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Documenting (re)design of self-management tools for type 1 diabetes. Towards a continuity of knowledge sharing?

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Abstract

This paper describes a continuous process of making, sharing and using 'thick' documentation in a project wherein we co-designed three self-management tools with three participants with type I diabetes. Making, sharing and using thick documentation of these processes increased the individual cases' impact beyond the three participants and the design team involved. Thick documentation represents the material and immaterial aspects of a design process - the latter referring to the dynamic range of participants' perspectives- in a readable way and motivates use and documentation by others. We discuss the development of two different kinds of thick documentation for two processes and evaluate how they enabled knowledge building among existing and new participants and how all actors valued this.

Keywords: documentation, participatory design, video, diabetes

Evaluating thick documentation in Bespoke Design

In *Bespoke Design* we designed three self-management tools (Funnel & Anderson, 2004; Wootton, 2000) for three persons with type I diabetes. We increased the project's impact by documenting and sharing the prototypes and related insights with others (designers, artists, people with diabetes, etc.), allowing these processes and results to transcend the particular project, participants and team. We investigated documenting material elements – predominantly shared in design contexts – and immaterial (i.e. viewpoints, insights of participants) (Schoffelen & Huybrechts, 2013). We refer to documentation combining material and immaterial information as 'thick documentation', corresponding to thick descriptions of fieldwork (Geertz, 1973). This paper evaluates how making, sharing and using thick documentation enabled sharing knowledge and practices among the designers and participants. Furthermore we discuss how uses of and contributions to the documentation by new participants (Bödker *et al*, 2000; Huybrechts, Storni & Schoffelen, 2014) enable a project to continue.

During two years we investigated supporting a continuous process of making, sharing and using documentation among the design team and participants. The variety of participants (the extent of being part of the project, having experience in designing, documenting or participating in participatory processes, etc.) allowed evaluating (1) how to enable and motivate people to make, share and use the documentation and (2) how and with which goals the participants approach thick documentation. The project's duration allows evaluating the role of documentation for the progress of the project, becoming active players in the process. Although the process mainly allowed assessing this role during project-time, the inclusion of new participants illustrates documentation's potential to enable use by new participants after project completion, allowing us to carefully reflect on use-time.

Methodology

We explored four qualities of thick documentation:

(1) representing the immaterial perspectives on the project next to its material output;

(2) representing the dynamic range of participants' perspectives;

(3) being readable for others; and

(4) motivating others to use the documentation and contribute to it (Schoffelen *et al*, 2013; Huybrechts, Schoffelen & Hagenaars, 2014).

We investigated two documentation processes in relation to two participants, being Sue and Zoë. Both processes involved one participant during one year as a design partner and shared

documentation to stimulate new contributions, involving different types and amount of participants and documentation methods.

The case studies describe:

- how the design team made documentation, supported the (new) participants in making their own, and how these participants made documentation. These participants are the (four) team members, the participants with type I diabetes, and other designers, engineers, researchers, etc. who participated.
- how the design team edited the documentation footage - collected from participants - in order to share it and how new participants shared documentation.
- how the design team supported the participants to use the documentation (e.g. video stills to support scenario building), what kind of use it allowed and how the actors valued this.

Each documentation act is evaluated on the four qualities of thick documentation. We analysed several data: participant observations of what the team and participants expressed on making, sharing and using documentation; discussions with the participants; in-depth interviews with designers participating during short periods; and an analysis of the (reuse of the) different documentation videos.

Sue

Sue's trajectory - starting from her hesitance to handle self-care in public - involves three cycles of making, sharing and using documentation, involving different goals and methods. The team designed a dress allowing injecting insulin discretely, two types of video documentation and a series of workshops wherein new participants used the video documentation to further research handling self-care publicly.

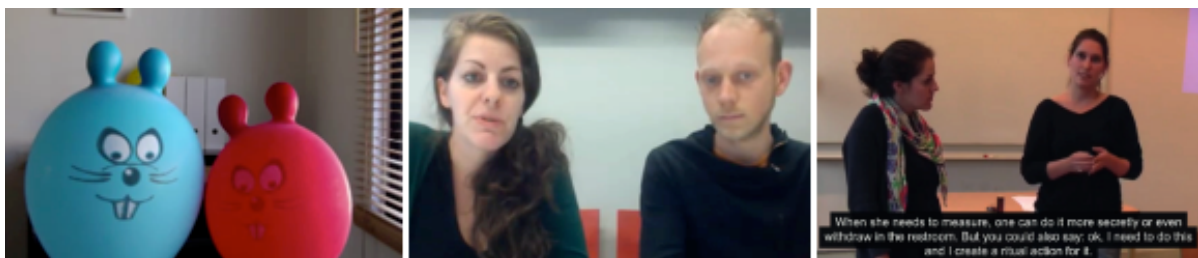## 1. Making, sharing and using documentation in the exploratory process

Figure 1. Videos of Sue, the team and the workshop

Sue video documented her view on using self-care tools publicly. Two team designers similarly video documented their view to tackle the tools' medical aesthetics and connotation.

Subsequently, the design team remixed both perspectives into a new video to share a nuanced view on the issue at stake in a workshop wherein 7 (new) designers and researchers developed prototypes for Sue.

After seeing this video (and videos of other cases), participants shared their ideas and formed groups. We briefed them to develop a prototype and video, without dictating what and how to document. The participants decided to film their presentation. They explained the goal was ritualising the act(s) of handling self-care when for instance having a lunch meeting (Sue often has) and designing a napkin that introduces the steps of pricking the finger, capturing blood, measuring the glucose level and cleaning the finger. Instead of hiding these acts (as Sue often does), they aim to challenge the taboo by showing them.

The design team and Sue explored this idea of ritualising. During this process, they filmed their sessions with Sue and Sue filmed herself, e.g. wearing a prototype shirt. However, because Sue did not felt comfortable showing her self-care acts, they explored how to inject insulin discretely (Sue would often withdraw to the restrooms) and designed a dress to do so. This dress is a solution for Sue but only partly tackles the taboo of handling self-care publicly.

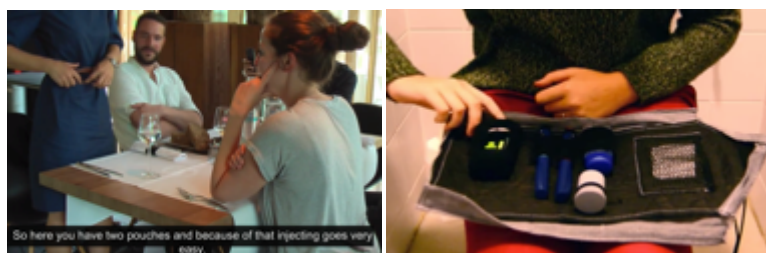## 2. Making, sharing and using documentation in a student workshop

Figure 2. Videos of the dress and the bag

To share this trajectory and outcome, the design team edited all video footage made throughout Sue's process into two videos. The first video represents the challenge of designing for publicly using self-care tools (immaterial approach), which could not be fully explored with Sue, while the second represents the dress and the design process (a material approach). During two workshops, new participants elaborated on the process: students of the master program Interaction Design, and three participants that responded on an open call for participation.

The design team shared the two videos with the students and gave a lecture on making, sharing and using thick documentation. The students choosing Sue's case decided not to support handling self-care publicly, but instead tackle the hygienic and practical challenges of handling it in public restrooms (i.e. supporting hiding self-care). They designed a 'bag' for the tools that can be unfolded in a little table when sitting on the toilet. Their video represents the design process, motivation for their outcome and a call for others to design for these contexts.

3. Making, sharing and using documentation in an open workshop

Figure 3. Video stills, storyboard, video booth

For the second workshop, the design team shared the video of the challenge and the videos of the dress and bag, both representing opposite answers to the challenge. To support the participants to elaborate on the videos, we provided video stills (image and subtitling) and game rules to co-design a new scenario. The rules included mapping what was appreciated, missing, and could be altered according to the elements of a scenario (i.e. tools, person, value, setting), and translating this workshop outcome into a readable storyboard. Their scenario described tackling the taboo of handling self-care in a lunch setting by a playful set-up surrounding a bag containing self-care tools that shares blood glucose levels with table-companions. In a video booth the participants answered specific questions about their motivation to participate and their personal ideas about the design challenge.

Zoë

Zoë shared two issues. First, when having a hypo, it is difficult to remove the packaging of dextrose. Dan, member of the design team, designed and documented a fast sugar dispenser. Second, Zoë wishes carrying her insulin pump close to her body. Julia, a textiles designer invited to participate, designed a pocket-system and a video to share it.

Zoë explains in a video her experience with managing type I diabetes. Dan's video represents his idea of a modular toolbox containing different tools (including dextrose), depending on the needs of a person. Both videos were edited into one new and shared in an open workshop (supra). A team of participants designed a fast and easily refillable sugar dispenser for the toolbox. Dan and Zoë created (different versions of) this dispenser. Dan made videos documenting the design challenge and the prototype. For the first, he edited the briefing - used in the workshop - into a short clip of Zoë explaining the need for quick access to sugar. For the second, he documented the iterative prototyping process illustrating how to make a sugar dispenser. Despite a close collaboration with Zoë, her perspective was not documented.

Figure 4. Dan sharing his video of the process

Zoë wore her insulin pump attached to her bra but did not feel comfortable with it and stopped wearing certain garments (e.g. blouses with cleavage). We shared Zoë's video with Julia and explained the goal of making documentation to share processes, insights and/or outcomes, but allowing documenting her collaboration with Zoë in any preferred medium. Searching for a solution that is applicable to different kinds of clothing, Julia and Zoë designed a set of pockets to hold the pump, attachable to clothing using iron-on adhesive paper. Julia created a professional video to increase the attractiveness of using this low-tech design and stimulate others in making them, which Zoë immediately shared on social media and diabetes forums. The documentation became part of the material outcome of the design. Additionally, Julia collected the communication between her and Zoë in a booklet to inform others about the process.

Figure 5. Left: Zoë sharing the video on social media. Right: still from Julia's video

Evaluation

Analysing making, sharing and using the different kinds of documentation provided further insights into the qualities of thick documentation. Furthermore Sue's case illustrates how documentation supports generating participation by different participants and Zoë's case how different participants make thick documentation and for which purpose.

First, Sue's case illustrated how *making, sharing and using documentation of material and immaterial elements supported progressing in the design process, and both iteratively and collaboratively exploring design scenarios*. Different actors documented rather general perspectives that later were combined with others, generating a dynamic range of perspectives and inspiring new participants. Iteratively sharing and using the documentation made it richer (i.e. revealing more knowledge and ideas) and more focused (i.e. making self-care visible to break the taboo). Furthermore, this documentation did not impose a specific use, allowing various appropriations by new participants and enabled the process, designs and insights to move beyond the design team.

Second, documenting the immaterial elements enabled the team to share their challenge of co-designing with Sue. Typically for participatory processes, the team's vision differed from Sue's. However, sharing documentation allowed continuing researching this vision, while developing a solution for Sue. Disconnecting the material from the immaterial in two videos allowed sharing the differing documented approaches (i.e. theirs, the students' and the participants') on the challenge the team shared. Because, the students, Dan and Julia only shared the outcome and design process, the team made the video booth to support documenting perspectives. This allowed the participants to reflect on their individual purpose of participating in the workshop, and others to understand the outcome, revealing (1) why participants value it and (2) how it relates to personal experiences. Future research should further investigate combining guidelines for documenting (e.g. how to include immaterial aspects) with the freedom to decide what to document.

Julia documented the pocket system to share with other people with diabetes. In an interview, she discussed reflecting upon video documenting exchanging of viewpoints with Zoë throughout the process, but did not know how to do this in a readable and attractive way. Dan documented the iterations of the sugar dispenser, as he is used to do for his open source projects. Similar to Sue's documentation, he documented the challenge involved through Zoë's perspective. Dan's perspective is mainly represented in the documentation of the prototypes. However, a conceptual explanation could be valuable for new participants contributing to a more substantiated approach of designing for this context.

Third, Sue's case illustrates how editing the growing collection of backstories - without losing the dynamics of the sometimes opposites perspectives - is vital to make the project readable for others. The team can choose to allow diverging use of the documentation by providing an open design space (e.g. sharing the challenge for Sue and all corresponding answers) or narrow it down

by for instance sharing one solution. Further research should explore these possibilities and their effects. Readability of documentation can also be supported by ways in which others are stimulated to use it. For instance, the games rules and video stills mediated deconstructing the videos and reconstructing them into a new scenario.

Fourth, video is interesting for making thick documentation. Video is multisensorial, allowing similarly sharing several perspectives (e.g. combining audio from one documentation with images from another), which is almost impossible to do in other ways. However, making video footage is not easy, since participants and designers often lack the skills or time to film participants' perspectives and edit them into an engaging and readable video. Moreover, editors have to consider the authenticity of the perspectives, allowing participants to recognise their perspectives (Venturini, 2010). Future research can explore ways of co-editing the footage with participants, similar to the card sorting game of Buur & Soendergaard (2000).

Fifth, documenting processes demands time. Setting up alternative documentation methods can reduce this investment. The storyboard, game rules and video booth facilitated documenting the outcome and perspectives during a short workshop. In the future we will further explore alternative ways for documenting in shorter time spans.

Conclusion

We analysed two processes of making, sharing and using thick documentation in the context of designing self-management tools for type I diabetes. Sue's video documentation supported designing with new and already involved participants. Documenting material and immaterial elements of a project supports sharing knowledge among them. This illustrates the potential of thick documentation making room for a discourse in the field of designing for health by allowing changing and diverging perspectives on the issues at stake.

The design team shared fieldwork, challenges, outcomes, insights, etc. as an invitation to elaborate on these elements. However, the team still played a deciding role in these 'outsourcing' processes. Future outsourcing projects should therefore continue supporting making and sharing documentation and specifically approach how to document and share immaterial information.

We investigated the qualities of thick documentation within project-time, wherein the design team controls mediating participation. Nonetheless, using documentation for inviting new contributions and for exchanging knowledge and practices illustrates the potential of thick documentation to continue supporting participation in use-time. We continue investigating this mediating role between participants with type I diabetes and designers, researchers, etc. designing for these specific issues. Documentation of these processes allows continuing sharing the knowledge generated throughout contributions. Along with this, the documentation will

become richer and a community of practitioners in this field may grow, having the potential to become mediators in their turn.

Acknowledgments

References

BUUR J. and SOENDERGAARD A. (2000). Video Card Game: An augmented environment for User Centred Design discussions. *Proceedings of DARE 2000*, 63-29.

FUNNELL, M. and ANDERSON, R. (2004). Empowerment and self-management of diabetes. *Clinical Diabetes*, 22, 123 -127.

GEERTZ, C. (1973). *The interpretation of cultures: Selected essays* (Vol. 5019). Basic books.

HUYBRECHTS, L., SCHOFFELEN, J. and HAGENAARS, B. (2014). Make-and-tell in Haspenwood: on generativity in sustainable design. *Proceedings PDC 2014*, 37-40.

SCHOFFELEN, J., HUYBRECHTS, L. and DREESSEN, K. (2013). Please resuscitate! How to share a project concerning self-management in diabetes to enable participants to elaborate on it after project completion? *Proceedings of the Second European Conference on Design 4 Health 2013*, 238-246.

SCHOFFELEN, J. and HUYBRECHTS, L. (2013). Sharing is caring. Sharing and documenting complex participatory projects to enable generative participation. *Interaction Design and Architecture (s) Journal*, 18(1), 9-22.

VENTURINI, T. (2010). Building on faults: How to represent controversies with digital methods. *Public Understanding of Science*, 21(7), 796-812.

WOOTTON, R. (2000). The development of telemedicine. In M. RIGBY, R., ROBERTS and M., Thick (Eds.). *Taking health telematics into the 21st century* (pp. 17-26). Abington: Radcliffe Medical Press.