EMPATHY IN A TECHNOLOGY-DRIVEN DESIGN PROCESS: DESIGNING FOR USERS WITHOUT A VOICE OF THEIR OWN

ELINA ILEN
AALTO UNIVERSITY
SCHOOL OF ARTS, DESIGN AND ARCHITECTURE,
DEPARTMENT OF DESIGN,
HELSINKI FINLAND
ELINA.ILEN@AALTO.FI

MARKUS AHOLA
AALTO UNIVERSITY
SCHOOL OF ARTS, DESIGN AND ARCHITECTURE,
DEPARTMENT OF DESIGN,
HELSINKI FINLAND
MARKUS.AHOLA@AALTO.FI

CAMILLA GROTH
AALTO UNIVERSITY, SCHOOL OF ARTS,
DESIGN AND ARCHITECTURE,
DEPARTMENT OF DESIGN (UNIVERSITY OF
GOTHENBURG, SWEDEN AND UNIVERSITY
OF SOUTH-EASTERN NORWAY)
CAMILLA.GROTH@AALTO.FI

KIRSI NIINIMÄKI
AALTO UNIVERSITY
SCHOOL OF ARTS, DESIGN AND ARCHITECTURE,
DEPARTMENT OF DESIGN,
HELSINKI FINLAND
KIRSI.NIINIMÄKI@AALTO.FI

ABSTRACT
Smart textiles are often developed in sports-oriented contexts through technology-driven processes. In the medical context, practitioners themselves also invent and develop technological aids in response to needs that emerge in practice. In these cases, novel technology may be the first driver for design to secure functionality and reliability, but our study shows that these processes benefit from human-centric and empathic design approaches. The project develops smart textiles for infants with medical adversities, such as preterm birth, neonatal infections, or birth asphyxia, collaboratively with medical researchers. Our pilot research illuminates the need to use the interest group’s empathic understanding as a starting point for design, as the user of the garments does not yet have a voice of their own. In this paper, we develop the argument for empathic design in a technology-driven design process in the medical context.
INTRODUCTION

Each year, about 15 million children worldwide are born prematurely (Parikka & Lehtonen, 2017, p.10). These children face greater risks of neurological adversities and abnormal bodily functions. This paper presents the first developments of the research project Rhythms in Infant Brain: Wearables for Computational Diagnostics and Mobile Monitoring of Treatment (RIB). The overall goal of RIB is to bring together the latest advances in neuroscience, pediatrics, psychiatry and different fields of technology – from signal processing to smart textile product enhancements – to improve the care and future brain development of neurologically compromised infants.

A brain disorder may manifest itself through abnormal movements and sleep cycles. Therefore, in addition to monitoring brain signals with electroencephalography (EEG), the infant is also monitored by measuring other vital signs; heart rate is tracked with electrocardiography (ECG), breathing rate and sleep cycles are monitored, and movements are analyzed by applying electromyogram measurements (EMG) or accelerometers to detect possible adversities. The research aims to develop three distinct wearable medical “devices” using smart textiles: an EEG beanie, sleep monitoring pants and a movement measuring bodysuit. From a design point of view, this means that the project also demonstrates the clinical utility of smart textiles by quantifying their efficacy in clinical interventions.

In past decades, textile-based wearable technology concentrated on solving challenges related to electronics and ICT (Axisa et al. 2005). Today, technological readiness has reached a level that enables a shift from technology-driven development towards human-centered design processes. The understanding of users’ behavior, needs and emotions is now better taken into account to create meaningful applications (Kim et al. 2016). However, an empathic approach to smart textiles design in the medical context is new.

In this study, the main user belongs to the category of users who do not possess a voice of their own, and thus traditional user experience studies are not feasible. The present research thus asks: How can design researchers gain an empathic understanding of users who are not able to voice their own experiences? We studied these aspects through interest group interviews with a focus on the empathic aspects encountered.

POTENTIALS OF SMART TEXTILES IN THE MEDICAL CONTEXT

Significant progress has been made in the use of smart textiles in wearable technology, especially in the sport and well-being sector. However, the medical sector still lacks commercial and viable solutions. The main advancement in the smart textiles industry has been the integration of “smart components” into textiles without compromising the user experience and usability of the garments. The benefit of wearable textile electronics in the medical context is that they enable detecting, recording, analyzing and transferring the data and then finally reacting to these stimuli (Kim et al., 2016).

Electronic textiles, i.e., conductive textiles, have the added ability to provide an unobtrusive means of performing long-term body monitoring, as these electronic textile components are soft, elastic, washable and even sterilizable (Ilén, 2015; Van Langenhove et al., 2007). These conductive textiles have multiple roles within wearable technology – they can be used as detectors, actuators, antennas, and heating elements, as well as to transfer power and signals. In sensing or detecting, the textile electrodes can monitor several biosignals such as ECG, EMG, EEG and electrobioimpedance (EBI), (Cochrane et al., 2016; Marques et al., 2009; Ilén, 2015). The textile product provides a platform for wearable electronics, boasting nearly seamless and invisible integration. Additionally, it guarantees that the electronics will be positioned correctly on the body.

By monitoring the movements of infants via smart textile wearables such as a bodysuit or sleep monitoring pants, it is possible to collect a database of general patterns from healthy children against which to compare unhealthy patterns. Wireless, quantitative home-monitoring through smart textiles would enable not only earlier diagnosis, but also earlier physiotherapy intervention, and evaluation of the therapy. Longitudinal measurements in a natural home environment are likely to facilitate the detection of qualitative movements that may go unnoticed in a hospital setting.

In the following we will give an outline of the design research-related theory and methods that foreground the research process and the interest group interviews. We then present the data and the results from the interviews and discuss these in relation to design research theory.

EMPATHY IN A TECHNOLOGY-DRIVEN DESIGN PROCESS

Technology as a driver of a design process generally refers to an approach where products, systems, and services are developed based on their technical abilities. This development focuses on exploring the possibilities that new technologies can offer or what can be achieved with new combinations of existing technology. Technology-driven design is an inherently trial-and-error based approach executed by technologists who are experts in their area and who create new designs based on their inner vision or just because they can. The resulting innovations are not driven by formal studies or analyses (Norman & Verganti, 2014).
The main drivers of a human-centered design (HCD) approach to innovation are a deep understanding of human needs and their alignment with the technological and economical context (Gruber et al., 2015). HCD features a variety of approaches and frameworks that emphasize the human as a participant in the design process, such as user-centered design, participatory design and user experience design. Generally, these approaches follow three general principles: collaboration (ideating and designing together with people), empathy (deep understanding of people), and experimentation (verify hypotheses with people) such as experience prototyping (Buchenau & Fulton Suri, 2000). Thus, in contrast to a designer-led and technology-driven design process, HCD is based on formal studies and direct generation of meaningful solutions (Brown, 2008). Having human experiences as a starting point of the design process helps designers to move away from existing solutions and expand their design scope to invent solutions that may even be radically new (Lu & Roto, 2014).

Empathy has been described as the ability to understand what something feels like for another person – or how something is experienced from another person’s perspective (Wright & McCarthy, 2008). Empathic design is a design research approach that draws on a rich understanding of human emotions, experiences, and everyday lives and translates this gained knowledge into products or service development (Wright & McCarthy, 2005). Roberts Fisher, Trowbridge, and Bent (2016) evaluate the impact of design thinking in healthcare innovation and weight empathy as the most critical method in the design framework for revealing new perspectives into how individuals and communities experience health problems; they suggest that this should be supplemented with radical collaboration and rapid prototyping.

In this context-sensitive design approach, designers study how people make sense of emotions, talk about them, and share them (Mattelmäki, Vaajakallio & Koskinen, 2014). The process typically uses different kinds of simulations to enhance experience sharing between the designers and observed participants. Jäliskö and Mattelmäki (2003; see also Mattelmäki, 2006, 2008) have developed the Probing method, inspired by Cultural Probes (Gaver, Dunne & Pacenti, 1999). Empathic design is considered most valuable in the early phases of the design process and when new product opportunities and concepts are developed (Koskinen & Battarbee, 2003).

METHODOLOGY
Our design process is based on constructive design research (Koskinen et al.) and it started with background research on the hospital as a design context to reveal opportunities and limitations for future testing of the wearable concepts. The developed prototypes were tested through several iterations in a real-life setting, taking users’ feedback into account. The need for empathy was obvious as the context involves caring for premature infants and other compromised babies, who represent the perhaps most sensitive members of our population (Figure 1).

Figure 1: PR material: Prematurely born infant. Photo: Courtesy of BABA Research Center, Children’s Hospital, University of Helsinki, with permission.

In our present case, the design process needs to utilize both a technology-driven and human-centered approach in parallel, as the validation of the technology and the unconditional acceptance of the user/s are equally important for the success of the whole research and development project. In addition, the design process made use of design research methods. To understand users who are unable to share their experiences, it was vital to gain a deep understanding of the context and the situation of the user via other interest groups; thus, empathic design research involving interest group interviews and probes, was the only suitable approach.

MULTIPLE USERS AND INTEREST GROUPS
In a human-centric approach the identification of direct and indirect user groups is vital. However, the medical context is complicated, as each product has multiple users (Martin et al., 2006). The role of the designer in this context is to facilitate the smooth combination of complicated technological components, material choices, and cost-efficiency of the product, and ensure agreeable design and
functionality while keeping an eye on the user experience of all users (Figure 2). Users in this case include the infant, the nurses, other medical personnel, as well as the parents, who indirectly experience stress in relation to the added measures performed on their already compromised child. Additionally, the doctors need a clear dataset to make the correct diagnosis, relying on the assistance of data analysts.

For the purpose of neurodevelopmental diagnostics, the infant’s biosignals were measured with three wearable medical devices developed in the process (Figures 3-6): (A) a disposable EEG hat (beanie) for brain signal monitoring in intensive care; (B) wireless pants for ambulatory monitoring of the sleep-wake cycle by measuring ECG and respiratory rate at home; and (C) a bodysuit with integrated accelerometer to allow analysis of spontaneous infant movements wirelessly.

When the functionality of these prototypes is tested, there is no possibility to hear about how the main users – the infants – experience these products in the user tests. It proved necessary to study emotional aspects of the multiple users, and an emphatic design approach supports this kind of study in multiple ways: the context is sensitive and emotionally charged, and the designer has very limited access to observe the users’ experiences (Mattelmäki, Vaujakkio & Koskinen,
FINDING EMPATHY
Two design researchers, Elina Ilén and Camilla Groth, visited the children’s hospital in order to conduct background research on the prematurely born child’s journey through the different care units and treatments during their first year after birth, including all routine and special check-ups and what actions these activities entail. The background research was conducted through interest group interviews in two phases: the first five interviews were conducted in groups in the spring and four individual interviews in the autumn of 2018 (nine people were interviewed in total). In the first two meetings, we met a professor of child neuroscience and two physiotherapists and one of the nurses who works closely with the physiotherapists. In the third meeting, we met with two doctors, the professor of child neuroscience and the initiator of the RIB project, who is also the leader of the RIB medical research team. After the initial prototypes and testing we decided to conduct more interviews with the purpose of investigating, among other things, the role of empathy in this project. The interviews amounted to 7.5h of audio recorded data that was transcribed and analyzed by both researchers through thematic content analysis and discussions. Table 1 and 2 presents the educational background and the role the interviewees play in the project.

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<th>Table 1: The educational background, role and interest group category of the practitioners interviewed in the first round.</th>
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<td>E Child neurophysiologist</td>
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<th>Table 2: The educational background, role and interest group category of the practitioners interviewed in the second round.</th>
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<td>Education</td>
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<td>F Clinical neurophysiologist</td>
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<td>G Child neurologist and PhD candidate</td>
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<tr>
<td>H Master student in Neuroscience</td>
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<td>I D.Sc (Tech) Post-doc</td>
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INTERVIEWS OF THE INTEREST GROUP
In the initial group meetings in the spring we discussed the journey of the child starting from the expected date of birth to the age of one year. After asking our interview questions, we introduced a whiteboard with only a timeline drawn on it (Figure 7). This was intended to form the basis for the journey map that would enable us to start visualizing the child’s journey together from different perspectives: the child and parents, or the medical practitioner, the different stages of expected development and what kind of check-ups are done, where, how and by whom.
At this point the interview turned into a co-creation workshop (Mattelmäki & SleeswijkVisser, 2011) where new suggestions and possible use cases and utilization areas for the different products were drawn and envisioned. Also, possible sites for conducting the research and the timing of the measurements and how the parents might react to additional measurement sessions and the designs were discussed.

During a check-up, the child is either in the arms of the parents or in the arms of the nurse/therapist to enable the nurse/therapist to feel the tension in the child’s body. “We construct our overall understanding of the child’s condition through several tiny parts of knowledge,” said the child neurologist, “and much of our knowledge is in our hands.” During the interviews, the physiotherapists often refer to the hardness or softness of the baby’s body as an indication of the condition of the baby. An overly limp or stiff body can be an unhealthy sign; the sense of what is normal and what is on the edge of normal is thus sensed tacitly by the therapist.

After drawing the journey map, the preferred design of the bodysuit was envisioned using yet another visualization template, the baby body (Figure 8).

We used both templates in both interviews and all interviewees marked them in a similar way. Thus, we found that the nurses are in broad agreement with each other when it comes to the facts about the care of children and the procedures discussed as well as about where and how the electrodes should be placed on the body of the child (through the jumpsuit). As in the jumpsuit design, movement detection is performed with EMG measurements and the electrodes are concentrated on the torso, which the doctor explained is the starting point for all movements. The second important area is the neck as it carries the head, and thus electrodes are needed especially on the neck muscles (Figure 9).

The visualization was useful to communicate and agree on the things discussed but also to document the findings in both visual and verbal terms. The visualization templates thus served as design probes that facilitated discussions related to the function of the intended design; they also evoked and brought to the surface the bodily and psychological experiences involved in interactions with the infants and their parents. A premature baby is very small and sensitive, which heightens touch and haptic perception in particular; the texture and feel of the clothes are thus very important. “Anything that we feel, they feel four times stronger,” said one of the physiotherapists. The extreme sensitivity of the premature infant and the restrictions posed by their limited capabilities and treatment options was often reflected on in emotional wordings and expressions.

The second interview also took place at the children’s hospital. This time we met the child neurologist and also the research group leader, a professor of neurology, to discuss the first prototypes and the research process for other designs, such as the beanie and pants. To this meeting we brought material samples of the textiles being considered as alternatives for the first prototypes.
Although these two practicing professors have a very similar background and role in the hospital, the research group leader’s role in this project is geared more towards the development of measurement technologies whereas the child neurologist focuses more on the diagnosis of the children. Previously, the interview contexts took a human-centered perspective, focusing on the child’s experiences and the journey through the hospital care units and homecare situations. Now, the discussions approached the subject from a new direction right from the start, focusing clearly on the technological aspects, such as the reliability of the electrodes and how to ensure clear and good quality signals. Instead of going further with designing for the infants, the doctor suggested making “quick and dirty” easy-to-wear prototypes for him, in adult size, so that he could start using them straight away to test the quality of the signal. He suggested that he could wear “strips” with the electrodes attached to his hands, wrists and/or legs or even his torso to test them. In this way, we could ensure that the technology worked as intended before going further.

Based on this initial understanding, and parallel to the iteration of prototypes for validating the technology, we decided to conduct more interviews in the hospital context, now in the research department. We asked the other medical researchers in the RIB project general questions about their role and motivations in regard to their work and how they take the child’s experiences into account. Regardless of what role the respondents had in the project, their answers highlighted issues related to empathy.

The interviews gave insight into the realities of working with children and their families in the clinical setting, trying to make reliable measurements while attending to the sensitive psychological states of both the parents and the baby. The first interviewee, a medical doctor and PhD candidate, told us that she practices her skills of dressing the electrodes on a baby doll (Figure 9) before handling real infants, in order to become quicker and more self-assured in her movements. This enables her to not only calm the parents by projecting a more confident impression, but most importantly to avoid a stressful or painful situation for both infant and parents:

“I have been practicing with baby dolls before I did it with the real baby, so the process was actually really fast, and did not stress the baby at all. And of course, we try to be very gentle and fast when doing the measuring as well.”

The second interviewee, a child neurologist, set up the system for behavioral scoring of movements. She uses EMG recordings to read how the child’s movements are organized, and thereby determine if these tracings can be used to distinguish normal patterns from the atypical. When she was asked how she takes the child’s perspective into account in her work, she answered:

“It’s really, really important that the child is in a good situation (relaxed) and that the child is nested in some relations. You always have to introduce yourself to the child and to put yourself in a relation to the child and the family.”

As in the previous discussions, this practitioner also points to the importance of being sensitive to the emotions and the state of mind of the child in order to conduct the necessary measurements and the clinical check-up:

“If the child is not motivated to do what you want, then you don’t do anything and you just lose your time and make that child lose his time too, and also you don’t have any instrument to study the child and to learn what he is going to do or understand his situation. This is most important with sick children because they are really, really sensitive to the environment.”

Also, the worries of the parents need to be taken seriously, as a practitioner explained that the child mirrors their parents’ emotions. If the parents are stressed, the infant will react similarly. This practitioner had previous experience of working with designers and said that when the designers changed the colors of an EEG hat, the parents started taking photos of their child during the EEG treatments, instead of forbidding the treatments as was customary in her home country.

The third interviewee’s role in the project is to collect and analyze the data from the home use of the sleeping pants. Her work thus involves collaborating with us designers by providing us with phase feedback from the

Figure 10: Image of doll used for practicing the placing of electrodes. Photo by Sampsa Vanhatalo.
users, the parents, and indirectly from the infant using the pants. She takes the child’s and parents’ perspectives into account by highlighting the functionality of the garment, which keeps the parents motivated to use it even when they are stressed and nervous because of the condition of their neurologically compromised child:

“It should be very user friendly – I mean, small babies have very sensitive skin and sensitive everything, and this should be taken into account. For me it is also important for my work to ensure that it is as safe and comfortable as possible.”

The last interviewee is responsible for signal processing and data analysis from a signal quality point of view. Although he is not in direct contact with the infants, it makes him feel good to be part of something that will help children in the future: “It sort of feels like it’s obviously going to be helping kids – that is of course the nice thing.”

RESULTS
At the time of conducting the background research, we did not as yet have a working prototype for home use and thus we did not have access to the parents’ point of view and the user experience of the child via their observations at home. However, when considering the context and the practitioners’ points of view, empathy-related issues emerged in several ways. 1) First of all, motivational issues emerged in all practitioners’ statements as they have an overall interest in the wellbeing of their patients, even if they are not in direct contact with the infants in their work (as in the case of the data analyst). The development of a pain-free EEG hat had a particularly direct influence on the initiation of the whole RIB project. 2) Secondly, all practitioners are acutely aware that the quality of the measurements is dependent on the psychological wellbeing of both infant and parents, and that both their own conduct and way of arranging the measurement session affects their state of mind. This awareness leads them to imagine the situation in which they meet the infant and parents and to rehearse and prepare themselves in several ways. 3) Thirdly, in their communication with the designers, they are keen to convey their concerns and actively suggest improvements and suggestions for how the prototypes could be enhanced. The medical practitioners shared their deep knowledge of the context and their embodied and empathic understanding of the infants’ experiences not only with the designers during the interviews, but also among themselves; to this end, they used the probes to facilitate discussions.

DISCUSSION
Ultimately, we found that the different actors in the medical field have their separate responsibilities and duties that limit the channels and resources for collaboration on the improvement of technology, including their many personal insights. The connecting activities of the design researchers enable gathering information from various instances, which facilitates the emergence of both the technological needs and the human-centered aspects, as well of sharing this understanding between the interest group members. This result is confirmed by previous similar design research projects in which it was found that collaborative projects are often complex and there is a need to connect the different activities, such as bringing together the different actors and maintaining an overview of the project as a whole (Bowen et al., 2016).

Our findings also show that in developing new medical devices for users without a voice of their own, it is necessary to take an emphatic design approach in parallel with the technological development, instead of contradicting these two design strategies. Researchers should first determine the interest group of the product and then listen to persons in that group to learn how the infant perceives its environment and what issues affect it. This would enable researchers to gain a deeper and more empathic understanding of the infant users’ perspective and possible experiences of the intended designs.

In the first phase of background research interviews, the physiotherapists and the child neurologist were engaged in the discussions while drawing collaboratively on the image “probe” representing the baby’s body (see also Jääskö & Mattelmäki, 2003). While doing so they imagined the baby’s condition and the possible discomfort or stress that the infant might experience. Also, they reflected on their own conduct in this situation, and brought to light issues such as how the therapists and nurses communicate with and “handle” the child. These issues contribute to these practitioners’ knowhow, which is tacit and built on years of experiential knowledge and accumulated expertise and sensitivity towards the child’s behavior, the expressions of the child’s needs and general condition. The visual probes brought to the clinic not only worked as documentation kits but also had the additional effect of eliciting the empathic emotions of the personnel. This enables the design researchers to understand the possible experiences of the speechless infants that need to be taken into account in the design process.

When it came to empathy for the child in the medical professionals’ research practice, and in connection to collecting data for the analysis of qualitative movements, it became clear that empathy for the child helps in retrieving the data. This motivated caring for the child during the measurements, but cannot be reduced to only this dimension. In the interviews, we were also made aware of the practice of using models and images of children’s facial expressions during intense pain to differentiate this from pain from stress-related crying, as research has shown that facial expressions differ in these states (Benuzzi et al., 2018; Schiavenato, & von Baeyer, 2012). In such research, the
participants’ own facial expressions are used as models, as one’s own face is more closely connected to the self. However, the language the participants used in the interviews while talking about the child’s experiences reveals that they also have a humane understanding of the child’s possible pain. Pain relief was also one of the initial reasons for starting the beanie design, as the use of this textile equipment would reduce the need for needles.

In the end, the design process included a strong co-creational aspect, as the test iterations at the hospital clearly indicated design needs that had to be implemented rapidly. The technology had to be tested on its own first to validate the quality of the signal, which meant that the design of the more human aspects had to be set aside until these issues were resolved. The following iterations were made in a technology-driven way by testing and making iterations in several stages while the data analysis models were developed further solely in the medical context. However, the fact that the doctor used himself as a device test subject indicates that his motivation for reaching a functional solution exceeds the role he has as a practitioner.

While the technology-interested professor tried the electrodes on himself in the first attempt to test and validate the technology, usability was not measured but rather the functionality of the technology. The use of designs on oneself in a way resembles empathic design methods, such as experience prototyping (Buchanan & Fulton Suri, 2000). The use of “proxies” like these is needed especially in situations where the real end users have difficulty in expressing their own opinion (Martin et. al., 2006), and this is how “design” is often done in practice where practitioners without a design education use the opportunities offered to enhance situations in their practice. Designers and design research play an incremental role in organizing a meaningful progression in which all interest groups’ needs are taken into account and the relationships between stakeholders are mapped out (Bhömer, Tomico, Kleinsmann, Kuusk, Wensveen, 2012). Therefore, the contribution of designers comprises not only the artefact but also the creation of situations in which creative exchange can take place (Bowen et al., 2016, Sanders & Stappers, 2008). In relation to this, it could be useful to manufacture a working prototype of the three garments in adult size so that the design researcher and medical personnel could perform empathic and autoethnographic research on its perceived comfort and quality as well.

ETHICAL ASPECTS
The research has been conducted according to sound ethical principles. No personal data was collected during the research and we avoided featuring faces in the images. The parents of the babies featured have given their consent for using the images.

CONCLUSION
The main contribution of this paper is that smart textiles have a great potential in facilitating durable and reliable measurements in the medical context, but that empathic research processes are paramount in cases where the main user does not have a voice of its own. Here it is important to use the empathic understanding of the user’s closest and most intimate interest groups and caretakers as well as the more strategic actors such as the practicing professors and researchers in this professional sector. Without this knowledge, the developed design is unlikely to be accepted by the main user and thus consequently also by the extended user group.

The “unofficial” design and development work that is conducted due to the needs emerging in the professional context is facilitated by the design researcher’s more holistic understanding, research on multiple users and the possible advantages of empathic research methods as well as the knowledge of the technical, material and senso-aesthetic qualities and implications of the design. Bringing in designers into these processes also facilitate the discussions and sharing of experiences between medical practitioners who otherwise are short of time to engage in developing such understandings.

LIMITATIONS AND FUTURE RESEARCH
This design and research project is still in its early stages and the results from validating the smart textiles are not yet reported here, but rather the preliminary observations made by the design researchers from their point of view. More research on the benefits of empathic research methods in the context of medical devices is required, especially in relation to users who may not be able to express themselves.

ACKNOWLEDGEMENTS:
This research was supported by the Academy of Finland Health from Science (TERVA) under Grant 314572. RIB: Rhythms in Infant Brain: Wearables for Computational Diagnostics and Mobile Monitoring of Treatment. We would like to thank the Finnish Brain Foundation and the Foundation for Pediatric Research for supporting this research and the BABA Center, Pediatric Research Center, Children’s Hospital, and the University of Helsinki who participated in this research.

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