

## **From understanding to solutions: understanding the experience of a client with PIMD through designing a co-design toolkit for formal and informal networks.**

HAN University of Applied Sciences is developing the Helpende Hand method. This method helps care professionals and care facilities find a meaningful way to implement assistive technologies for individuals with Profound Intellectual and Multiple Disabilities (PIMD). To counter the shortage of personnel, assistive technologies can help users when needed. To design such technologies we make use of the experiential knowledge of the informal and formal networks, such as family, friends and (professional) caregivers. They have much valuable information, that people with PIMD typically cannot articulate well themselves. The formal network consists mainly of professional caregivers, offering more clinical information with regard to the client. They understand the client while reflecting on the academic courses they studied compared to the experiential knowledge of the formal network.

The Helpende Hand aims to develop a method by which care professionals can use the knowledge of the informal network to better personalize assistive technologies for these persons with PIMD. This thesis is part of the overarching Helpende Hand method and will focus on one co-design case study in the PIMD context. Within this case study, a design toolkit will be developed to tackle practical problems. The insights from this case study will be used to investigate possible tools that help make the networks understand the experience of the client better. This understanding of experience will be gained in the frame of design, which is a new subject for the networks.

Thus the central questions for this research is: how can designing a co-design toolkit in a PIMD context, help the informal and formal networks with understanding the experience of a PIMD client? This is done by doing a literature review, context mapping, and co-design case study. This thesis looks at experience and especially the experience of people who can not communicate this verbally. During the course of this project, the literature is combined with context mapping and the case study to create an partly individualizable co-design toolkit, which will aid the networks in understanding the experience of the client better, think of making the knowledge they have more explicit and investigating the knowledge gaps. The toolkit is digital and consists of four phases, which are evaluated during the different co-design sessions with the networks of the client. With the aim of creating a toolkit, which can be used without the need for the facilitation of a professional designer or researcher. During the design of the toolkit it was important to keep in mind that there is heterogeneity within this group (clients with PIMD), thus a generalized list of what to look out for in terms of experience will not work.

This toolkit provides exercises to be done with the client and with the networks which act as proxies, to create this understanding. One of the bigger problems that appear is the time the networks have, co-designing takes time, but this is time the formal and informal networks do not have. Besides this, it is important to look at how people not trained in design, can use the toolkit to be designers and researchers themselves. The designing of the toolkit helped in various ways with creating a better understanding of experience for the networks. First, the iterative process of design was a cycle of reflecting and talking through current problems, which helped the network with actively thinking about the client and their experience. Instead of doing everything on autopilot like they were accustomed. Besides this, the exercises and its answers and artifacts provided a new awareness about the the situation and the experience of the client. The networks mentioned that the knowledge for these exercises was already existing, but they never thought about in a way of solving problems. Thus better understanding for this case study was creating awareness about the existing knowledge by iterating and doing co-design exercises together within the design triangle.

The result of these co-design sessions consisted of a first iteration of a co-design toolkit. Aspects of the toolkit that resulted from the research were: partly individualizable exercises, adding a secretary, making the toolkit digital and sharable, and the toolkit working as a facilitator itself. The first aspect was important because the co-design sessions were not only done by proxy, but the client needs to be included as well, however, all clients are unique, thus a general set of exercises will not work. The secretary helps the design triangle by noting down the results of the exercises, as from the case study it became apparent that this was too much for the design triangle. The digital aspect is used to make it fit in the busy PIMD context, providing the possibility of resuming the sessions later on. Lastly, co-design sessions need facilitators to work, but because this research tried to find ways to design a toolkit without the interference of an external designer, the toolkit itself guides the design triangle through the exercises.

As the designed toolkit went through one iteration, there are some aspects that need further research. Starting with the design phase. Within this phase the design triangle comes up with an idea, designs this, and makes a prototype to evaluate. Because of the time frame of this thesis, and the time the design triangle had, they were not able to make a prototype themselves. This phase, together with the evaluation phase where the prototype is tested, need some further co-design sessions, to understand if these exercises work in this context. Besides this, some aspects like the secretary and the toolkit facilitator need to be evaluated in-depth, to conclude if the toolkit can be designed without the interference of outside help. Overall, at least one extra iteration of the toolkit and its content is needed to go from prototype to final toolkit design.

The following figures highlight and explain the results of this thesis.

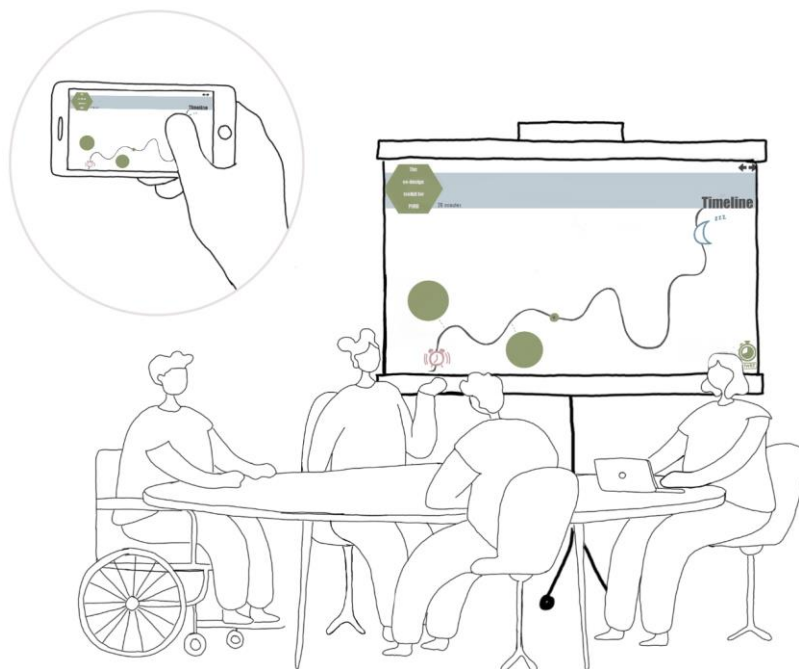


Figure 1. How to use

Figure 1 explains how the toolkit will be in use. The client and the networks together will go through the phases presented within the toolkit, and solve a problem or part of a problem in the PIMD context of the client. There is a secretary noting down all important information. This is a digital toolkit, accessible from anywhere and presented on a bigger screen during the sessions.



Figure 2. Client page

Figure 2. Shows the different phases and the client page. From this page the design triangle can start or resume a phase, check the calendar, share the information with other people or add spontaneous ideas. This is the starting point of the toolkit.

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