevent SIDS or to predict which infants may die of SIDS, these risk reduction strategies and recommendations are ways to reduce an infant's risk for SIDS [15 – 19]. The modifiable risk factors and the protective factors are related to parents' behavior, habits and cultural background, which can be influenced and triggered.

Table 1A. Summarization of risk factors categorized as modifiable and non-modifiable risk factors for SIDS [15,16,17,18,19].

Non-Modifiable Risk Factors	Modifiable Risk Factors
1.Pre-term delivery	1.Prone or Side sleeping position
2.Low birth weight	2.Maternal smoking during pregnancy
3.Male gender	3.Parental smoking after delivery
4.Age of the mother	4.Fluffy, stuffed bedding, pillow, duvet
5.Low socio economic status	5.Bed sharing
6.Parity	6.Overheating
7.Ethnicity	7.Swaddling
8.Multiple Birth	8.The use of alcohol and illicit drug during pregnancy and after birth
9.Pospartum Depression	9.Sleep inducing medication
10.Winter Months	10.Lack of supervision
	11.Changes in daily routine of the infant

Table 1B. Summarization of protective risk factors and recommendations for SIDS [15,16,17,18,19].

Protective Factors
1. Supine position for every sleep until the age of 1 year
2. Avoid smoke exposure during pregnancy
3. Avoid smoke exposure after birth
4. Keep soft objects and loose bedding away from the infant's sleep area
5. Room sharing, close to the parents' bed but on a separate firm surface for infants, for the first year of life
6. Avoid overheating and head covering in infants
7. There is no evidence to recommend swaddling as a strategy to reduce the risk of SIDS
8. Avoid alcohol and illicit drug use during pregnancy and after birth
9. Avoid sleep inducing medication
10. Breast Feeding is recommended
11. Avoid changes in daily routine of the infant
12. Offer a pacifier at nap time and bed time
13. Infants should be immunized in accordance with recommendations
14. Avoid the use of commercial devices that are inconsistent with safe sleep recommendations
15. Do not use home cardiorespiratory monitors as a strategy to reduce the risk of SIDS
16. Supervised, awake tummy time is recommended to facilitate development and to minimize development of positional plagiocephaly (flat head syndrome)
17. Pregnant women should obtain regular prenatal care

MAIN CHILD HEALTHCARE PROVIDERS

In The Netherlands, a large number of health care providers from the primary and secondary care are involved in the care for the infant and the (preventive) health education of the parents concerning their pregnancy and raising a child throughout its childhood. All health care providers need to know the guidelines for SIDS. However the main actors that are responsible for the promotion and education of SIDS, are the midwives, maternity nurses, and youth health care physicians and youth health care nurses from the child health clinics *(consultatiebureau)* [19], hereafter referred to as the main health care professionals. These main health care professionals take part in the primary care. In The Netherlands, the role of the gynecologists, obstetricians and pediatricians from hospitals is minor in a normal pregnancy and infancy period, and they are in most cases not involved at all [20]. They provide secondary care, and are only present when obstetric problems occur or when pediatric problems, disorders or death occur, which require further investigation and/or treatment and cannot be granted at the primary care[20]. The General Practitioners (GPs) have a major role in the primary care. They provide personalized help and information and will refer to the secondary care health care providers when they are not able to help the patient. All these main primary care professionals perform consecutively or simultaneously their tasks during the prenatal period, the delivery and postnatal period and throughout the childhood period. Characteristic for this chain of child healthcare is the collaboration of the primary and secondary health care professionals that are able to function both independently and interdependently, and perform coherent actions with a common goal that the individual professionals cannot achieve on their own.

Currently, the health promotion and education about SIDS is based on guidelines provided as written (leaflet) and oral information [19,21]. In the following, the different tasks of the main health care professionals responsible for the health promotion and education about SIDS are discussed.

"The midwife is recognized as a responsible and accountable professional who works in partnership with women to give the necessary coaching, support, care and advice during pregnancy, labour and the postpartum period, to conduct births on the midwife's own responsibility and to provide care for the newborn and the infant" [22,23]. Midwifery care includes preventative measures, the promotion of normal birth, the detection of complications in mother and child, the accessing of medical care or other appropriate assistance and the carrying out of emergency measures [22,23]. Midwives also provide the parents with information about a safe sleeping environment for the baby, including the right equipment, especially concerning SIDS.

Maternity care is a medical service in The Netherlands, where postnatal care is provided to a mother and her baby. The support comes from a maternity nurse, who comes to the home in order to take care

of the mother and the newborn [23]. Maternity nurses have a key role as educator to parents and their family by providing health promotion and education concerning SIDS. They are the role models for new parents especially regarding newborn sleep position, and are in a unique position to influence parents' decisions about how to care for their newborns at home [24]. They have a vital role in preventing SIDS by educating the parents and families about the risks of SIDS. They can take care of household chores, prepare meals, but also perform medical checks, support breastfeeding, give information and advice about how to care for a newborn, how to wash them, feed them, clothe them, in short, all the information needed for the right parental behavior [23].

A municipal health service (GGD), including the child healthcare clinic provides basic preventive child health care with health education, information, advices, instructions and guidance for a healthy development, and monitors and signalizes the health and safety, of all children from birth until they are 18 years old [25,26]. The consultations with parents of children between 0 and 4 years, are being executed by a youth health care physicians and a youth health care nurse. From the age of 4 till 18 years, the physician assistant executes the consultations as well. Examples of tasks are giving vaccination, following the development and growth of the children, signaling risks, but also supporting the parents, answering questions and problems of parents about breastfeeding, parenting and behaviors [25-28]. For SIDS it is important that the municipal health service and child health care clinic team answer the parents' questions, support them and give advice and information about preventive behaviors by providing them leaflets and oral information. Appendix A includes a stakeholder map with all the important stakeholders that could be included in the development process of an eHealth intervention in this context.

HEALTH PROMOTION AND EDUCATION OF SIDS

Over the past couple of decades, health care providers and other caregivers have made significant progress in reducing the number of infants who die each year of SIDS. This decrease was largely the result of the actions of health care providers and public health campaigns that have educated parents and caregivers about the risk factors of SIDS [29]. Health promotion can be defined as *"the process of advocating health in order to enhance the probability that personal (individual, family and community), private (professional and business) and public (federal, state and local government) support of positive health practices will become a societal norm"* [30].

In 1972, advice to place infants prone, which is front sleeping, was followed widely after publications in the medical journals that babies with respiratory problems might benefit from front sleeping and that babies with severe gastro-esophageal reflux might be less likely to choke when sleeping on their fronts [31]. This led to the assumption that the safest sleeping position for all babies was on their front

[31]. At the same time the incidence of SIDS increased [32]. In 1987, De Jonge detected a correlation between the prone sleeping position and an increased risk of SIDS. This finding resulted in a campaign in the Netherlands in the same year, advising parents to place their infant to sleep on their back, supine, and from then on the SIDS incidence rates decreased from 103 deaths per 100.000 new born in 1986, to 10 per 100.000 new born children in 2004 [33]. A lot of countries followed this campaign. One of the most known and effective awareness campaign was the *"Safe to Sleep"* campaign, formerly known as *"Back to Sleep"* campaign, which was an initiative by the US National Institute of Child Health and Human Development and First Candle, implemented in 1994, to raise awareness among parents and caregivers and stimulate them to use the supine position for their infants during sleep [34,35].

From then on, additional recommendations were added to the SIDS prevention guidelines, namely type of bedding that should be used, and discouraging the use of duvets and pillows and bed sharing [33], resulting in public health campaigns, to disseminate the new risk factors and recommendations among the population.

In 1996, the Consensus Prevention Sudden Infant Death Syndrome, was introduced [4,32,36]. This consensus contains the risk factors and recommendations for the care of the infant concerning SIDS [4,32,36]. In 2009, this consensus was replaced by the Dutch Child Health Care Guideline Prevention of SIDS [36]. This guideline gives recommendations for parents concerning SIDS. Professionals working in child care are responsible to give these advices to the parents of children between one day and three years of age [4,36].

Currently, there are no public campaigns, everyone who takes care of an infant can get information about SIDS from his or her health care professional [19,21]. Leaflets and websites are especially designed for parents searching for reliable, evidence based (internet) information [19,21]. A well-known leaflet provided by every healthcare professional about SIDS is *"Sleep Tight",* with a corresponding application *"Grow up Safely".* This application helps infant carers to make their home safe for children between 0-6 months, 6-12 months, and 1-4 years old [19,21]. Recommended websites are www.veiligheid.nl and www.opvoeden.nl , both websites contain a lot of reliable advices and recommendations for the safety of the children and also about safe sleeping concerning SIDS [19,21,37]. Of course, there are a lot more websites and applications with a lot of information, however these are applications or websites of private clinics or individual designers, not tested neither evaluated or recommended by health care providers.

CHANGING BEHAVIOR OF PARENTS

The precious paragraph showed some successful public health promotion campaigns about SIDS, which were followed by a decrease in the SIDS death rates. However the behavior of parents is changing continuously and the current health education might not be able to cope with this. Due to the low incidence of SIDS in The Netherlands in recent years, the idea can be taken by parents and caregivers that prevention is no longer necessary. This is a known phenomenon that successful prevention tends to be neglected [33]. The awareness of SIDS might reduce and the risky behaviors already known to be related to an increased risk for SIDS, will be performed again. Several studies show that the safe sleep messages are not sufficiently reaching all segments of society [38,39]. Different studies tried to explain this phenomenon.

Ottolini et al (1999), observed in a prospective study that parents without repeated instructions during the first six months of the infant's age, started using the prone position again, usually thinking that prone sleeping will improve the baby's sleep quality [40]. In the same study, parents rated the media (47%) and friends or relatives (18%) as the most influential sources of sleep position information. They used the prone sleeping based on infant's comfort (76%), previous experience (12%) and fear of choking during back sleeping due to regurgitation and aspiration (12%) [40]. The study of Boschert (2004), showed that advice from the mother's own mother, sister, aunt or grandmother was seven times more influential than were other health promotion and education materials [41]. The same study showed that the mother's own perception that her baby slept better, more deeply and comfortable, on his/her side or prone, was 11 times more influential than were other materials that recommended back sleeping [41,42]. (Mis)beliefs caused by (wrong) information provided by others than healthcare professionals regarding back sleeping position, are the major reason parents avoid it. Beside this, culture and tradition has also influence on parents' choices. It makes the diffusion of health education harder. It is important to know that some of the behavioral risk factors appear because of cultural issues. Sleeping on soft bedding and bed sharing, are common among minority populations [42,52], and dressing an infant in multiple layers of clothing, sleeping bag and bed sheets, can lead to overheating, which are also behavioral risk factors in minority populations [42,52].

Besides the information searching behavior of parents is also changing. Internet and technology play an important role in everyone's daily lives. Although, the internet is also increasingly used as a health information source for gathering information, parents still indicate that it can be difficult to find trustable information [43]. This causes feelings of disempowerment and anxiety in parents [43,44]. Some studies have even shown that health education materials, such as leaflets and web-sites, give information and recommendations that deviate to various degrees from the recommendations in the general medical guidelines [43,45]. A lot of materials that contain trustable information, appear to be

written at a level far above the average adult's reading ability and may not be appropriate for many adults [46]. This can make understanding the health education and deciding whether it is in accordance with the guidelines, more difficult. Besides, it is difficult for the healthcare professionals to monitor the information searching behavior of parents or to find out what their (cultural) beliefs and misbeliefs are to base their feedback on. Currently, the monitoring is performed by direct observations and questioning the parents during contact moments. However, this is prone to the Hawthorne effect and therefore causes bias such as the social desirability bias, whereby the answers are in a manner that is viewed favorably by the healthcare professionals [85]. It can take the form of over-reporting the good behavior or under-reporting the bad/undesirable behavior for SIDS [85].

So parents have different reasons to deviate from the guideline recommendations and despite the progress made, there are still infants dying because of SIDS. Due to the continuously changing behavior of parents, the current way of health education might not be able to cope with this. The lack of awareness might increase due to not realizing the consequences of poor or non-compliance with certain recommendations, low death rates and changing behavior. 'Live' monitoring of the behavior, providing just-in-time feedback and user centered health education by triggering or using real-time reminders for example by showing the consequences of bad behavior, could be implemented to improve the current way of health education and make it more suitable [49,53,57,59]..

E-HEALTH

Nowadays, technology has great promises. The use of information, communication and internet technologies to support or improve health and health care, is also called eHealth [47]. A well-known and frequently used definition of eHealth is formulated by Eysenbach (2001):

> *"EHealth (electronic health) is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, to improve health care locally, regionally, and worldwide by using information and communication technology"* [47].

eHealth can be an interactive technology and has the potential to provide individualized, tailored feedback about the behavior of the users and health education about SIDS. The feedback and education can be based on monitoring certain proceedings, such as keeping track of readings or environment and support parents 24/7 in the prevention of SIDS by providing just-in-time relevant information whenever they want it and where they want it, because it has considerable potential for acquiring data with automated analysis processes, which can be used locally to monitor and assess

user specific proceedings continuously and objectively, or behavioral actions. This way awareness concerning the risk factors of SIDS might be increased. eHealth is also able to support the adoption of healthy behavior [47,48,49,53,57,59].

As already described, parents indicated that internet information caused feeling of disempowerment and anxiety [43,44]. eHealth is known by being able to empower the users to take care of themselves or their infants [50]. This way, the burden on the healthcare system decreases, while parents will gain control [50]. Furthermore, eHealth is also able to improve the health education by increasing the equity. Access to health education for more people independent of time, place, in many forms and for everyone. Parents who are not reachable through the current way, could be reached by using eHealth whenever they require it and in the format in which they need it [50]. Another mentionable potential is that eHealth can play an import role by offering opportunities to improve the effectiveness of the health education of parents. Even though the incidence of SIDS is very low in The Netherlands, every life matters and using eHealth the same or even better outcome may be achieved with fewer resources [53]. EHealth can also be of added value for healthcare professionals [86,87]. It can improve the patient-professional's communication and support the professionals to reach the minority or solve other problems related to health education about SIDS, such as cultural barrier and language problems.

Also eHealth has some issues about the uptake and impact. The adherence could be low. The eHealth intervention could be demotivating or not used as intended by the parents. Lack of motivation and ability in the parents to use technology could also be one of the main issues. Furthermore, the impact of the eHealth intervention could be lower than expected, because it is not optimally implemented and not productive. However, the power of eHealth lies within its ability to use Behavior Change Theories to influence the behavior of its users, and its ability to be a persuasive technology, which can motivate, stimulate and support using the eHealth intervention and behavior change.

There are various eHealth technologies, such as informational websites, interactive health communication applications (i.e. e-consultation, online communities, online health decision-support programs, and tailored online health education programs), online health care portals, and electronic health records. It also includes mobile health communication programs (mHealth) and other advanced technologies such as Virtual Reality programs (i.e. serious gaming to stimulate exercise or 3-dimensional applications for the treatments of anxiety disorders), home automation (domotics), sensor technology for independent living, remote monitoring (telemonitoring), and robotics, the deployment of robots for assisting people with domestic tasks or to perform surgery [47,48,49]. To determine whether, how and which eHealth intervention could be used a research is needed.

Many technologies are not successful in realizing sustainable innovations in health care practices, because the broad range of possible end-users are not involved throughout the development process [49]. To develop a successful eHealth intervention that is easy to diffuse, an User- or Human Centered Design (HCD) with a holistic approach for the development of eHealth intervention is needed, one that takes the complexity of the specific needs, expectations and behavior and habits of the end users and other stakeholders into account through iterative process[49]. According to James (1984) holistic approach means that "the properties of individual elements in a complex system are taken to be determined by the relations they bear to the other elements". So, each term owns its meaning to its relation with the others [47,49,56].

HCD is a framework that aims to develop solution to problems by involving the user/human perspective in all steps of the process (co-creation), via observing the problem within context, brainstorming, conceptualizing, developing and implementing the solution. Co-creation means development *with* the end users, instead of designing *for* the end users, which is the key for a human centered design [47]. HCD has a deep respect for the user, and a realization that the user is the most important partner in design for whom you develop the eHealth intervention. The lives and desires of the end-users are central and the eHealth intervention should match these. Furthermore, HCD is an iterative process of design and redesign through formative evaluation cycles (going through several cycles of design and evaluation) [47,49]. At each stage, the design is reconsidered and given feedback before progressing to the next. The key to HCD is keeping users and stakeholders in the process through requirements definition, early feedback, evaluation and field testing. Therefore, all HCD methods are based on cycles of iteration, which is the key to continually ensure empirically that the design (intervention) is calibrated to the needs of the users and will help them effectively. When done properly, HCD empowers the users to engage in the improvements of their own situation, which will make the diffusion of the eHealth intervention easier. A practical model which uses this User/Human Centered design and holistic process for developing new eHealth technologies, improving existing technologies, and evaluating and implementing eHealth, is the CeHRes Roadmap [49].

Figure 2. CeHRes Roadmap
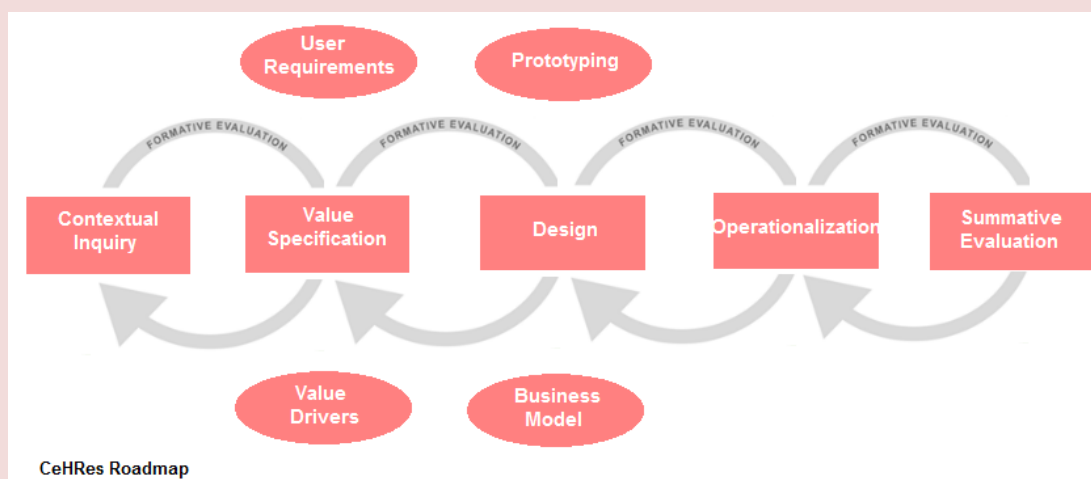
The CeHRes roadmap can be used to help, plan, coordinate and execute the involved development process of eHealth. It consists of five main phases: contextual inquiry, value specification, design, operationalization and summative evaluation (Figure 2).

During the first phase, the design team wants to identify who the future users and stakeholders will be and describe what their problems are by defining their perceived barriers and needs [57]. The second phase consists of determining what the different users and stakeholders find important, the values. The added value the stakeholders consider as important for the intervention can be examined through the interviews. These are input for the requirement elicitation in phase two. "A requirement is perceived as a functionality that a system has to comprise to satisfy the end-users' and key stakeholders' needs established to resolve experienced problems within the organizational context" [58]. Requirements are technical directives, specifying how the eHealth intervention should be designed, what a technology should do, what data it should store or retrieve, what content it should display, and what kind of user experience it should provide [56,59]. Between the second and third phase, there is actually another phase, the early design phase, which is used for the Human Centered Design process, where personas and use-case scenarios will be designed. Personas are defined as "hypothetical archetypes of actual users". They are descriptions (biographies) of fictitious users whose characteristics resemble one typical group of end-users [60]. This way, the eHealth intervention can be designed, tailored towards the needs and wishes of the end-users [47,61,62]. Use-case scenarios are "fictitious anecdotes of a persona experiencing an illness and the associated healthcare". In other words, use case scenarios are different daily situations in which the future eHealth intervention could be used [63]. The interaction between the product or system and the people who use it in practice are described. Interview quotes and the personas are an input for the use-case scenarios. In the use case scenarios, the goals, motivations, actions, and reactions of the users are also mentioned. The third phase is where the actual end product will be designed. The fourth phase concerns the introduction, adoption and employment of the final version of the eHealth intervention in its intended setting [47]. The fifth phase is the last phase, and has the aim to determine what has been achieved and realized at a given time. The output of each phase, is input for the next one. And through iterative process and formative evaluation, each phase can be re-evaluated and redesigned to improve the process and the eHealth intervention.

The research aim is to investigate whether and how an eHealth intervention can be developed to support the current health education about SIDS. To answer this, the experiences of the (prospective) parents and healthcare professionals with the current health education and their expectations towards health education support through an eHealth intervention to prevent SIDS, should be determined. To analyze the experiences, the positive experiences, the perceived barriers, and the needs will be determined. To analyze the expectations, the values the respondents assign to a possible eHealth technology and the requirements will be formulated. The main research question is as follows: *"What are the experiences and expectations of prospective parents, parents with an infant between 0 and 12 months old, and healthcare professionals with the current health education about Sudden Infant Death Syndrome and towards health education support to prevent SIDS through an eHealth intervention?"*. To answer the main research question, sub questions are designed. Table 2 includes these questions, divided into two phases of the CeHRes roadmap. To better understand the primary end-users, they will be analyzed and processed in initial persona descriptions.

Table 2. Research questions

Phase CeHRes Roadmap	Research Question
Main Research Question	"What are the experiences and expectations of prospective parents, parents with an infant between 0 and 12 months old, and healthcare professionals with the current health education about Sudden Infant Death Syndrome and towards health education support to prevent SIDS through an eHealth intervention?"
Contextual Inquiry	1) What are the positive experiences, perceived barriers and needs of prospective parents and parents with infants between 0 and 12 months old, concerning the current health education about SIDS?
	2) What are the positive experiences, perceived barriers and needs of youth health care physicians, youth health care nurses, midwives and maternity nurses, concerning the current health education about SIDS?
Value Specification	3) What are the values of prospective parents and parents with infants between 0 and 12 months old, concerning a persuasive eHealth intervention to support the current health education about SIDS?
	4) What are the values of youth healthcare physicians, youth healthcare nurses, midwives and maternity nurses, concerning a persuasive eHealth intervention to support the current health education about SIDS?
	5) What are the requirements for the eHealth intervention to support the current eHealth education about SIDS?
Early Design phase: Human Centered Design	6) What do the initial persona descriptions look like?

2.METHODOLOGY

DESIGN

Qualitative research was carried out with semi-structured in-depth interviews. The data collection is performed through interviews with important key stakeholders and end-users. Qualitative research is a good method to get more information about the background, the vision, the argumentation and the consideration of the primary and secondary end-users [64]. This type of research aims at discovering the underlying motives and desires, using in depth interviews for the purpose, for instance, when interested in investigating the reasons for human behavior, qualitative research will be able to understand the human behavior in depth [65]. Semi-structured interviews are a suitable method for the development of an eHealth intervention, because it uncovers the behaviors, opinions, motivations and rationale, and the needs and values of the end-users regarding an eHealth intervention and therefore a more comprehensive understanding of the end-users can be achieved [66-68,65]. The flexibility gives the participants the opportunity to provide additional information and to expand their responses further than the answers to the predefined questions [67]. The first two phases of the CeHRes Roadmap, were executed [47]. Taking into account that this roadmap follows a Human Centered Design, the primary and secondary end-users (the important stakeholders) must be involved throughout the whole development process [47]. Different analyses were therefore needed, to answer the main research question and the sub questions. Table 4 gives an overview of the research plan, explaining the analyses that were performed in the first and second phase of the CeHRes roadmap, the method that was applied, the study population that was included and the outcome of each phase.

Table 3. Overview of the research plan

Phase CeHRes Roadmap	Method	Study Population	Outcome
Analysis 1 Contextual Inquiry	Literature Study Needs Assessment (Semi structured Interviews)	Youth healthcare physician and nurses from child healthcare clinics Maternity nurses Midwives Pregnant women Women with an infant between 0-12 months	1)The perceived barriers and needs concerning the current health education about SIDS of the primary and secondary end-users
Analysis 2 Value Specification	Translating interview transcripts and records (outcome phase 1)	Same study population	2)The added values assigned by the primary and secondary end-users 3)Requirement elicitation
Analysis 3 Human Centered Design	Translating the needs, barriers and values of the participants (output phase 1 and 2)	Same study population	4)Initial personas descriptions

PARTICIPANTS

All participants were recruited by means of nonprobability sampling, namely convenience sampling, purpose sampling and snowball sampling. Convenience sampling is based on what is accessible [69], purpose sampling is based on who the researcher thinks would be appropriate for the study, because there is a limited number of people that are interested [70] and snowball sampling is when the first respondent refers an acquaintance [71]. In other words, participants were asked to volunteer for participation in this study during conferences for child health care professionals, from child healthcare centers nearby, and from social media and family and friends connections, all from the region Twente. Also participants were asked to invite others who possibly would too participate in this study and meet eligibility criteria. The number of participants in this study was selected according to theoretical saturation, which is the point in data collection when new research data no longer adds further knowledge to the research questions [66].

The primary end-users are pregnant women and parents of infants between 0 and 12 months. The inclusion criteria for the primary end-users were pregnant women and parents of infants between 0 and 12 months old. An age above 18 years, speaking and understanding the Dutch language, and living in The Netherlands, were required. Exclusion criteria were (prospective) parents with abnormalities during pregnancy, who have a child with complications or disorders, or who doesn't receive child health care from The Netherlands.

The inclusion criteria for the secondary end-users, the main health care professionals, are the midwives, maternity care nurses, youth healthcare physicians and youth healthcare nurses who are involved in and responsible for the care of children between 0 and 12 months old and parent education during and after pregnancy. These stakeholders were recruited from conferences by asking them to volunteer and tell others about it. Contact details were exchanged and an information letter was handed out. Also, the child healthcare clinics nearby were asked to invite their professionals for this study. Further inclusion criteria were professionals who speak Dutch and work in The Netherlands. Exclusion criteria were youth healthcare doctors and nurses not working at child healthcare clinics, and who are not involved in the care of children between 0-12 months old. This because youth healthcare doctors and nurses from other settings, such as hospitals, perform different tasks and therefore demand different guidelines and different criteria's. Further exclusion criteria were professionals who don't work in The Netherlands.

PROCEDURE

Firstly, a literature research was performed to identify the primary and secondary end-users and the other stakeholders, resulting in a stakeholder map, which is included in appendix A. The data collection was done with face-to-face semi structured in depth interviews. Due to the short time period given for this study, not all stakeholders were involved for the development process. Therefore, only the primary end-users and secondary end-users were interviewed. Appendix B includes the interviews. Each participant was interviewed separately at his or her own workplace or home within working hours or after, depending on the participant's preferences. After a short introduction about the purpose of the interview, the participants got the opportunity to read the written information in order to make an informed decision whether to participate or not. Appendix C contains the information letter. The information letter contained briefly the aim of the study, what is expected from the participant, what they can expect from this study, the ethical considerations concerning anonymity, and contact information. Prior to the interview, the participants were asked whether they fully understood all the aspects of the study, they were told that they have the right to withdraw from the study at any time without further explanation. Their permission was asked for to record the interview, and all participants were asked to sign the informed consent form. Appendix D contains the informed consent. They got the opportunity to ask questions before and after the interview. Throughout the interviews, the interviewer posed questions in a casual, natural conversational way. Furthermore, the participants were verbally informed that the purpose of the study is not to evaluate them, but to explore their daily practices. This procedure permitted the participants to articulate their experiences, perceptions and ideas around the current SIDS preventive child care and parents' health education, as freely as possible thereby avoiding bias or pre-conceived perceptions imposed by the interviewer.

The interview started with general questions for the persona creation. These questions were based on demographics, health care specifics and technical specifics [72]. Then questions to uncover the participants behavior, their thoughts about the current care and education were asked. Interviews ended with questions about expectations and thoughts about a future eHealth intervention. The interviews took between 30-45 minutes each and were recorded by using a digital voice recorder or mobile phone.

The research protocol was submitted to the Ethical Commission of the Faculty of Behavioral Science at the University of Twente. The research meets the certain ethical standards, namely voluntary cooperation, right information and anonymity [73]. Therefore, the research proposal and interview for the participants were approved by the ethical commission with reference number 17383.

MATERIALS

Two different interviews have been developed to answer the main and sub research question(s). One for the (prospective) parents, and the other for the main health care professionals. The interview of the healthcare professionals consisted of 4 parts. Questions were asked regarding the following themes: 1)demographics, 2)experience current contact moments 3)Information and knowledge, 4)attitude towards, experience and expectations of eHealth. The interview of the parents consisted of 8 parts. The first three were based on the persona attributes by Le Rouge [67]. The themes were as following: 1)demographics focused on participant characteristics such as age, family situation, function 2)technical specifics about their skills, possession of mobile technology, web-based information sources they used or advised, and in which situation they use technology were discussed 3) healthcare specifics, zoomed in on the participants knowledge about SIDS, the frequency they visit the child healthcare clinic, their attitude towards eHealth intervention, 4)current information searching behavior, 5)experience current health education SIDS, 6) expectations, 7) Attitude towards and experience with eHealth interventions, 8)expectations of eHealth intervention.

ANALYSIS

All recorded interview data was de-identified and remained anonymous for analysis. After transcribing the interviews, recorded data was removed. The transcripts were systematically coded based on The Framework Method by Jane Ritchie and Liz Spencer, which provides seven stages to follow and produces highly structured outputs of summarized data [74]. This Framework Method sits within a broad family of analysis methods often termed thematic analysis. Thematic Analysis is *"a method for identifying, analyzing, and reporting patterns (themes) within data. It minimally organizes and describes your data set in (rich) detail. However, it also often goes further than this, and interprets various aspects of the research topic"* [75]. A theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set [76].

The interview transcripts were analyzed with both deductive approach, themes and codes were pre-selected, and inductive approach, whereas themes were generated for the data through open (unrestricted) coding [74]. The Framework Method can be adapted for use with both (and combined) approaches of qualitative analysis. A combined approach was needed in this research, because the main research question and sub questions have some specific issues to explore, but also aims to leave space to discover other unexpected aspects of the participants' experience or the way they assign meaning to phenomena [74]. Each quote from the transcripts was attribute to a code, until no new codes were found. Two transcripts were re-coded by an independent coder (master Health Sciences student), and discussed until consensus was reach within all quotes and codes and inter-rater reliability

was reached. All transcripts were coded manually using computer assisted qualitative data analysis software Atlas.ti. to retrieve a more thorough comprehension of the data. Atlas.ti. makes the process of analyzing more systematic, ordered, transparent and accessible [77]. The participants of the interviews were referred to by study numbers based on an interview number. Appendix E includes the coding scheme for all the interviews.

In total, three analyses has been performed. The first analysis was for the Contextual Inquiry phase, determining the perceived barriers and needs of the primary and secondary end-user from the coded transcripts. The second analysis was for the Value Specification phase, determining the values of the primary and secondary end-users. These outputs were then used for the requirement elicitation. The third and final analysis was for the Human Centered Design process applied in this research. This resulted in the creation of personas.

For the requirements analysis, the perceived barriers, needs and the values of the end-users were determined. The values are ideals or interests that future end-users aspire to or have [56,59]. Values are important directives for the design of the requirements of a future intervention [56,59]. The procedure of requirements notation of Van Velsen et al. was used to ensure a reliable translation of interview data into requirements [56,59]. In the first method, for each part of a transcript that is worthy of translation into a requirement, three derivatives were determined: values, attributes and requirements. The quotes that capture something important in relation to the overall goal of the eHealth intervention, are listed in the 'user expression' column. Then for each quote, the attribute(s) is determined. Per attribute, one or more requirements are formulated. There ae five different requirements types: namely functional & modality requirements, service requirements, organizational requirements, content requirements, usability & user experience requirements. Functional and modality requirements are requirements specifying technical features and on what kind of technology and operating systems the technology need to be organized. Service requirements specify how services surrounding the technology need to be organized. Organizational requirements specify how the technology should be integrated in the organizational structure and working routines. Content requirements, specify the content that needs to be communicated via the technology, the language level, persuasive approach and special accessibility demand. Usability & user experience requirements specify the interface and interaction design of the technology, and how user experience factors should be integrated into the technology [56,59].

The interviews made clear who the primary end-user groups exactly are and look like. For each of the specific group, personas were created based on the persona attributes by LeRouge [72]. The personas are presented by means of a short biography with a photo. The advantage of creating personas is that they are easy to understand for the system developers.

For the inter rater reliability a second independent coder coded two transcripts, namely interview R1 and interview HP1. Afterwards the codes and the quotes were discussed. In total transcript R1 had 40 quotes that were selected and linked to a code. From those 40 quotes, only two quotes were assigned to different codes. Transcript HP1 had 52 quotes that were selected and linked to a code from the coding scheme and from those 52 quotes, only two quotes were assigned differently again. Afterwards these two quotes and the codes were evaluated, because they were interpreted differently. In the end it was decided to merge these two codes into one code and all the quotes were linked to this one.

3.RESULTS

STUDY POPULATION

Throughout the study, nine mothers with an infant between 0 and 12 months, one pregnant woman, and seven health care professionals, namely one youth healthcare physician, two youth healthcare nurses, two maternity nurses and two midwives, were interviewed. Table 4 is an overview of the demographic data from the health care professionals group. The table includes information about the gender, age, years of working experiences with their current job, current job and the work place of the healthcare professionals. All healthcare professionals who participated were female. The mean age of this groups was 44.4 (SD=14.1) and the mean years of working experience 18.3 years (SD=13.6).

Table 4: Detailed demographic characteristics of the health care professionals group (n = 7)

Participant Number	Gender	Age (years)	Job	Work experience (years)	Work place
HP1	Female	59	Youth healthcare physician	32	Child health care clinic/centre, GGD Twente
HP2	Female	59	Youth healthcare nurse	20	Child health care clinic/centre, GGD Twente
HP3	Female	53	Youth healthcare nurse	30	Child health care clinic/centre, GGD Twente
HP4	Female	51	Maternity nurse	32	Maternity practice
HP5	Female	30	Maternity nurse	1	Maternity practice
HP6	Female	31	Midwife	9	Midwifery practice and hospital
HP7	Female	28	Midwife	4	Midwifery practice
N (Mean SD/SE)	10	44.4 SD=14.1	-	18.3 SD=13.6	-

Table 5A gives an overview of the demographic data from the (prospective) parents, including the gender, age, level of education, country of origin, cultural background, current relation, job, number of children and the age of the youngest child. Table 5B gives and overview of some healthcare specific knowledge about SIDS and the technology usage. All the respondents were female, all but one respondent had Dutch nationality, and three participants had a Turkish cultural background. Mean age was 27.2. All the participants had access to a smart phone, tablet, and smart TV/iTV. All the participants had access to internet at home and outside and all of them used internet every day.

Table 5A: Detailed demographic characteristics of the (prospective) parents group (N = 10)

Participant number	Gender	Age	Level of Education*	Country of Origin	Cultural Background	Relation	Job	Number of Children	Age youngest child (months)
RN1	Female	29	High[A]	NL	Turkish	Married	No	3	8 weeks
RN2	Female	26	Middle[B]	NL	Dutch	Living together	No	2 (twin)	8 months
RN3	Female	29	Low[C]	NL	Dutch	Living alone	Full time	1	7 months
RN4	Female	25	Low[C]	NL	Dutch	Living together	No	2	6 weeks
RN5	Female	26	Middle[B]	NL	Dutch	Living alone	No	2	12 months
RN6	Female	26	Middle[B]	NL	Turkish	Married	Part time	1	5 months
RN7	Female	38	High[A]	NL	Turkish	Married	Full time	3	10 months
RN8	Female	23	Low[C]	NL	Dutch	Living together	No	1	10 months
RN9	Female	28	High[A]	NL	Dutch	Married	Part time	2	11 months
RN10	Female	22	Low[C]	DE	Dutch	Married	No	- (pregnant)	- (pregnant)
N	10	Mean27.2	High=3	Dutch=9	Dutch=7	Married=5	No=6		
Mean(SD)		SD=4.44	Middle=3	Non-Dutch=1	Non-Dutch=3	Together=3	Part=2	Mean=1.9	Mean=7.5 months
			Low=4			Alone=2	Full=2	(SD=0.78)	(SD=3.66)

*Level of Education: [A] hbo,wo,doctor [B] havo,vwo,mbo 2-4 [C] vmbo,mbo and first three years of havo,vwo [Verweij, 2014].

Table 5B: the healthcare specific knowledge and technology use characteristics of the parents.

Participant number	Technology use	Internet access	Internet usage	Sleeping position infant	Body heat regulation infant	Pacifier	Knowledge about the age of cot death	Sleeping place infant	Familiar with interventions for SIDS or pregnancy/infant care
RN1	>3	At home Outside	7 days per week After my child is sleeping	Back sleeper	Baby blanket and Zensy heater	Yes	Yes	Own bed, own bedroom	Yes
RN2	>3	At home Outside	7 days per week Only evenings	Back sleeper	Hot water bottle, baby blanket	Yes	No	Own bed, parent bedroom	Yes
RN3	≤3	At home Outside	7 days per week Whole day	Back sleeper	Baby blanket, swaddling	No	No	Own bed, own bedroom	No
RN4	≤3	At home Outside	7 days per week Whole day	Prone sleeper	Hot water bottle, baby blanket	Yes	No	Own bed, own bedroom	No
RN5	>3	At home Outside	7 days per week Whole day	Prone sleeper	Baby blanket	No	No	In parents bed	No
RN6	>3	At home Outside	7 days per week After my child is sleeping	Back sleeper	Baby blanket, sleeping bag	Yes	Yes	Own bed, own bedroom	No
RN7	≤3	At home Outside	7 days per week Only evenings	Prone sleeper	Sleeping bag	Yes	No	Own bed, own bedroom	No
RN8	≤3	At home Outside	7 days per week Whole day	Side sleeper, back sleeper, Prone sleeper	Hot water bottle, swaddling	Yes	No	In parents bed	No
RN9	>3	At home Outside	7 days per week Whole day	Back sleeper	Baby blanket, swaddling	Yes	Yes	Own bed, own bedroom	Yes
RN10	≤3	At home Outside	7 days per week Whole day	-	-	-	-		Yes

1) *What are the positive experiences, perceived barriers, and needs of prospective parents and parents with infants between 0 and 12 months old, concerning the current health education about SIDS?*

2) *What are the positive experiences, perceived barriers, and needs of youth healthcare physicians, youth healthcare nurses, midwives and maternity nurses, concerning the current health education about SIDS?*

PARENTS

Table 6 shows the perceived barriers and positive experiences of the (prospective) parents concerning the current health education about SIDS provided by the health care professionals. A noteworthy barrier, mentioned by all parents, is that the health education about SIDS has been provided too late (interview number 1,2,3,4,5,6,7,8,9). The parents prefer this information before the delivery. Secondly, parents perceived the current health education about SIDS too standardized (interview number 3,4,5,8,9). They mentioned that the contact moments were based on general information and questions. Some other perceived barriers mentioned by the parents were the lack of detailed health education, intrusive way of providing health education about SIDS, unattractive written information and unattractive oral information. Those were related to the health education about SIDS.

The positive experiences they had concerning the health education about SIDS was the fact even though the information and questions were experienced as standardized, it was still personalized. Almost all parents mentioned that they created a bond with the health care professionals because they remembered you as their client. Furthermore, some parents had even the possibility to WhatsApp their healthcare professional (interview number 1,8). This was experienced as positive because they got the chance for informal way of contact with their healthcare professional.

Table 6: The perceived barriers and positive experiences of parents concerning the current way of health education about SIDS

Code Barrier	Interview numbers	User expression
Insufficient / lack of detailed health education about SIDS	Rp2,3,4,5,8	"I still don't know what causes cot death and why back sleeping is so important, I thought it was choking till today" Rp2,
Intrusive provided health education about SIDS	Rp4,5,7	"The presence of the maternity nurse at my house is too obtrusive, and prominent, like I will do something wrong and she will get angry" Rp4 "When I tell the youth healthcare physician/nurse that I do something else, they look at me like I'm a bad mother." Rp5
Too late provided information about SIDS	Rp1,2,3,4,5,6,7,8,9	"After the delivery, the maternity nurse came to my home and told me that I couldn't use that pillow, or this sheet, or the toys and sleeping bag. I had to change the whole bedroom. Why couldn't the midwife provide me this information before the delivery" Rp7

General information	Rp3,4,5,8,9	"All the healthcare professionals act like every baby is the same, why can't they accept that my baby is different" Rp8 "Every appointment they just ask me what they have to ask according to their protocols, always the same questions and same advice: back sleeping"
Unattractive written information about SIDS	Rp2,3,4,5	"I didn't read the leaflets they gave me. I actually can't even remember that the maternity nurse or youth healthcare physician gave me leaflets" Rp5
Unattractive oral information about SIDS	Rp2,5,7,9	"I don't even remember what the youth healthcare physician told me when I leave the child healthcare clinic" Rp5

Code positive experience	Interview number	User expression
Personalized information	Rp1,2,3,4,5,6,8,9	"The youth healthcare physician and nurse remember you, they know who you and your child are and that creates a trustable bond/relationship" Rp4
Easy informal access	Rp1,8	"You can call the healthcare professionals whenever you want, they even gave me their WhatsApp number" Rp1

Table 7 shows the needs of the (prospective) parents. Those are the wishes and their expectations concerning the current health education about SIDS. The majority of the parents mentioned that they did not want any replacement for the current way, but only a supportive tool to solve the perceived barriers (interview number 1,2,3,4,5,6,7,9,10). From this it can be concluded that there might be space for ' blended care'. Also, the parents indicated that they needed no anxiety provoking information, even though they also preferred more detailed health education. Personalized and visualized, easy to understand but still detailed and relevant information is preferred as well. From this it can concluded that change is needed in the way the health education is provided, besides there might also be a space for ' blended care'.

Table 7: Needs of (prospective) parents concerning the current health education about SIDS

Code Need	Interview number	User expression
Easy to understand language	Rp1,3,5,6,7,10	"Non-native speakers or low-educated parents should be able to understand it as well" Rp 5
Detailed/relevant health education SIDS	Rp2,3,4,5,8	"The healthcare providers should provide me detailed information, however they expect from me to ask for it. How can I ask for it, when I don't know anything" Rp2
Not anxiety provoking health education SIDS	Rp3,4,5,7,8,9	"The maternity nurse gave me information that made me afraid, I couldn't sleep the first two month, because I thought that when my baby turned on his back, he would die" Rp3
Attractive way of information SIDS	Rp2,3,4,5,7	"I can't remember that I received leaflets from the healthcare professionals" Rp5

Health education SIDS before delivery	Rp1,2,3,4,5,6,7,8,9	"Before the delivery is the best moment for the maternity nurse and midwives to provide me more information about SIDS at home. I was after the delivery so tired, that I did not even listen to the maternity nurse" Rp3
Personalized information	Rp3,4,5,7,8,9	"They should take my norms and values into account, not every baby or family is the same" Rp3 "We have a different culture, and a lot actions and behaviors are normal for us" Rp7
Visual health education SIDS	Rp1, 2,3,4,5,6,10	"With short videos, you can see it and learn it, however with written information it is up to the reader to understand and image it, which might be a wrong interpretation/imagination" Rp1 "pictures, short videos or short written information are useful. It takes less effort to read and understand something" Rp10
Consistency	Rp2,3,4,5,9	"All health care professionals should know about it and recommend or oblige it, because than I will realize it is a useful and important tool to have at home" Rp4
No replacement of current health education	Rp1,2,3,4,5,6,7,8,9,10	"I prefer a professional who can see my child and touch it, while talking to me."Rp4 "Technology should never replace face to face contact with a health care professional" Rp2
Supportive tool (Blended care)	Rp1,2,3,4,5,6,7,9,10	"Digital information is a good way to replace the old leaflets and support the current health education" Rp1

Table 8 shows the perceived barriers and positive experiences of the healthcare professionals. Firstly, the language barrier and cultural differences are a remarkable perceived barrier, because it was mentioned by all healthcare professionals (interview number 1,2,3,4,5,6,7). Also, some health care professionals mentioned that detailed information about SIDS is a barrier, because it causes anxiety and decreases the empowerment and confidence of the parents, which they do not prefer (interview number 1,2,4). Compared with the parents, the health care professionals generally perceived less barriers in the current health education about SIDS. The positive experiences the healthcare professionals had concerning the health education about SIDS, was that they were as transparent and personalized as possible (interview number 1,2,3,4,5). The information they provided was easy to access, beside the leaflets, they also gave some websites for online information.

Table 8: The perceived barriers and positive experience of healthcare professionals concerning the current health education about SIDS

Code Barrier	Interview numbers	User expression
Language barrier	HP1,2,3,4,5,6,7	"The biggest challenge for us is to provide health education to parents who do not understand Dutch or English" HP1
Cultural differences	HP1,2,3,4,5,6,7	"Cultural challenges are a problem as well, but if there is a language barrier and cultural difference, the problem gets even bigger" HP1 "Cultural differences are not always a problem, but for SIDS we know that some risky behaviors are cultural related and those increase the risk for SIDS" HP1
Anxiety / detailed information	HP1,2,4	"We think that detailed information about all risk factors, will cause anxiety, healthcare professionals don't want that, we want independency, empowerment and confidence in parents." HP2
Unattractive written information	HP1,2,4,6	"A lot of parents throw the leaflets away, or don't even remember we provided them the information. I think you need to design something that is more attractive" Hp1

Code Positive experience	Interview Number	User expression
Transparent	Hp1,2,3	"I write everything in the "kraamdossier" and leave this file at their house, so they can actually read their own personal information. In the same file we include safe sleeping messages and other health education" Hp4 "At out child healthcare clinic, it is possible to get access and insight in their personal health record. We are not hiding information or something" Hp2
Easy to access	Hp1,4	"We provide them when the right internet sources so that they can easily get access to trustable information about SIDS, but unfortunately we are not able to check what they read or do on the internet" Hp1
Personalized	Hp1,2,3,4,5	"We adapt our SIDS information to the character of the parents, some parents understand higher level Dutch, the others prefer basic, some ask for detailed information, the other are like 'fine'. How personalized can you make it?" Hp1

Table 9 shows the needs of the health care professionals concerning the current health education about SIDS. The health care professionals indicated that the current SIDS health education through leaflets needs modernization. All of them expect a supportive eHealth intervention that solves the cultural challenges and language barriers (interview number 1,2,3,4,5,6,7). The healthcare professionals also indicated that they need visual health education about SIDS, because the current leaflets are not attractive enough and probably do not even get the attention of the parents. Therefore, they mentioned that visual health education could be a good support for the leaflets and the oral information, and probably improve the patient-professional's communication (interview number 1,2,4,5,7). Some health care professionals mentioned that non-verbal health education would be even better (interview number 1,4). Lastly, it was mentioned that unnecessary costs should be avoided (interview number 2,3,7).

Table 9: Needs of health care professionals concerning the current health education about SIDS

Code Need	Interview numbers	User expression
Cultural Challenges taken into account	HP1,2,3,4,5,6,7	"Asylum seeker, refugees and immigrants are increasing in the Netherlands, and we need to adapt our health education taking their cultural background and languages into account". HP1
Health education in different languages	HP1,2,3,4,5,6,7	"Asylum seeker, refugees and immigrants are increasing in the Netherlands, and we need to adapt our health education taking their cultural background and languages into account". HP1
Visual health education	HP1,2,4,5,7	"Providing information in a visual way would be great. Almost all health care professionals use an laptop or Ipad and if we could have every topic we talk about also in other languages and visual way, the communication between the health care providers and the minority will improve" HP4
Non-Verbal health education	HP1,4	"I sometimes open YouTube videos or search for images when the parents do not understand me, to explain things better, but this is not a useful option because sometimes they still do not understand the video and the images are not clearly enough" HP4
Avoid unnecessary costs	HP2,3,7	"Unnecessary costs should be avoided, therefore it must be affordable or reimbursed" HP2
Supportive tool (Blended care)	HP1,2,3,4,5,6,7	'We definitely need new supportive tools" HP4 "Face to face contact and oral health education can never be replaced because we as health care providers have to check the health of the mother and the baby, but supporting parents in their own environment could improve the current way" HP1
Modernization of current information providing	HP1,2,4,6	"Currently, oral and written information is the only way we provide health education at our child health care clinic, however we can see that modernization is needed, because people throw the leaflets away, and listen to us while their baby is crying. Modernization will fit the needs of parents better" HP1

3) What are the values of prospective parents and parents with infants between 0 and 12 months old, concerning a persuasive eHealth intervention to support the current health education about SIDS?

4) What are the values of youth healthcare physicians, youth healthcare nurses, midwives and maternity nurses, concerning a persuasive eHealth intervention to support the current health education about SIDS?

5) What are the requirements for the eHealth intervention to support the current eHealth education about SIDS?

Table 10 shows the values of the (prospective) parents and the health care professionals. The interview quotes are grouped on an attribute level, per attribute one or more requirements are formulated, and then values are linked to attributes. The translation table containing these information is designed according to the development approach of Van Velsen, and included in Appendix F.

These values are improvements the parents and healthcare professionals want to be realized in the healthcare by the eHealth intervention. Some of the values formulated here are improvements for better health & wellbeing, such as change in attitude and behavior by increasing awareness and knowledge, increase empowerment. The other values are for a better health care delivery, such as time saving, easier to understand health education, reduce healthcare costs or make it affordable, improve communication between professionals and patients, providing personalized/relevant information, easy integration into work routine.

Table 10: Values of the primary and secondary end-users

Values of (prospective) parents	Values of healthcare professionals
Easy to understand	Easy to understand
Easy to use	Easy to use
Raise awareness/increase knowledge	Raise awareness/increase knowledge
Affordable	Affordable
Personalized/relevant information	Increase empowerment
Consistency	Improve patient-professional communication
Trustworthiness/evidence	Time saving
	Easy integration into current work routine

The above mentioned values resulted in some requirements, shown in appendix F in the translation tables. In table 11 the requirements are listed. In total 16 requirements has been determined, divided in five different requirement types, namely: functional & modality requirements, service requirements, organization requirements, content requirements and usability & user experience requirements.

The requirements are formulated as "the eHealth intervention must have/should have/could have/won't have...". This is based on the MoSCoW-method for priority rating. The 'must haves' have a high priority, the 'should and could haves' have medium priority, and the 'won't have' has no priority [84]. The priority is determined by deciding whether the requirement captures and solves something important in relation to the overall goal of the eHealth intervention, which was increasing awareness again.

Table 11: Requirements

Requirement type	Requirement (#requirement number)
Functional & modality requirements	1)The eHealth intervention must be easy to use and familiar. 2)The eHealth intervention should change behavior and attitude by addressing the awareness about the importance of complying with the SIDS recommendations.
Service requirements	3)The eHealth intervention must be affordable.
Organizational requirements	4)The eHealth intervention must be easy to integrate into the current work routine of the health care professionals.
Content requirements	5)The eHealth intervention must be offered in different languages: Dutch, English, Turkish and Arabic. 6)The eHealth intervention must show evidence of the provided information. 7)The eHealth intervention must provide unambiguous information based on scientific and reliable/trustable papers and prevention guidelines, in accordance with healthcare professionals. 8)The eHealth intervention must address the awareness about the importance of complying with the SIDS guidelines. 9)The eHealth intervention must show the consequences of poor and non-compliance. 10)The eHealth intervention must provide information that is consistent. 11)The eHealth intervention should provide personalized information and advice.
Usability & user experience requirements	12)The eHealth intervention must give the information in (short) easy-to-understand, written form and in (short) easy-to-understand spoken (visual) form. 13)The eHealth intervention must have non-verbal communication, such as understandable images and videos. 14)The eHealth intervention should give clear instructions about how to use it. 15)The eHealth intervention could use an evaluating approach for the habits and behaviors of the end-users to provide tailored feedback. 16)The eHealth intervention must provide clear explanations of the risk factors, and what action the users should take to remove the fear.

Three different personas, based on ten interviews, have been created, which are representative for the primary end-users. All the personas had the ability and skills to use and understand technology. The differences were found in the health care specific knowledge and actions, the intention and motivation to use eHealth and the way the participants currently search for information. In appendix G, the relevant interview quotes and segments are shown in a table, used to design the personas according to Le Rouge. In Figure 1,2, and 3 (the following pages), the personas are shown.

The first persona (Elise), wants to do everything as best as possible and to know what's the best way for her child. This person has sufficient motivation to change certain behaviors and to use a new intervention for this purpose. However, she doesn't see the added value of information provided by health care professionals, because she beliefs she has the ability to do her own research, which results in the same information.

The second persona (Rana), believes that she has sufficient knowledge about cot death and how to care for her children because of her experience. However, it is not always the right information. She thinks that after a couple of kids, no health education or information is needed, because she thinks that you will develop the skills and knowledge by experiencing it. She believes that you can't learn everything by reading. When she faces health problems, she firstly asks her friends and family for their advice or reads internet forums to see what other mothers did in the same situation. If it's not working, she will call the general practitioner. She has not an intrinsic motivation to use a new intervention, but she has the intention and motivation to try a new intervention if it's not too difficult, easy to understand and useful for her and her children. So she is waiting for extrinsic triggers.

The third persona (Aria), represents the pregnant women. She wants to learn everything, and is afraid that she will never know enough to care for her baby. She believes that everyone should be provided with the right knowledge, and not only mothers. She has the intrinsic trigger to learn everything and to do anything.

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PERSONA 1: ELISE

Elise is 28 years old and lives with her husband David in Enschede. Together, they have one child, who is a six months old baby boy. She started one month ago with her job again as policy worker, but this time she has to work part time. David works 40 hours a week, and therefore Elise has to leave their child at her moms and dads place three days a week.

Elise knows a lot about child diseases. During her pregnancy she bought a lot of books and did a lot of research on the internet to know everything about having a baby and caring for a baby. When she was searching information about whether a baby could choke during breastfeeding, she read something about cot death and did further research about it. Hence, she knows every risk factor and is still afraid her baby, because she knows that there is a risk till the age of 24 months. Her baby has the ability to turn during sleep, and every time Elise wakes up during nights to feed him, she turns him back to a supine position. She also told David about the risk factors of cot death, and he also takes those preventive measures to prevent their baby from a cot death.

Elise prefers to do her own research first, before calling a general practitioner for an appointment. She thinks the GP is there to do a medical check and prescribe medication if needed, but the knowledge the GP will provide her, is the same as her own research. Therefore, the information a general practitioner and a youth healthcare doctor provide, has no added value for her. But she always goes to her baby's appointments at the child healthcare clinic for the vaccinations and growth and weight checks, because she cannot perform those actions by herself.

Her digital skills are perfectly fine. She has numerous apps on her iPhone for healthy eating and healthy lifestyle, and takes her phone and iPad everywhere because the security cameras at home are connected with her iPad and iPhone. She uses internet for information and advice from other parents facing the same problems about their child. She also watched YouTube videos to understand how to give breastfeeding and give birth. Currently , she uses Zensy, which is a "Soft Baby Warmer" that replaces the old hot water bottles used to provide warmth for babies in bed without the risk for burnings or overheating. She also used Zensy during her pregnancy for her back pain. She is very interested in new innovations and thinks that the old way of information through books and leaflets should be replaced by something that is accessible anywhere and by everyone, because she uses internet for every health problem that occurs instead of reading old books or leaflets. Her intrinsic motivation is her child; she would do everything for him.

"…He does not have a choice. I know that stomach sleeping is not okay. So I always put him on his back. He cries, but he will fall in sleep. Now, he is old enough and has the ability to turn during his night sleep. But when I weak up to feed him, I turn him back…"

"…The current why of information is not the best way. No one reads the books or leaflets. They throw it away. Everyone uses smartphones and internet. So you can easily design something, that can be accessed everywhere on the phone. I would use it, why not?..."

PERSONA 2: RANA

Rana is 30 years old and she lives together with her boyfriend. They have two children, one boy and one girl. The oldest one is 6 years old and the youngest 6 months. She is not working because she cannot leave her children with someone. Rana has a different cultural background.

Rana does not know what cot death exactly is and how it happens. She thinks that her children are both old and strong enough to survive and that nothing will happen from this time. She learned from the maternity nurse that a child needs to sleep on his back. Even though this is contradictory to what she thought, because she believed that cot death was caused by choking. Besides this, she actually does not want to place her child on his back to sleep, because of the risk for plagiocephaly, flat head syndrome, therefore she prefers side sleeping. She still sleeps with her youngest child in the same bed as well. She says that it's easier to give her breastfeeding and that children grow fast and she want to spent every minute with her. She could not believe that sleeping with your child could be unsafe.

During her first pregnancy, she tried to learn a lot, but now she does not even remember whether she received information about cot death. She has problems with the prescribed Vitamin D as well, she forgets to give them to the children, but prefers to not to tell this to the child healthcare doctor and nurse as well. She believes that doctors and nurses cannot accept that every child is different and she thinks that the child healthcare clinics are too strict and intrusive. She believes that she developed enough skills and knowledge to care for her children.

For advices or tips she firstly asks her family, mother and grandmother, and her friends. They have a WhatsApp group called "Mommies", and it includes her friends with children. When she is not able to solve the problem, she will call the general practitioner.

Rana had a smartphone and tablet, which she takes everywhere. She uses the tablet for the children, because she can keep them quiet with a movie on the tablet. She uses the internet for information, online shopping or for social media. She has also apps for healthy eating, counting her steps and calories. She is not very interested in eHealth intervention, but if it's really useful for her children, easy to use and to understand, she will try it.

"…She slept the first months with me in my bed. But that's also how it should be huh? The first three months in your own bed is safer, so you can intervene immediately when something happens with your baby…"

"…Why don't they understand that every child is different? They are all so strict and intrusive. That's why I prefer to lie about some questions. I prefer to do it on my own way, like I learned it…"

"…I thought that cot death was caused by choking, choking because of vomiting during the sleep. Actually, I still don't have any idea about what it is and how it happens…"

"…After your first child, you don't need the same information again for the second. I also did not want a maternity nurse in my house, as if she is there to check what I am doing with my child. No need for that…"

PERSONA 3: ARIA

Aria is 22 years old and is married with Ian. Aria is 7 months pregnant. This baby will be her first child. She does not work; she is at maternity leave now. Ian still works full-time as a financial manager.

Aria heard about cot death, bus she does not know how it happens and what she can do to prevent her baby from it to happen. She thinks that when the time comes, she will receive the right information from someone. She prefers to receive the information before the delivery, because she has the time for it now.

When she heard that she was pregnant, she went to a book store to buy some books about caring for a baby, pregnancy and delivery. She read them a couple of times, but currently, it is easier for her to use Google for information, because her phone is easier to use than searching in books for information. According to her, internet contains so much information, such as useful experiences of other pregnant women, which can't be found in books. She also asks her grandmother and mother for information. They helped her a lot during her pregnancy, and will also help her after the delivery. She believes that her mother and grandmother have enough experience and know things better than her. She thinks that after the delivery, she will ask first her mother for advice, then search information on the internet, and if needed visit the general practitioner, if the case is not emergent.

She believes that everyone is responsible for babies and therefore everyone should get the option to learn about cot death or other child related subjects. The pressure should not only rest on the shoulders of the mothers, according to her. She believes that education is like preventive vaccinations: even if not everyone is educated, if enough people around them have the right knowledge, they will protect the ones who haven't, so provide them with the knowledge when necessary.

Her digital skills are perfect. She uses Internet for everything and watches videos as well when needed. She has numerous apps on her iPhone, like home workout apps, and healthy eating apps. Beside this, she uses her phone for social media, games and photography. She has a positive attitude towards technology, because she thinks that technology makes life easier. She has the intrinsic motivation and ability to learn everything for her baby. However, she is a bit restrained when it comes to checking symptoms on the internet. Internet can make you unnecessarily anxious. Therefore, she believes that internet should only be used for tips and advice or experiences of other mothers in the same context. For symptoms and complaints, she should go to the general practitioner.

"…I had already bought books, but the internet is more convenient. It is easier, however it makes you unnecessarily anxious, but you should not look for that kinds of information. Just tips and advice…"

"…Try to reach the whole population with your new idea, that will work like herd immunity. If enough people know the risk factors, they will warn the others who doesn't know…"

4. DISCUSSION

The main question of this study was: "What are the experiences and expectations of prospective parents, parents with an infant between 0 and 12 months old, and healthcare professionals with the current health education about Sudden Infant Death Syndrome and towards health education support to prevent SIDS through an eHealth intervention?"

Parents

The first noteworthy need was that the parents preferred to start with the health education about SIDS before the delivery, because they mentioned the transitioning to parenthood as a major life changing event, and experience an overflow of emotions after the delivery. They also mentioned that their motivation and their eager to learn was higher during the pregnancy than after the delivery. This is also seen in the study of Edvardsson et al (2011), for some people the transition to parenthood triggers a reappraisal of lifestyle and initiate psychological changes related to increased motivation for engaging in healthy behaviors and making positive lifestyle changes in order to create a healthy environment for their child(ren) [83]. Furthermore, parents mentioned that they would use the eHealth intervention if it will be useful for their children and will be recommended by the health care professionals. This is an phenomenon that was also explained in the study of Edvardsson et al (2011). It seems that health promotion strategies in pregnancy and early parenthood did not seem to influence parents to make lifestyle changes primarily to promote their own health: a healthy lifestyle was simply perceived as common knowledge. However, perceptions about risks to the offspring's health appeared to be the primary driving force for lifestyle change during pregnancy and early parenthood. Parent's motivation to prioritize their own health per se seems to be low during this period, future health promoting programs need to take this into account and prioritize the health of their offspring to motivate them to change their behavior and be more aware of the behavioral risk factors [83]. Furthermore, the parents perceived the current way of health education not personalized and tailored enough, but too simplistic, which they experience as a lack of knowledge created by the healthcare professionals. They want detailed information that is also tailored and personalized, but not anxiety provoking. In communication, tailoring is the personalization of health education or health messages for an individual based on his/her beliefs, traits or abilities [89]. Past studies have found that tailored health education and messages can improve behavioral outcomes, including adherence to recommendations [90]. Additionally, the current way of health education about SIDS, is based on leaflets and oral information. However, the parents mentioned that they could not remember the written information, or that they did not read it at all. Maybe the current information is not attractive enough and needs modernization to get the attention of the parents and stimulate any behavior change. Lastly, they all still prefer the current face to face provided information, and see the eHealth intervention as a possible supporting tool. This is an important result, because even though parents have negative experiences

about the current health education, they still prefer it and do not want it to be replaced by a technology. This is also seen in the qualitative study of Van Der Gugten et al (2016), which suggests that despite the increasing patient activism in seeking information for reassurance on the internet, only face to face consults with the physicians were seen as the most important source of health information and only they could give complete reassurance [80,93]. Their motivation for this was that the physician was seen as the only one who could assess the illness related symptoms in the whole context of the infant and has the capability to examine the infant, evaluate the situation and provide tailored information [80,81,92]. This was also mentioned in this study by the parents and the healthcare professionals. The information gathered online may complement the information from the healthcare professionals, rather than replace it.

Health care professionals

One of the biggest perceived barriers of the healthcare professionals is the cultural differences and language barriers, which make the diffusion of the health messages and education difficult. Their need is a solution for the cultural difference and language barrier to improve the patient-professional communication and increase the awareness about the behavioral risk factors related to cultural beliefs or caused by miscommunication in the minatory population. The study of Morris et al (2009) to healthcare barriers showed that language and communication along with acculturation barriers and cultural beliefs, were perceived by all groups in that study to be the most immediate and common barrier affecting health care utilization [82]. Another perceived barrier by them is the dependency of the parents on confirmation of healthcare professionals. Healthcare professionals stimulate empowerment and confidence in parents and therefore prefer something that doesn't counterwork this aim. Furthermore, the healthcare professionals also prefer the eHealth intervention as a supporting tool, rather than replacing the current health education. A noteworthy quote is: *"We are able to recognize behaviors and risky situation. Parents don't always tell the truth, however we can see, smell and feel in what kind of environment the infant is living in"* . So they are needed for tailored care and information. This was also mentioned in the study of Van Der Gugten et al (2016), in which physicians were seen as the only ones who could assess the symptoms in the whole context of the infant and have the capability to examine the infant, evaluate the situation and provide tailored information [80,81].

Values

The most important value mentioned by the primary and secondary end-users concerning a persuasive eHealth intervention is raising awareness / increasing knowledge about SIDS behavioral risk factors. An eHealth intervention could raise awareness among the parents with regard to the compliance with SIDS recommendations by showing the consequences of poor or non-compliance, because parents underestimate the consequences of their behavior. Furthermore, it is meaningful to take into account the added value of using evidence based information. The eHealth intervention should be considered as a trustable source and of added value by all its users. The relevance of using the eHealth

intervention should be clear to all the end-users. Another value mentioned is based on consistency: the information provided by the eHealth intervention should be consistent and should be the same as the information provided by every healthcare professional. The healthcare professionals value an intervention that fits within the existing work routines and daily activities, otherwise the intervention will not be used as designed for according to them. Furthermore, personalized/relevant education, empowerment increasing and patient-professional communication improving intervention was valuable. Other values were based on more practical issues, such as that it should be easy to understand, easy to use, affordable and time saving.

Requirements

The most important requirements are that the eHealth intervention should be able to raise awareness/increase knowledge about the SIDS behavioral risk factors and the consequences of poor or non-compliance with the recommendations. This is necessary to make the users aware of their current behavior. Behavior change methods can be applied in order to improve the adherence and compliance with recommendations, and change the behavior by triggering. Furthermore, personalized/tailored feedback was also an important requirement, which the intervention can provide by evaluating the end-users own behavior and proceedings. To stimulate this some important content requirements are formulated: the intervention must be offered in different languages, the information must be offered in spoken and visual form and short easy to understand health messages. This to make sure that the minority population can be reached as well. Another important need was an intervention that is familiar, easy to understand and easy to use everywhere.

Initial persona descriptions

It is tried to give an impression of how the end-user personas look like. Three personas are designed, which are the initial designs. These persona descriptions are based on the interviews and designed using the article of Le Rouge. All three personas are females, because no male primary end-users participated in the study. Furthermore, the personas are based on the demographics, technological knowledge and domain specific knowledge. The biggest differences were found in the domain specific knowledge and the motivation to use an eHealth intervention and change their behavior. As seen in the persona description, parents prefer to use their own knowledge first, and then their friends, family and social media as the most important sources of information. This is also seen in the study of Ottolini et al (1999), which indicated that parents rated the media (47%), and friends and relatives (18%) as the most influential source of information concerning sleep [40]. The Study of Boschert (2004) showed that advice from the mother's own mother, sister, aunt or grandmother was seven times more influential than were other health education and promotion materials [41] and that the mother's own perception was eleven times more influential than were other recommendations [41,42].

There is a need for raising awareness by personalized and relevant information. An eHealth intervention that is future proof, able to visualize information, is easy to understand and use, and that fits in the current work routine of the parents, could be of added value. The behavior of parents concerning SIDS and information searching is also changing and taking into account that the parents still prefer the current health education, because it is face to face, "blended care" can be an option in this case. Blended care or blended learning is the combination of traditional face to face learning and e-learning or e-health, which appears to have a consistent positive effect in comparison with no intervention, and to be more effective than or at least as effective as non-blended care [91]. Blended care could fulfil the need for a supportive tool instead of a replacement of the current health education. Taking into account that easy to use and understand, familiar and affordable technology that fits easy in the daily working routines of the users, mHealth or mobile health, can be considered. mHealth, or mobile health, which is the use of wireless, portable information and communication technologies to support health and health care, seems to fit the needs and requirements of the end-users [98]. There are also numerous example of effective mHealth interventions being used to support mothers through safe pregnancy and childbirth and to facilitate neonatal and infant health [93,94,95]. There is a growing body of research indicating the potential of mHealth interventions for improving maternal, newborn and child health in low- and middle income countries [93]. In a pragmatic cluster RCT of Jareethum R et al., in which women receiving SMS prenatal support were comparable to those who received routine prenatal care, however, the risk of perinatal death decreased by half in the SMS group compared to the routine care groups (95% CI 0.27-0.93). Two different studies, in which the effect of SMS vs no SMS (routine prenatal care) on breastfeeding was compared, showed that the rate of exclusive breastfeeding for three or four months was higher in the SMS group than in the non-SMS group [94,95]. Also Learning modules seem to fit the current requirements. eLearning is also widely used to increase knowledge. Parents use the internet as an information source for their children, and the use of an education e-learning module to increase patient's knowledge is also a possible eHealth intervention.

Both possible interventions have the ability for changing users' attitudes or behavior, which is known as persuasive technology [96]. Persuasive systems may be defined as 'computerized software or information systems designed to reinforce, change or shape attitude or behaviors or both without using coercion or deception [97]. The web, internet, mobile and other technologies create opportunities for persuasive interaction to motivate people toward healthy behavior, and thereby possibly delay or even prevent health problems [97].

The behavior of the parents needs to be changed in a good way to raise awareness about SIDS again. According to Fogg's behavior model, three elements must converge at the same moment for a behavior to occur: Motivation, Ability and Trigger. When a behavior does not occur, at least one of

those three elements is missing [100,101]. Looking back at the initial persona descriptions, the persona with the lack of motivation will be the one who will probably not use the intervention. They all have the ability. To increase the motivation of the potential end-users some triggers could be given. According to the PSD model of Oinas Kukkoken [61], there are persuasive features that can be implemented in an eHealth intervention, which will persuade the users to use the intervention and perform the expected behavior. The PSD model has four design principle: primary task, dialogue, system credibility, and social support category [61]. Some features that can be considered based on the needs, values and requirements of the end-users are: tailoring the health education to the potential needs, interests, personality or other factors, so that it will be more persuasive, personalization of the education content, monitoring to let the end-users keep track of their own performance, rewarding the target behavior, reminding users of their target behavior so that they are more willingly to achieve their goals, offering parents suggestions, liking, so making the system visually attractive, a social role can be adopted such as a virtual specialist supporting them and communicating with them. Furthermore, trustworthiness, verifiability and authority are also persuasive features, which are mentioned by the respondent.

LIMITATIONS OF THE STUDY

In total ten primary end-users and seven secondary end-users were interviewed. It was not possible to use a random sample of the study population to increase the reliability and validity of this research. The limited amount of available time and the underestimated difficulty of recruiting respondents for a qualitative research resulted in the use of nonprobability sampling, namely convenience sampling, purpose sampling and snowball sampling. In other words, the participants who meet the eligibility criteria, were asked to volunteer for participation in this study. It is possible that the participants were more open towards and motivated for a research and an eHealth intervention than the ones who did not want to participate. This could give a distorted view of the results and create bias. Besides that, which is the second limitation of this study, the participants were all female. The male partners of the primary end-users, did not want to participate in this study. Neither did male health care professionals participate, also causing distorted view of the results. The perspective of male end-users could deviate from the female perspective. This needs to be taken into account when looking at the results. Besides, other child healthcare clinics, maternity and midwife practices in The Netherlands, might be using different methods and tools for the health education, resulting in different experiences and needs of (prospective) parents and health care professionals regarding the health education about SIDS and an eHealth intervention. Therefore, external validity is probably not reached in this research.

The interviews were held with a semi-structured interview matrix. The interviews were performed face-to-face. This approach might have caused the participants to have socially acceptable answers during the interviews. They could for example been influenced by the researcher's intonation of the

questions or unconscious facial expressions or the word and question order. The expressions used for the persona descriptions could be based on socially acceptable answers and quotes.

Another important limitation of this research is confirmation bias/recall bias caused by biased memory. The answers were strongly based on retrieve and memory of the participants, and therefore the results as well. Confirmation bias/recall bias the tendency to recall information in a way that confirms one's pre-existing beliefs or hypotheses and gathering and remembering information selectively, or interpret it in a biased way [99]. The effect of recall bias is even stronger for emotionally charged issues and for deeply entrenched beliefs. If we keep in mind that pregnancy, giving birth and first months of parenthood are life influencing experiences, this limitation might be one of the heaviest weighing of this research. The answers could be based on over and under estimation, wrong imagination or overstatement of the emotions and experiences.

Furthermore reporting bias is also one of the limitations. It is tried to prevent this as much as possible by comparing and testing the coding of the transcribed data for inter rater reliability, which is a strength. However, because of limited time, it was unfortunately not possible to let the independent student check all the coded transcripts, neither to let them check by a supervisor or another researcher. Therefore, the coding is still based on one dominating perspective. Even though there were no major differences in coding in the two transcripts that were checked and compared, there is always a possibility that there are differences in interpretation of the other transcripts. The same applies to the priority rating of the requirements, which is also based on the opinion and perspective of one person, namely the researcher. So the priority rating of the requirements isn't verified yet by the end-users themselves.

STRENGTH OF THIS STUDY

This study has some strengths as well. The first strength is the systematic approach that has been used for this research, namely the CeHRes roadmap. The CeHRes roadmap proved to be of added value because it offers a systematic and theoretically substantiated way to develop an eHealth intervention. The second strength is the Human Centered Design approach used in this study. The primary and secondary end-users were included in each and every phase of the roadmap. Interviews were held with the primary and secondary end-users. Requirements and the personas were developed based on these interviews to meet their expectations and ensure long-term use of the intervention.

The third important strength is the qualitative part, because the semi structured in-depth interviews provided details about the user behaviors, needs, preferences and variety of other information as emotions and personality characteristics, that are essential in designing an intervention that will actually fit into an users life. In addition, it reveals aspects that are needed for the design of an eHealth intervention. The use of transcripts and voice records prevented subjectivity, possible distortion of the

results and reporting bias, with the aim to ensure the inter rater reliability of the results. This was enhanced by a second coder, to reduce reporting bias.

Lastly, despite the small number of interviews that were performed, there was agreement between the different parents concerning the topic. During the last interviews, no new information was provided, so the theoretical saturation was reached, which means that all the possible information has been collected in this study.

RECOMMENDATIONS FOR FURTHER RESEARCH

The next step according to the CeHRes roadmap is to evaluate the outcomes of the value specification in order to adjust the outcomes and to proceed to the next phase, which is the design phase. This pre-design phase can be used to determine whether the requirements satisfy the primary and secondary end-users and to expose possible (usability and system) problems. The formative cycles in between each phase of the roadmap, has to be used for this process. Scenario based interviews could be of added value. Scenarios based evaluation and asking participants to think aloud, could be a method. Currently, the priority of the requirements are rated as a '*Must, Should, Could or Won't have'*, based on the analysis of the researcher. Further research should verify the requirements and its priority by presenting the requirements to the study population. The same verification needs to be performed with the persona descriptions.

Subsequent research could also aim at establishing the psychological factors underlying the patients preferences and needs. Hereby, possible persuasive features as described by Oinas Kukkonen can be determined and verified by the end-users and Behavioral Change Theories can be implemented in the intervention to coach the end-users [61]. The PSD model of Oinas Kukkoken contains persuasive features that can be implemented in an eHealth intervention. To raise awareness about the SIDS risk factors and keep the adherence to the eHealth intervention high, persuasive features can be used. Taking the values into account, features such as reminders, rewards, personalized and tailored information can be used and translated into scenarios. It is also of added value to develop use case scenarios based on the formulated values and initial requirements and personas and present these scenarios to the end-users, asking for any feedback.

PRACTICAL RECOMMENDATIONS

Despite the best efforts of the healthcare professionals, cultural practices and other issues such as language, can affect compliance with SIDS risk-reduction recommendations. It is important that advice on SIDS risk reduction be as clear and as culturally appropriate as possible. When educating parents about SIDS risk reduction, cultural practices that may exist in the parents' community must be considered. The possible eHealth intervention should take this into account and must be able to solve this problems.

To increase the use of and the adherence to the intervention, the *'must have'* and *'should have'* requirements, must be implemented in the initial design of the system to meet the current needs and expectations of the primary and secondary end-users as far as possible. The *'could have'* requirements of the system should be implemented if there is still time and money.

Furthermore, the parents mentioned that they will use the intervention if it will be recommended by all the health care professionals. Therefore, the health care professionals have to promote the eHealth intervention during their contact moments. This increases the trustworthiness of the application. Beside this, the eHealth intervention should be used as a supportive tool, because the primary and secondary end-users all mentioned that a replacement of the current health education was not preferred.

5.CONCLUSION

In this study the perceived barriers, needs and values of the primary and secondary end-users regarding the current health education about SIDS and a possible eHealth intervention that could support the health education and compliance with SIDS recommendations, were collected performing semi-structured interviews. It can be said that the conducted interviews were successful in order to gain important information to create the values, and initial development of requirements and personas. The results, requirements and personas, can be used in the following steps for the design of an eHealth intervention after evaluating them. From the results, it can be concluded that the current way of health education about SIDS needs modernization and that blended care could be of added value.

The eHealth intervention's goal will be to increase and maintain the compliance with SIDS in order to prevent the increase in SIDS death rates by raising awareness about the risk factors. The primary and secondary end-users were of the opinion that in order to improve the compliance with SIDS, everyone need to be aware of the consequences of behavioral risk factors and why these are important. It is essential to address the awareness issue in order to let the eHealth intervention be successful. The main value that the eHealth intervention must contain according to the results was to raise awareness in order to improve compliance with SIDS recommendations. This can be done using behavior change methods and after changing behavior, it is important to be able to maintain this on the long term. Furthermore, a non-time consuming, fitting in the current work routine, familiar to use and easy to understand intervention was preferred. The new eHealth intervention could be an e-learning module, or an application (mHealth) for the smartphone or tablet. In which a behavior change model and persuasive features can be implemented and used to achieve the main goal. The consequences of the behaviors of parents can be shown, and their learning can be monitored, or a smart environment can be created with the help of sensor technology or tele-monitoring the usage. These results can be used in the following steps of the CeHRes Roadmap for the design of an eHealth intervention, after they are verified.

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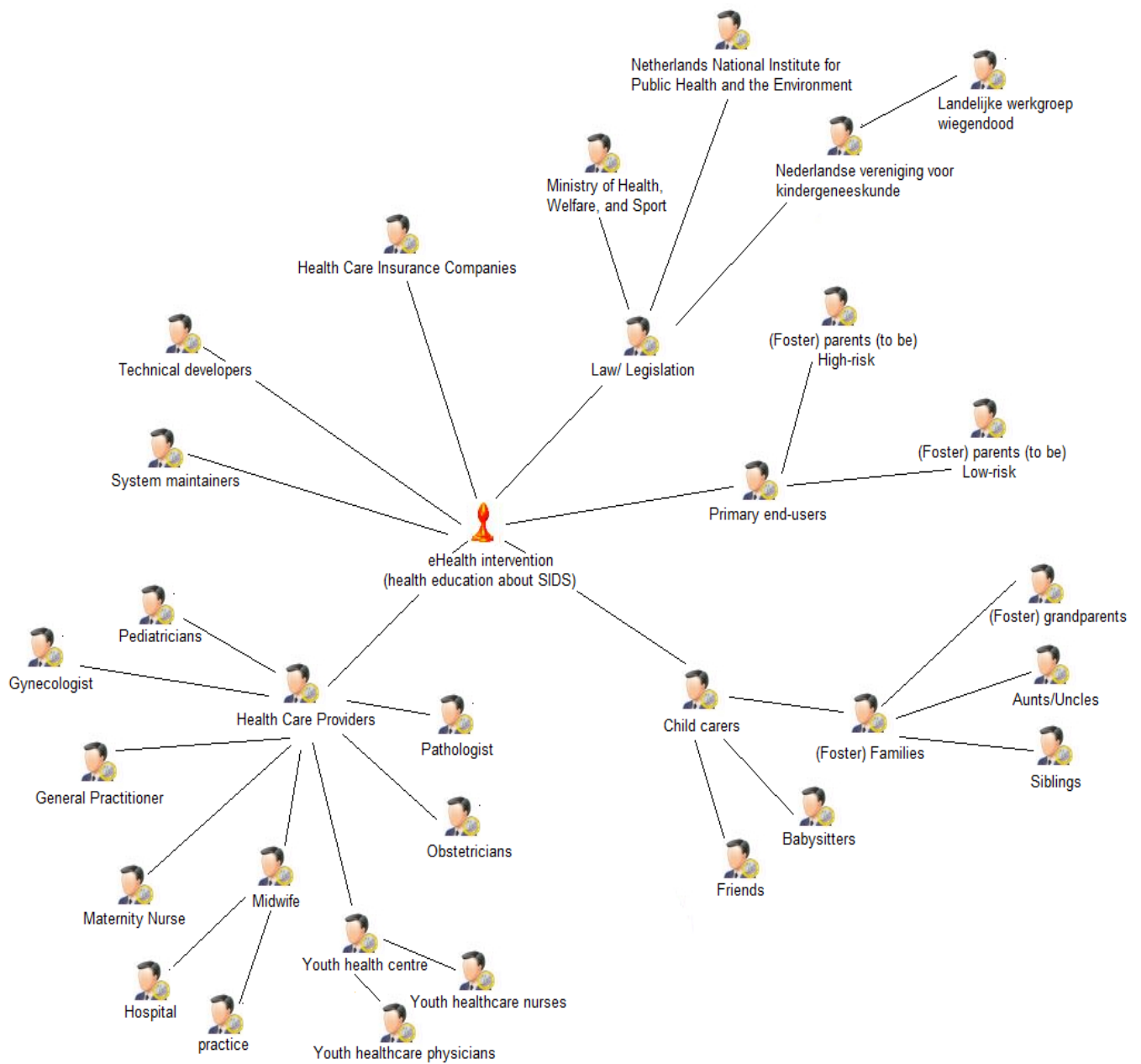
Draaiboek Interviews

Meenemen:

- Voice recorder en batterij
- Mobiel voor tweede opname
- Powerbank en oplader
- Interview
- Pen
- Informatiebrief en toestemmingsverklaring

Mezelf voorstellen

Doel van het onderzoek uitleggen en nodige informatie delen

Toestemming vragen voor een opname

Ruimte voor vragen

Toestemmingsverklaring laten tekenen

(Semi) gestructureerd interview: <u>OUDERS</u>

Datum: Tijd: Locatie: Interviewnummer:

Persoonlijke gegevens: (voor de personas: Demographic)
1) Wat is uw leeftijd, geslacht?
2) Hoeveel kinderen heeft u?
3) Wat is de leeftijd van uw jongste kind op dit moment?
4) Wat is uw samenlevingsvorm: getrouwd, samenwonend, bij ouders, alleen
5) Wat is uw geboorteland?
6) Wat is uw culture achtergrond?
7) Welke opleiding heeft u afgerond?
8) Bent u op dit moment werkzaam?
     o Zo ja, part-time of full-time?
     o Wat is uw functie?

Technologie gebruik: (voor de personas: Technical)
9) Tot welke technologieën heeft u toegang thuis?
10) En welke technologieën gebruikt u het vaakst? (top 3?)
     o Doorvragen: waarvoor gebruikt u deze technologieën dan het vaakst?
     o Wanneer gebruikt u deze het vaakst?
     o Welke neemt u overal mee naartoe?
11) Hoe vaak maakt u gebruikt van het internet?
     o En waarvoor gebruikt u het internet het vaakst voor?

Gezondheid specifiek gedrag (voor de personas: health care specifics: knowledge of application domain: what behavior do you want to address)
12) Wat weet u al over wiegendood?
13) Risicofactoren wiegendood
     o Waar slaapt jullie kind op dit moment? determinant 1: modifiable – bed/room sharing
          ▪ Doorvragen: waarom?
     o Hoe laat u uw kind slapen? Determinant 2: modifiable
          ▪ Buik of rug ligging (buikslaper?)
               • Als buikslaper: hoe gaan jullie hiermee om?
               • Rugslaper: heeft dit nog een speciaal reden?
     o Hoe regelt u de warmte van uw kind? Determinant 3: modifiable)
          ▪ Doorvragen: Waarom
     o Maakt u gebruik van een fopspeen?
          ▪ Wat is de reden voor het gebruik van een fopspeen?

14) Van welke zorgprofessional of zorgprofessionals heb je voorlichting gekregen over wiegendood?
     o Wanneer heeft u deze informatie gekregen?
          ▪ Voor/Na bevalling?
               • Was dit een goed moment?
     o Op wat voor manieren heeft u deze informatie en adviezen gekregen over wiegendood?
          ▪ Wat vond u van de informatie (adviezen)?

- Doorvragen
  - Wat vind u <u>van de huidige manier waarop</u> de informatie wordt gegeven?
    - Hoe zou u willen dat de informatie werd gegeven?
      - Doorvragen
  - Is het voor u mogelijk om alle adviezen toe te passen in de verzorging van uw kind en uw handelingen zo nodig te veranderen?
    - Waarom wel/niet, wat voor problemen ervaart u
      - Kunt u voorbeelden geven om welke handelingen het gaat?
      - Wat doet u dan bijvoorbeeld?

15) Worden informatie en adviezen nog herhaalt tijdens contactmomenten door jeugdartsen of jeugdverpleegkundigen vanuit consultatiebureaus?
  - Zou u willen dat deze adviezen worden herhaald?
    - Waarom wel/niet

Contactmoment met professionals

16) Wat vindt u van de tijd die jullie hebben tijdens een contactmoment?
  - Doorvragen
17) Maakt u aantekeningen of notities tijdens de contactmomenten?
  - Doorvragen
18) Bent u tevreden met de huidige manier van informatievoorziening, dus voorlichting met betrekking tot preventie van wiegendood? Of vervaart u problemen?

Zoals u weet begint tijdens uw zwangerschap al een dossier van u en uw kind bijgehouden te worden, en na de geboorte worden hierin alles over uw kind genoteerd, zoals groeiontwikkeling, gewicht, klachten, vaccinaties, maar ook de dingen die u zegt of doet.

19) Vindt u het goed dat deze gegevens door de jeugdarts, jeugdverpleegkundige, kraamverzorger of verloskundige worden bijgehouden?
  - Zou u deze dossiers en gegevens ook thuis willen inzien?
  - Monitort u nog gegevens van uw kind?

Informatie Voorziening

20) Welke informatievoorzieningen gebruikt u voor de vragen die over uw kind gaan?
  - Doorvragen: Wat? Waarom? Op welke manier? Etc.
  - En als er sprake is van wat serieuzere klachten?
21) Wat vindt u over de beschikbaarheid van informatie op het internet over de gezondheid, ontwikkeling, opvoeding van uw kind?
  - Doorvragen
22) Past u uw gedrag en handelingen aan de informatie die op internet te vinden is, dus maakt u gebruik van de tips of adviezen die u leest op internet?
  - Doorvragen
23) Wat is volgens u de rol van de arts/verpleegkundigen ten opzichte van internet informatie?
24) Wat vindt u belangrijk aan de informatie die u krijgt of zelf opzoekt?

eHealth

eHealth technieken zijn technologieën die als doel preventie of genezing op afstand via internet, hebben. eHealth interventies kunnen verschillende system op afstand zijn, hierdoor ontbreekt fysieke contact ook over het algemeen.

25) Maakt u zelf nog gebruik van bepaalde eHealth interventies speciaal voor de gezondheid, of opvoeding van uw kind, of tijdens uw zwangerschap voor uzelf?
    o Doorvragen
    o Bent u wel bekend met bestaande interventies?

eHealth kan dus van alles zijn, een is duurder dan de ander, een kan je niet overal mee naar toe nemen, en de ander juist weer wel. Wat voor soort eHealth interventie ziet u voor u, dat als doel zal hebben om de huidige manier van voorlichting te verbeteren, ter preventie van wiegendood?
    o Denk hierbij ook aan iets wat u dus ook zou kunnen gebruiken
26) Staat u open voor nieuwe interventies?
    o Zou u een mogelijke eHealth interventie willen gebruiken?
        ▪ Waarom wel/niet?
27) Wat is voor u nou de toegevoegde waarde van een eHealth interventie? Of wanneer heeft een interventie nou een toegevoegde waarde voor u?
28) eHealth interventies kunnen veel dingen mogelijk maken. Wat zou u willen dat zo'n eHealth technologie mogelijk zou moeten kunnen maken voor u en uw kind met betrekking tot voorlichting over wiegendood, dus aan welke eisen moet het voldoen voordat u het zou willen gebruiken?
29) Ziet u mogelijke voordelen in het gebruik van een eHealth interventie?
    o Zo ja, welke?
    o Zo nee, waarom niet?
30) Ziet u mogelijke nadelen?
31) Vindt u het fijn als de gegeven informatie algemeen en van toepassing op iedereen is of specifiek op u en uw kind?
32) Zou u willen dat deze eHealth interventie ook beschikbaar is voor anderen die zorgen voor uw kind?

Dit was het laatste deel van het interview. Nu wil ik u de ruimte geven voor het maken van opmerkingen…

(Semi) gestructureerd interview: <u>ZORGPROFESSIONALS</u>

Datum: Tijd: Locatie: Interviewnummer:

Persoonlijke gegevens (nodig voor representativiteit van het onderzoek) :
1) Wat is uw leeftijd?
2) Geslacht?
3) Waar bent u op dit moment werkzaam?
4) Wat is uw functie hier op dit moment?
5) Hoeveel jaar ervaring heeft u in uw [functie]?

Contactmoment met ouders in het algemeen
1) Wanneer vindt een eerste consult plaats met ouders of aanstaande ouders?
2) Welke informatie behandelt u tijdens een consult met ouders?
   a. Op welke informatie focust u <u>tijdens een eerste contactmoment</u> met ouders?
   b. Welke informatie herhaalt u tijdens contactmomenten?
   c. Op welke manieren geeft u deze informatie?
      i. Mondeling, folders, boekjes, websites, appjes, video's etc.

Dan wil ik het nu specifiek hebben over wiegendood.
1) Geeft u ook voorlichting over de risicofactoren van wiegendood aan ouders?
   a. **<u>Zo ja:</u>** Hoe behandelt u deze/op welke manieren voorziet u ouders van informatie *(tijdens de eerste kraamdagen met hun baby)*?
      1. Bent u tevreden met de huidige manier van voorlichting die u geeft?
         a. Waarom wel/niet?
      ii. Op welke momenten gaat u in op dit thema (wiegendood)?
         1. Doorvragen
      iii. Herhaalt u ook de risicofactoren van wiegendood tijdens contactmomenten met ouders?
         1. Doorvragen
      iv. Zijn er handelingen die ouders toch blijven verrichten ook al vormen ze risicofactoren voor wiegendood?
         1. Hoe gaan jullie hiermee om? Is het voor jullie mogelijk om deze te controleren?
   b. **<u>Zo nee:</u>** wie geeft er dan voorlichting over de risicofactoren van wiegendood?
      i. Zou u willen dat iemand anders ze ook zou behandelen?
         1. Doorvragen
2) Heeft u na een consult het gevoel dat u alles heeft kunnen vertellen?
   a. Waarom wel/niet?
3) Zou u willen dat de besproken informatie tijdens een consult achteraf beschikbaar zou zijn voor de ouders?
   a. Waarom wel/niet?
4) Op dit moment houden jullie gegevens bij van patiënten, dus moeders en baby's, zou u willen dat ouders ook gegevens/data bijhouden van hun kinderen vanuit huis?
   a. Doorvragen
5) Zou u de informatie die u wilt bespreken tijdens een consult, vooraf met ouders willen delen, zodat zij met gerichtere vragen kunnen komen? (informatie uitwisseling)

a. En wat zou u ervan vinden als dit ook andersom ging, dus ouders van te voren jullie informeren over wat ze wel willen bespreken, zodat u beter kunt voorbereiden?

6) Wat vindt u van het feit dat ouders steeds vaker gebruik maken van internet?

    a. Wat vindt u zelf van internet informatie over het algemeen?

    b. En als het gaat over wiegendood?

7) Merkt u binnen uw functie moeilijkheden of verschillen tussen bepaalde groepen ouders? En dan met betrekking tot de manier waarop u voorlichting geeft, of de manier waarop zij omgaan met de adviezen en tips, bijvoorbeeld ter preventie van wiegendood?

    a. Is de hulp en informatie die u levert aan deze groep mensen afwijkend van de rest?

    b. Doorvragen

Informatie en kennis voorziening

1) Volgen jullie dezelfde of andere richtlijnen of protocollen voor preventie van wiegendood vergeleken met andere zorgprofessionals die ook zijn betrokken bij de voorlichting van ouders?

    a. Ervaart u problemen met het naleven van de richtlijnen voor preventie van wiegendood?

        i. Wijk je wel eens af van wat er in de richtlijnen staan?

2) Hoe blijft u zelf up to date met betrekking tot de nieuwe risicofactoren van wiegendood?

    a. Maakt u zelf nog gebruik van extra informatievoorzieningen om meer te weten te komen over een bepaalde onderwerp?

eHealth voor wiegendood preventie

eHealth zijn diverse technieken die op afstand werkzaam zijn met behulp van internet en als doel preventie of genezing/behandeling hebben. Meestal ontbreekt fysieke contact ook.

3) Maken jullie al gebruik van eHealth interventie om ouders bijvoorbeeld beter voorlichting te geven?

    a. Zo ja, welke

    b. Zo nee, bent u bekend met de al bestaande eHealth interventies die als doel hebben om ouders ook beter voorlichting en regie over eigen gegevens te geven?

4) Merkt u vanuit uw functie dat er onbewust of bewust een vraag is naar een eHealth interventie om de huidige manier van voorlichting te verbeteren?

    a. Toelichting, doorvragen

5) Wat zou voor u de meerwaarde zijn van een mogelijke eHealth interventie ter ondersteuning of vervanging van de huidige manier van voorlichting van ouders met betrekking tot preventie?

    a. Doorvragen

6) Zou u een mogelijke eHealth interventie willen integreren in uw werk

    a. Past een eHealth interventie binnen uw huidige werkproces?

        i. Doorvragen

7) Op welke manier zou deze eHealth interventie het beste aangeboden kunnen worden in deze context, dus dat als doel heeft om de huidige manier van voorlichting over wiegendood te verbeteren, ondersteuning of vervangen?

    a. Doorvragen

    b. Wat zou het mogelijk moeten maken?

    c. Aan welke eisen/voorwaarden moet het worden voldaan, voordat u het zou willen gebruiken en adviseren aan ouderen?

    d. Welke informatie zou het moeten geven?

      e. Zou u zelf informatie willen kunnen toevoegen?
         i. Zo nee, waarom niet?
        ii. Zo ja, op welke manier ziet u dat voor u?

8) Wat is voor u de toegevoegde waarde van een eHealth interventie?
9) Wat zijn mogelijke voor en nadelen van het gebruik van een eHealth interventie vanuit uw perspectief?\
10) Moet de mogelijke eHealth interventie focussen op een specifieke groep ouders, of op hen allemaal?
      a. Doorvragen

Dit was het laatste gedeelte van het interview. Nu wil ik de ruimte geven voor het maken van opmerkingen.

APPENDIX C: INFORMATION LETTER

Informatiebrief

Master afstudeeronderzoek: Een behoefte onderzoek naar eHealth interventies ter ondersteuning van de huidige manier van voorlichting van (aanstaande) ouders over de preventie van wiegendood.

Geachte heer/mevrouw,

Mijn naam is Gülsen Öcal en namens Universiteit Twente doe ik een afstudeeronderzoek voor mijn master Gezondheidswetenschappen aan de Universiteit Twente. Middels deze brief wil ik u vragen om mee te doen aan een behoefte onderzoek. U beslist zelf of u wilt meedoen. Voordat u de beslissing neemt, is het belangrijk om meer te weten over het onderzoek. Lees deze informatiebrief daarom rustig door. Heeft u na het lezen van de informatie nog vragen? Dan kun u terecht bij de onderzoeker. Verderop kunt u de contact gegevens van de personen aan wie u uw vragen kun stellen, vinden.

Doel en achtergrond van het onderzoek

"Men spreekt van wiegendood als een baby onverwacht overlijdt zonder dat daar ogenschijnlijk een oorzaak voor is. Als ook na volledig postmortaal onderzoek geen verklaring wordt gevonden, noemt met dat wiegendood. Als wiegendood zich voordoet, is het vrijwel altijd in het eerste levensjaar, maar het komt soms ook in het tweede jaar voor." Dankzij voorlichtingscampagnes over verzorging van baby's is het aantal kinderen dat sterft ten gevolge van wiegendood drastisch gedaald. Het feit dat het aantal sterf gevallen nog steeds laag is in Nederland, kan leiden tot een afname van het bewustzijn van ouders over handelingen en risicofactoren waarvan bekend is dat het een verhoogd risico op wiegendood geeft. Verder ontdekken onderzoekers steeds meer nieuwe handelingen en factoren die het risico op wiegendood vergroten. Tegelijkertijd kan de huidige manieren van verspreiding van preventieve boodschappen aangepast worden aan de huidige levensstijl van ouders.

Universiteit Twente in Enschede doet onderzoek of eHealth interventies bij de voorlichting van de ouders met baby's kunnen worden gebruikt met betrekking tot de preventie van wiegendood. Dit onderzoek zal uitgevoerd worden door middel van interviews met jeugdartsen, jeugdverpleegkundigen, kraamverzorgers en verloskundigen, die allemaal betrokken zijn bij de voorlichting van ouders. Ook aanstaande ouders, en ouders met baby's tussen 0 en 1 jaar zullen geïnterviewd worden voor dit onderzoek.

Hoe wordt het onderzoek uitgevoerd?

Er zal een semigestructureerd interview uitgevoerd worden. Het interview zal één op één plaatsvinden en opgenomen worden. Er zijn voor u geen risico's verbonden aan deelname aan het onderzoek. Het zal ongeveer 30 minuten in beslag nemen. De vragen zullen vooral gaan over de contactmomenten, de huidige werkwijze met betrekking tot preventie van wiegendood en uw mening over een mogelijke eHealth interventie. Het doel van dit onderzoek is **niet** om uw handelingen of praktijk te evalueren, maar om motivaties voor en meningen over bepaalde handelingen te kunnen begrijpen.

Wat wordt er van u verwacht?

U beslist zelf of u meedoet aan het onderzoek. Deelname is vrijwillig. Als u besluit niet mee te doen, hoeft u verder niets te doen. U hoeft ook niet te zeggen waarom u niet wilt meedoen. Als u wel meedoet, kunt u zich altijd bedenken en toch stoppen. Ook tijdens het onderzoek, dus interview, heeft u het recht om vragen niet te beantwoorden of te stoppen zonder toelichting.

Vertrouwelijkheid

De gegevens die tijdens het onderzoek over u verzameld worden, behandel ik vertrouwelijk volgens (inter)nationale regels en wetten, waaronder de Wet Bescherming Persoonsgegevens**. Ik wijs er met nadruk op dat de informatie die u verstrekt hoogst vertrouwelijk zal worden behandeld en nooit zal worden doorgegeven aan derden.** Ik zal uw gegevens coderen op een manier dat ze niet tot uw persoon herleid kunnen worden. De codering is dan ook niet gebaseerd op bijvoorbeeld uw geboortedatum, voornaam of achternaam. Verder is dit onderzoek getoetst en goedgekeurd door de ethische commissie van Universiteit Twente onder aanvraagnummer 17383.

Als u besluit deel te nemen aan dit onderzoek geeft u toestemming voor het volgende:
- Indien u zou beslissen niet meer deel te nemen aan het interview/onderzoek, mag ik de gegevens die verzameld werden vóór deze beslissing nog steeds verwerken en gebruiken voor het onderzoek
- Dit onderzoek brengt geen risico's met zich mee, waardoor er geen proefpersonenverzekering afgesloten zal worden.

Vergoeding

De onderzoeker/interviewer zal voor het interview een eenmalige bezoek bij u thuis, op het werk of een locatie dichtbij u brengen of het interview via de chat afnemen. Hierdoor zal er **géén** vergoeding van de afgelegde kilometers plaatsvinden.

Ten slotte

U bent gevraagd deel te nemen aan een wetenschappelijk onderzoek. De internationaal vastgestelde richtlijnen voor dit onderzoek zullen nauwkeurig opgevolgd worden. Wanneer u nog vragen heeft over het onderzoek, kunt u die stellen aan de interviewer/onderzoeker of aan een verantwoordelijke onderzoeker van de Universiteit Twente. De toestemmingsverklaring kunt u ondertekenen als u wilt deelnemen aan het onderzoek. Dit is een formulier waarmee u aangeeft dat u begrijpt wat het onderzoek inhoudt en dat u wilt meewerken. Deze krijgt u vóór het interview.

Het zal mij enorm helpen als ik uit uw praktijk ook respondenten kan werven. Ik zie uw reactie daarom graag per mail tegemoet en alvast hartelijk bedankt.

Met vriendelijke groet,

Gülsen Öcal, Master Gezondheidswetenschappen studente, onderzoeker en interviewer:
Telefoon: 06-48241470 - e-mail: g.ocal@student.utwente.nl
Magda Boere-Boonekamp, Associate Professor en epidemioloog aan de Universiteit Twente, en arts maatschappij en gezondheid in de jeugdgezondheidszorg:
Telefoon: 053-489 4483 , e-mail: m.m.boere-boonekamp@utwente.nl

Titel van het onderzoek: **Een behoefte onderzoek naar een mogelijke eHealth interventie ter ondersteuning van de huidige manier van voorlichtingen, voor (aanstaande) ouders met betrekking tot wiegendood**

Ik bevestig dat ik vooraf voldoende informatie gekregen heb en ben in de gelegenheid geweest om vragen te stellen. Deze vragen zijn naar tevredenheid beantwoord.

Ik geef toestemming voor deelname aan bovengenoemde wetenschappelijk onderzoek.

Ik weet dat mijn deelname geheel vrijwillig is en dat ik mijn toestemming op ieder moment kan intrekken zonder opgaaf van redenen.

Ik weet dat met mijn gegevens en de resultaten van het onderzoek alleen anoniem en vertrouwelijk omgegaan zullen worden en niet aan derden bekend gemaakt zullen worden.

Ik begrijp dat de geluidsopnames tijdens het interview uitsluitend voor analyse zullen worden gebruikt.

Ik geef toestemming dat ik kan worden benaderd voor vervolgonderzoek:
Ja ☐   Nee ☐

Ik wil graag een samenvatting van de resultaten van dit onderzoek ontvangen:
Ja ☐   Nee ☐
Zo ja, email_____

Naam proefpersoon: Handtekening: Datum:

In te vullen door de uitvoerende onderzoeker
Ik heb een mondelingen en schriftelijke toelichting gegeven over het onderzoek en ik zal vragen over het onderzoek naar vermogen beantwoorden.

Naam onderzoeker: Handtekening: Datum:

APPENDIX E: CODING SCHEMES

Coding Scheme Health Care Professionals (in Dutch)

1.Persoonlijke gegevens:

1.1Respondent benoemt leeftijd

1.2Respondent benoemt geslacht

1.3Respondent benoemt waar hij/zij op dit moment werkzaam is

1.4Respondent benoemt specifieke functie

1.5Respondent benoemt met welke leeftijdsklasse kinderen hij/zij werkt

1.6Respondent benoemt aantal jaren ervaring in de functie

2.Contactmoment met ouders in het algemeen:

2.1Respondent benoemt zijn/haar eerste contactmoment met (aanstaande) ouders

2.2Respondent benoemt welke informatie zij/hij tijdens eerste contactmoment behandelt

2.3Respondent benoemt welke informatie hij/zij herhaalt

2.4Respondent benoemt huidige manieren waarop hij/zij voorlichting (algemeen) verstrekt aan (aanstaande) ouders

2.5Respondent geeft aan of hij/zij ook wiegendood voorlichting behandelt

2.6Respondent benoemt de huidige manieren waarop hij/zij voorlichting ter preventie van wiegendood behandelt

2.7Respondent geeft zijn/haar mening over de huidige manier van voorlichting over wiegendood

2.8Respondent geeft aan op welke moment hij/zij ingaat op het thema wiegendood en zijn/haar mening over dit moment.

2.9Respondent benoemt hoe de risicofactoren van wiegendood worden herhaald

2.10Respondent geeft aan hoe hij/zij omgaat met (aanstaande) ouders zonder de gewenste gedragsverandering / ouders die risicovolle handelingen blijven verrichten

2.11Respondent benoemt welke zorgprofessionals ook voorlichting over wiegendood moeten geven

2.12Respondent geeft aan of de tijd voor een contactmoment voldoende/onvoldoende is

2.13Respondent benoemt welke informatie/gegevens zij/hij van (aanstaande) ouders bijhouden/noteren

2.14Respondent geeft aan of deze informatie wel/niet beschikbaar moet zijn voor (aanstaande) ouders

2.15Respondent geef aan of (aanstaande) ouders vooraf een contactmoment nodige informatie moeten krijgen

2.16Respondent geeft aan hoe hij/zij zelf internet informatie ervaart

2.17Respondent geeft aan wat hij/zij vindt van (aanstaande) ouders die gebruik maken van internet informatie

2.18Respondent benoemt de meest veelvoorkomende vragen van ouders

2.19Respondent geeft aan met welke groepen (aanstaande) ouders hij/zij moeilijkheden ervaart

2.20Respondent geeft aan met welke moeilijkheden/barrières hij/zij te maken heeft met "moeilijke" groepen (aanstaande) ouders

2.21Respondent benoemt zijn/haar werkwijze van voorlichting om de "moeilijke" groepen (aanstaande) ouders beter te bereiken/voor te lichten

3.Informatie en kennis voorziening:

3.1Respondent benoemt in hoeverre hij/zij informatie heeft gekregen over eHealth interventies

3.2Respondent geeft zijn/haar ervaring met de huidige manier waarop hij/zij wordt ingelicht over nieuwe risicofactoren van wiegendood

3.3Respondent geeft zijn/haar ervaring met protocollen/richtlijnen over preventie van wiegendood

4.eHealth:

4.1Respondent benoemt vormen van eHealth die toegepast worden in hun praktijk

4.2Respondent geeft aan of er bewust/onbewuste vraag is naar een eHealth interventie voor voorkomende problemen

4.3Respondent benoemt de mate waarin hij/zij denkt de eHealth interventie nodig te hebben in deze context en de manier waarop dit nodig te hebben

4.4Respondent benoemt in hoeverre zij/hij bekend is met eHealth interventies aangeboden in deze context

4.5Respondent benoemt in hoeverre en met welke middelen hij/zij eHealth interventies promoot bij (aanstaande) ouders

4.6Respondent benoemt de ervaren problemen met de huidige manier waarop hij/zij voorlichting over wiegendood geeft

4.7Respondent benoemt hoe hij/zij staat tegenover (attitude) digitalisering/eHealth in de zorg staat

4.8Respondent benoemt de mate waarin hij/zij denkt dat een mogelijke eHealth interventie voor hem/haar effectief/van toegevoegde waarde is

4.9Respondent geeft aan of een mogelijke eHealth interventie past binnen hun werkwijze/geeft aan of implementatie in zijn/haar huidige werkwijze mogelijk is/geeft aan in hoeverre een mogelijke eHealth interventie ingevoerd moet worden

4.10Respondent benoemt in hoeverre hij/zij verwacht dat de mogelijke eHealth interventie voor hem/haar potentieel nuttig is

4.11Respondent geeft aan in hoeverre hij/zij de eHealth interventie in de toekomst zal gebruiken

4.12Respondent geeft haar voorkeur aan een soort eHealth interventie

4.13Respondent benoemt aan welke voorwaarden/eisen de eHealth interventie moet voldoen, voordat hij/zij het zou willen implementeren/gebruiken

4.14Respondent benoemt welke informatie/voorlichting de eHealth interventie moet aanbieden

4.15Respondent benoemt op welke manier zij informatie/voorlichting het liefst wil zien via de eHealth interventie

4.16Respondent benoemt op welke wijze de eHealth interventie geïmplementeerd mag/moet worde

4.17Respondent benoemt mogelijke voordelen in een eHealth interventie aangeboden in deze context

4.18Respondent benoemt mogelijke nadelen in een eHealth interventie aangeboden in deze context

4.19Respondent benoemt welke groepen personen/(aanstaande) ouders volgens hem/haar baat hebben bij de eHealth interventie

4.20Respondent benoemt aanbevelingen/ideeën/suggesties met betrekking tot de toekomstige eHealth interventie

Coding Scheme Parents (in Dutch)

1.Persoonlijke gegevens (demographics persona):

1.1Respondent benoemt leeftijd

1.2Respondent benoemt geslacht

1.3Respondent benoemt aantal kinderen dat hij/zij heeft

1.4Respondent benoemt leeftijd jongste kind

1.5Respondent benoemt samenlevingsvorm

1.6Respondent benoemt geboorteland, moedertaal

1.7Respondent benoemt educatie leven en huidige werksituatie en functie

2.Technische vaardigheden (technical skills persona)

2.1Respondent benoemt tot welke technische hulpmiddelen ze toegang hebben thuis

2.2Respondent benoemt welke technische hulpmiddelen ze het vaakst gebruikt en welke ze overal mee naar toe neemt

2.3Respondent benoemt waarvoor ze internet gebruikt en hoe vaak ze internet gebruikt

3.Gezondheidspecifieke kennis (healthcare specific knowledge persona)

3.1Respondent geeft aan waar hun baby op dit moment slaapt

3.2Respondent geeft aan hoe hun baby op dit moment slaapt

3.3Respondent geeft aan hoe zij hun baby warm houden

3.4Respondent geeft aan tot welke leeftijd er risico bestaat voor wiegendood

3.5Respondent benoemt zijn/haar algemene kennis over het ontstaan van wiegendood

4.Huidige manier informatie zoeken

4.1Respondent benoemt welke hulpbronnen ze gebruikt om informatie te verkrijgen

4.2Respondent haar mening en ervaring over internet informatie

4.3Respondent benoemt voor welke onderwerpen ze internet gebruikt

4.4Respondent benoemt de toevoegde waarde van arts vs internet

5.Ervaring huidige manier van voorlichting over SIDS

5.1Respondent geeft zijn/haar ervaring over de afspraken bij de consultatiebureau

5.2Respondent benoemt zijn/haar ervaring over de huidige manier van voorlichting over SIDS bij consultatiebureau

5.3Respondent benoemt zijn/haar ervaring over de contactmoment met de kraamverzorgende

5.4Respondent benoemt zijn/haar ervaring over de huidige manier van voorlichting over SIDS gegeven door kraamverzorgende

5.5Respondent benoemt zijn/haar ervaring over de contactmoment met de verloskundige

5.6Respondent benoemt zijn/haar ervaring over de huidige manier van voorlichting over SIDS gegeven door verloskundige

5.7Respondent benoemt op welke manieren zij informatie heeft gekregen en zijn/haar ervaring hiermee

5.8Respondent benoemt zijn/haar ervaring met het naleven van de adviezen

6.Verwachtingen

6.1Respondent benoemt op welke manier informatie wel/niet geboden zou moeten worden

6.2Respondent benoemt algemene verwachtingen

7.Attitude over en ervaring met eHealth interventies

7.1Respondent benoemt zijn/haar ervaring en mening over eHealth interventies

8.Verwachtingen van eHealth interventies

8.1Respondent benoemt op wat voor een manier een mogelijke eHealth interventie geboden moet worden in deze context

8.2Respondent benoemt op wat voor een manier hij/zij informatie via een eHealth interventie zou willen ontvangen

8.3Respondent benoemt toegevoegde waarde van een eHealth interventie

8.4Respondent benoemt mogelijke voor en nadelen van een eHealth interventie

8.5Respondent benoemt aan welke eisen een eHealth interventie zou moeten voldoen, voordat hij/zij het zou willen gebruiken

8.6Ruimte voor opmerkingen

User expressions, value, attributes and requirements of (prospective) parents

User expressions (Interview number)	Value	Attribute	Rationale	Requirement and requirement type
"With short videos, you can see it and learn it, however with written information it is up to the reader to understand and image it, which might be a wrong interpretation/imagination" Rp1	Easy to understand	Provide simple (audio-) visual and written information	SIDS education should be experienced easy and understandable to comply in order to maintain compliance by the end-users.	The eHealth intervention must give the information in (short) easy-to-understand, written form and in (short) easy-to-understand spoken (visual) form.
"Pictures, short videos or short written information are useful. It takes less effort to read and understand something" Rp10		Accessible in different languages to overcome language barrier and reach more people		The eHealth intervention must have non-verbal communication, such as images and videos.
"There are a lot of non-Dutch speakers, you must offer language options" RP1,RP3,RP5,RP6,RP7,RP10				The eHealth intervention must be offered in different languages: Dutch, English, Turkish and Arabic.
"I always lose leaflets and books. On my phone, everything will be available everywhere and anytime"RP1	Easy to use	An intervention that is easy to use or already familiar for the end-users.	The provided information should be presented in an easy and already familiar manner, due to time pressure and not lasting attention of the end-users.	The intervention must be easy to use and familiar.
"It should be something that I can use anywhere, that is affordable and time-saving" RP3				
"It is easier to use something which is familiar to you and others" Rp6		Instruct users		The eHealth intervention should give clear instructions about how to use it.
"Why too difficult, if it can be easy as well. Not too difficult, not too much effort needed nor a difficult layout. Just one click should be enough for you goal. Name 'Menu option', 'Menu' and Library a library or account, account." Rp2				
"The difficulty level is something you should keep an eye on, because I think that designers				

make an application unnecessary too difficult. I would prefer something that is easier and more consequent to use than the current way ” Rp1

“If a website or video does not look professional or trustable, I will not even look at it” RP2, RP4, RP6 “If there is evidence for something I will trust it easily” Rp1,3,4,5,8,9 “If the information is provided by professionals, and recommended by them, I will take a look at it” Rp1,3,4,5,8	Trustworthiness/Evidence	Provide trustable information recommended by healthcare professionals	Evidence based information are more likely to comply with.	The eHealth intervention must provide unambiguous information based on scientific and reliable/trustable papers and prevention guidelines, in accordance with healthcare professionals. The intervention must show evidence of the provided information.
“I would like to receive feedback that is relevant for me and my child” RP3, RP4, RP5, RP8, RP9 “Just send me specific information such as what complaints I can expect during that particular week of my pregnancy, or when it comes to my child, how he should grow and eat, and what I should do during fewer, washing or teeth pain of my baby for example”. Rp1,4,5,7,9,	Personalized / relevant information	Providing personalized short health messages and feedback based on end-users behavior	People will become more motivated and aware if there is a possibility of evaluating their habits and proceedings afterwards.	The system should give personalized and tailored short health messages or feedback.
“I see sometime scary images and ads on television, trying to convince you not to smoke, but you do not really learn from that. Everybody knows that you might get lung cancer from smoking cigarettes. You should give the facts and fiction, like during a bleeding nose, you should not bend your head backwards, but forward. That will help.” RP4 “I still don’t know what cot death is” Rp2,3,4	Raise awareness / increase knowledge	Change behavior and attitude	Raising awareness about the importance of SIDS guidelines compliance gives improved compliance in return, if people are more aware of the behavioral risk factors, and the consequences of non-compliance with the SIDS guidelines. But demonstrating the consequences, would be possibly raise awareness and lead to behavior	The system should change behavior and attitude by addressing the awareness about the importance of complying with the SIDS recommendations. System should show the consequences of poor and non-compliance.

"I thought it was choking"Rp2			change, however will be anxiety provoking as well.	
"Everyone should get access to it" Rp1 "If it's affordable, anyone can use it. I may be able to pay for it, but another not. I would rather have something that anyone could use and buy. You must take this into account as well." Rp1' "It must be free of charge, or reimbursed by the health insurer." Rp9	Affordable	An intervention that is cheap or free of charge to use	Everyone should get the chance to make use of the eHealth intervention, because it is not ethically acceptable to invent an intervention that is too expensive for parents to use.	The intervention must be affordable.
"the information should be consistent, I read sometimes different things on the internet, and don't know what to trust" R,3,4,5 "even the healthcare professionals are not consistent in their information" Rp1,7,8	Consistency	The provided information must be consistent	The provided information regarding SIDS has to be uniform and consistent. If the SIDS information is consistent to all, then there will be no case of ambiguity and unwillingness.	The eHealth intervention must provide information that is consistent.

User expressions, value, attributes and requirements of health care professionals

User expressions (Interview number)	Value	Attribute	Rationale	Requirement
"Short animation video for clarification, and short written information in bullet point with facts and fiction" HP4,HP5,HP6 "The biggest problems we face during consultations and providing health education are the language barrier and cultural challenges". HP1,HP2,HP3,HP4,HP5,HP6,HP7	Easy to understand	Provide simple (audio-) visual and written information Accessible in different languages to overcome language barrier and reach more people	Providing the information as easy and understandable as possible, will make the diffusion and understanding of the information more effective.	The eHealth intervention short must give the information in (short) easy-to-understand, written form and in (short) easy-to-understand spoken (visual) form, such as short sentences and simple words. The eHealth intervention must have non-verbal communication, such as images and videos, and simple verbal communication. eHealth intervention must be offered in different languages: Dutch, English, Turkish and Arabic
"People are getting lazier day by day. I know that when I recommend web site, they will never look at it, because we are too lazy. And I think that if you make an intervention too difficult, people get irritated, bored, and will not use it" HP1, HP4, HP6,HP7	Easy to Use	A system that familiar and easy to use and understand Instruct users	A system that familiar and easy to use and understand will make the acceptation and diffusion easier.	The eHealth intervention should give clear instructions about how to use it. The eHealth intervention must be easy to use and familiar.
"Fortunately, almost all subjects have one factor common, and that is lifestyle. Understanding the lifestyle factors influencing parents, such as habits, their faith and beliefs, cultural background, but also, their eating, smoking and alcohol behavior, exercise behavior, and social economic status. When we are able to talk about this, and try to change and influence their 'bad' behaviors by showing them the consequences, a lot of pregnancy and infant related problems will be prevented" HP1,HP4,HP6,HP7	Raise awareness/increase knowledge	Increase awareness by providing personalized and relevant feedback and information Change behavior and attitude	To change behavior, personalized and tailored feedback and information is needed. Using behavior change theories in the intervention and persuasive features, will make this possible.	The system should give personalized information and feedback.

"The biggest problem we have to encounter are language barriers and behavioral risk factors related to cultural challenges". HP1, HP2, HP4, HP5, HP6 "Asylum seekers, refugees and immigrants are increasing the western countries, and therefore the different cultures, and languages as well" HP1, HP4, HP6	Improve patient-professional communication	Solve cultural barrier Solve language barrier	Offering the right information in different languages and personalizing the information based on expected cultural background, will make it easier to reach the end-users.	The eHealth intervention must be offered in different languages: Dutch, English, Turkish and Arabic
"We always stimulate the actions of parents, and motivate them to not to hesitate, and they should not be afraid of trying. So we will never recommend anxiety provoking information, that is contrary to what we want, and that is courage to use their own skills and knowledge." HP1,HP3,HP4	Increase empowerment	The content of the information should be as neutral as possible (no anxiety provoking information)	To increase empowerment and the self-esteem of the parents, which are stimulated by the health care professionals, their fear should be removed and no anxiety provoking information should be provided.	The eHealth intervention must provide clear explanations of the risk factors, and what actions the users should take to remove the fear.
"We don't have time to control or check what parents are doing with a new eHealth technology, simply design something that does not asks time from us, but is a supporting system for parents" HP1, HP3, HP6	Easy integration into current work routine Time saving	Useful and efficient information exchange/ sharing in advance	Healthcare professional doesn't want an intervention that is time consuming, instead if it saves time or is easy to integrate into their current working routine, it will be accepted easily.	The system must be easy to integrate into the current work routine of the healthcare professionals.
"People will not use an intervention where they have to pay for, even though its just 1 cent. Why? Like I said, we are too lazy, and do not want to pay for information. It is not medicine or a cure you are inventing. HP1, HP6	Affordable	An application that is cheap or free of charge to use	Parents will not pay for information that is also available on the internet. This will demotivate them to use the intervention.	The application must be affordable.

Persona 1: Elise

Classification	Quotes	Persona characteristics
Demographic Personal information (age, number of children, marital status, job, age of the children)	Based on the interviews	Elise is 28 years old. She is married and has one child, who is six months old. She just started working again as a part-time worker. Her husband works fulltime. She leaves her child at her mom's house sometimes.
Knowledge About SIDS risk factors	*"…My child sleeps with me in my room. By in her own bed, because Im still breastfeeding her and at night it is easier to have her in my room. Then I don't need to leave the room. She is now sleeping on her back as well, I've always done this, because of the maternity nurse. She gave me the information, and told me about cot death. Sometimes I let her sleep on her side, during the day but then I am with her, in case she turns on her face…" Rp1* *"…I use pacifier because I know that it stimulates her to suck and breath I guess. Anyway, it was good for something…" Rp7*	She knows a lot. She did a lot of research and read a lot of books. She knows all risk factors for cot death.
Technological skills Technology use Attitude towards eHealth / motivation to use eHealth Information searching behavior	*"The current why of information is not the best way. No one reads the books or leaflets. They throw it away. Everyone uses smartphones and internet. So you can easily design something, that can be accessed everywhere on the phone. I would use it, why not?" RP1* *"…Computer, laptop, Ipad and Iphone ofcourse, playstation and ITv as well.."* *Rp1,2,3,4,5,6,7,8,9,10* *"…I ask my mother for information and sometimes my friend, but Internet is also very useful. To read other mothers experiences…" Rp1,2,3,4,5,6,7,8,9,10* *"…Yes, I'm always interested in new interventions. Especially if its for my children.." Rp1,9,10* *"…I used Zensy as well, it was definitely a safe replacement of the old hot water bottles. So if it's a good replacement of the current way, why not…" Rp1,9*	Sufficient motivation to change her behavior and use an intervention. Open for new interventions Beliefs she has the ability to do her own research. Does not see the added value of health education provided by health care professionals. Perfect digital skills. Uses interventions that had added value or are good replacements. Intrinsically motivated to do everything for her child.

Persona 2 Rana

Classification	Quotes	Persona characteristics
Demographic Personal information (age, number of children, marital status, job, age of the children)	*Based on the respondent characteristics*	Renske is 23 years old. Lives together with her boyfriend. Has two children, both girls. She does not work.
Knowledge About SIDS risk factors	*"…I thought that cot death was caused by choking, choking because of vomiting during the sleep. Actually, I still don't have any idea about what it is and how it happens…" Rp2 ,4*	Renske thinks she has sufficient knowledge, but she hasn't.
	"…After three children, you don't need the same information. I also did not want a maternity nurse in my house, as if she is there to check what I am doing with my child. No need for that…" Rp7	She thinks you learn and develop skills by experience.
	"…I've done what they liked the most, and they were all stomach sleepers, so I just let them, so that they could sleep well the whole night…" Rp7	
	"…She slept the first months with me in my bed. But that's also how it should be huh? The first three months in your own bed is safer, so you can intervene immediately when something happens with your baby…" Rp8	
	"…Why don't they understand that every child is different? They are all so strict and intrusive. That's why I prefer to lie about some questions. I prefer to do it on my own way, like I learned it…" Rp2,3,4,5,7,8	
	"…I don't use a pacifie, because I have to get rid of it again later. That is a quiry hassle. So better not to start with it at all…" Rp3 *"…They both sleep on their stomach. I neither use a special mattress or something and they are still alive. I mean, I know that the youth healthcare physician would be shocked if I told them, so I didn't tell them either…" Rp4,5*	
	"…She sleeps with me in my room and in my bed, but you shouldnot include that in your research…" Rp7	
Technological skills Technology use	*"…Why not, if it's not too difficult to use, easy to understand and of course useful. I will put effort in it. Apps or websites can be made so difficult, that's not necessary…" Rp2*	She believes you can't learn everything by reading.

Attitude towards eHealth / motivation to use eHealth	"…*Computer, laptop, Ipad and Iphone ofcourse, playstation and ITv as well..*" Rp1,2,3,4,5,6,7,8,9,10	Askes friends and family first for advice.
Information searching behavior	"…*I ask my mother for information and sometimes my friend, but Internet is also very useful. To read other mothers experiences…*" Rp1,2,3,4,5,6,7,8,9,10	Renske has not an intrinsic motivation to use a new intervention.
	"…*No, I will not use it I guess. Im not interested at all…*" Rp3,7,8	However, she might be triggered extrinsically, if it's important for the health of her children, easy to use and to understand, and time saving.

Persona 3: Aria

Classification	Quotes	Persona characteristics
Demographic Personal information (age, number of children, marital status, job, age of the children)	*Based on the interviews*	Aria represents the pregnant women. It's her first pregnancy, she is 7 months pregnant.
Knowledge About SIDS risk factors	*"…No, we didn't discuss cot death. I also didn't know what cot death was, I just googled it…" Rp10*	Aria doesn't know anything about cot death. She heard from it, but she does not know what causes cot death.
Technological skills Information searching behavior	*"…I had already bought books, but the internet is more convenient. It is easier, however it makes you unnecessarily anxious, but you should not look for that kinds of information. Just tips and advice…" Rp10*	She is high motivated to learn everything.
Technology use		She has the intrinsic and extrinsic motivation to learn to use eHealth interventions
Attitude towards eHealth / motivation to use eHealth	*"…My mother and grandmother tell me a lot. They tell me what I should eat, and what I had to do during morning nausea and backache. I searched for information on the internet, looking what others did in the same situation…." Rp10* *"…Try to reach the whole population with your new idea, that will work like herd immunity. If enough people know the risk factors, they will warn the others who doesn't know…" Rp10* *"…I use my smartphone, Ipad and television a lot…" Rp10* *"…Yes, I use FitBit connected to my phone. And I also bought an electric baby sheet, and everything that's new actually…" Rp10* *"…I'm always interested, if its recommended for my baby, ofcourse I will use it…" Rp10* *"…Computer, laptop, Ipad and Iphone ofcourse, playstation and ITv as well.." Rp1,2,3,4,5,6,7,8,9,10* *"…I ask my mother for information and sometimes my friend, but Internet is also very useful. To read other mothers experiences…" Rp1,2,3,4,5,6,7,8,9,10*	Uses technology like everyone does.