

Exploring the Value of Parent-Track Baby Data in Interactions with Healthcare Professionals: A Data-Enabled Design Exploration

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ABSTRACT

This paper presents a designerly exploration of the potential values of parent-tracked baby data in interactions between parents and healthcare professionals (HCPs). Where previous work has used parent-tracked data as part of the solution to a problem, we contribute by starting our design exploration from data, using it as creative material in our design process. As we intend to work towards a system that could be viable across different levels of care, we invited three different types of HCPs and five families with newborns, for a five-week situated design exploration. Facilitated by an open and dynamic data collection toolkit, parents and HCPs could together decide what data to collect. In a continuous dialogue, they reflected on the relevance of that data in their interaction. Based on this, we continuously and remotely developed two concepts.

Author Keywords

Data-enabled Design; Healthcare Professionals; Babies; Parents; Health; Data; Exploration; Personal Informatics.

ACM Classification Keywords

H.5.2. User Interfaces.

INTRODUCTION

Personal informatics systems [24, 9] gather data about our behavior, facilitate interpretation of the data, and thereby help us in gaining a better understanding of ourselves (e.g. Fitbit [11], Nokia Health [31], Apple HealthKit [3]). When applied in the healthcare domain, personal informatics systems can be valuable enablers of patient-provider collaboration [14,16,19,28]. These can support diagnosis; personalize treatment; increase patient motivation and accountability; highlight unarticulated patient goals; and facilitate visit management [5, 6]. However, commercially

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CHI 2018, April 21–26, 2018, Montréal, QC, Canada.
© 2018 ACM ISBN 978-1-4503-5620-6/18/04...\$15.00.
<https://doi.org/10.1145/3173574.3173871>



Figure 1: the uGrow baby app

available personal informatics systems are generally not developed with a healthcare professional perspective in mind and thereby often lack mechanisms for effective communication, resulting in overwhelmed healthcare professionals (HCPs) and frustrated patients [7, 41].

The *uGrow baby development tracker* app, launched by Philips in 2016, is a personal informatics system that aims to help new parents in understanding and supporting their baby's healthy development (figure 1). It provides personalized feedback, advises on what to expect at each stage of development, and gives assurance that the development of the baby is on track. This is driven by the data collected through manual trackers in the app (e.g., how long the baby sleeps, how much the baby is eating) or through a range of automated loggers in the form of connected products (e.g. Philips Avent [34] smart ear thermometer, smart baby monitor).

As part of the uGrow innovation team at Philips Design, we see potential in bringing parent-tracked baby data [12,26,30,33] into interactions with healthcare professionals (HCPs), yet a direct transfer of uGrow (developed for family use) to the healthcare domain would likely be unsuccessful. We therefore set out to explore, in a designerly manner, *what* and *how* parent-tracked baby data can be of value in the interaction between parents and HCPs.

In our data-enabled design approach [4], we use situated explorations with remote design interventions to translate

insights into new designs continuously. To do this, we shape a playground of physical data loggers and screen-based dashboards, enabling parents and HCPs to explore together what data is of interest and how it can be relevant in their specific use cases. By making changes to the playground – or *data-enabled canvas* – inspired by contextualized insights, the design researchers continuously make new ideas experiential.

In this paper, we first outline and reflect on previous work, both in the domain of parent-tracked data for HCPs and self-tracked data for HCPs in general. These insights helped in shaping the initial setup of our ‘*data-enabled design canvas*’. Based on our design exploration with three HCPs and five families over five weeks, we describe how different insights have led iteratively to new design implementations. Finally, the paper discusses our findings and how our approach has influenced these. The contribution of this paper is found in how data is used as a creative material in the process of design for interaction between parents and HCPs.

RELATED WORK

The related work we outline here falls into two categories: (1) case studies that operate in the same application domain as our work, and (2) other approaches to self-tracked data and HCPs in other healthcare domains. We used the insights from these case studies as inspiration for our design exploration, and reflect on their approaches to inform construction of our own. These particular case studies were selected as we see them as representative of a larger body of work in this research area.

(1) Health technologies in parent-HCP interactions

The projects *Baby Steps* [18] and *@Baby Steps* [38] show a new approach to existing development assessment surveys, used for preventative care, which are not reliably completed by parents. This software tool helps parents to remember and record developmental milestones on a daily basis. Design recommendations highlight the importance to design for limited anxiety by mixing more serious medical-related features with lightweight features, such as capturing the milestone of a first haircut.

For aiding diagnosis in higher levels of care, the *MediCubes* [39] project shows the value of bringing playful technology-aided diagnostic tools to the home context. The child’s health is monitored via a set of noninvasive sensors placed on the toy (e.g. measuring pulse, temperature and lung capacity) while interacting with a storytelling game. Monitoring the child’s health in their natural environment can lead to better health assessments, since the examination is decoupled from the data-gathering process, and thus any anxiety relating to the examination no longer influences the data collected.

The *ENSURE* concept [32] supports parents in automatically recording, retrieving and transferring health information (related to medication adherence) to their HCP.

The concept was an answer to the needs of parents finding it difficult to adhere to medical advice and prescription regimens due to having hectic lives, and the need of HCPs to make effective use of consultation time. The work highlights that data collecting technologies in the home context should consider multiple caregivers (e.g. babysitters), multiple locations and timings of care. Additionally, it argues for easy data collection via automated trackers (e.g. smart thermometer with automated temperature history), and a comprehensive yet clear data overview for HCPs to make consultation more efficient.

Conclusion:

Previous work shows how parent-tracked baby data, collected at home, has potential value across multiple levels of care, from prevention to diagnosis and treatment. However, all case studies in this domain start from pre-defined challenges and needs. They define a specific set of data as part of the solution to the problem, and parents’ and/or HCPs’ experience of the solution is then evaluated. Building on our previous experience designing the connected baby bottle, we were curious to find out what would happen if we again took the (parent-tracked) data as a starting point instead of concrete needs. We expected this to result in a variety of use cases and pitfalls of data usage not yet identified in previous work.

(2) Explorations starting from data in other healthcare domains

When broadening our perspective to work that explores how home-collected data can be valuable in interactions with HCPs which are not specific to babies, we see a larger body of work that does start with the data itself.

Mentis *et al* [28] present a case study that explores the value of Fitbit step count data in a clinical visit. They stress that when self-tracking is brought into a clinical consult, the data is reshaped by the goals and expertise that exist within that healthcare framework [29]. Building a common understanding of the data requires work by both the patient and the clinician, as it is shaped and co-interpreted by both [1,13,15,17,35]. The approach whereby patient and clinician build a shared understanding of the data (e.g. by discussing outliers) provides a valuable additional layer of meaning to the data.

The Fitbit data used by Mentis *et al* is a clear example of how the domain of self-tracking and quantified-self shows a clear trend from manual tracking towards automated or passive tracking. Challenges that are often associated with manual tracking in the healthcare domain include: (1) that it is more difficult to maintain manual logging because of the higher burden [40,21], and (2) that the data is less reliable than data collected automatically [20].

However, Yamashita *et al* [40] highlight that manually logging data can be advantageous as it can lead to more careful self-observation, which increases self-awareness and engagement [23,25]. Their study, which was designed

to explore the value of manually tracked data for caregivers, focused on a manual mood-tracking system for family caregivers caring for a depressed family member. The study found that it helped the caregivers gain better insight into the behavior of the care recipient, for example, and to develop concrete action plans.

Conclusion:

Although not in the domain of baby care, there are clear examples of studies that depart from data rather than from problems and needs. The direct insights are arguably less valuable to us, as they are heavily influenced by their context. The approach, however, is of interest. In the Fitbit case study, the building of a shared understanding of the data by patients together with clinicians is of value. Even though the study started from exploring the potential value of data, it were the researchers who defined *what* data was used. A similar argument could be made for Yamashita's case study, as the application provided a fixed template for what data to manually keep track of. Although we have only highlighted a limited number of cases, we have not found case studies that do not pre-define the data involved. As we set out to use data as creative material to inspire our design iterations, we argue for a more open and dynamic approach, as described in the following section.

DATA-ENABLED DESIGN (METHOD)

We build on our data-enabled design approach [4] to explore what data is valuable in what way. This approach was developed and described at an earlier stage, based on a design exploration of a connected baby bottle. The approach is outlined below, after which we elucidate how it was used in the case.

Data-enabled design sets out to use data as creative material from the early stages of the design process to ascertain new design directions. This is very different from a data-driven design approach [8], in which data is used as evidence for design decisions (i.e. in AB testing). Discussions about the data become far more personal and detailed if the *data is real* and belongs to an individual [22]. We use a combination of *sensor data* to gain detailed insights in behavioral patterns and *qualitative methods* for providing a detailed understanding of related experiences. Consequently, the data-enabled explorations are *situated in a real-life context*, for a *longer period of time*. We deliberately refer to these as '*situated explorations*' because they are not static validations, field trials or home placement tests.

Data is used as a means to *collect insights remotely and continuously*, but also to *remotely design interventions*. For example, in the connected baby bottle case, bottle feeding data was remotely collected and displayed in real time on a researcher data-dashboard. This screen-based interface displayed data visualizations that gave insight into the behavior, experiences and context of the participants. Based on insights from this data, content was then sent to a connected mobile app.

The playground that is shaped through all the tools involved (e.g. physical and digital prototypes, software platforms, apps, researchers' dashboards) is what we refer to as the *data-enabled canvas*. The data-enabled canvas facilitates the explorative and open nature of this approach. It is designed to be sufficiently open to facilitate a variety of explorations, based on the insights gained during the situated explorations. These cannot be planned upfront, and thus will continuously change. Our data canvas *needs to grow* together with our solution to enable continuity of the design explorations [37]. More simply put, by collecting and showing data to participants, they come up with new questions or ideas. From a distance, we can quickly update elements of the data canvas to embody these ideas, and participants can then experience them. These again trigger new ideas for participants and researchers. In this way, we can explore continuously and remotely.

DESIGN CASE

Our design case in this paper is a data-enabled design exploration of how baby data collected in the home can be valuable in the interaction between parents and HCPs. For our situated explorations we invited three HCPs from the Netherlands. As we set out to design for a system that is valuable across different levels of care, we invited (1) a *consultation office nurse*, who takes a preventative and informative role in screening the overall health and development of children, executing vaccinations and providing parenting strategies; (2) a *general practitioner*, who helps parents in solving common medical conditions or refers them to a specialist in a higher level of care; and (3) a *pediatrician*, who is there for newborns that need specialist treatment in hospitals or other medical services.

The three HCPs were each asked to recruit two families to participate in the study for five weeks (see table 1). Families involved in current, ongoing treatment with the pediatrician were excluded, as from a medical ethical point of view we did not want to interfere with diagnosis or treatment of severe issues. The pediatrician had difficulty in recruiting families, and so started the study supervising only one family. However, Family 4 was, coincidentally, referred to the pediatrician by the GP during the situated explorations; hence, all HCPs interacted with two families. When referring to participants hereafter, we refer to all participating families and HCPs. This setup was positively evaluated in a Philips internal ethical committee board and the Dutch Medical Ethical Committee at Maxima Medical Center [27].

Part of our data-enabled design approach was to shape a data-enabled canvas that allowed us to gain insights, and to respond to these insights in a continuous manner through design interventions. This meant that after two weeks the canvas could be completely different for Family 1 than for Family 5. As a whole, our data-enabled canvas comprised of (1) a family toolkit; (2) a healthcare professional dashboard; and (3) a researcher dashboard.

(CON) Consultation Office Nurse		(P) Pediatrician		(GP) General Practitioner
Family 1	Family 2	Family 3	Family 4	Family 5
Baby: 5w Father: 37 Mother: 34	Baby: 3w Father: 33 Mother: 32	Baby: 5m Father: 35 Mother: 34 Sister: 3y	Baby: 3m Father: 27 Mother: 26	Baby: 6w Father: 37 Mother: 30
High level of education	High level of education	Middle level of education	Middle level of education	Middle level of education
No health issues	Born lightweight	Was hospitalized	Excessive crying	Reflux
Preventative focus	Focus on growth	Issue solved, prevention	Unraveling cause	Lowering medication
Two home visits of CON	Two home visits of CON	6 consults & hospitalized	Family is 2 years with GP	Family is 1,5 years with GP
Handwritten diary	Babytracker app	No tracking of data	No tracking of data	Handwritten diary

Table 1. Overview of participating healthcare professionals and families with ages, education levels, health problem, care focus, patient-provider relationship, and data experience.

A data-enabled canvas

The domain of home-collected (baby) data is heavily connoted with apps, screen interfaces and quantified self products. We aimed to enable participants to think freely about the possible benefits of sharing data with HCPs, instead of what the next great app (feature) could be.

(1) Family Toolkit

By introducing a *physical* ‘family toolkit’ for parents, as part of our data-enabled canvas, we aimed to position ourselves outside of the *digital only* frame of reference. In addition, we hoped that the physicality of the loggers made them stand out in the home context, so that everyone (e.g. mother, father, grandmother, sister, nanny) could decide to keep track of things, instead of only those who had the app installed on their phone. Especially in the context of family care where, for example, grandparents and daycare are also responsible for the care of the baby, it would be a missed opportunity not to include them in data collection.

The family toolkit (figures 2 & 5) can facilitated a dialogue between the parents and the HCPs through data collected at home. As related work has given little insight into *what* data may be relevant for parents to keep track of (let alone how this could be tracked), the toolkit does not define this. Instead, it is set up as a multi-purpose and dynamic set of tools for parents and HCPs to use in a way they see fit. The toolkit consisted of (a) a collection of physical data loggers and (b) a parent dashboard displayed on a touchscreen (see figure 2).

The physical data loggers are generic, internet-connected, manual trackers (see figure 3) that could be placed anywhere the parents wanted. Every data logger has a different interaction style, resulting in different types of data (see table 2). Using the parent dashboard, parents could, together with their HCP, define what the physical loggers would be used for. For example, if they decided it

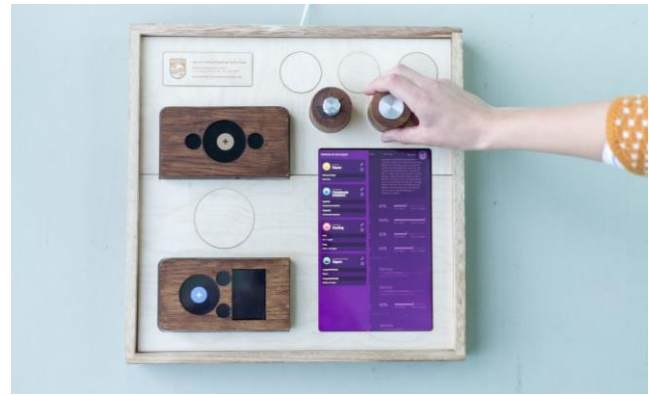


Figure 2. The family toolkit. Clockwise from bottom-left: text module, video module, rotating knob, push button (in hand), parent dashboard.

Was valuable to keep track of how often a baby was being fed, they could use the parent dashboard to assign the label ‘feeding’ to the push button. From that point onwards, when the push button was pressed, a new ‘feeding’ event would be recorded. The assigned labels could be freely changed at any point in time. All recorded events would be displayed on the parent and HCP dashboard as a simple log of all events (figure 4). In addition, a message center in all dashboards allowed communication between the parents, HCPs and design researchers.

It is important to note that the physical loggers were deliberately designed to be used for a single purpose. Hence, it would be impossible for parents to start logging everything; they had to make conscious decisions on what data was most relevant.

Data logger	Functionality
(a) push-button module	saves <i>when</i> it is pressed
(b) rotation-knob module	saves <i>when</i> it is pressed and at what <i>position</i> (from 0 to 100)
(c) video module	saves short videos (max. 5 mins)
(d) text module	saves text messages

Table 2. Overview of physical data loggers, with functionality

Not only did we envision the physical trackers to be open-ended, we also designed the underlying technology in a way that would allow us to quickly design and introduce new physical data loggers. The smaller cylindrical loggers (A, B) were built using the same hardware platform (i.e. ESP8266 [10] with custom-designed printed circuit board). They were battery operated and could run for more than five weeks without a recharge; they were also wireless, enabling parents to place them at a convenient place associated with the event (e.g. putting a ‘wet diaper’ logger next to the diaper changing table). Loggers C and D were

built using Android phones, and could be used wirelessly and charged, but only had a battery lifespan of about a day.



Figure 3. The physical data loggers

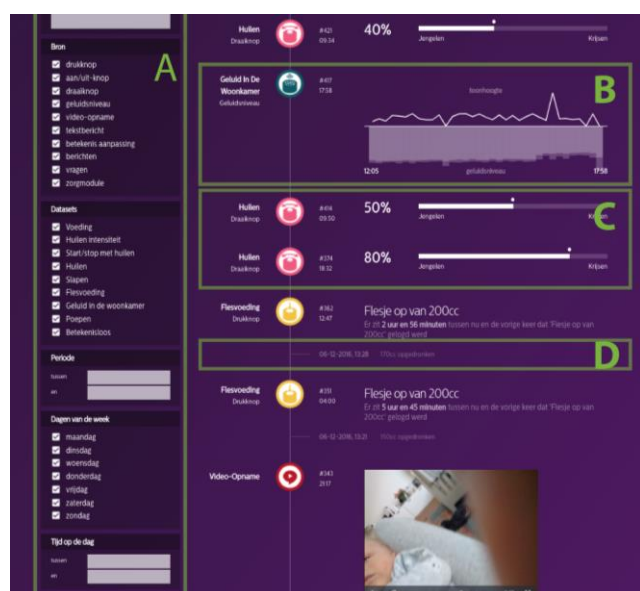


Figure 4. Different elements of the HCP dashboard: (A) data filters for the HCP; (B) visualization of the audio tracker (introduced later); (C) data logs of the physical trackers; (D) annotations on data points.

(2) HCP Dashboard

In the system, each family was connected to their HCP, giving the HCP access to that family's data. As with the parent dashboard, the HCP dashboard initially displays the logbook (figure 4), but also offers some additional filters and controls to zoom in/out to discover relations and patterns (figure 4-A). The HCP also has access to the messaging interface.

(3) Researcher Dashboard

The design researchers had access to the data of all families and HCPs. As well as having a copy of the HCP dashboard, the researcher dashboard contains more experimental data visualizations and some metadata (when participants visit the dashboard) to gain insight into the current exploration. It can also be used to communicate with the participants and as a place to try out new features before going 'live'.



Figure 5. The 5 toolkits handed out to families

Procedure

The situated explorations were planned to run for five weeks for all participants. Participants were phased in at different times to allow for any technical immaturities at the start, and to provide more time for new explorations. The study therefore ran for nine weeks in total. We hereafter refer to week numbers in relation to the starting date of each participant (i.e. week 1 of Family 1 will have a different date range to week 1 of Family 3).

– For families

In the introductory meeting at the family's home, we introduced the purpose of the study and the functionality of the toolkit (figure 6). To help them become acquainted with how to log data and change the labels assigned to the data loggers, the parents were asked to label each module, based on what they thought could be useful to keep track of. In this way, we quickly learned about aspects that are of (temporal) relevance for them to discuss with their HCPs. We explained that the toolkit allows for quick updates, and so encouraged them to actively think and make suggestions that we could respond to.

In the second week, a session was held with the parents in which we discussed their first experiences. In the weeks thereafter, there were only contact moments when specific issues arose (e.g. technical malfunctioning, questions about the study, changing health condition of the baby requiring exclusion from the study).

In the fifth (i.e. final) week, we met with the families twice. The first meeting was a session at home to reflect on their experiences, and to discuss their perspective on the relevance of home-collected baby data for themselves and their HCPs. The second was in a consult with the HCP and design researchers, where they shared and discussed experiences and asked any remaining questions.

– For healthcare professionals

In an introductory meeting at the HCP's office, the purpose and setup of the study was explained. Both the family toolkit and the HCP dashboard were introduced. To give HCPs a better understanding of the potential opportunities of the family toolkit, the researchers gave some hands-on

demos. *Once every week* the researchers visited the HCP to review the data collected by their families through the HCP dashboard, and to discuss new ideas. We explained that we intended to design and explore ‘on-the-fly’, meaning that things would continuously change as their ideas and feedback were directly implemented.



Figure 6. The family toolkit installed during the situated explorations

– For design researchers

In a weekly design meeting, all results and insights from interviews and dashboard reviews were discussed. These ranged from participant quotes and study questions to technical difficulties or bug fixes. When participants sent messages using their dashboard message center, we aimed to respond within a couple of hours. Based on these insights, the team would collectively brainstorm and decide which actions and new designs would have the largest priority. The designs would balance the questions and ideas from the participants with the ideas of the design team, based on their insights.

SITUATED EXPLORATIONS

In this section, we share two design narratives which describe the evolution of our situated explorations, and the rich and detailed stories that have driven them. These narratives are formed from a study timeline where, throughout the exploration, we tracked user behavior and experiences, resulting insights and new design interventions. As most design interventions were directly connected to one or more insights resulting from other design interventions, they clearly show the design narratives throughout the situated explorations. Where relevant, we use reflection on action, as described by Schön [36], to describe the design narratives. From a collection of multiple narratives, we selected those that lead to the more concrete design concepts.

Cumulatively, families participated for 127 days over a period of nine weeks. In total, we collected 1372 data entries from the physical data loggers, which were divided over 25 different assigned labels. The HCPs typed 20 messages to families. We sat together with participants for a total of 36 hours, and made changes to the data-enabled canvas continuously.

In general, the system was very well received. Initially, parents struggled with defining which labels to assign to the physical loggers, as the system was so open that it was challenging to find a starting point.

“I am doubting what kind of information I should collect: information around my questions of care or information about everything I do? I would like to have answers to my questions but think it might also be interesting to have the HCP access my routines. There might be aspects which I find normal but which the consultation officers find striking.” – Family 1

After using the system for several days, and as a result of interactions with their HCP, this became clearer. From this point onwards, the parents started to enthusiastically collect extensive datasets.

Although very curious, the HCPs were more reluctant at first. It was not immediately clear how the data could help them, as it was hard to imagine what the parents would use the data loggers for. This quickly changed once they received real data, as this gave them a better idea of what access to the data could mean for them, and what changes were required to move towards that. We present two distinct directions, as the insights from the general practitioner and pediatrician showed large similarities but were unlike the insights from the consultation office nurse.

A design narrative towards My Care Question (for the consultation office nurse)

The families started to collect data before having data-related interaction with their consultation office nurse. At this level of preventative care, the issues are less prominent and the parents found it difficult to pinpoint what data to collect. Consequently, they began with the most commonly tracked data: feeding and sleeping. Parents were very dedicated to tracking this repetitive information accurately, as they valued a *complete* overview.

“Sometimes I click the button twice as I forgot to log the previous one. But that doesn’t show the real situation.” – Family 2

As this seemed an important value, we introduced the ability to manually add data points at a certain time (in the past) and the ability to delete (wrong) data points (figure 4). To achieve this, we integrated a comment option for each data point. Parents could use the comment facility to record what was wrong with a given data point and what needed to be changed. This was visible to the design research team, who initially updated the data manually.

“I am so pleased with the adaption possibilities. When I forget it in the middle of the night and enter the data in the morning, it automatically ‘jumps’ to the right position on the timeline – so nice.” – Family 3

After the first weeks, the consultation office nurse received extensive overviews of accurately tracked data in the form of a timeline. There was so much data that it took the HCP about 30 minutes to go through it. At many points she saw something she thought could be worth giving feedback

about, however, she also did not want to worry parents about something that was not causing any problems.

“I am doubting. I see a lot of data that I could respond to, but I’m hesitant to do so as I do not want to create issues or concerns that are not there.” – Consultation Office Nurse

The nurse made a case for easier browsing through the data, as this could significantly speed up the task of reviewing it. We therefore implemented data filters so that irrelevant data could be hidden.

In the meantime, the parents continued to track the same data but also started to use the comments facility. Although intended as a workaround for manual data adjustment, they also used comments to give more qualitative information about the data they collected. As the comments were previously only visible to the design research team, we quickly enabled the HCP to not only see them, but also to write new comments.

As a comment on “sleep” by the parent – “Baby went to sleep at 21:00, after a feed at 18:30 we took a shower, baby was awake in my arms. In his crib he cried a lot, fell asleep in my arms in the nursing room, then I put him to bed in the nursing room.” – Family 1

The comment above shows the ‘obvious’ first data tracked by the family becoming more detailed and nuanced through the addition of context and personal experiences. As the HCP started to gain a better understanding of what the data might bring, she started to ask for other details that could provide more contextual insight. Together, the HCP and the family decided to start tracking the ‘easiness of falling asleep’, using the rotation knob. After doing this for several days, based on whether her experience of ‘falling asleep peacefully’ matched what can be expected of a five-week-old baby, the HCP discussed this with the parents further.

Although the consultation office nurse was now equipped with a dashboard that allowed for easier filtering of data and had a better contextual understanding of the data through the comments from the parents, she still clearly struggled with the large amount of data and how to deal with it. In contrast to her normal approach, where parents ask questions and she tries to answer them, there now seemed to be an expectation for her to give advice without a clear question. She clearly appreciated it when a concrete question appeared in one of the comments, and explained that she always used a question-based approach whereby parents explained what was on their mind and she would try to find a solution.

Inspired by this, we built the ‘My Care Question’ concept. This is a different tab/window in the parent dashboard where new questions can be initialized and data points (historic or to be collected) can be selected, where the data points are relevant for the HCP to better help with the question (i.e. the question module provided a filter on the data set by the parents for the HCP). Based on the data points, the system creates a simple data summary overview,

and the HCP receives the list of questions with associated data.

The My Care Question module was introduced to Family 2 two weeks before the end of the situated explorations. It immediately proved its relevance, as shown below.

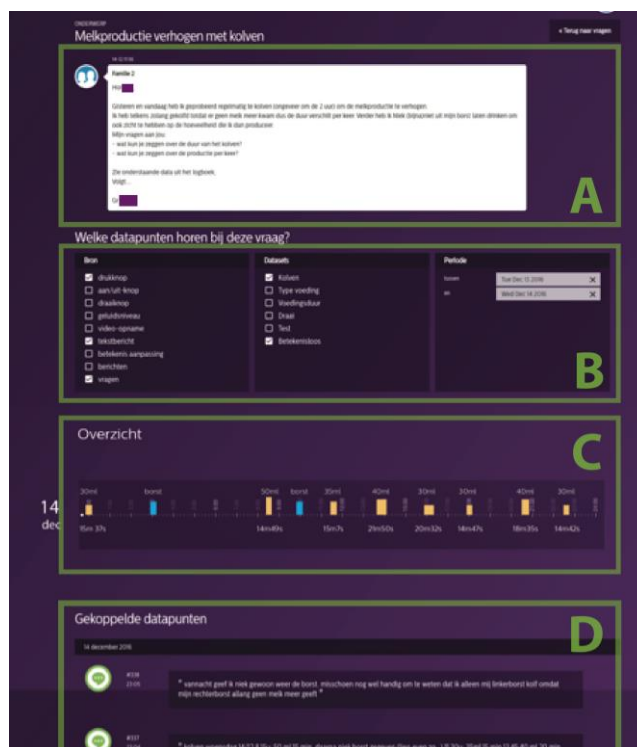


Figure 7. An example question asked in the My Care Question module. At the top, the question is formulated (A). Next, the relevant data types can be selected, using a number of filters (B). A simple summary data visual is then shown (C), followed by all data points (D).

The mother of Family 2 used the new My Care Question module to ask how she could increase her breastfeeding supply through expressing (i.e. pumping) (figure 7). She connected data about the duration and volume of expressing to the question. As this clearly illustrated a highly irregular routine during that time, the consultation office nurse advised her to pump delicately every two hours for two days. Unfortunately, that advice did not have the desired effect (also visible in the data).

“After 29 years of experience, I have not often experienced that breastmilk amounts do not increase [after giving this advice].” – Consultation Office Nurse

To find suitable advice, the consultation office nurse reached out to a lactation consultant. She communicated the new advice through the My Care Question module, and it had a positive effect. In the reflective session, both the mother and the consultation office nurse reported being very satisfied with the functionality of the module.

“Now I get much more information (...). Maybe, when you [mum] had seen me two weeks after, you might have already stopped

expressing. You might have thought ‘this isn’t working out’ and maybe you would have switched to bottle feeding already. [mum confirms]” – Consultation Office Nurse

A design narrative towards Care Paths (for the GP and pediatrician)

When the parents received the toolkits, we encouraged them to start logging the data they expected to be relevant for them in interactions with their HCP. Compared to the families participating with the consultation office nurse, these families found it a little easier to define what their data loggers would collect as there was a clearer issue at hand. They appreciated the fact that they were now able to keep track of a problem so that their HCP would “*see what our baby is going through*” (Family 5).

After the first week, the data collected by the families was presented to the GP and pediatrician in the form of a logbook of events (figure 4). Both professionals struggled to make sense of the data. It was difficult to get an overview as an extensive set of data had already been collected. We agreed that this was probably the case because having an overview alongside the ability to look at the data from different angles was necessary, but widely missing. In response, we developed the first version of a timeline data visualization, for the HCP dashboard (see figure 8).

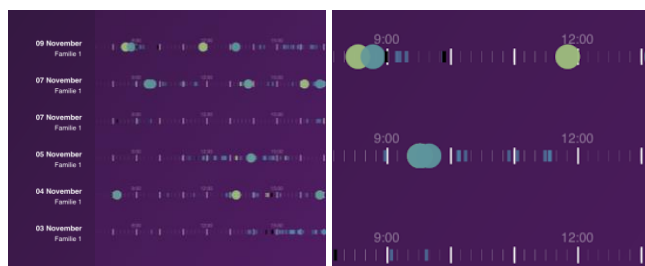


Figure 8. Data visualization, first version. The color of the dots is mapped to the type of physical data logger used.

The new visualization did not provide a solution to the issues highlighted during the first meeting. It was still difficult for the HCPs to get a good overview, and they argued strongly that the data collected by the parents was way too much: they only needed to see specific things that could help to answer some of their unanswered questions. Also, the GP felt that by tracking data some parents may become so obsessed with it that it had the potential to magnify the problem. As a result, both HCPs asked parents to keep track of specific things.

“I am a GP, I only want to see information related to the care question. Parents visit me because they have a problem, not to show videos of how cute their baby is.” – GP

“I want to stimulate the family to make videos of skin rash or uncommon behavior, that is very valuable to me. We can stop with tracking full (poo) diapers, and replace it by wet diapers. Also, I want the family to track sleep.” – Pediatrician

Where the HCP partly found a solution to data overload by helping parents focus on what data to collect, we together

still struggled in coming up with more usable data visualizations. As the physical loggers could be used to keep track of any kind of data, our visualizations needed to be abstract representations that had no understanding of context. As they had to be generic, we kept coming back to timeline visualizations that stayed the same conceptually but had improved readability.

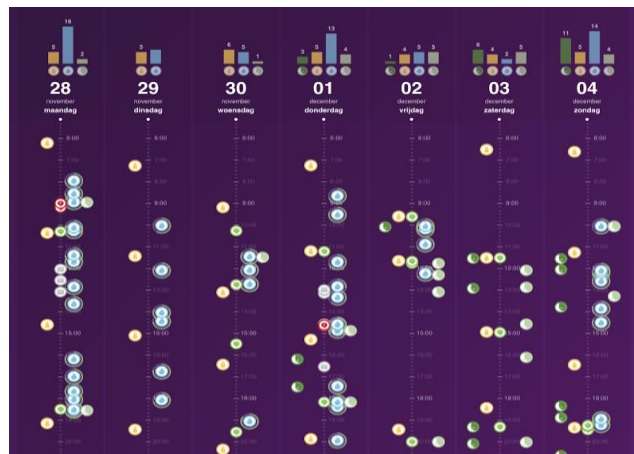


Figure 9. A new data visualization. Different days are shown next to each other; icons represent labels. At the top, cumulative charts show how often events occur.

From the HCP perspective it was clear what kind of data was needed in a specific case. In an ideal world that data would be collected as accurately as possible. Manually tracked data had clear advantages, as it was open and almost anything could be collected, but the HCPs sometimes questioned its quality. For example, was there no feeding at a given point because there was no feeding, or because it was not logged?

To support a request for sleep tracking and explore the value of an automated data logger, we introduced two new data loggers: (1) the two-state toggle button, and (2) the audio module.

(1) The two-state toggle button (figure 10) was introduced to support the sleep request. Where the other buttons only register an event at a particular moment in time, this button registers when it is in its pressed state and thus logs the duration of events. (2) The audio module (figure 10) was introduced to elicit responses about automated data loggers. The module can be freely placed throughout the house and continuously keeps track of environmental sound levels and tone heights. Approximately every five hours a visualization appears in the parent and HCP dashboard, summarizing that time slot (figure 4).

Although the data in current form was hard to interpret initially, the parents started exploring how these modules could be valuable. They came up with unexpected use cases and questions as to how this information could be relevant.

Although both HCPs expected to see a ‘universal truth’ from the automated data collectors, it became clear that, for

both the manual and the automated loggers, it was important to build a shared understanding of what the data means. Only then can it become meaningful for both parties.



Figure 10. The toggle button (left) and audio module (right)

“I wonder, if he [my baby] makes a lot of noise during the night, is he doing that constantly or only 15 minutes before he wants food?” – Family 2

We see a good example of this in how Family 4 used the video module to annotate the rotation knob. Initially the rotation knob was set to track ‘crying’. The minimum of the knob was manually defined as ‘whining’, and the maximum as ‘screaming’. Upon questions from the GP, the mother made two videos, one showing whining, and the other screaming. Immediately, the GP had a frame of reference for that data.

In short, we discovered that the HCP would like to be in control and somehow regulate what is being kept track of, to prevent parents from worrying too much.

Building on this, we introduced ‘Care Paths’: problem-specific care modules. HCPs could start these modules when there was a clear indication for a problem or a diagnosis had already been made. Each problem-specific module pre-lists a set of data points that are important for the parent to keep track of. After the HCP initializes a module, the request shows up on the parent dashboard. Upon acceptance, all the labels for the physical loggers automatically update to those defined by the module. For example, the *allergies* care module may ask parents to take a video of a skin condition, using the video module, every day. As the Care Path modules focus on more specific issues, they can also involve function-specific automated loggers (e.g. a smart baby bottle for feeding issues).

We implemented a Care Path reflux module during the last week of the situated explorations and discussed this in final interviews. Although the HCPs were enthusiastic about the concept, the parents were less convinced of it in its current form. In the current setup, they felt that what they found to be valuable was not integrated enough. This is clearly evident in the following quotes:

“In this case, I just want to know when the baby is fed, when he spits up and when he cries. It is as simple as that.” – GP

“If I only tracked feeds, spitting up and crying, I don’t think the GP would have enough understanding of the situation. Sometimes my baby is not crying but clearly uncomfortable, you could notice that by not going to sleep.” – Family 5

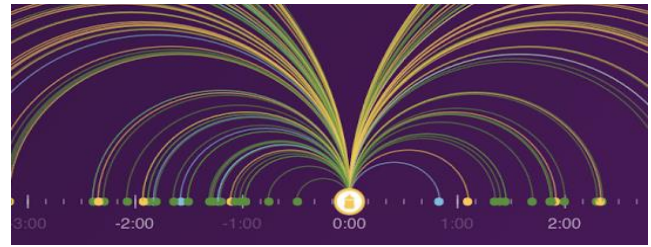


Figure 11. A care path-specific data visualization for reflux, showing the time between feeding and spitting up

Because the care paths pre-define the problem and concurrent data request, where the data gains contextual value, we were able to move away from generic timeline visualizations. This allowed us to create care path-specific data visualizations that would emphasize other elements.

Figure 11 shows the first version of a care path-specific visualization for reflux. It shows the temporary relation between feeding (in the center) and spitting up (the green lines), compiled from data from the reflux module gathered by Family 5. From this visualization, it can be seen that, over the previous 14 days, the baby never spat up within an hour after feeding. We presented this visualization to the GP, who quickly responded:

“There is no spitting after a feed, only before. That doesn’t seem to be a reflux problem...” – GP

Mother elaborated: *“When my baby spits up, I give him a little sip to rinse away that disgusting taste.” – Family 5*

The care path-specific data visualization helped the GP to gain insight into what might be causing the baby to spit up, and how she could best help the family to make it better. In addition, it provided her with the tools to monitor improvement.

Together with the HCP, we developed six Care Path modules, and defined what data was relevant for each one. However, we also learned that the set of data defined by the HCPs; the Care Path modules should have the flexibility to enable parents to track extra data points if they want to.

DISCUSSION

In this paper, we presented a data-enabled design exploration where we explored, in context, how parent-tracked baby data can be valuable in the interaction between parents and HCPs. We chose this approach because (1) we wanted to explore *what* data could be valuable, in contrast to prior work that defined this upfront; and (2) because we wanted to be able to translate our insights immediately into designs that could be experienced, thus enabling us to explore *how* data can be relevant in their interactions.

The exploration of *what* data is relevant

By enabling parents and HCPs to have a continuous dialogue about what data was relevant for them, working together, they quickly went beyond the most commonly

tracked data (e.g. feeding, sleeping, diapers, milestones). The data loggers were set to track more detailed and nuanced activities that often provided an experiential layer on top of the data [2]. The assigned labels ‘easiness of falling asleep’, ‘response to reflux’, and ‘position of waking up’ as well as parents’ comments to data points are good examples of this. It is interesting to see how these labels became more detailed over time, as the questions of the parent and HCP did. We would argue that, had we started this exploration from existing baby apps as uGrow, without a dynamic data-enabled canvas, it would have been more difficult to go beyond this (in our eyes, superficial) layer.

By selecting HCPs from different levels of care, we were able to corroborate our belief that different types of professionals have different data needs [6]. The consultation office nurse, for example, wanted to understand development, while the pediatrician wanted to know how long after a feeding the baby would spit up. Alongside the differences between types of professionals, the personality of individual professionals also played a role. All had developed their own way of working throughout their careers and preferred that the data respected that. The open nature of the data trackers proved to be very valuable in allowing professionals to use them in a way that they saw fit.

A critical note here is that although we clearly created more openness in what data was used than other case studies in this domain have shown, the boundaries of what could be collected were not infinite. Through our toolkit, we created a frame of reference for the participants that clearly influenced their perspective (i.e. nobody asked for medical measures such as pulse or lung capacity).

The exploration of how data can be relevant

In the section on the situated explorations, we presented a variety of real-life use cases. For example, we saw the GP using manual feeding, spitting up and crying data to gain insight into potential reflux-related issues; the pediatrician using video to monitor allergic skin responses; and the consultation office nurse using breast pumping data to give advice on how to increase milk production. Exploring through these real-life use cases gave us a better understanding of the full complexity of the design space [5, 7, 19, 28]. As a result, we were not only able to identify certain pitfalls but could also explore how to design around them. For example, the GP strongly argued for limiting the amount of data that was collected by the families, as it would only make them more worried and focused on the problem. Our response to this was that the design of the Care Path modules would only allow certain types of data collection for a fixed moment of time. For example, it would only allow tracking of crying for two weeks. The situatedness of the explorations also allowed for the continuous emergence of inspiring and unexpected use cases. Whereas the GP argued strongly against the logging of ‘see how cute my baby is’ videos (and manually

removed almost all of them), the pediatrician really appreciated these. He argued that because he has no background knowledge of the family coming to the consult, the videos could help him to get a rich contextual snapshot of the family (e.g. a chaotic household) and thereby allows for advice personalization [32]. This example, again, reinforces the fact that different HCPs have different needs and different ways of working.

At the start of the situated explorations, parents and HCPs initially struggled to find a direction for data gathering. However, regardless of their initial choices, the experience of gathering and reviewing data inspired a collaborative data-relabeling process between the parent and HCP. It made them, and thus also the design research team, see possibilities and pitfalls of data that they would not necessarily have thought of before. For the same reason, we directly implemented new design ideas arising from the insights that emerged. And again, it was the experience of participants using the updated data-enabled design canvas that gave the most valuable insights to move forward. As the tools were designed to be open for remote updates, we have been able to run multiple insight-to-design iterations in a single set of continuous situated explorations. The participants (i.e. families, healthcare professionals and researchers), study location and setup have had a clear impact on how these situated explorations developed. Hence, we treat the presented narratives and concepts as well-grounded starting points for future research rather than fully evaluated outcomes.

CONCLUSION

From related previous work, we saw two clear ways in which others have approached data-intensive projects. The first uses data only as part of the solution; the second departs from data and questions how it might be relevant in a given context. The latter, however, always defined what data was used upfront. In this paper, we present a third approach, based on situated and explorative data-enabled design approach. Many of our initial insights show a large overlap with those presented in previous work. However, as we moved forward and used different designs to embody these insights, they became more detailed, nuanced and, simply, different; they build on more complex insights from combinations of data in different settings that continuously evolve. In the case study, we have shown how we brought together parents, HCPs and design researchers who were enabled to actively contribute by means of the data-enabled canvas. Through this, we demonstrated how different stakeholders, as experts in their own areas, together with design researchers have used data as a creative material to allow new design interventions to emerge iteratively, while situated in real life.

ACKNOWLEDGEMENTS

This research was supported by the IMPULSE perinatology framework.

REFERENCES

1. Margunn Aanestad. 2003. The Camera as an Actor Design-in-Use of Telemedicine Infrastructure in Surgery. *Computer Supported Cooperative Work (CSCW)* 12, 1: 1-20.
2. Amid Ayobi, Paul Marshall, Anna L Cox and Yunan Chen. 2017. Quantifying the Body and Caring for the Mind: Self-Tracking in Multiple Sclerosis. In *proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI'17*, 6889-6901.
3. Apple. 2017. A bold way to look at your health. Retrieved December 11, 2017 from <https://www.apple.com/ios/health/>
4. Sander Bogers, Joep Frens, Janne van Kollenburg, Eva Deckers, and Caroline Hummels, 2016. Connected Baby Bottle: A design case study towards a framework for data-enabled design. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems (DIS'16)*, 301-311.
5. Chia-Fang Chung, Jonathan Cook, Elizabeth Bales, Jasmine Zia, and Sean A. Munson. 2015. More than telemonitoring: Health provider use and nonuse of life-log data in irritable bowel syndrome and weight management. *Journal of Medical Internet Research*, 17(8). doi: 10.2196/jmir.4364.
6. Chia-Fang Chung, Kristin Dew, Allison Cole, Jasmine Zia, James Fogarty, Julie A. Kientz and Sean A. Munson. 2016. Boundary negotiating artifacts in personal informatics: Patient-provider collaboration with patient-generated data. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*.
7. Mary Jo Deering, Erin Siminerio, and Scott Weinstein. 2013. Issue Brief: Patient-Generated Health Data and Health IT. Office of the National Coordinator for HealthInformation Technology
8. Biplap Deka. 2016. Data-driven Mobile App Design. In *Proceedings of the User Interface Software and Technology Symposium –UIST '16 Adjunct*, 21-24.
9. Daniel A. Epstein, An Ping, James Fogarty, and Sean A. Munson. 2015. A Lived Informatics Model of Personal Informatics. In *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing (UbiComp '15)*.
10. Espressif Systems IOT Team. 2017. ESP8266EX Datasheet. Retrieved September 18, 2017 from https://cdn-shop.adafruit.com/product-files/2471/0A-ESP8266__Datasheet__EN_v4.3.pdf.
11. Fitbit. Find your fit. 2017. Retrieved December 11, 2017 from www.fitbit.com/.
12. Glow Inc. 2017. Glow Baby - Baby Tracker App. Retrieved September 18, 2017 from <https://itunes.apple.com/us/app/id1077177456>.
13. Stefan Hirschauer. 1991. The Manufacture of Bodies in Surgery. *Social Studies of Science* 21, 2: 297-319.
14. Nicholas Huba, and Yan Zhang. 2012. Designing patient-centered personal health records (PHRs): health care professionals' perspective on patient generated data. *Journal of Medical Systems* 36, 6: 3893-3905.
15. Kelly Joyce. 2005. Appealing Images: Magnetic Resonance Imaging and the Production of Authoritative Knowledge. *Social Studies of Science* 35, 3: 437-462.
16. Marije Kanis, Saskia Robben, Judith Hagen, Anne Bimmerman, Natasja Wagelaar and Ben Kröse. 2013. Sensor Monitoring in the Home: Giving Voice to Elderly People. In *proceedings of conference on Pervasive Computing Technologies for Healthcare*. 97-100.
17. Bonnie Kaplan. 1995. Objectification and negotiation in interpreting clinical images: implications for computer-based patient records. *Artificial Intelligence in Medicine* 7, 5: 439-454.
18. Julie Kientz, Rosa Arriaga, Gregory Abowd. 2009. Baby Steps: Evaluation of a System to Support Record-Keeping for Parents of Young Children. In *Proceedings of the 2009 CHI Conference on Human Factors in Computing Systems - CHI'09*, 1713-1722.
19. Soo-Cheol Kim, Young-Sik Jeong, Sang-Oh Park. 2013. RFID-based indoor location tracking to ensure the safety of the elderly in smart home environments. *Pers Ubiquit Comput* 17:1699–1707.
20. Yoojung Kim, Eunyoung Heo, Hyunjeong Lee, Sookyoung Ji, Jueun Choi, Jeong-Whun Kim, Joongseek Lee, Sooyoung Yoo. Prescribing 10,000 Steps like Aspirin: Designing a Novel Interface for Data-Driven Medical Consultation. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI'17*, 5797-5796.
21. Predrag Klasnja and Wanda Pratt. 2012. Healthcare in the pocket: Mapping the Space of Mobile-phone Health Interventions. *J Biomet Inform* 45, 1: 184-198.
22. Janne van Kollenburg, Sander Bogers, Eva Deckers, Joep Frens, Caroline Hummels. 2017. How Design-inclusive UXR Influenced the Integration of Project Activities: Three Design Cases from Industry. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI'17*, 1408-1418.
23. Eun Kyoung Choe, Nicole Lee, Bongshin Lee, Wanda Pratt and Julie Kientz. 2014. Understanding Quantified-selves' Practices in Collecting and Exploring Personal Data. In *Proceedings of the 2014 CHI Conference on Human Factors in Computing Systems - CHI'14*, 1143-1152.
24. Ian Li, Anind K. Dey and Jodi Forlizzi. 2010. A stagebased model of personal informatics systems. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '10)*. ACM

25. Ian Li, Anind K. Dey and Jodi Forlizzi. 2011. Understanding my data, myself: supporting self-reflection with ubicomp technologies. In *Proceedings of the Conference on Ubiquitous Computing - UbiComp '11*, 405-414.
26. Life'n Stats LLC. 2017. MammaBaby - Breast feeding App & Baby Log Tracker. Retrieved September 18, 2017 from <https://itunes.apple.com/us/app/mammababy-breast-feeding-app-baby-log-tracker/id618601202?mt=8>.
27. Máxima Medisch Centrum. 2017. De METC van het Máxima Medisch Centrum. Retrieved September 18, 2017 from https://www.mmc.nl/professionals/wetenschappelijk_onderzoek_in_mmc/metc/introductie.
28. Helena Mentis, Anita Komlodi, Katrina Schrader, Michael Phipps, Ann Gruber-Baldini, Karen Yarbrough and Lisa Shulman. 2017. Crafting a View of Self-Tracking Data in the Clinical Visit. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17*, 5800-5812.
29. Gina Neff and Dawn Nafus. 2016. *Self-Tracking*. MIT Press, Cambridge, MA.
30. Nighp Software LLC. 2017. Baby Tracker (Feed timer, sleep, diaper log). Retrieved September 18, 2017 from <https://itunes.apple.com/us/app/baby-tracker-feed-timer-sleep-diaper-log/id779656557?mt=8>.
31. Nokia. 2017. An ideal weight loss companion. Retrieved December 11, 2017 from <https://health.nokia.com/us/en/body-plus>.
32. Sun Young Park, Hee Young Jeong, John Zimmerman. 2008. ENSURE: Support for Parents in Managing their Children's Health. In *Proceedings of the Conference on Design and Emotion*. The Design and Emotion Society.
33. Philips AVENT. 2017. Philips AVENT. Retrieved January 22, 2017 from <http://www.philips.co.uk/c-m-mo/philips-avent-and-your-baby>.
34. Philips AVENT. 2017. uGrow- the world's first medical baby app with connected devices giving you personal advice that matters. Retrieved September 18, 2017 from <http://www.philips.co.uk/c-m-mo/ugrow-healthy-baby-development-app>.
35. Amit Prasad. 2005. Making Images/Making Bodies: Visibilizing and Disciplining through Magnetic Resonance Imaging (MRI). *Science, Technology & Human Values* 30, 2: 291-316.
36. D.A. Schön. 1983. *The Reflective Practitioner: How Professionals Think in Action*. New York: Basic Books.
37. Jelle Stienstra, Sander Bogers, Joep Frens. 2015. Designerly Handles: Dynamic and Contextualized Enablers for Interaction Designers. In *Proceedings of Conference on Design and Semantics of Form and Movement 2015*. 86-94.
38. Hyewon Suh, John Porter, Alexis Hiniker, Julie Kientz. 2014. @BabySteps: Design and Evaluation of a System for using Twitter for Tracking Children's Developmental Milestones. In *Proceedings of the 2014 CHI Conference on Human Factors in Computing Systems - CHI '14*, 2279-2288.
39. Emanuel Vonach, Marianne Ternek, Georg Gerstweiler, Hannes Kaufmann. 2016. Design of a Health Monitoring Toy for Children. In *Proceedings of the 2016 Interaction Design and Children Conference - IDC '16*, 58-67.
40. Naomi Yamashita, Hideaki Kuzuoka, Keiji Hirata, Takashi Kudo, Eiji Aramaki and Kazuki Hattori. 2017. Changing Moods: How Manual Tracking by Family Caregivers Improves Caring and Family Communication. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17*, 158-169.
41. Haining Zhu, Joanna Colgan, Madhu Reddy, and Eun Kyung Choe. 2016. Sharing Patient-Generated Data in Clinical Practices: An Interview Study. In *AMIA Annual Symposium Proceedings American Medical Informatics Association*, 1303-1312.