

An arousal communication system for parents and their child with Prader-Willi syndrome

The development of a new system

Melissa Bremmer, Misha Croes
en Paula Sterkenburg

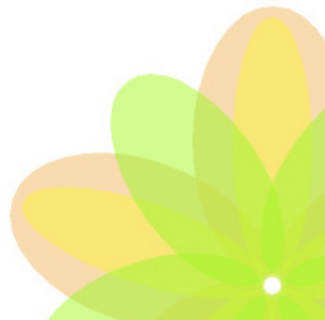




Table of Content

Chapter 1 Scientific background	04
Bonding	04
Bonding and PWS	05
Communication system	06
Chapter 2 Background of the project	08
Pilot studies	08
GSR sensor	10
Chapter 3 Goals	11
General goals	11
Sensor	12
App	12
Chapter 4 Unobtrusive GSR measurements	14
Unobtrusive GSR measurements	14
Intelligent sock	16
Adult sock	18
Young infant sock	20
Newly born infant sock for hospital	20
Chapter 5 GSR communication to parents	23
Prototype 1	24
Prototype 2	25
Prototype 3	26

Chapter 6 Conclusion and future steps	29
Conclusion	29
Chapter 7 References	32
List of references	32



1. Scientific background

Infants diagnosed with Prader-Willi syndrome (PWS) can show severe hypotonia, which might cause the child to express movement, sounds, and crying to a lesser extent. Due to this behavior, parents can expect to experience difficulties in reading and interpreting the child's small interaction signals. In order to support parents in noticing these small signals and support the bonding process with their child, a new communication system is proposed. The communication system exists of a Galvanic Skin Response sensor, integrated in an intelligent sock, that communicates wirelessly to an app running on a tabletPC or smartphone. In turn, this app communicates the amount of arousal experienced by the child to the parents.

Bonding

Rubin first introduced the concept of bonding in 1967, but it became more widely spread through the work of Klaus and Kennell in 1976 (Kinsey, Hupcey, 2013). Although literature does not provide one fixed definition of parent-infant bonding, it is usually described as the tie from the parent to the infant (Kinsey, Hupcey, 2013). According to Klaus and Kennell, a strong bond from a mother to her infant has a positive effect on her parenting behavior and on the cognitive and neurobehavioral development of the infant (Kinsey, Hupcey, 2013). A positive attitude, realistic parenting expectations, breast feeding, holding the infant, and cues from the infant, like crying, smiling, or looking at the parent, positively stimulate the parent-infant bonding process (Kinsey, Hupcey, 2013).

The tie from the infant to the parent is most often described as attachment (Kinsey, Hupcey, 2013). First introduced by Bowlby in 1958, attachment is

formulated as a strong emotional tie between an infant and his parents that results from their shared interaction (Bowlby, 1958). Young children seek comfort and safety from a caregiver in times of (dis)stress (Howe, 2006; Rikhye et al., 2007), which is according to Bowlby a biological survival mechanism in infants (Swain et al., 2007).

Emotionally available caregivers who are responsive ensure a secure attachment, while a caregiver who is unpredictable and neglectful creates an insecure attachment (Swain et al., 2007). Sensitive caregivers teach the child to cope with stress and to understand people's mind on emotional, behavioral and intentional level (Howe, 2006). On the other hand, children who are insecurely attached to their caregiver are at risk of developing behavioral problems (Howe, 2006).

The tie between parent and child depends on the sensitivity both feel for each other (Howe, 2006). The parent's sensitivity depends on their ability to recognize, understand and interpret the child's behavior (Howe, 2006). Not being able to understand their child's needs and an experienced lack of interest in interaction from the child, tends to increase the stress felt by parents (Howe, 2006). The child becomes distressed when his needs are unrecognized or misunderstood (Howe, 2006). Due to stress, children tend to be less responsive to external stimuli (Janssen, Schuengel, Stolk, 2002), and stressed parents become less sensitive to their child, which endangers their process of bonding (Howe, 2006).

Bonding and PWS

In the first six months after birth, infants with PWS are likely to have severe hypotonia (Priano et al., 2009). Due to being hypotonic, the infants hardly cry or do not cry at all (Paterson and Donaldson, 2003) and express movement to a lesser extent (Mann and Butler, 2009). Furthermore, children with PWS tend to be excessively sleepy (Haig and Wharton, 2003), show decreased spontaneous arousal (Mann and Butler, 2009), and often have a mild intellectual disability (Dykens and Roof, 2008). This makes it difficult for parents to interpret their child's signals. Furthermore, young children with PWS seem to ask less for care from their parents than their peers, due to their decreased ability to cry and produce sounds (Haig, 2008). This behavior in infants with PWS could result in parents being less

invited to interact with their child (Cassidy, 1988). The child's behavioral characteristics and the difficulties parents experience to understand their child's needs might cause a risk for the bonding process between parents and their child with PWS.

Communication system

To support parents in noticing, understanding, and interpreting their child's behavioral signals, the VU University Amsterdam (VUA) and the Eindhoven University of Technology (TU/e) are developing a new communication system, based on the idea of biofeedback. Biofeedback is a self-regulating skill where individuals learn to control their biological functions based on feedback (Rovers, Feijs, van Boxtel, Cluitmans, 2009). These biological functions can be heart rhythms, heart rate variability, activity of the sweat glands, muscle tension, and body temperature (Rovers et al. 2009). These feedback signals are activated by the sympathetic nervous system. By applying specific sensors to the human body, these reactions in the user's nervous system can be registered and communicated back to the user.

Nowadays, commercial biofeedback systems are available as an aid product for relaxing and reducing stress. Well-known products are the 'stress eraser' (www.stresseraser.nu) and the 'emWave' (www.heartmathbenelux.com). These products measure the heart rate variability and communicate this to the user, who can decrease his stress levels and the risks of health issues caused by stress with help of breathing and relaxation exercises (under the guidance of an expert).

The here presented communication system has a distinct difference from these biofeedback systems. Where a biofeedback system provides feedback to the user, our system takes these signals and communicates them to others (parents/caregivers). For instance, it is possible that the child reacts to his parent, but is not that expressive in his communication. The child's nervous system is likely to be activated when the child reacts to his parent. Therefore measuring biological functions is not only suitable for self-managing stress, but potentially also for noticing a reaction in somebody else. A very well known use of such systems is the "lie detector" used in law enforcement. Instead of communicating the biological signals back to the participant,

they are communicated to an expert who is trained in reading these specific signals.

Although innovative, this principle of communicating signals from the sympathetic nervous system to caregivers is not new. In 2009 Kobayashi, Nunokawa and Ooe developed a system that communicates the reaction of people with severe motor and intellectual disabilities to their caregivers with the use of heart rate measurements (Kobayashi, Nunokawa and Ooe, 2009). Although similar in approach, our communication system differs in various ways. First of all, we use a different sensor to measure the child's arousal, namely a Galvanic Skin Response (GSR) sensor. We believe that the GSR sensor is similarly adequate to detect a person's arousal, but is also robust enough to be integrated in a garment for measuring with more wearing comfort. Even more importantly, our communication system is completely focused on the home environment, in contrast to of a lab environment. This means that the systems should be more robust, easy to use, and most of all have a 'friendly' appearance.



2. Background of the project

Pilot studies

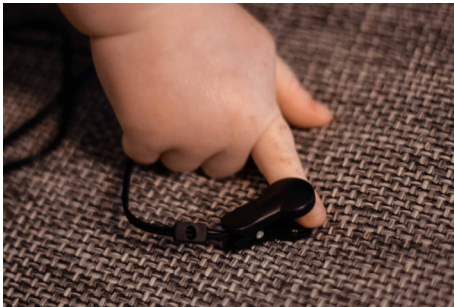
Preceding the project, a set of two pilot projects had taken place. Two students from the TU/e, in collaboration with the VUA, explored two different sensor systems and developed first prototypes of a new communication system. The goal of these prototypes was to retrieve parents' opinions about their systems and to retrieve more insight into various arousal measuring sensors.

First, the sensors were explored with a small group of adults, followed by a pilot test with three young children (aged 9 to 30 months old) with PWS and their mothers. The first project, from Jacqueline Nanne, used a heart rate sensor (figure 2.01a). Although the sensor proved to be working well with adults, it unfortunately did not function well with the children. Due to the large amount of movement by the children, the sensor signal was influenced a lot, resulting in invalid measurements. The second project, performed by Kyra Frederiks, used a Galvanic Skin Response sensor (figure 2.01b). This sensor worked well during both the adult and child tests. During the test with the children, the sensor signal corresponded with the expression of the children. Where with one child, the sensor was able to show small reactions from the child on the parent's actions, while the child had a blank expression.

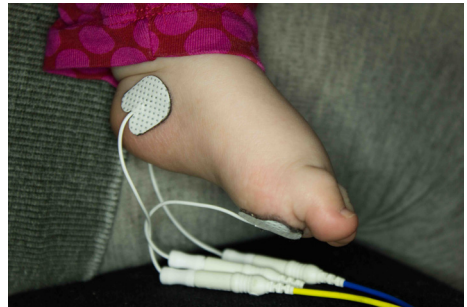
Besides testing the sensors, the students each made a prototype that communicated the sensor's signal in a comprehensible and pleasant manner to the parents. Jacqueline Nanne created a sound based prototype that could alert parents when their child's arousal was high. Small bells

with a crocheted cover, jingled when the sensor noticed a reaction from the child (figure 2.02a). Parents were enthusiastic about this prototype, since they would be able to perceive the feedback even when they would be in a different room than their child.

Kyra Frederiks created a movement based prototype to support parents during the interaction with their child. A small wooden butterfly moved its wings depending on the amount of arousal measured (figure 2.02b). Also this prototype received positive comments from parents, since it allowed them to see how strong the arousal was. All parents indicated they would like to combine the features of both prototypes into one portable product



a.



b.

Fig. 2.01 a. Heart rate sensor
b. Galvanic skin response sensor



a.



b.

Fig. 2.02 a. Sound prototype: bells
b. Movement prototype: butterfly

that would support them during the interaction with their child as well as alert them when the child is in a different room and in need of their attention.

GSR sensor

With the knowledge gained from the first prototypes and tests described in the previous section, in combination with further literature studies, we feel confident that a GSR sensor can be applied to measure the child's arousal level. GSR reflects the activity of the eccrine sweat glands, which are directed by the sympathetic nervous system (Das, Pal, 2011). When the child reacts to his environment, his eccrine sweat glands become more active and the moisture on the skin increases (Vetrugno et al., 2003). More moisture on the skin increases the skin's conductance and decreases the skin's resistance. This increase of conductance can be measured by a GSR sensor. In the GSR signal two domains can be extrapolated. The Tonic domain of the signal tells something about the general arousal state of the person, where the Phasic domain indicates the effect of direct stimuli acting on the person (sounds, light, etc.) (Benedek and Kaernbach 2010).

The GSR sensor used in the second pilot test was a clinically used GSR device called a "pain monitor" (Storm, 2012), borrowed from the Maxima Medical Centre (MMC) in Veldhoven, the Netherlands. In the MMC, it is used in combination with special observational techniques to determine a child's pain response. This particular sensor uses three sticky electrodes, one on the sole of the foot and one on each side of the ankle (see figure 2.01b). The sticky electrodes are connected with cables to the pain monitor. The pain monitor itself is connected with one wire to a laptop PC and has a second cable for power supply. This large amount of cables limited the freedom of movement of both parent and child during the pilot study. The parents who held their child, had to be careful not to disconnect a cable from the electrode, while the older children liked to walk around, but could not do so, due to the length of the cables.



3. Goals

General goals

The main goal for this project is to create a communication system in order to perform research on supporting parents in noticing, recognizing, and interpreting the small interaction signals from their child with PWS. The system should support parents in perceiving their child's reaction and their child's interest in interaction with them. From earlier pilot studies the following wishes for the system were expressed:

- 1) The system should be able to measure the child's arousal in an unobtrusive and comfortable manner.
- 2) The system should be completely wireless in order to make sure the child's freedom of movement and the child-parent interaction isn't obstructed.
- 3) The system should be able to communicate the child's measured arousal in a comprehensive way to the parents and be available to them at any place inside the house.

Initiated by the pilot studies, we further investigated the theoretical background and evidence of the GSR sensor and its capabilities. Over the years, the use of GSR has proven itself to be robust, reliable, and safe (Arunodaya & Taly, 1995). Furthermore, GSR is widely applied in clinical and lab use in order to not only determine a person's arousal response, but also to diagnose possible malfunctions in the sympathetic nervous system (Vetrugno et al., 2003). To us, this proved that the technology behind GSR measurement is mature enough to make the transition from a clinical/lab environment to the home environment.

When a child is born, during the first period of life parents usually express

having difficulty in ‘reading’ their child’s behavioral signals. Not knowing whether a cry means “I am hungry” or “I need comforting” is something parents will learn along the way. For parents of a child diagnosed with PWS this learning transition is made more difficult. What we want to achieve is to develop a system that provides parents of a child with PWS with a similar learning experience as if they would have a healthy child. This means that we don’t want to provide them with the exact emotional state of their child, but with a reaction from their child from which they have to learn what the reaction might mean, just like with the crying behavior new parents experience in a healthy child. We believe GSR is able to achieve this. We therefore aim at developing a wireless system that can measure the child’s arousal level, through a GSR sensor, and communicate these levels of arousal comprehensibly to the parents. However, before we can test our hypothesis in the field, a fully functioning prototype is required.

Sensor

The GSR sensor used during the preceding pilot study had a wired connection and therefore limited the movements of both parents and children. To allow parent and child to behave naturally we searched for a wireless GSR sensor. After careful consideration the GSR sensor of Shimmer (<http://www.shimmersensing.com>) was selected for the new prototype system. The Shimmer module is able to communicate wireless (via Bluetooth) with PCs, smartphones, and tablet PCs. This means we should be able to provide parents with a means to observe their child’s arousal system on their mobile device anywhere within a 15 meter radius of their child. A range that is more than adequate for a home environment. Although being wireless, the current Shimmer system still uses sticky electrodes and push button connections on the sole of the foot to measure GSR. However, we believed to be able to develop a fully unobtrusive and comfortable measuring system by incorporating the sensor in a garment to be worn by young children with PWS.

App

As explained before, the Shimmer GSR module is able to communicate its measurement data to any mobile device over Bluetooth. The problem however persists that ‘raw GSR data’ is incomprehensible for non-trained

observers. We therefore set the goal to develop an app that would translate the raw data measured by the Shimmer module into a comprehensible and pleasant visualization so parents could understand their child's reactions.



4. Unobtrusive GSR measurement

This chapter and the following chapters will explain the design process of the development of the new prototype to achieve an unobtrusive and wireless arousal communication system. As discussed in the previous chapter, the development exists of two parts: the redesign of the GSR sensor module for unobtrusive GSR measurement and the development of an app that is pleasant and comprehensible for parents. This chapter will describe the development of an ‘intelligent sock’ that is able to unobtrusively measure GSR in young children with PWS. The next chapter will describe the development of an accompanying app, which translates the GSR signal into a comprehensible form.

Unobtrusive GSR measurement

The new communication system will make use of GSR sensor for detecting a person’s arousal level. Being widely used in clinical and non-clinical research (Vetrugno et al., 2003). We believe the main reason why there are still no GSR instruments used in the home environment is because most researchers want to detect a person’s valence of emotion (positive vs. negative emotion) with GSR (see figure 4.01). However, GSR is only capable of measuring the strength of arousal levels. It can’t judge whether the arousal is positive or negative (valence). If one would like to know the valence of the arousal, GSR alone isn’t enough. Heartbeat, breathing rate and such should be added, hence making a system incredibly complex.

Although we do not desire to attribute the valance to our arousal measurement we still faced the problem of finding a way to unobtrusively measure a child’s GSR. We want parents and child to look, feel, and interact



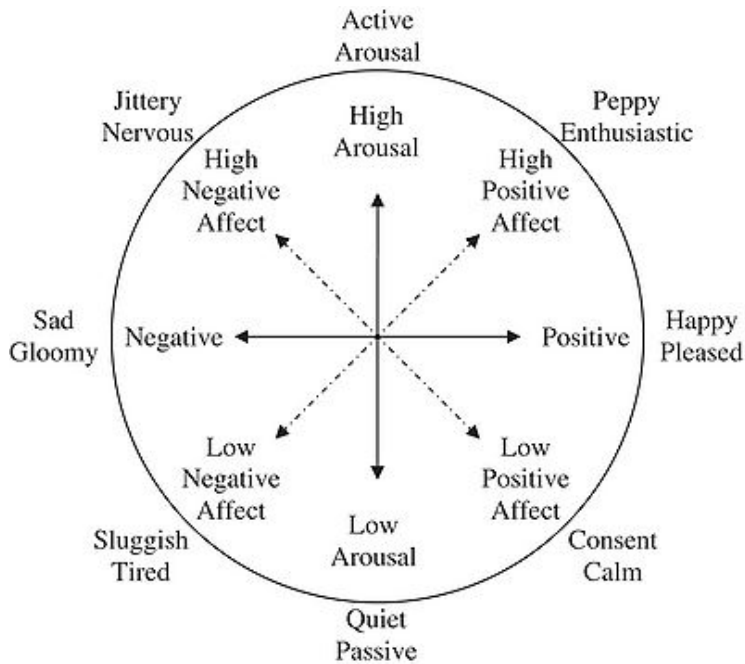


Fig. 4.01 Valence versus arousal

(http://white.stanford.edu/teach/index.php/The_Neuroscience_of_Happiness)

with each other as naturally as possible. The system shouldn't obstruct parents in their interaction with their child, and visa versa. GSR is mainly measured by means of (medical) sticky electrodes (see figure 4.02). Although perfect for obtaining data, these electrodes ensure an undesirable sensation in the child, and an unpleasant look for parents. The electrodes also make a system feel 'medical' and 'clinical', a feeling we want to avoid in the home environment.

When looking at other research fields, like high performance sports, we see a trend emerging of sensors being integrated into wearables or clothing. One can imagine that in high performance sports an obtrusive measuring device would be undesirable and influence the sportman's performance. The integration of sensors into textiles ensures that the wearer is unaware and unobstructed by the measuring devices, which ensures a more natural and comfortable manner of collecting data. For this project, we set the goal

to implement similar textile electrodes into a wearable for young children with PWS.

In order to measure GSR, one needs at least two electrodes attached to a part of a person's skin containing a (relatively) large amount of eccrine sweat glands. Although various desirable locations on a person's body exist (van Dooren et al., 2012), the most commonly used sections of the body to measure GSR are the palms of the hands and the sole of the foot (van Dooren et al., 2012). Young children, who are still in their early developmental stage (age 0-18 months), are mainly exploring the world with their hands, and possibly only crawl around the floor. This means that the hands are mostly in use when the child is awake and exploring/playing. The soles of the feet on the other hand are mainly unused. We therefore decided to develop a sock that would have unobtrusive textile sensors integrated in the bottom side of the sock to measure the child's GSR.

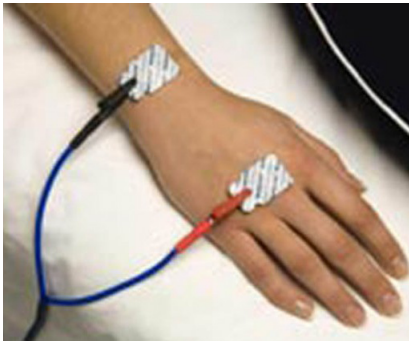


Fig. 4.02 Sticky electrodes



Fig. 4.03 Sensors embedded in sportswear

Intelligent Sock

As explained in chapter 2, generally used research GSR systems are connected to a computer by means of cables. We believe these systems are unsuitable for our home environment focused system. The child should be able to move around when desired, and parents should not be obstructed in their interaction with their child. Furthermore, we believe

these measurement devices generally look ‘bulky’ and ‘unfriendly’. Luckily, current technological innovations allow GSR measurements to be done with much smaller and wireless devices.

At this moment, the Shimmer module also uses sticky electrodes. The GSR module is connected to these electrodes by means of push buttons, which is common for clinical and lab testing. Since we want to develop a comfortable, unobtrusive, and pleasant looking system, we took on the challenge to remove these sticky electrodes and replace them with textile electrodes integrated into a sock. This, however, meant that various challenges had to be overcome.

First of all, a sock is made out of a highly stretchable material, because feet are never exactly the same size. Second, the soles of our feet are one of the more sensitive parts of our body, and any unpleasantness will quickly be felt by the user. This means that especially comfort for the wearer is of high priority. Finally we had to ensure that the Shimmer module could be attached to the sock in a comfortable way as well. As explained above, the current practice is to use push buttons to connect the GSR module to the sticky electrodes. However, placing push buttons under a child’s foot, will cause great discomfort in case the child decides to stand or parents decide to train walking with the child. Henceforth, this wasn’t an option.

Trying to integrate sensors into wearables or garments, means going into the field of wearable & textile electronics. A field mainly applied in high performance sports and research for future medical applications. Being part of a research organization ourselves, we took on the challenge of making our own contribution to bridging the gap between the lab and the home environment. By implementing specialized conductive textiles and conductive yarns into the sock, we believed it would be possible to measure GSR in an unobtrusive and comfortable way. Being inspired by the “Smart Jacket” (Bouwstra et al., 2009), we decided to use a silver coated textile named “Shieldex” to function as a replacement of the sticky electrodes. Due to the silver coated yarns with which the textile is woven, the material feels and acts like a fabric, but conducts electricity at the same time. This would mean, in theory, that applying two patches of this material onto the sole of a person’s foot, would mean that it is theoretically possible to measure GSR.



Fig. 4.04 Smart jacket

First prototype series - adult sock

Before diving into the matter unprepared, we decided it would be necessary to first develop a prototype and see whether or not our theory of integrating a conductive textile into a sock would actually work. Therefore an initial prototype of an adult sock was made. In this prototype the GSR module was still connected to the sole of the foot by means of push buttons for practical purposes. The use of the sock quickly confirmed our suspicions of the push buttons being highly uncomfortable on the sole of the foot. It did show us however that the use of textile electrodes is promising. A clear signal was observable on the PC monitor. Unfortunately the stretchable qualities of the electrodes ensured a large portion of noise was observed in the signal whenever the foot was moved. This is because the stretching of the conductive fabric causes the conductive properties of the material to change. In order to solve the problem, for now, we decided to add two elastic bands to provide more pressure on the electrodes and therefore enhance the signal quality.

A second prototype was built to see if we could replace the push buttons from the sole of the foot to the ankle. In order to do so we used steel coated conductive yarn to connect the textile electrode on the sole of the foot to pushbuttons on the ankle. By using a 'zigzag' stitching pattern we were able to keep the stretching qualities of the sock alive without losing connectivity. Furthermore, it was highly important that the conductive yarn would not



Fig. 4.05 Adult sock - first prototype

go through the fabric of the sock and touch the skin, because this would interfere with the measured GSR.

While wearing the new sock, it became immediately apparent that a large step with regards to comfort was made. It was now nearly impossible to feel the textile electrodes relative to the fabric of the sock. However, the elastic bands were still necessary for providing a strong signal. By attaching the GSR module to the ankle, we managed to turn the sock into a fully wearable GSR measuring product. Although improvements could still be made with regard to the signal quality and aesthetical appearance, a big step towards realization was made.

A final model of this sock was made to be able to test the function of a GSR sock in the lab on adult subjects in the future. The goal of these lab tests is to ensure we can more easily obtain important data in order to adjust the system for children with PWS.



Fig. 4.06 Adult sock - final prototype

Second prototype series - young infants

Due to the lessons learned from the development of the adult sock, we felt confident to develop a children's sock that would be able to measure GSR in a comfortable manner. Two non-stretching electrodes were integrated into one sock for infants aged 6 to 12 months. Although similar in approach, the main challenge of this prototype series was the miniaturization of the integrated electrodes. Eventually, we managed to seamlessly integrate two electrodes into two socks of different pairs of children's socks. An expected advantage was the reduction of noise, due to the reduction of the length of conductive yarn from the bottom of the sock to the ankle. The final hurdle to take was to ensure the sock would stay in place and preferably add slight pressure to the sensors inside the socks. Fortunately, a simple solution was found in so called 'Sock Ons', which are used to ensure young children cannot take off their own socks. The 'Sock Ons' proved to do just the job of providing slight pressure on the sensors without adding discomfort.

Third prototype series - newly born infants in the hospital

The goal of this project was to develop a system that communicates the arousal from a young infant with PWS to their parents. Although our main focus was initially on the home environment, another environment was brought to our attention during the project. When a child is born and

diagnosed with PWS it is possible for the child to spent the first weeks of his life in the hospital. In the theory of bonding, it is stated that bonding between parents and infants starts prior and directly after child birth, and is preferably initiated as soon as possible (Kennell & McGrath, 2005). In our vision we want to support the bonding process between parents and their child with PWS as soon as possible, we therefore upgraded our goal to also support parents in the hospital with the ability to use our system and start to 'get to know' their child as soon as possible.

This meant we faced a new challenge, being the Shimmer module that we planned on using in our new communication system uses wireless technology. This ensures that it is not possible to use the Shimmer module for clinical hospital use, even though our purposes are not clinical measurements. The solution however was found in our earlier trials, where students used the hospital's GSR sensor system to determine the arousal levels in children with PWS. During one of our pilot studies prior to the project, students showed that hospitals are used to using GSR in clinical practice. Although it is used to determine a child's pain perception, it does mean we can use this same GSR sensor to detect the child's arousal as well. With this issue solved, we took on the challenge of further miniaturizing the existing sock design to fit newly born infants and adding another textile electrode, since the clinical GSR sensor uses three electrodes instead of two.

Inspired by the 'Sock Ons' from the second prototype series described above, we managed to developed a tiny full term infant's sized sock with integrated textile electrodes and connectors for the clinical GSR sensor (figure 4.07 b). We believe this is a huge achievement and something never attempted before. In contradiction to the young infant socks developed in the second series, we decided not to develop an accompanying 'dummy' sock (containing no sensors), because in our experience the other foot is commonly used to attach, for instance, a SPO2 monitoring sensor and such. We did however take care that our sock still looks relatively non-medical, friendly and is easy to handle for nurses and parents. By doing so we believe to have implemented an idea that was theoretical at first into not only the home environment, but also into an even more difficult field of clinical validity.



Fig. 4.07 Children's sock (left) and Newborn infant's sock (right)



Fig. 4.08 Complete system(left) and integrated textile electrode (right)



5. GSR communication to parents

In parallel of developing an arousal measuring sock for young infants with PWS, we also set the goal to develop a way of communicating the measured arousal to the parents/caregivers in a comprehensible way. During an earlier pilot study with young children with PWS and their parents, some early criteria for such a system were gathered. First of all, parents indicated they would like the means of communication to be genuine and ‘non-medical’. Since PWS already involves enough times in a medical environment, parents didn’t want to emphasize this even more in their homes. Furthermore, parents indicated they would like to have a system that would support them in their interaction with their child. Whenever they were playing, talking, or otherwise interacting with their child, they would like to have more insight into what effect this interaction would have on their child.

Although the requests from the parents were clear, we still had quite some technical difficulties to overcome before we could start implementing these wishes into the new communication system. First of all, a choice had to be made about how to ensure a full wireless and portable system for parents to use. As explained before, the smallest connection possible for GSR measuring devices used to be a laptop computer that records and displays GSR data to researchers. However, due to recent rapid innovations in operating power in the field of tablet PC’s and smartphones, it was now technologically possible to implement these functions in a fully mobile device.

The choice was made to develop an Android based application that would function on both smartphones and tablet PCs. By doing so we ensured

that parents would have the complete freedom of movement within the operating range of the Shimmer module (about 15 meters). Although the Shimmer company had developed an app for Android before, this app only had very minimal functionality, no user friendly interface, and was clearly meant for research practices. We therefore decided to adjust the Shimmer app to present GSR data to parents in a pleasant way and with the use of an easy user interface.

Prototype 1

For the first prototype a tablet PC was acquired from the university in order to test whether an initial app could be made. This app needed to connect to the Shimmer module, acquire GSR data, and somehow present this data to the parents without using a graph. By adapting the app developed by Shimmer, we managed to connect a dedicated Shimmer module to a 10 inch Samsung tablet. By rewriting parts of the code, we were able to remove the graph that the app would originally show and replace it with a new graphic, in this case a green circle. Inspired by our colleague's work (Bouwstra, 2013 (Thesis Sibrecht)), the circle would grow and shrink relative to the amplitude of the signal received from the Shimmer module.

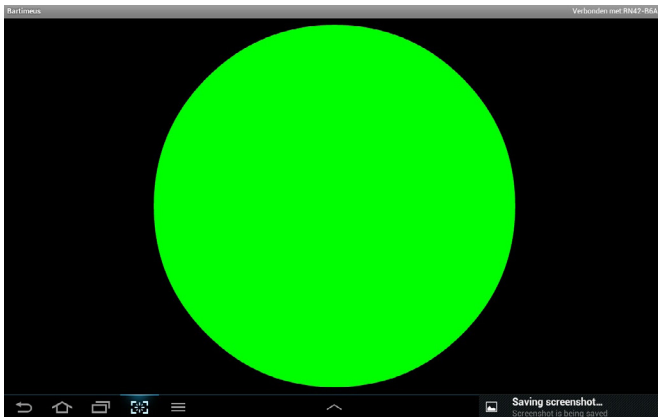


Fig. 5.01 First app design

Although a good first step, it soon became clear the app design was more complicated than expected. The circle would first only show very minimal changes in its size. After some alterations in the code we managed to make

the circle change size more adequate in proportion to the screen's size. This showed, however, that the amount of fluctuations in the signal was so big, that the circle would depict a very chaotic feeling. This was due to the original app from Shimmer simply presenting a graph with the raw data gathered from the Shimmer GSR Module. As explained before, the GSR signal consists of two main elements, a Tonic signal and Phasic signal. This meant that before we could go any further we needed to develop a dedicated algorithm that would filter out both signal elements. In parallel to this, we decided to hire a student assistant to design a clever presentation of the two signals simultaneously on one screen.

Prototype 2

App design

Due to her experience in programming tablet applications, we hired bachelor graduate student Lisa Vork to design the representation of the GSR signal on the screen. Over the course of six weeks she completely re-designed the user interface of the app and added various other features as well. Her interpretation of the app was now able to connect immediately to a dedicated Shimmer module. This made sure no extra knowledge or settings are required by any future users. Her new redesign of the interface was much more pleasant, had a proper 'home feeling', and was accompanied by a clear and clever depiction of the data. She used the circle as a starting point and developed a flower to represent the data instead. The size of the flower would indicate the child's Tonic arousal level (Figure 5.02a). Being a slowly varying signal, this would ensure that the flower would peacefully change size. Accompanying this feature, she decided that the amount of petals on the flower would represent the amount of peaks or Phasic element of the GSR signal (Figure 5.02b). By implementing a continuous transition between the petals she ensured that, again, a peaceful and friendly transition would occur in the changes in the Phasic signal.

Algorithm

In parallel to the development of the app, we developed a dedicated algorithm to filter out the two elements (Tonic and Phasic) of the GSR data. Although done before by other researchers, no evidence could be found of others trying to implement such algorithms into an app on a tablet PC or

smartphone. This meant that we had to build the algorithm from scratch. Eventually, we managed to develop a filtering algorithm that would filter out both elements of the GSR data and feed these separated elements into the ‘flower’ design. This resulted in a fully functioning app that could be installed on any Android based smartphone or tablet and communicate with a dedicated Shimmer GSR Module.

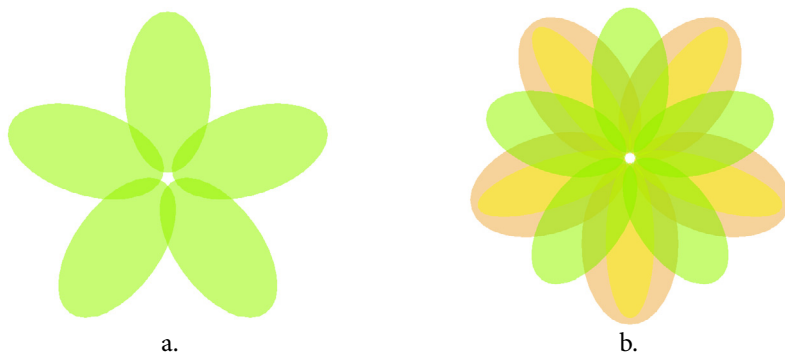


Fig. 5.02 Final app design
a. Flower representing base signal
b. Flower petals representing reaction signal

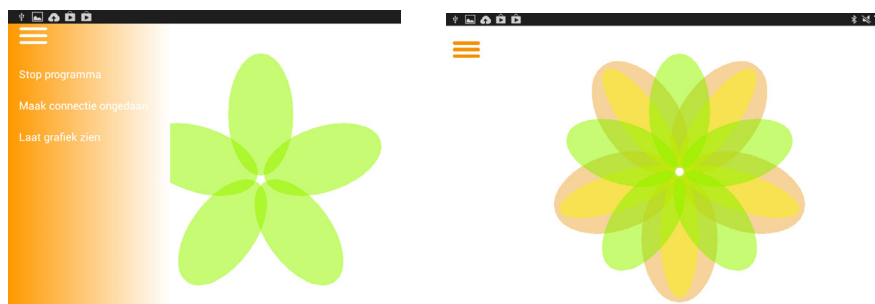


Fig. 5.03 Final app design

Prototype 3 - Integrating SmartWatch

The original goal of the project was to develop a fully wireless system that would enable parents of children with PWS to be informed about their

child's arousal state. After the second round of app prototyping, we fulfilled this goal by enabling the connection of an unobtrusive GSR sensor to a mobile device running a dedicated app. To our knowledge this has never been done before and is therefore already a great achievement in itself. However, besides the development of new and more powerful mobile devices like smartphones and tablet PC's, new innovations in the field of smartwatches is also rising quickly. We therefore foresee that in the future the integration of smartwatches will be complete and most people will use and wear something like a smartwatch.

We believe it is necessary to be ahead of these innovations and see if they can enhance our products today. In case of our system, the advantage of a fully wearable system for parents is greatly desired. One of the wishes expressed by parents was to be able to be warned by our system whenever a child would desire attention. Although a smartphone or tablet could do this already, it isn't always practical. Especially whenever a parent is performing a task that requires both hands (e.g. doing the dishes). In these cases, it would be desirable if the parent would be informed by a smartwatch about the desire of the child to interact or receive attention.

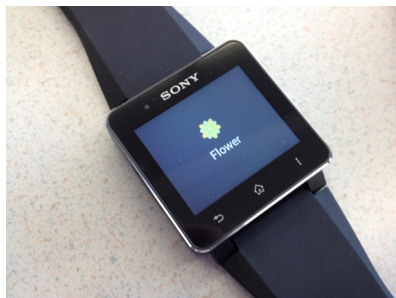


Fig. 5.04 Integration of the Flower app on the SmartWatch

During the third iteration of our prototyping phase we decided to take the leap and implement the use of a smartwatch into the system to inform parents. Although current smartwatches aren't technologically advanced enough to run their own app, it is possible to send a message from the smartphone or tablet to the watch. In the end we managed to implement

the feature that whenever the signal would reach a certain arousal level, a message would be sent to the smartwatch, informing the parent about the child's desire to interact. We have to indicate however, that further research is needed to fully implement this feature into our future system. Since it is currently not known when exactly a child desires attention based on his arousal level, this function isn't fully implemented yet. However, when future research informs us about this tipping point, the integration of this feature is ready.



6. Conclusions and future steps

At the start of the project we set the goal to develop a system that would ensure the unobtrusive measurement of GSR in young children with PWS and communicate this in a comprehensible and wireless manner to their parents. The purpose of this project was to develop this system to be able to perform research in the field. This research would be needed to not only further fine-tune the system, but also to adapt it to the further needs and wishes of parents and young children with PWS.

Although the project only lasted for three months, we managed to fully realize our ambitions. Through the use of an iterative design process we managed to develop both an unobtrusive GSR measuring sock for young children with PWS and an accompanying app for parents. Instead of using sticky electrodes, textile electrodes are incorporated into our socks. This integration ensures that the wearing comfort of the sock isn't compromised, while still allowing the system to sense the child's GSR signals. In the end three sizes of socks were developed. First, an adult sock that would allow us to perform lab testing on adults in order to acquire adequate data without the use of children as participants. Second, we developed a dedicated sock for children in the age group of 6-24 months. These socks are integrated with smaller textile electrodes and are ready for testing in the field with young children with PWS and their parents. The third set of prototypes is for the smallest, newly born, children. After being informed that children born with PWS generally spent the first time after birth in the hospital, we decided to accommodate to this situation as well. These socks are specifically developed to be attached to clinically tested GSR measuring systems.

The developed app runs on any Android based mobile device (smartphone

and tablet pc) and allows parents to observe the arousal changes in their child in a comprehensible and friendly way. Through a friendly looking flower, the complex GSR data is translated to a shape that is recognizable for parents and informs them 'in a glance' about their child's arousal state. Furthermore, the app itself also has a friendly presence and an easy user interface, in order to accommodate the desired user experience. From these achievements we believe to have developed a system that is ready to be implemented into the field as it is. It is able to measure and communicate arousal to parents/caregivers in a unobtrusive and comfortable manner.

This is however not where the project stops. The goal of the project was to develop a system that would be used in future research, and that is exactly what it will do. During an earlier pilot test it became apparent that parents had various wishes and desires to exist in our system:

- 1) First, parents want the system to support them in the interaction with their child. Whenever they were playing, talking, or otherwise interacting with their child, they would like to have more insight into what effect this interaction would have on their child. Although we believe to have accommodated this goal, it is necessary to apply our system in the field and obtain data to further adjust the system to the target group.

- 2) Second, parents would like the system to alert them whenever the child would like to have attention from them in case they are in the same room, but not directly interacting with their child. Due to the full wireless capabilities of our new communication system we believe to have largely fulfilled this goal already. However, since we are the first ones to implement such a system in the home environment further data needs to be acquired to determine 'attention' moments in the young child with PWS. Through tests in the lab with adults and in the field with parents and their young children with PWS we want to further test the system in order to implement this feature in the system.

- 3) Finally, parents had the wish that the system could inform them when their child would wake up at night. Although similar to the second wish, this point would mean that the system should also be able to distinguish between sleep and awake states in the child. Scientific literature suggests it should be possible to measure the transition between sleep and being awake with GSR [...], however to our knowledge nobody has done this before with this target group, which means further testing in the lab is

needed before we can implement this feature into our system. However, the system is completely ready to implement this feature. By means of a smartwatch, parents can wear the system at all times and be informed about their child's sleeping state in a comfortable way.



7. References

1. G. Arunodaya, and A. Taly. "Sympathetic skin response : a decade later. *Journal of the Neurological Sciences*". Retrieved from <http://www.sciencedirect.com/science/article/pii/0022510X9400265P>, 1995
2. S. Bouwstra, W. Chen and L. Feijs. "Smart jacket design for neonatal monitoring with wearable sensors." 2009 *Body Sensor*. doi:10.1109/P3644.39, 2009
3. J. Bowlby. "The nature of the child's tie to his mother." *The International Journal of Psychoanalysis*, 1995
4. Bretherton, "The origins of attachment theory: John Bowlby and Mary Ainsworth." *Developmental Psychology*, vol. 28, no. 5, pp. 759-775, 1992
5. S.B. Cassidy. "Management of the problems of infancy: hypotonia, developmental delay, and feeding problems." In: M.L. Caldwell and R.L. Taylor (eds), *Prader-Willi Syndrome. Selected Research and Management Issues*, pp. 43-51. Springer Verslag, New York, 1988
6. S. Dal, S. Pal, "The design of a low-cost galvanic skin response meter." *Indian Streams Research Journal*, Vol 1, Issue 6, 2011.
7. E.M. Dykens, and E. Roof, "Behavior in Prader-Willi syndrome: relationship to genetic subtypes and age", *Journal of Child Psychology and Psychiatry*, vol. 49, no. 9, pp. 1001-1008, 2008
8. D. Haig. "Conflicting messages: genomic imprinting and internal communication". *Sociobiology of Communication: an interdisciplinary perspective*, pp. 209-223, 2008
9. D. Haig and R. Wharton, "Prader-Willi Syndrome and the Evolution of Human Childhood", *American Journal of Human Biology*, vol. 15,

- pp. 320–329, 2003.
10. D. Howe, “Disabled children, parent-child interaction and attachment.” *Child and Family Social Work*, vol. 11, pp. 95 – 106, 2006.
 11. C.G.C. Janssen, C. Schuengel and J. Stolk, “Understanding challenging behaviour in people with severe and profound intellectual disability: a stress attachment model”, *Journal of Intellectual Disability Research*, vol. 46, pp. 445-453, 2002.
 12. J. Kennell and S. McGrath. “Starting the process of mother-infant bonding”. *Acta Paediatrica* (Oslo, Norway : 1992), 94(6), 775–7. doi:10.1080/08035250510035634, 2005
 1. C.B. Kinsey and J.E. Hupcey, “State of the science of maternal–infant bonding: A principle-based concept analysis”. *Midwifery*, vol. 29, pp. 1314-1320, 2013
 2. I. Koboyashi, H. Nunokawa, H. Ooe, “ i-HR System: Analysis and Application of Heart Rate Responses for Interaction between Individuals with Severe Motor and Intellectual Disabilities and Others.” *Conference Proceedings of HCI International 2009*.
 3. C.L. Lim, C. Rennie, R.J. Barry, H. Bahramali, I. Lazzaro, B. ManorE. Gordon. “Decomposing skin conductance into tonic and phasic components.” *International Journal of Psychophysiology : Official Journal of the International Organization of Psychophysiology*, 25(2), 97–109. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9101335>, 1997
 4. N.P. Mann and G.E. Butler, “Prader-Willi-syndrome: clinical features and managment”, *Pediatrics and Child Health*, vol. 19, pp. 473-478, 2009
 5. W.F. Paterson and M.D.C. Donaldson, “Growth hormone therapy in the Prader-Willi syndrome”, *Archives of Disease in Childhood*, pp. 283–285, 2003.
 6. L. Priano, G. Miscio, G. Grugnio, E. Milano, S. Baudo, L. Sellitti, R. Picconni and A. Mauro, “On the origin of sensory impairment and altered pain perception in Prader-Willi syndrome: A neurophysiological study”, *European Journal of Pain*, vol. 13, pp. 829-835, 2009
 7. K. Rikhye, A.R. Tyrka, M.M. Kelly, G.G. Gagne, A.F. Mello, M.F. Mello, L.H. Price, L.L. Carpenter, “Interplay between childhood

- maltreatment, parental bonding, and gender effects: Impact on quality of life.” *Child Abuse & Neglect*, vol. 32, pp. 19–34, 2008
8. H. Storm, “Pain Assessment in Neonates”. In W. Chen, S. Bambang Oetomo, & L. Feijs (Eds.), *Neonatal Monitoring Technologies: Design for Integrated Solutions*. IGI Global, 2012. Chapter 13, pp. 278-302.
 9. J.E. Swain, J.P. Lorberbaum, S. Kose and L. Strathearn, “Brain basis of early parent–infant interactions: psychology, physiology, and in vivo functional neuroimaging studies”, *Journal of Child Psychology and Psychiatry*, vol. 48, pp. 262–287, 2007.
 10. M. Van Dooren, J.J.G. de Vries, and J.H Janssen. “Emotional sweating across the body: comparing 16 different skin conductance measurement locations.” *Physiology & Behavior*, 106(2), 298–304, 2012, doi:10.1016/j.physbeh.2012.01.020
 11. R. Vetrugno, R. Liguori, P. Cortelli and P. Montagna. “Sympathetic skin response: basic mechanisms and clinical applications.” *Clinical Autonomic Research : Official Journal of the Clinical Autonomic Research Society*, 13(4), 256–70, 2003. doi:10.1007/s10286-003-0107-5