Tangible Tools & Techniques: Co-Designing with Locked-In Syndrome

Laura Beunk

Faculty EEMCS/BSS

Supervisor dr. F. Nijboer
Critical Observer dr. J. van Dijk

2019

UNIVERSITY OF TWENTE.

Abstract

There has been a paradigm shift in design methodology from user centered design towards co-design. During a co-design process users are closely involved as experts of their own experience to maximize user-value of the design output. A user group that hasn't been involved are individuals with Locked-In Syndrome. This group has lost most or all control over voluntary movement and thereby most ways to interact with their environment. This pioneering study set out discover how to apply co-design methodology to design a technical solution with a locked-in individual to enhance his interactive ability. Existing tools and techniques (e.g. probing and scenario-based design) were adapted to form a co-design method suitable for working with locked-in individuals. This method was then applied to design the technical solution with a single locked-in participant. A method with three phases was developed. The main activities in the three phases are a day in the life probing activity resulting in a problem statement, a generative session with scenario enactment resulting in a concept idea and a prototype discussion resulting in a final concept, respectively. Each activity had a tangible component and was performed with the locked-in participant in his home context. After qualitative evaluation of the method and design output it can be cautiously concluded that a focus on tangible interaction is beneficial to the application of co-design methodology with locked-in individuals and individuals with similar impairments.

Contents

List of Figures

List of Tables

Chapter 1

Introduction

The locked-in syndrome is a serious neurological condition in which individuals lose almost all ways to interact with their environment due to a loss of movement and speech. This means these people have lost a significant amount control over their life. In order to help them interact with their environment in an empowering way, co-design may be a methodology that holds a lot of potential.

1.1 Current situation

Ever since the 1980's design practice and research has become more focused on the user. Before this shift, design was for the user [8]. A product would be designed and only tested for success in a late stage of the design process, for example in focus groups lead by market researchers. This meant designers were less concerned with what they would design, they were mostly executioners of their client's ideas. User centered design practice shifted the focus from designing for the client to designing for the user. User's wants and needs were considered in earlier stages, however they remained mostly a passive object of observation. By consulting with users in earlier stages, it became a role of the designer to determine what to design as well as how. Designers included more research in their work and vise versa [8]. This has lead to the co-design approach that has been gaining traction. It aims at designing together with the user, not just for the user. This means that users play an active role in the design process to varying degrees. Designers, researchers and users work together, instead of separately as illustrated in figure 1.1 [1].

Locked-In syndrome (LIS) is a state where a person is almost completely or completely paralysed while conscious and cognitively intact. A person with LIS can perceive the environment they are in but is almost unable to interact with it. This includes the inability to communicate through speech. LIS can be divided into three types [9]. First, classical LIS which is characterized by vertical eye movement as the only possible type of movement. Second, incomplete LIS which can include small movement of other muscles. Third, total LIS, where no movement is possible at all. The cause of LIS is often a brain stem lesion, in most cases a bilateral ventral pontine lesion [9]. Neurorehabilitation can lead to varying degrees of improvement in physical ability, from being able to swallow autonomously, to increased walking ability [10].

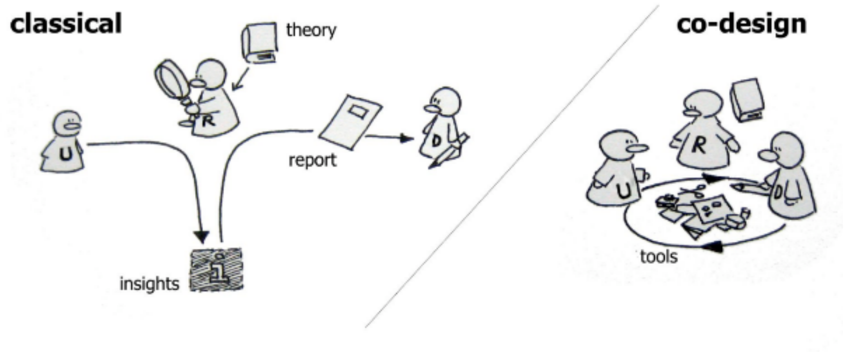


Figure 1.1. Changing of roles from a classical design approach (left) to the participatory design approach (right) [1].

1.2 Problem statement

Due to the state of their being, locked-in individuals lack power in their lives. The limited ways they have to interact with their environment often put them at the mercy of others around them. This lack of autonomy or even the fear of it can be detrimental to the individuals mental health [11].

1.3 Research objectives

Co-design is especially empowering due to its participatory nature, and therefore interesting to explore with this group. By designing a technical solution to enrich the ways locked in patients can interact with their environment with a participatory approach, the user is empowered in two ways. However, there is a lack of research on co-designing with locked-in individuals. Therefore, the objective of this research is to adapt and develop co-design methods for people with locked-in syndrome, and test these methods by applying them to the design of a technical solution with a locked-in patient.

This leads to the following research question: *How can co-design methodology be applied to design a technical solution for a person with Locked-in Syndrome?*

1.4 Research outline

By looking at existing literature about co-design and practical cases involving impairments similar to the locked-in syndrome, possible co-design methods will be formulated. These methods will then be tested and iterated upon throughout the design process of a technical solution for a locked in patient, in accordance with research through design methodology [12].

Chapter 2

State of the Art

This chapter discusses the state of the art in co-design and technology related to locked-in syndrome. In the co-design section, approaches to co-design tools and the co-design process will be described followed by a review of co-design with both verbal and physical impairments. In the section about locked-in syndrome, the means of communication and interaction will be discussed followed by a review of technology used by people with locked-in syndrome.

2.1 Co-design

2.1.1 Co-design Tools and Techniques

A key aspect of co-design is recruiting end users as “experts of their own experience” [2]. There are the past, present and future experiences, as illustrated in figure 2.1. The goal is to capture these experiences and use them to explain the context of the design problem.

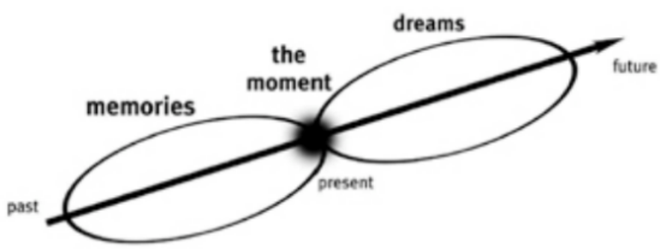


Figure 2.1. The experience domain: what is experienced depending on the moment it took place [2].

Generative techniques can help get deeper into the participants mind. It can expose tacit and latent needs [13]. Figure 2.2 illustrates how people, techniques and knowledge relate to each other in this context.

These generative techniques can be seen as the making part of the making, enacting and telling framework proposed by Brandt, Binder and Sanders

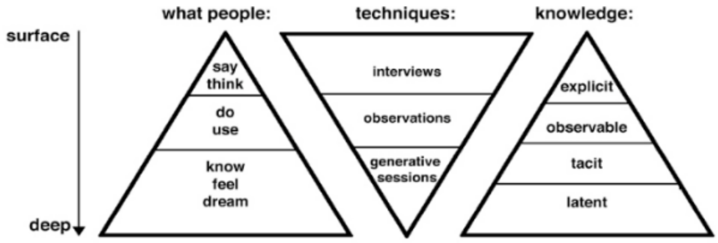


Figure 2.2. Relationship between the different layers of people, techniques and knowledge [2].

[3]. Each of those aspects relates to the techniques mentioned in figure 2.2: interviews are about telling, observations about enacting and generative sessions about making. However, these aspects cannot be separated from each other, as illustrated in figure 2.3. As Sanders & Stappers [6] have observed: "We have seen in practice that people make artifacts and then readily share their stories about what they made or they naturally demonstrate how they would use the artefact". They even conclude that the meaning of the generated artifact is often only brought out when there is a story around it or when it is actually placed in a usage context. This was already stated by Sleeswijk-Visser as fundamental in their 2005 paper on context mapping [2]: "The basic principle behind generative techniques is to let people make designerly artefacts and then tell a story about what they have made".

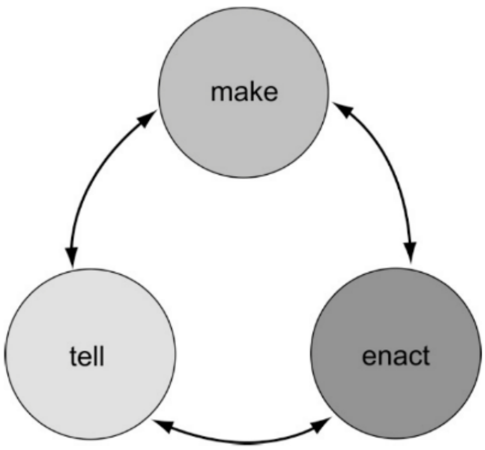


Figure 2.3. Relationships between make, tell and enact [3].

The make, tell, enact framework is only one way of looking at the types of co-design tools. Tools in each of these categories can have certain purposes, sometimes overlapping. An overview of the framework proposed by Brandt et al. [4], relating these purposes to the make, tell and enact tools can be seen in figure 2.4. They propose four purpose dimensions: probing, priming (preparing the users for later phases), understanding experience and the generation of design ideas and concepts.

TOOLS AND TECHNIQUES	PROBE	PRIME	UNDERSTAND	GENERATE
MAKING TANGIBLE THINGS				
2-D collages using visual and verbal triggers on backgrounds with timelines, circles, etc.	X	X	X	X
2-D mappings using visual and verbal components on patterned backgrounds		X	X	X
3-D mock-ups using e.g. foam, clay, Legos or Velcro-modeling			X	X
TALKING, TELLING AND EXPLAINING				
Diaries and daily logs through writing, drawing, blogs, photos, video, etc.	X	X	X	
Cards to organize, categorize and prioritize ideas. The cards may contain video snippets, incidents, signs, traces, moments, photos, domains, technologies, templates and *what if* provocations.			X	X
ACTING, ENACTING AND PLAYING				
Game boards and **game pieces and rules** for playing		X	X	X
Props and **black boxes**			X	X
Participatory envisioning and enactment by setting users in future situations				X
Improvisation				X
Acting out, skits and **play acting**			X	X

Table 1: The tools and techniques of PD organized by form and by purpose.

Figure 2.4. A framework relating make, tell and enact tools to purpose [4].

The first dimension, probing, is to evoke answers from participants by prompting them in an ambiguous way. In the Cultural Probes method introduced by Gaver et al. in 1999 [14], the results of this would be interpreted by designers only, and the answers to the probes would be the end result. In the context mapping approach [2] sensitizing tools fulfill a similar role. However, the output coming from the tools is not only to inform the designers about the participants' experiences, but also to prepare the participants for upcoming generative sessions. As stated in the context mapping paper: "The main objective of the sensitizing tools, is to establish self-reflection on the part of the participants, which is then harvested during the generative sessions." So in that case the probing also has a priming function.

Probing

Probing is done to elicit inspirational responses from the participant by giving them ambiguous prompt encouraging novel interpretation [14] or to gather information [15]. Participants are provided with a toolkit consisting of several prompts and answering tools for them to respond to in their own time. The goal is not directly to get an objective view of the users needs, but The prompts are questions open for interpretation ranging from questions about the participants personal life to ones relating more to the design challenge at hand. After the user finishes the self documentation, the probes are delivered back to the designers who can do the initial analysis, which can then be discussed with the users, using the probes to spark discussion. The combination of raw results and insights from the discussion can then serve as input for the rest of the design process [5]. The probing process is pictured in figure 2.5.

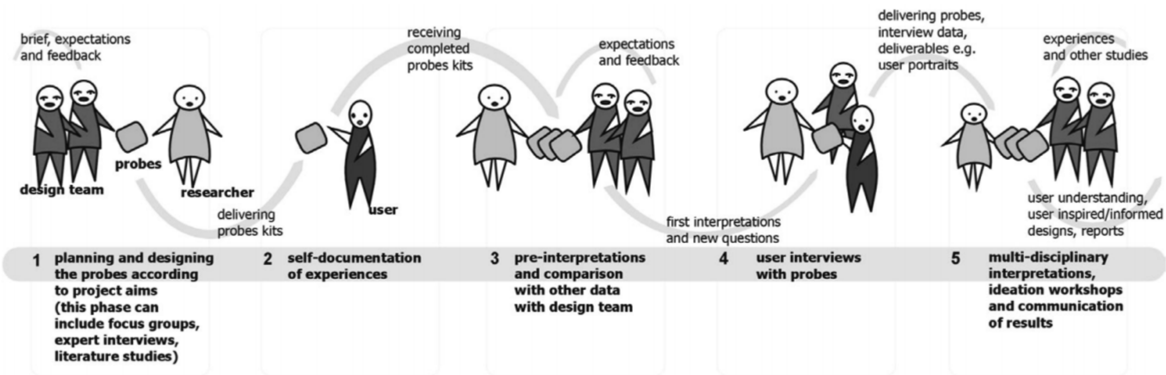


Figure 2.5. Probing process as seen by Mattlemaki. [5]

The answering tools can be diaries, postcards, cameras, maps, anything. Several aspects of these tools can be taken into account to make them more tempting to interact with [5]. The tone of the materials, aesthetically or otherwise, influences this. Participants should not feel pressured, and reducing the distance between designer and user can make them feel more comfortable. On one hand a casual look of the material can make it look less boring and official and more personal, while presenting abstract materials can lead to a more a detached attitude to requests, encouraging the participants to use the materials as they see fit. The designer can reveal themselves through the design of the tools and prompts, making the process more communicative.

2.1.2 The co-design process

According to Sanders & Stappers [6] the co-design process exists of four phases: pre-design, generative, evaluative and post-design. The pre-design and post-design phases focus on understanding people's daily life experiences: past, present and future. Additionally in the pre-design phase the people involved can be primed, i.e. prepared to co-design. The generative phase is focused on producing ideas, insights and concepts for future designs. The design space and contexts of use are explored. Lastly, the evaluative phase is for assessment of design outcomes, in the present and near future. A comprehensive overview can be seen in figure 2.6.

Design research	Pre-design and post-design	Generative	Evaluative
Purpose	To understand people's experiences in the context of their lives: past, present and future dreams	To produce ideas, insights and concepts that may then be designed and developed	To assess, formatively or summatively, the effect or the effectiveness of products, spaces, systems or services
	To prepare people to participate in codesigning	What will be useful? Usable? Desirable?	Is it useful? Usable? Desirable?
Results	Empathy with people	Opportunities for future scenarios of use	Identification of problems
	Creative codesigners	Exploration of the design space	Measurement of effectiveness
Orientation	Past, present and future	Future	Present and near future

Figure 2.6. Relationships between make, tell and enact [6].

They also show three approaches relative to the phase in the design process, as can be seen in figure 2.7. The three approaches are probes, generative toolkits and prototypes, the former two relating to earlier mentioned techniques. The approaches can be used to explore the three time frames by tailoring them to the time context. An overview of different applications in each time frame can be seen in figure 2.8.

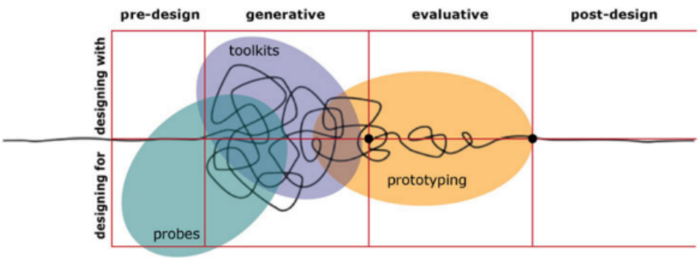


Figure 2.7. The co-design process with four phases (horizontal), two design approaches (vertical) and three methods (ovals) [6].

The approach not yet introduced, prototypes, can play multiple roles, according to Stappers [16]: evoke focused discussion, testing of hypotheses, confronting theories, experience new situations. They fit very well in the evaluative phase, since they can be build from the ideas generated from earlier phases. Actually, each of these approaches can use input from the previous ones. In this way participants are lead in their creativity levels as proposed by Sanders in 2008 [1]: doing, adapting, making and creating, see figure 2.9. In this way, even people that are at level 1 at the start of the process can be guided to create.

	Probes	Toolkits	Prototypes
The world as it is	Cultural probes (Gaver, Dunne, and Pacenti 1999)	Toolkits for understanding experience: a day-in-the-life exercise	Usability testing of an incrementally improved redesign
	Design probes (Mattelmäki 2005)		
The near future	Design Noir (Dunne and Raby 2001)	Toolkits for exploring future experience: my-ideal-future-product exercise	Usability/field testing of a radical new product
The speculative future	Diegetic prototypes (Kirby 2011)	Toolkits for experimenting with experience: make-believe role-playing with co-constructed artefacts	Research through Design prototypes (Keller et al. 2009)
	Artefacts from the future (WIRED magazine)		

Figure 2.8. Relationships between the three methods and time perspectives [6].

Level	*Type*	*Motivated by*	*Purpose*	*Example*
4	*Creating*	*Inspiration*	*'express my creativity'*	*Dreaming up a new dish*
3	*Making*	*Asserting my ability or skill*	*'make with my own hands'*	*Cooking with a recipe*
2	*Adapting*	*Appropriation*	*'make things my own'*	*Embellishing a ready-made meal*
1	*Doing*	*Productivity*	*'getting something done'*	*Organizing my herbs and spices*

Figure 2.9. The four creativity levels [1].

2.1.3 Co-design with verbal impairments

Both methods relying upon language and omitting language have been implemented successfully to co-design with people that are verbally impaired. Virtual environments where participants have means to express themselves are used successfully by both Galliers [17] and Wilson [18]. Galliers used games to gain latent insights while Wilson's environment was more a simulation of everyday life, which made it more of a direct communication tool. Both were effective, though had different purposes. The gamification is a more accessible way for the participants to engage and relies more on researchers to extract insights, while the other virtual environment enables participants to be more active in the design process.

The use of proxies to communicate during the design activities might impede upon the empowerment of the participants. In their study, Hamidi [19] chose the Participatory Design with Proxies approach based upon earlier successes. The proxies are people that stand in or for the target users, or join as a communication intermediary, usually people close to them or similar to them. According to Hamidi in their study the main benefit of the proxies was that communication barriers between researchers and users could be overcome more quickly. Indeed, communicating with people that are verbally impaired often takes effort and time. However using proxies takes away power, according to Galliers [17]. They strongly reject using proxies, instead focusing on creating a bond with the users over an extended period of time. Konnerup [20] acknowledges both the benefits of proxies and building a relationship with the participants. In their opinion, the proxies are an aid for the latter. The focus is on choosing the right communication method for each participant. It seems important that participants are respected and that time is taken to communicate with them in order to understand them. However, communicating through proxies would take away an opportunity to empower the participant. Therefore proxies can assist in establishing means of communication and building a relationship, but should not be the only channel of communication.

2.1.4 Co-design with physical impairments

There is a lack novel co-design methods specific for people with physical impairment, tangible tasks are often delegated or forgone completely. In their study with cerebral palsy patients and their caregivers Bernatchez [21] uses video recording of the current showering process to omit the participants having to describe the situation in interviews. In this way a lot of details about the process and context can be conveyed efficiently. The goal of the study was to redesign the bathroom to better cater to adolescents with cerebral palsy. After the recording participants were asked to come up with design solutions themselves. However, creating the designs was delegated to the researcher, who created drawings of design solutions as participants described them. Morales [22] uses the same type of delegation, however they do encourage sketching by the participant as a "homework activity". Krishnaswamy [23] completely forgoes the physical by only engaging with participants virtually through an online survey where they are shown virtual prototypes to comment upon. Similarly, Daveler [24] depended solely on language in their participatory activities. An interview and a questionnaire were conducted. To conclude, due to the physical impairments, there seems to be less involvement of the participant in the generative and tangible parts of the design process. Designers rely on descriptive verbal communication for these type of tasks, making them less generative and more reactive.

2.2 Locked-In Syndrome

2.2.1 Communication with Locked-In Syndrome

The most basic way of communication locked-in individuals use is some form of eye movement code [9]. This is usually a binary code, for example blinking once for yes and two for no or looking up for yes and down for no. This would mean only closed questions could be answered, however multiple systems have been developed to prompt locked-in individuals for more complex answers. The most common ones are alphabetical communication systems. In order to communicate a specific phrase, locked-in individuals spell every letter separately. The alphabet can be divided in a number of sections, where the locked-in individual will first respond positively when the right section is mentioned, and then to the right letter. Sometimes the letters are sorted by frequency and mentioned one by one, omitting the sectioning. There are many variations to this technique. The downside to this way of communication is that another person always needs to be present.

However, there are alternative and augmentative communication (AAC) methods that make it possible to communicate independently, even with a single movement [11]. Locked-in individuals are able to use on screen virtual keyboards to type out phrases. They are able to interact with this keyboard in several ways. Some interaction methods are precise enough to use the keyboard like a mouse would be used, while others use a similar way of prompting the user to select letters as with the alphabetical systems. This way of selecting things by either going over the options one by one or going over them in multiple sections is called scanning [25]. This text can then be read out loud by a speech synthesizer.

2.2.2 Interaction with technology with Locked-In Syndrome

Locked-in individuals are able to interact with technology through multiple access technologies. If enough movement is possible, a switch can be used. This switch could be operated for example by a thumb or sometimes head movement [7]. Another possibility is gaze tracking, either with camera guided systems or infrared sensors [26]. The last way of interaction are Brain Computer Interfaces (BCI). This way of input is independent of any movement possibility. Brain activity is recorded and mapped to input signals [27]. This method is however the most invasive since electrodes have to be either attached or inserted into the individual [26]. In figure 2.10 an overview of the types of access technologies can be seen. The access technology is only a part of the access solution as defined by Tai et al. [7]. Between the user's functional intent and the functional activity there is both the access technology and a user interface where the type of user interface usually determines the functional activity. Figure 2.11 illustrates the entire access solution.

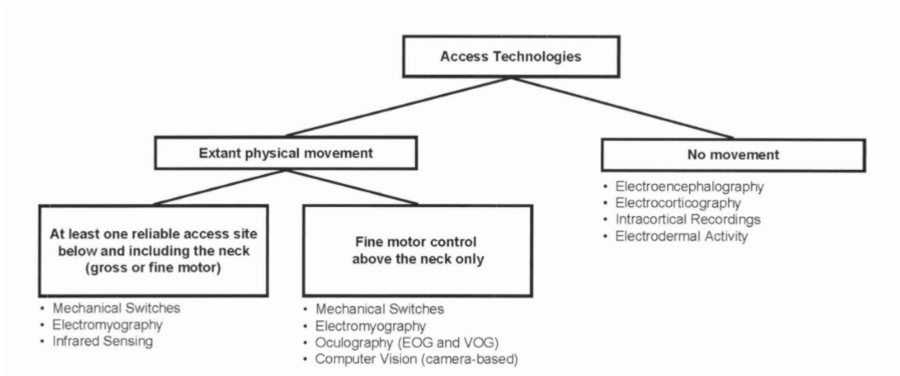


Figure 2.10. Overview of access technologies categorized by the level of physical movement the user is able to achieve [7]. Locked-in individuals can be on any of these levels.

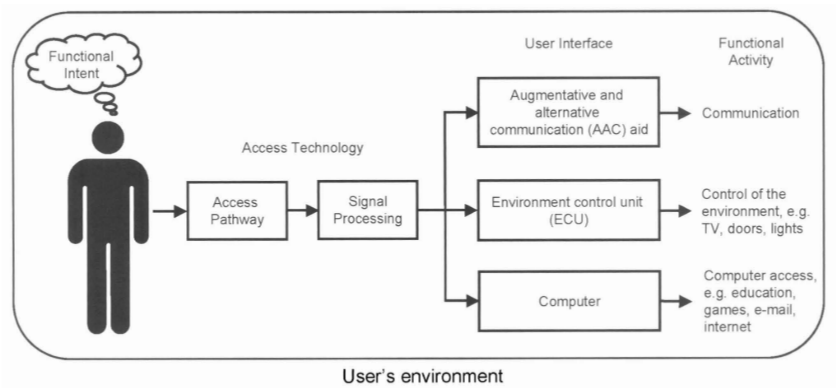


Figure 2.11. Overview of an access solution through an access technology and a user interface the user's functional intent is translated into a functional activity [7].

Three types of user interfaces are identified by Tai et al.: (1) AAC aids which facilitate communication; (2) environment control units (ECU) which facilitate control of the environment and (3) computers which facilitate access to the functions usually present on a computer. Accessibility options on traditional computer-type user interfaces - including smartphones - facilitate the use of mainstream technology, e.g. Android switch access[1]. Many of these options use the scanning method to go over the elements on the screen that can be interacted with, or even provide the ability to do point based scanning for more precise control. These ways of scanning are illustrated in figure 2.12 and figure 2.13 respectively. ECU's like GEWA connect[2] allow users to control many aspects of their home like lighting or the TV.

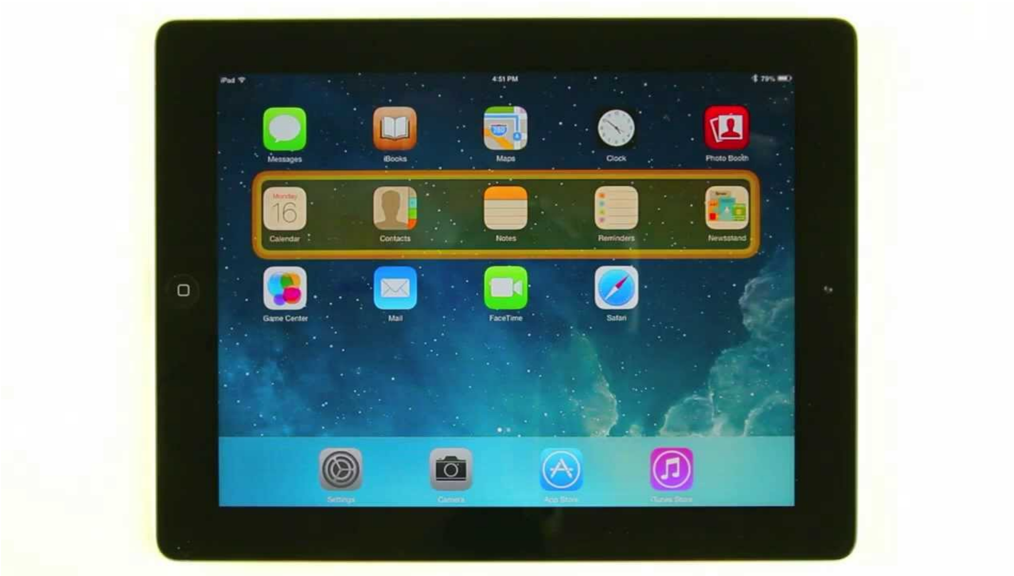


Figure 2.12. Grid based scanning on a tablet.

2.3 Conclusion

In order to go through a co-design process three types of methods should be present: probes, generative toolkits and prototypes. Within these types of methods tools should be present that allow artifacts to be created and discussed. The tools throughout the the methods should build upon each other and gradually build up the creativity level of the participant.

Some obvious hurdles are visible when making and discussing with locked-in individuals. From literature some examples of co-design with similar impairments could be found. One of the ways to co-design with verbal impairment is to get the user in a context where they do not have to talk. This means either a change of environment that has alternative means of communication,

[1] https://support.google.com/accessibility/android/answer/6122836?hl=en
[2] https://www.abilia.com/en/product/gewa-connect

Figure 2.13. Point based scanning on a tablet.

for example a computer simulation; a change of activity into one where the researcher can extract insight by observing, for example a game; or an alternative communication method in a setting where talking would usually take place, for example using organization of pictures, to communicate. What is important in this communication is to establish a relationship with the participant, proxies can be used to help in this process. In co-design with physical impairment it seems that language and verbal communication is the main way of interacting with participants and extracting information. Generative tasks were mostly by means of verbal description, delegating the physical aspects. Observation is one way to omit the verbal aspect.

By focusing on the abilities instead of the disabilities of the individuals, new context can be created for the design activities to take place in. These contexts could be both in virtual space or in physical space augmented by the right tools.

Chapter 3

Research Methods

This chapter describes the approach to research and design in this study. Research through design methodology served as a guideline for the approach to developing a co-design method. The co-design process provided a chronological structure and key outputs to work towards in each step. A structured approach with a consistent evaluation for tools and techniques allowed the co-design method to be assembled in a systematic way.

3.1 Research setup

The approach to research in this study was in accordance with the Research through Design methodology. The unique aspect of this methodology is that it aims to use design to generate knowledge, as opposed to using design only to generate solutions [12]. That knowledge is then used to inform design and so forth. In the case of this study, research was done to inform the development of tools and techniques which were combined into co-design activities. These design activities were then executed, yielding both a design insight that contributed to a solution and knowledge about co-design. That knowledge in its turn informed the further research and development of co-design tools and techniques. That cycle was repeated until there was a final solution concept and a co-design method. The cycle is illustrated in figure 3.1.

3.1.1 Participants

In total four people were involved in the research and design process. The main researcher took upon themselves the role of leading designer. The solution was mostly designed together with one person that has locked-in syndrome. Sessions with this person took place at their home or through a video call. In the generative phase multiple people participated, one close to the locked-in individual, the others other designer-researchers. This session also took place at the locked-in individuals home.

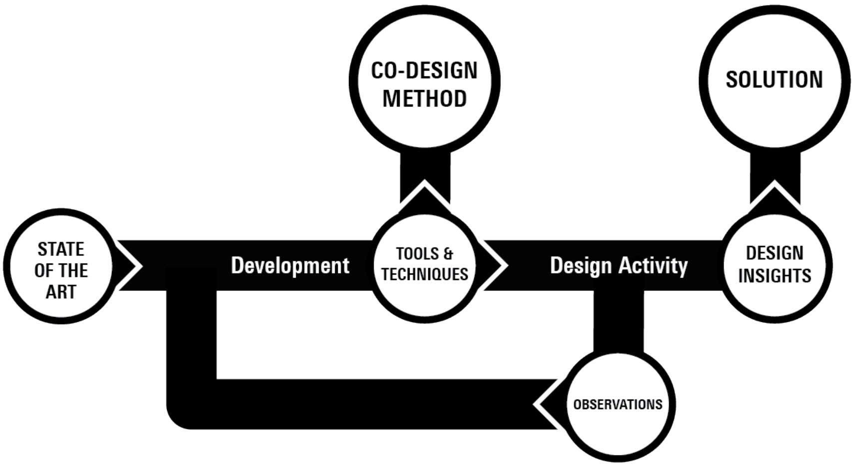


Figure 3.1. The Research through Design cycle in this study.

3.2 Co-design Process

The project was structured according to a four phase co-design process as proposed by Sanders and Stappers [1]. The process is pictured in figure 2.7. The four phases are the pre-design phase, the generative phase, the evaluative phase and the post-design phase. The model was adapted for this project to focus on the results of each phase, as can be seen in figure 3.2. From the pre-design phase a problem statement was to be obtained through researching the user's experience. In the generative phase the goal was to obtain one or several concepts for a solution to the problem statement through generative activities including the enactment of scenarios to prime users. In the evaluative phase the concepts were evaluated through iterative prototyping with the user which was supposed to lead to a final prototype. However, the process ended in the middle of this phase, with a final solution concept. The last phase, the post-design phase, was never reached, but it would have been used to determine the success of the solution.

The amount of insights, ideas and concepts over time was similar to the UK Design council's double diamond structure [28] where there is divergence in user research and convergence to a problem statement, followed by another divergence for possible solutions and again convergence to a final solution.

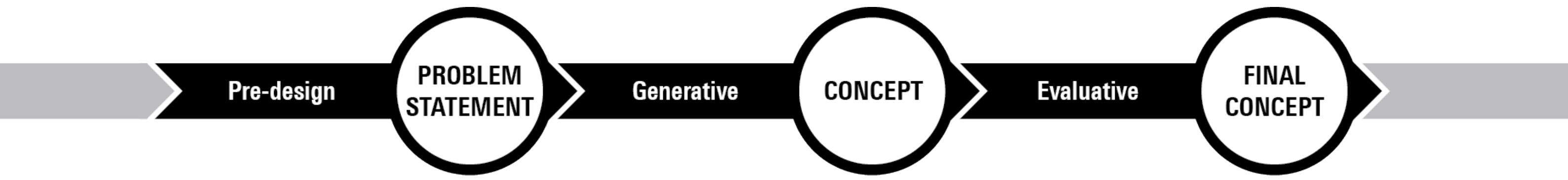


Figure 3.2. The design process as followed in this project. In circles the results of each phase.

3.3 Development of co-design tools & techniques

In order to systematically come up and test co-design tools and techniques in each phase, a consistent approach was needed. For each co-design method the following steps were followed: *defining a goal, research, brainstorm, formalization, application, and evaluation.* The first step, *defining a goal* was a crucial step to effectively design a method, since it gave direction to the research. It was also important in the evaluation process since one of the measures was if the goal was reached. The *research* was to be able to built upon existing tools and techniques on which was elaborated in the *brainstorm.* The *formalization* resulted in a process overview and a detailed approach. Before *application*, necessary tools were developed. After application the design activity was *evaluated* in a consistent way, as described in section 3.3.1.

3.3.1 Co-design Evaluation

The success of co-design processes can be measured from at least two perspectives. The first aspect is the the amount of participation from the user. Segalowitz [29] proposes to assess this in three dimensions: (1) the impact of the participant on the project, measured by the value and rate of implementation; (2) the influence of the participant, both in scope and quantity; and (3) agency, by looking at the participants solidarity and willingness. This assessment structure was successfully implemented by Garde & van der Voort [30].

Another aspect to assess is the key innovation outcomes existing of user benefit, feasibility and novelty as implemented by Trischler [31]. While Segalowitz assessment is more specific for co-design, the way of assessment presented second could be applied to projects that do not use a co-design process. The first takes participation as an inherently positive addition, while the second assessment does not assume this. To remain critical, it seems both assessments should be used in order to determine the success of a co-design process.

The aforementioned approaches are usually used to asses an entire design process. However in this research the individual parts of the process had to be evaluated, so the two scopes were applied to the individual design activities with some adjustments. Looking at outcome, three aspects could be qualitatively discussed. Firstly, reaching the goal. In the development of the method a clear goal was set. During evaluation it was assessed if and to what extent this goal was reached. Secondly, the novelty of the outcome was evaluated by comparing the outcomes to expectations set before the design activity was executed. Both the amount of novelty and its scope were taken into consideration. Lastly, the usefulness of the outcome was assessed by using it as input in the next phase and looking at the usefulness in extent and scope.

In the case of user participation, the impact of the participant was determined by looking at all the information that was gathered and assessing the quality and quantity of information that was actually used; the influence was measured by looking at the decisions that were made in the process, and how many of them were made by the participants and their scope; the agency of the participant was judged using observations made during the application of the method to asses their motivation and solidarity. An overview of the evaluation measures can be found in table 3.1.

Method aspect	Measure	Dimensions	How to assess
Outcome	Goal reached	Extent	Check against pre-set goal
	Novelty	Amount, Scope	Check against pre-set expectation
	Usefulness	Extent, Scope	Check in next phase
Participation	Impact	Quality, Quantity	Look at the information gathered
	Influence	Amount, Scope	Look at the decisions made
	Agency	Motivation, Solidarity	Look at observation

Table 3.1. Overview of the qualitative evaluation methods.

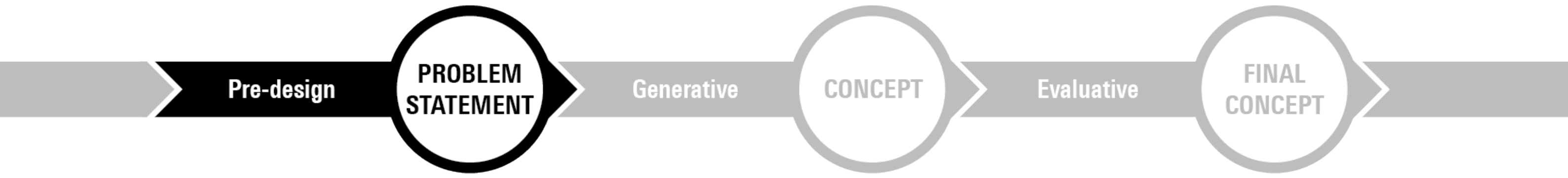
Because some of the evaluation measures needed input that was generated before the application of the method, the evaluation process had to consist of two phases. This lead to the following evaluation approach:

- *Before application:* write down goals and expected outcomes.
- *After application:* assess the outcome and participation according to table 3.1.

Chapter 4

Pre-Design Phase

This chapter describes the first phase of the design process, the pre-design phase. In this phase user experiences were collected and synthesized into a problem statement. This was done using several tools and techniques that were evaluated afterwards.



4.1 Overview of the Pre-Design Phase

4.1.1 Goals

This phase had two goals: gathering information and defining a problem. The information to be gathered was about the participant's *experience*, *context*, *motivations* and *opportunities* for improvement. A problem statement template from Stanford University [32] was adapted to capture both the information and the problem definition in one statement, the type of information is color coded to the topics above:

> As a *type of user*, who is *characteristics*, I am trying to *outcome/job* when *context* so that *goal*, but I keep experiencing *problem/barrier* because *root cause*, which makes me feel *emotion*.

4.1.2 Pre-design Expectations

Before the design activities in this phase some knowledge about the participant was already present. This knowledge was obtained from being introduced to the participant at the start of the project and visiting him once in his home. This knowledge could be categorized according to the main aspects of the problem statement as seen in table 4.1.

Aspect	Current knowledge
User and Experience	A locked-in individual, unable to talk, unable to move his body except for a thumb and his head, ambitious, stubborn.
Context	Lives in his own apartment with assistive personnel around, watches TV (sports).
Problems	slow spelling system hinders efficient communication and people can be impatient sometimes making communication fail completely.
Goals and Motivations	Communicate, express himself, run a business, give talks, be social

Table 4.1. Expectations before probing

4.1.3 Pre-design Process

The information to be gathered as represented in italics in the problem statement template can be related to a certain type of knowledge. The four types are as desicribed by Taylor et al. [13] as *explicit*, *observable*, *tacit* and *latent*. They are in that order from easiest to access to hardest to access, as is pictured in figure 2.2. Each topic of information has knowledge to be gathered of different types.

To gather these different knowledge multiple steps were needed. Therefore Sanders and Stapper's day in the life exercise [8] was adapted for the project. In this exercise a timeline is first filled with the participants activities (*explicit* or *observable*). The participant then mark high and low points (*tacit*) on which they reflect on the reasons (*latent*) in the next step. Figure 4.1 shows how different layers make up the exercise. In these layers the different types of knowledge can be acquired. All these relations are shown in table 4.2.

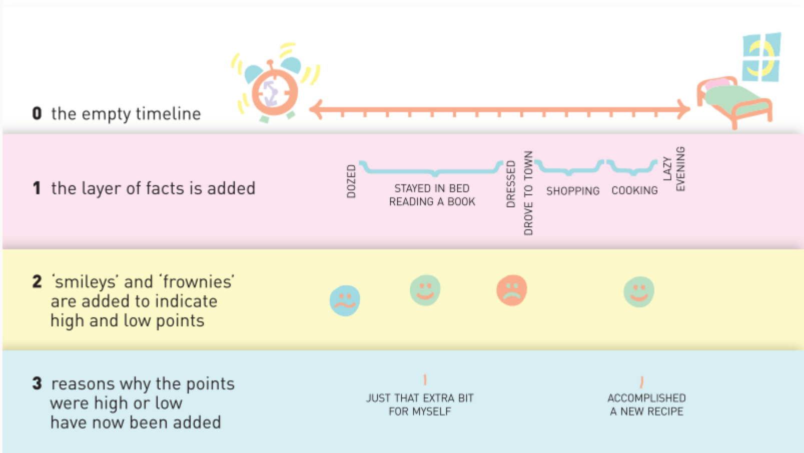


Figure 4.1. The layered day in the life exercise. [8]

During this phase, the day in the life exercise was the main structure. To get the activities for the timeline, the probing technique (see section 2.1.1) was used. Next, experience insights were gathered by assessing the participants mood during each activity and then gathering his reasons. Organizing these insights and ones acquired from an interview key themes were identified and eventually a final problem statement was formulated. An overview of this process can be seen in figure 4.2.

Figure 4.2. The pre-design process with the taken steps and the outcomes (circles).

CATEGORY	ASPECT	TYPE OF KNOWLEDGE	LAYER
Experience	Type of user	Explicit	1
	Characteristics	Observable	1
	Emotion	Tacit	2
Motivations	Outcome/job	Explicit	1
	Goal	Tacit	2
Context	Context	Observable	1
Opportunities	Problem/barrier	Observable/tacit	1/2
	Root cause	Latent	3

Table 4.2. Overview of information to be gathered in the pre-design phase.

4.2 Tools & Techniques for the Pre-design phase

4.2.1 Probing for activities

Since the first phase of this research was without a direction for the problem, the probes aimed to get a wide range of inputs from the participant, spread over multiple days. Insights about their characteristics, experience and context were all interesting at this point.

Due to the participant being locked-in, a special probing tool had to be developed. Common probing toolkits are comprised of tools like diaries and disposable photo cameras. However Locked-In individuals are unable to use such tools. In this case the participant was able to write emails, however it is a time intensive process for him to even write a single sentence. Since a picture "says more than a thousand words", this format seemed ideal, and a tool was developed for him to take pictures with.

The focus was on raw data in the self documentation phase, shifting all interpretation to the discussion part of the probing. This seemed like taking away freedom from the participant, though it was possible to have intermediate points of discussion during the self documentation that aimed less at conclusive insights but more on adding more to the raw data that was received. Another upside was that it enhanced the amount of dialogue between the participant and researcher-designer.

To emphasize the freedom of the participant, the initial probe delivery was kept very general. The goal at delivery was to communicate the process and the goal, but not yet provide the participant with too specific instructions. The instructions were in the spirit of the following:

1. *As mentioned before, the goal is very broad, I just hope to get to know you a little more, who you are, what you do, what happens around you.*
2. *I'll give you a tool, the camera, and you can do with it whatever you like. I hope you take a lot of pictures. You can move it too. Feel free to send me emails too, it'll be like a diary, or a notepad.*
3. *Over time I'll introduce some prompts, but anything is interesting! Just play around with having a camera.*
4. *At some points during the week I might ask you to elaborate on some pictures.*

Due to the tool behaving differently there was a lot more input from the participant, making extra prompts unnecessary. This means that there were no more instructions given to the participant.

Tool development

Due to the participant being locked-in, a special probing tool had to be developed. Common probing toolkits are comprised of tools like diaries and disposable photo cameras. However Locked-In individuals are unable to use such tools. In this case the participant is able to write emails, however it is a time intensive process to even write a single sentence. Since a picture "says more than a thousand words", this format would be ideal. Therefore the objective in developing the probing tool was to make a camera the participant could trigger himself. An additional requirement was the remote accessibility of the pictures, in order to be able to process data without having to physically retrieve it from the participant. This was realised in the form of a Raspberry Pi with a USB webcam and IR receiver attached, running a NodeJS program that takes a picture upon receiving a specific IR signal and uploads it to Google Drive.

Insights from development The tool was tested once together with the participant before it was finalized. He clearly expressed the need to have control over the device after the suggestion of using a time lapse setup. Then he was able to indicate where he wanted the camera to sit and where to aim it. The participant was able to communicate location by moving his head and looking in the direction of the spot he would like the camera to be placed. He showed his infrared based system GEWA, further described in section 6.3.2,from where he was able to control many appliances and lights in his environment. However, when suggesting to input the signal into the system, he indicated the entire manual had to be read first. This showed the system was really important to him, most likely since it is the device that allows him to control his environment. If the system would be configured incorrectly this would impact his autonomy greatly.

Assessing Moods and their Reasons

From the pictures received from the participant, a number was chosen to represent an eventful day in the life of the participant. They were placed in order with a time stamp, so the participant could place the picture in the right context. The participant was then given the option to choose from options to describe his mood about the picture:*very happy, happy, neutral, agitated, sad* and an open option. These were represented by the emojis pictured in figure 4.3. A complete activity as presented to the participant can be seen in figure 4.4. The participant was able to use the SpeakUP soundboard to select the moods. The soundboard would scan over 6 LED lights and played a relevant sound when the participated selected one using the button attached to his hand.

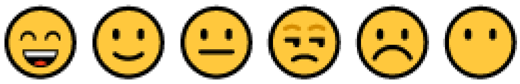


Figure 4.3. The emojis representing moods in order: *very happy, happy, neutral, agitated, sad* and an open option.

Figure 4.4. Example of an activity in the timeline as presented to the participant.

Extracting key themes

After the participant had chosen a mood for each situation, he was asked *Why did you choose this mood?* for each of them. This sparked a discussion about the situation and followup questions were asked depending on his answer. From the participants reasons for his moods, his goals and problems were extracted. He was asked if he had anything to add to this before the specification to a single problem.

Specifying the problem

The problems raised in the key themes were assessed together with the participant on their importance. The most promising and pressing problem was then chosen to further specify upon. This was done by asking why questions about the problem until a sufficiently open and abstract problem to design for was reached. This problem together with other information gathered was used to fill in the problem statement template in section 4.1.1.

4.2.2 Adapting the existing SpeakUP prototype

The participant had participated in another Creative Technology student project shortly before the start of this project and initially said he wanted to continue working on this. The prototype resulting from this project, called SpeakUP, was a soundboard scanning over six options, controllable by a single button. However, the participant had not been able to use the device since it had not yet been adapted to work with his personal button. At the start of this project he expressed the desire to finish this prototype first. Since it could be used as a co-design tool when working and the process of finishing it together with the participant could lead to some observations and insight, it was decided to first make this prototype functional.

Before meeting with the participant at his apartment, the soundboard device was adapted to have an input port for the participants button. At the apartment the device was placed on a communication pole together with some speakers to broadcast the sound. It was a good way to try out working together with the participant and getting used to the communication methods.

4.3 Design outputs of the pre-design phase

4.3.1 Indirect observations

Due to specific circumstances and people already familiar with the participant, a lot of information could be learned about him and his situation before directly contacting him.

A book about the participant The book about the participant [33] gave unique insights about his journey in making the most of his life after the brain stem infarct that caused his locked-in state. His attitude towards technology went through a major shift. In the beginning he did not want anything to do with technology, since he saw accepting the help of technology as surrender. However, once he accepted the help he strove to make the most out of his options. This served both an illustration of his personality and the technology he has access to.

Information given by the project supervisor An interview with the supervisor, who is also a friend and colleague of the participant gave more insight into his personality. She mentioned he has clear goals, sets up businesses and projects to help others fulfill their potential where he cannot, is persistent in getting what he wants and just wants to be treated like any other person.

4.3.2 Probing results

Due to a faulty implementation of the infrared receiver, a lot more pictures were made than the participant intended to make. A total of 365 pictures were taken, which is on one hand a lot of input, but on the other hand makes a lot of it meaningless. It did give a comprehensive impression of when the participant was active. Figure 4.5 gives an overview of all the pictures made over the course of three days.

4.3.3 Results of discussing the moods during daily activities

The results of the probing discussion are summarized in figure 4.6. The following statements summarize the results of the discussion following from the moods:

- The participant values being able to do his own thing without being disturbed.
- If someone else is in the room he is unable do do work because when he is distracted the system reads inputs wrong.
- Work is important to the participant, he owns two companies.
- The participant likes having a normal routine, since he is not sick. For example getting up from the bed into his wheelchair every day.
- The participant likes to socialize.
- The participant enjoys watching sports.
- The participant has a bed and a wheelchair and is able to do the same things in both.
- The participant can work most at night because he is disturbed less.
- The participant only needs four hours of sleep per day, so he is awake a lot.
- The participants sometimes has communication problems with the assistive personnel, due to difficulties with the spelling system.

The participant added the following statements after the discussion when asked about any other problems he had:

- The participant would like to be able to adjust his bed.
- The participant is curious about the functionality a splitter for his button might have.
- The participant would like to be able to add a flashing alarm light to the soundboard.
- The participant wants a more extensive calculator added to his device.
- The participant would like to make the soundboard more robust.

Figure 4.5. All pictures made with the probing tool over the course of three days. Each picture is a moment the participant was using a particular infrared frequency to control his environment.

Figure 4.6. Outcome of the probing, a timeline with pictures throughout the day with the associated emotion and comments.

4.3.4 Problem Statement

Insights about the participant and a main theme were extracted from the results of the probing to formulate the following problem statement:

> As a *Locked-in individual*, who is *ambitious, entrepreneurial and likes to work uninterrupted*, I am trying to *control my environment* when *I am by myself at home* so that *can live my daily life independent of others*, but I keep experiencing *the inability to control certain things* because *my current system is limited to infrared*, which makes me feel *dependent*.

4.4 Evaluation of the Tools & Techniques of the Pre-design phase

4.4.1 Observations

Visiting the participant's home gave both insight into his context and into ways of communication.

Communication Direct communication is done via the spelling system, but can also be done via the printer, and the participant can also move his head and look into certain directions to indicate the location of an object. The latter is an example of the non-verbal communication that being in the space with the participant enables. Working together on something, for example installing a prototype can be a mediator for communication. The common goal takes away some of the awkwardness that might occur in these situations where one person must take the lead in conversation.

In any case, the communication takes patience. During one of the sessions a nurse had trouble communicating with the participant. It turns out she didn't take the time to finish spelling with him. It can take some time learning the system, but with some practice reciting the letters in the right order comes naturally. An advantage of spelling with the participant as opposed to him typing is that words and sentences can be guessed. The participant confirmed that he prefers people guessing over them spelling out the word even though they have a hunch.

Context Visiting the participant at his home was an effective way to get information about his environment. He is the one with the most extensive knowledge about it, there seems to be no one that has a complete overview except for him. However, communicating such things over email or through a conversation would be very time intensive. By being in his environment with him, he could show most of the things he was able to do, and how.

4.4.2 Structured Evaluation of the Pre-design phase

In order to be able to consistently evaluate the method in each phase, the same aspects of participation and outcome as shown in table 3.1 are assessed in each phase. Table 4.3 shows the results for each measure in this phase. Broadly, the outcome the method generated satisfied the goal completely by generating a lot of novel insights about the participant's experience and context and lead to a problem statement that was useful in the next phases. In terms of participation, the participant was highly involved in the process and had as at least as much influence as the researcher.

Method aspect	Measure	Dimensions
Outcome	Goal reached	The goal for this phase was to define a problem and to gather information about the participant and his context. These goals were reached.
	Novelty	When comparing the results with the expectations, what was already known, there were definitely a lot of new insights. The different layers of the probing all gave unique perspectives on the participants life. Visiting him in his own context helped a lot in getting a clear image of the environment, that otherwise would have been very hard to obtain.
	Usefulness	The problem together with the insights were very useful in the rest of the process. The insights into the participant's daily life, his context and his values guided the entire process.
Participation	Impact	Lots of information was gathered from the participant and it was very useful.
	Influence	The problem statement was decided together with the participant. It was clearly one of his biggest wishes to be more independent and control specific things in his environment. So he really shaped the problem.
	Agency	The participant was highly engaged and motivated to enrich his life. Throughout the visits he was engaged and eager to work together.

Table 4.3. Evaluation of the pre-design phase according to table 3.1.

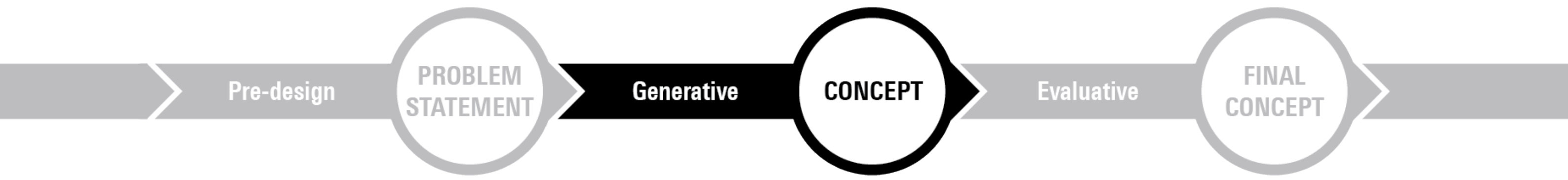
4.4.3 Conclusions from Evaluation of the Pre-design phase

The day in the life exercise combined different types of knowledge very well, providing an entire spectrum of insights. The probing tool malfunctioning showed that having pictures taken of mundane day-to-day activities is very valuable, because it gives an overview. A combination of timed and controlled pictures would be most effective. The home visits were extremely important, and the face to face communication was important to gauge the participants personality. By interacting in the context, showing rather than telling could be done.

Chapter 5

Generative Phase

This chapter describes the second phase of the design process, the generative phase. In this phase scenarios were used to explore the problem space and ideas were generated to solve it. First an overview of the phase is given including the process, goals and expectations. Then the tools and techniques used in the phase are explained. The design output from application of the tools and techniques is given and finally the method is evaluated.



5.1 Overview of the Generative Phase

In the generative phase, several steps were undertaken. The core activity involved a generative session with multiple stakeholders. The first step towards this session was to translate the problem statement into a multi-step scenario. This scenario was presented during the generative session where the participants were asked enact it with three different time perspectives in mind. From this session solution ideas and other insights were translated to a concept. This process is pictured it figure 5.1.

Figure 5.1. The generative process with all sub steps and outcomes (circles).

5.1.1 Goals & Expectations for the Generative Phase

One aspect of the co-design method evaluation is evaluating the design outcome that resulted from using the method. In order to assess the outcome a goal and expectations were set to compare the outcome to.

The goal of the generative phase was to generate multiple ideas for a concept that could solve the problem. One of these ideas was then elaborated upon in the next phase to be able to specify a final concept.

Since the outcome of this phase should be a concept, the expectations are noted in the form of ideas about a concept. Some ideas of solving the problem of environment control as stated in section 4.3.4 were present before the execution of the design activities in this phase. These ideas related to expanding the environmental control system of the participant to be able to control more modern IoT devices, as the limited communication protocols of his current system do not allow this. Importantly, these modern systems are much more widespread, which would allow the participant to control a wider range of devices. An example would be allow the participant to communicate to a smart home hub like Google Home, and add devices to his home that can be controlled with this smart home hub. Besides using these ideas to compare the result to they were also discussed during the generative session, insights from this discussion can be found in section 5.3.1.

5.2 Tools & Techniques for the Generative Phase

Several tools and techniques from scenario-based design were developed and used for the generative phase. A scenario was constructed and then enacted by participants in a generative session.

5.2.1 Making the scenario

The first step in the generative phase was to construct a scenario. In order to solve the problem, a proper understanding of the context was needed. Scenarios are a way of exploring the context [34]. By translating the abstract problem into a concrete story, it is easier to think about it. The scenario as seen in table 5.1 was created to give the participants insight into the currently possible and currently impossible. An activity where multiple actions could be integrated needed to be chosen from the timeline made in the previous phase. In this case, going to bed was chosen due to it being the biggest state change in the daily life of the participant. The activities were chosen such that they required different types of interactions, some of which already possible for the participant to do.

5.2.2 Enacting scenarios

The scenario described in table 5.1 in was used to help stakeholders and the participant become more aware of the problem context by letting them enact the scenario with multiple time perspectives. This means they enacted the scenario in the present, the past without any technologies and the future, where

It is time for Paul to go to bed. Before he does so he want's to accomplish a couple tasks:
1. Turn off the TV.
2. Turn off the lights.
3. Open the window.
4. Close the curtains.
5. Set the bed to a sleeping position.

Table 5.1. Bed time scenario used in the generative session.

anything is possible. This corresponds to the present-past-future model discussed in section 2.1.1, and is inspired by narrative futuring, a method from psychology where people are guided to an an image of the future and then work backwards to find out how to get there [35]. The present is in this case used to create awareness about the current situation. The past scenario intended to give the participants insight into the fundamental mechanisms of interaction with the environment of the locked-in participant. The future scenario was meant to stimulate their imagination without the current limits of technology.

5.2.3 The generative session

The scenario tool and enacting technique described in section 5.2.1 and 5.2.2 respectively, were applied in a generative session. The generative session took place at the participant's home and took approximately three hours. Besides the participant, someone close to him and another student joined the session. The structure was as follows:

1. Introduction.
2. Enacting the scenario in present time.
3. Enacting the scenario in the past, without technology.
4. Enacting the scenario in a future where everything is possible.
5. Discussion of insights.
6. Brainstorm sessions.

The external participants were not extensively briefed upon the possibilities and impossibilities to encourage communication with the participant. A paraphrased version of the initial briefing can be found in appendix A. They were also encouraged to explore the room and figure out the possibilities during the enacting of the scenarios. After enacting the future scenario the participants were provided with pens and paper to write down their ideas and encouraged to extract insights from the scenario enacting. They could then use these insights in the brainstorm session, which the researcher joined.

Extracting a concept

The ideas and additional insights from the generative session were compared to the problem statement and compiled into a general concept that would be able solve the problem.

5.3 Design outputs for the Generative Phase

The generative phase generated several insights and ideas, and finally a concept.

5.3.1 Insights into the problem and context

During the session several insights were generated and some insights from earlier phases were emphasized. The following insights were gained with regards to the locked-in *participant*:

- The locked-in participant explicitly wants to minimize his interaction with the nursing staff. This has multiple reasons. As discovered in the pre-design phase he wants to work uninterrupted. Besides that he wants to have control over his social environment, "choose his own friends". It would also mean less work for the staff. This gives him a sense of control, power, fulfilment, autonomy and efficiency. The less interaction with staff, the more control he has over his social situation and time.

- When the locked-in participant wants to interact with the environment, he goes through several steps. The steps from an intention to a functional result were mapped out. From this could be determined where a solution could intervene. This mapping is shown in figure 5.2.

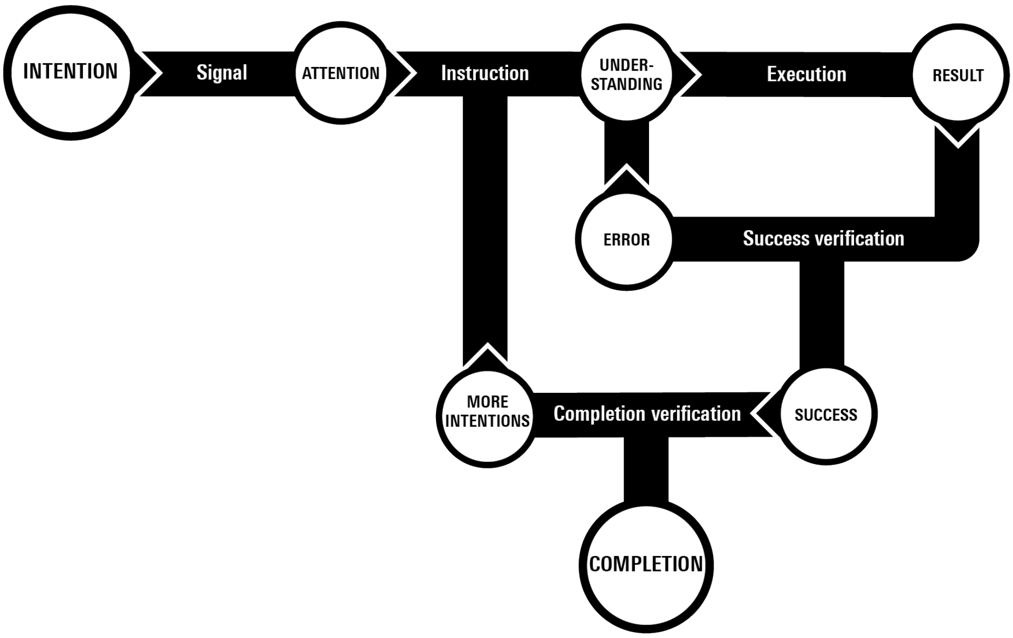


Figure 5.2. The steps from an intention to a function mapped out by the participants of the generative session.

Secondly, these insights were gained with regards to the *context*:

- With the current technology, the participant can control everything that works with infrared. However, things that require a physical mechanical action to be controlled cannot be controlled by the participant. This includes both completely analog things like the window or curtains, but also devices that only have a physical switch like the ceiling fan.
- Because the participant lives in a nursing home, some things that are integrated into the building like the ceiling fan would not be able to be replaced by a smarter solution. Therefore the solution must be external.

And finally, these insights were gained with regards to *technology*:

- A speech based system, or typing, would be too slow.
- Current assistive technology that the participant uses is quite sensitive. It has to be installed by specific people, since only they know how it works. However these people are not near the participant on a daily basis. The need for expert knowledge is detrimental to the accessibility of the technology. Therefore it would be important for the solution to be easy to use for anyone, and be well documented so that anyone can troubleshoot.
- The participant has built in a decent amount of redundancy in his system, so in case one thing breaks he has a backup. It could be a thing to keep in mind while developing the solution.

5.3.2 Ideas for solving the problem

The insights helped generate ideas that would intervene at several points in the intention-function process mentioned in figure 5.2.

- A flowchart for common tasks to be performed in order to make communication with staff more efficient.
- A card set to aid communication.
- A robot assistant or robotic arm that physically controls the environment.
- A system that makes everything controllable by infrared.
- A system that scans over the environment to select devices to control.
- Making devices controllable by fixating on them, i.e. look in their direction.

5.3.3 The chosen concept idea

Combining the ideas from the brainstorm the final concept idea was to design a modular system that can be controlled by infrared and has parts that can be combined together to do many kinds of actuation, including physical mechanical. People can form their own solutions by putting the parts together, like Lego. Making the parts open-source, more advanced users can make their own adjustments to expand the system.

The reason this concept was chosen is because of its wide applicability. The devices the participant is unable to interact with are so diverse that it would not be efficient to design one specific solution. A communication aid would also be widely applicable, however this would not decrease the amount of interruptions by staff, only the length. Additionally, such a system would be compatible with the participant's current way of interaction with the environment control, which works very well for him.

5.4 Evaluation of the Generative phase

5.4.1 Observations

During the generative session it took a some time for the participants to start the assignment of enacting the scenario. They started with a more passive approach, talking about the scenario rather than enacting it. However after some encouragement they started to become more active, walking around and taking pictures of the environment. In the past scenario they were able to imagine the place without technology, but needed steering to extract the detailed steps that were more abstract to get a system overview. The steering that was needed during the session made some of the output more reactive than generative. Giving the participants more ambiguous input like multiple scenarios or more detailed scenarios might help. The small scale of the session made it possible to have a focus on the locked-in participant, as can be seen in figure 5.3, however during the brainstorm more people might have been beneficial. With more relevant stakeholders it would not be an issue if some participants were not focusing on the locked-in individual.

Figure 5.3. Participants in during the generative session.

5.4.2 Structured Evaluation of the Generative phase

In order to be able to consistently evaluate the method in each phase, the same aspects of participation and outcome as shown in table 3.1 are assessed in each phase. Table 5.2 shows the results for each measure in this phase. Broadly, the method led to the outcome satisfying the goal and being useful for the next phase. Even though it was close to the initial idea that was generated before the start of the phase, some novel insights were gathered. The participation was successful in terms of impact, however the participants could have had more influence and the session could have been set up to give the participants more agency.

Method aspect	Measure	Dimensions
Outcome	Goal reached	The goal of generating a concept idea was reached.
	Novelty	Comparing the outcome to the expectations, the focus on IoT did not shift, however the idea of using an existing hub was rejected and insights into the participant's experience gave a novel direction to the idea.
	Usefulness	In the next phase it was shown that the concept that was generated was a sufficient base to be expanded upon.
Participation	Impact	The participants were able to gather a lot of information together. They took initiatives in asking questions and investigating the context, leading to valuable insights.
	Influence	The session had an abrupt ending due to time constraints from one of the participants. This means the final decision for the concept was made by the main designer. However, this was the concept that gathered the most enthusiasm from the participants, so they did contribute to the decision.
	Agency	The session was still quite guided, as mentioned in the observations. The participants were not always motivated to execute the assignment and needed encouragement. However, they were able to work together and nobody was excluded.

Table 5.2. Evaluation of the generative phase according to table 3.1.

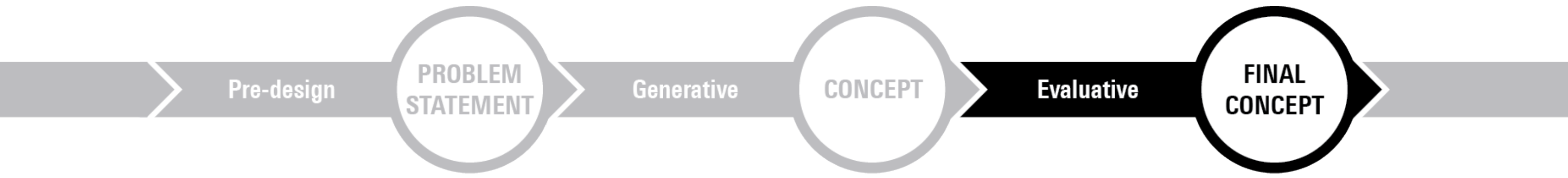
5.4.3 Conclusions from Evaluation of the Generative phase

Starting a session with enacting scenarios might have been to abrupt. The enacting of scenarios takes some initiative of participants, and without a warming up this seemed to hard. However, once participants started up, they were active and generated interesting insights. They could be primed better in order to raise their creativity and comfort levels. The scenario approach encouraged interaction in the context of the problem with the user, which seemed quite effective.

Chapter 6

Evaluative Phase

This chapter describes the third phase of the design process, the evaluative phase. In this phase the concept idea from the previous phase was explored, elaborated upon and eventually specified into a final concept. First an overview of the phase is given including the process, goals and expectations. Then the tools and techniques used in the phase are explained. The design output from application of the tools and techniques is given and finally the method is evaluated.



6.1 Overview of the Evaluative phase

The evaluative phase started with the general concept idea that emerged from the generative phase described in chapter 5. Multiple ways to translate this concept idea into a final concept specification were created using exploratory prototypes, insights from all the previous phases and state of the art research. Then, the options were discussed and a final concept specification was chosen. This process is pictured it figure 6.1.

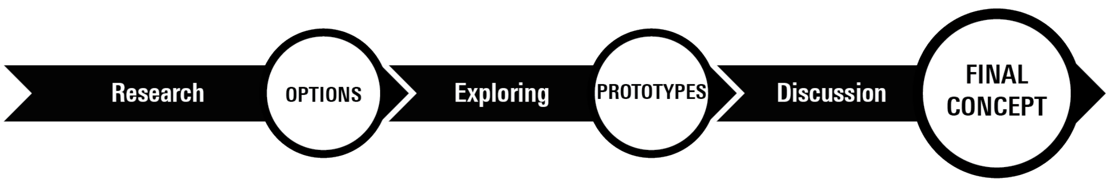


Figure 6.1. The evaluative process with sub steps and outcomes (circles).

6.1.1 Goals & Expectations for the Evaluative phase

One aspect of the co-design method evaluation is evaluating the design outcome that resulted from using the method. In order to assess the outcome a goal and expectations were set to compare the outcome to. The goal of this phase was to specify a final concept, which would also be the final outcome of the design process in this research. The phase started with a broad idea for a concept, a modular system controlled by infrared as described in section 5.3.3 without any technical specification. It was still unclear what would be the best approach to realizing this concept, so there were no additional specific expectations.

6.2 Tools & Techniques of the Evaluative phase

The main technique used in the evaluative phase was prototyping. The resulting prototypes were the tools. These were used in a discussion with the locked-in participant to come to a concept specification.

6.2.1 Diverging from the concept

With the general concept defined in section 5.3.3 as a modular system that can be controlled by infrared and can do many kinds of actuation, multiple approaches to elaborating upon the concept were generated. This was done by dividing the concept into components and researching the different options for these components, which lead to different combinations forming the different approaches. Additionally, state of the art relating to the concept was researched.

6.2.2 Exploratory prototyping

Exploratory prototyping was done to investigate the feasibility of individual system components where this was not clear. In an iterative way possible solutions to parts of the system were made tangible and then tested. First as a proof of concept and then as it could be used in the current concept. The prototypes provided a tangible way to interact with sometimes complex concepts, and served as a mediator for communication about them.

6.2.3 Specification of the concept

A final concept was determined by evaluating the different possible approaches on their feasibility and effectiveness, together with the participant. The prototypes functioned as a communication mediator.

6.3 Design outcomes of the Evaluative phase

6.3.1 Breaking down the concept

The concept was broken into three system components to explore options for. The first component was *interaction*, the way the user would control the system. The second component was *control*, the way the actuator units could be controlled within the system. The last component was *actuation*, how the units would actually actuate.

6.3.2 State of the Art relating to the concept

IoT infrastructure

GEWA control Gewa control[1] is an environment control device that can copy infrared signals, allowing it to control any device that works with infrared. The device can save up to 81 signals that can be accessed using a single button. The device is very accessible but the disadvantage is that it is only compatible with infrared.

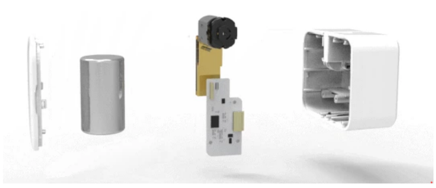
Node-RED Node-RED[2] is an IoT programming tool that requires no knowledge of programming. It can wire together hardware devices, APIs and online services. It works with a browser based flow-editor.

Homey Homey[3] is an example of an IoT hub that works with many different existing systems. The majority of these integrations are on the output side, which allows many devices to be controlled. However the control of the hub is limited, as only a Smartphone App, Google Assistant, Amazon Alexa and Facebook Messenger can be used.

IoT mechanical switching devices

Switchbot Switch Bot[4] is a small robot with an arm that can press buttons and pull switches. It is controlled by an app over bluetooth and a hub can be added for control over WiFi. The arm is a pivoting arm that seems to be controlled by a small DC motor. Images of the Switch Bot can be seen in figure 6.2a and 6.2b.

(a) The Switch Bot with the arm extended, pushing a button.



(b) Exploded view of the Switch Bot.

Figure 6.2. The Switch Bot.

[1]https://www.abilia.com/en/our-products/environmental-control/controllers/control-18
[2]https://nodered.org/
[3]https://www.athom.com/en/
[4]https://www.switch-bot.com/

Microbot Push The Microbot Push [5] is similar to the Switch Bot. The main difference is the pushing arm moves linearly, which allows more control over the movement. In addition, the pushing tip is capacitive, which enables the use of the bot on touchscreens. Images of the Microbot Push can be seen in figure 6.3a and 6.3b.

(a) The Micro Bot Push attached to a coffee machine.

(b) See through side view of the MicroBot Push.

Figure 6.3. The MicroBot.

6.3.3 Possible approaches to the system components

Interaction

The participant has two ways he interacts with technology. The first one is his GEWA device, for which he uses a button to scan through options. The second is his laptop, which uses infrared tracking to read his input. This means the system should either be directly controllable through the GEWA using infrared, or an interface compatible with his laptop should be developed. A third option could be to control the system directly with the button, however he needs this to control the GEWA and there is currently no way to split the signal.

Control

The control of the units could be done either directly or through a hub. Without the hub the system would be simpler. However, individual units would need to have more functionality. With a hub the units would be more light weight and it would make it easier to add communication protocols to the system while staying with the same interaction method for the participant.

Mechanical actuation

The mechanical actuation had two aspects to consider. One, the amount of actuators per unit and two, the type of actuation. The state of the art shows

[5] https://microbot.is/

two systems that have one actuator per unit. The downside of this would be that when there are multiple buttons close together, multiple units might not fit. Therefore it seemed beneficial to investigate ways to chain actuators together in an efficient way. However such chaining might be difficult considering different types of actuation like pushing, pulling and turning. Individual actuators would also be more straight forward and possibly easier to implement for users.

6.3.4 Exploratory prototypes

Exploratory prototyping was done to see how the concept multiple actuations from one could be implemented in an efficient way. First the mechanical principle was explored and subsequently it was investigated how this principle could be implemented in a space-efficient manner.

The mechanical principle

The goal was to come up with a way to use one motor for multiple actuations. This began with figuring out a way to translate the rotational movement of the motor to a linear movement. The base for this was a slider crank mechanism. One motor could quite easily actuate two sliders by attaching two cranks with a 180 degree angle to the motor. This would result in two sliders with opposite movements. A small prototype of this mechanism can be seen in figure 6.4a.

The next step was to combine two of the double slider mechanisms into a grid. Using paper the concept was explored, concluding that it was possible. After 3d printing components for one part of the grid to study the movement, a cad model of a four actuator grid was designed and 3d printed. this model had as input four sliders, which could be controlled with two motors. A picture of this prototype can be seen in figure 6.4c.

Approaches to implementing the mechanical principle

Realizing the crank slider grid with traditional joints would take up too much space and suffer from friction and misalignment. Therefore multiple alternative ways to realize mechanical movements were explored. With a focus on 3D-printablility due to its compatibility with open source three concepts were chosen: Meta-material mechanisms, compliant mechanisms and active origami. For each of these concepts it was explored how joints could be made and how rotational movement could be translated to linear movement.

Meta-material mechanisms Meta-material mechanisms [36] use a configuration of rigid and shearing cells to make a mechanism. The mechanism can be 3D printed in one piece. Figure 6.4d shows a prototype of a mechanism that converts rotational movement into linear movement.

Active Origami The principle of origami is that shapes are made from a paper without cutting it. Active origami [37] deals with folding structures that can move. Figure 6.4e shows a pattern where a square rotates when the corners are pulled apart.

Compliant mechanisms Compliant mechanisms translate force through elastic body deformation. These mechanisms are made from one piece of material and are jointless. Figure 6.4f shows an example of a compliant pair of pliers, that manage to output thirty times the input force [38].

6.3.5 Evaluation of approaches and prototypes with the participant

The prototypes were used to facilitate a discussion with the participant about the different approaches to elaborating upon the general concept. The aspects the prototypes embodied were explained through the prototypes and the rest of the system could be explained in relation to the prototypes. Discussing the prototype and findings from research with the participant provided the following insights:

- Infrared is essential, the participant cannot always control the laptop, e.g. when moving the bed, because the tracking system of the laptop is too sensitive.
- Control of units should go via a hub that can act as a bridge between the infrared environment control and devices working on wifi or other technologies. This would make the system quite expandable.
- The mechanical concept is promising, but it is unclear if the one-part approach is possible.
- Using physical actuators might not always be the way to go. Therefore it should be possible to connect other IoT solutions to the system.

6.3.6 Final concept

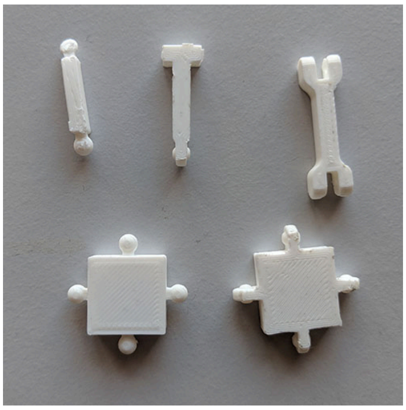
Using the insights from the discussion a final system configuration was chosen. Figure 6.5 shows the communication configuration with the GEWA talking to a hub over infrared, and the hub talking to individual units over WiFi. Figure 6.6 shows the information flow through the subsystems from user input to mechanical output.

6.4 Evaluation of the Generative phase

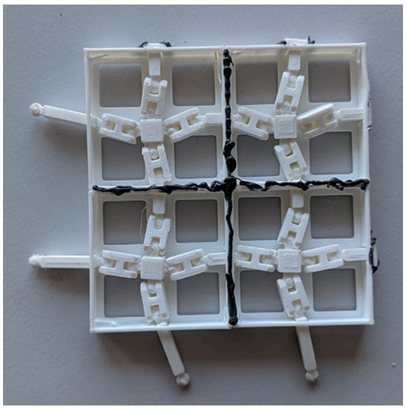
6.4.1 Observations

Thanks to the insights about the context and the user, it was quite clear what directions would be possible for the final concept. The tangible prototypes offered a great communication tool to talk to the participant about the options. By having a physical prototype, there is an object to talk about. The object can be referred to in relative terms instead of having to communicate the specifics explicitly, making communication more efficient. Additionally, the prototypes guided the conversation, as each of them represented a starting point for a part of the discussion. Finally, if the prototyped concepts would only be communicated in words or even drawings, they would have been much harder to explain. The participant gave unique insights that would have been overlooked if he was not consulted. In this way a suitable concept could be defined.

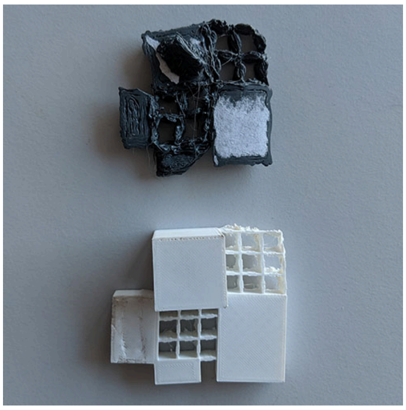
(a) Example of a rotational mechanism that could have two sliders attached.



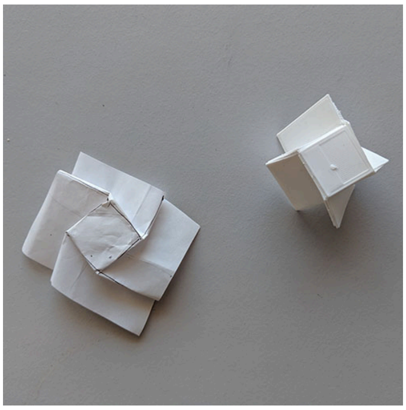
(b) Iteration of mechanical components for the a grid of crank slider mechanisms.



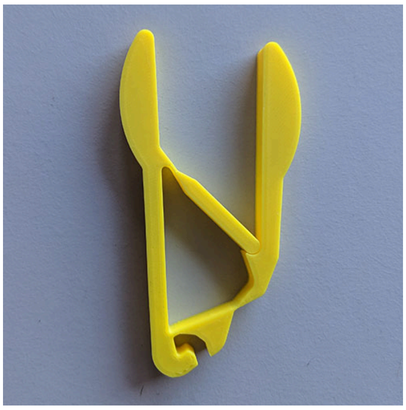
(c) Proof of concept prototype for the mechanical principle, a crank-slider grid that can push four buttons with two servos.



(d) Example of a meta-material mechanism that translates rotational movement into linear movement.



(e) Example of an origami pattern that translates motion. Pulling the corners causes rotation of the center square.



(f) Compliant pliers that output thirty times the input force. These pliers can be extruded from a single piece of material.

Figure 6.4. Exploratory prototypes.

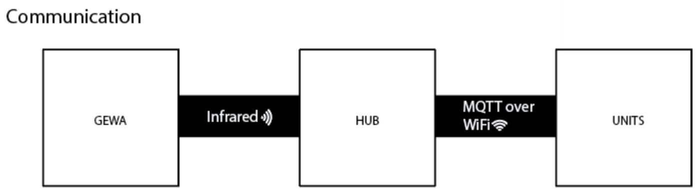


Figure 6.5. Schematic of communication in the proposed system.

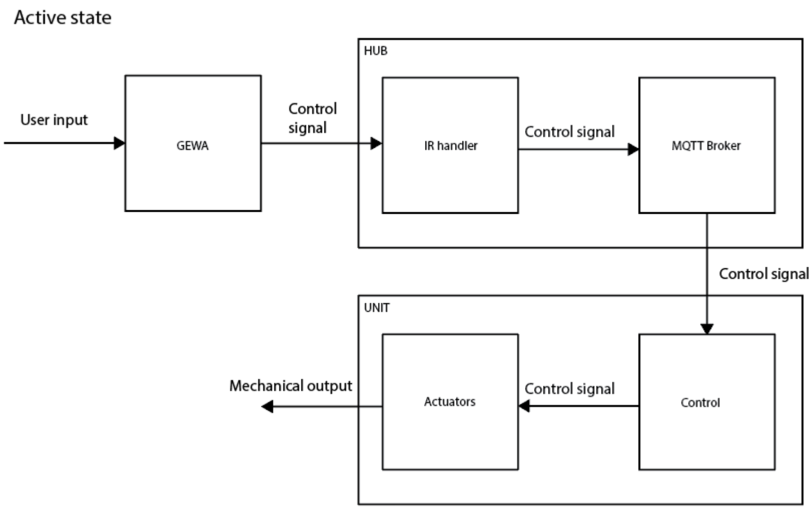


Figure 6.6. Schematic of the proposed system in an active state, converting user input into mechanical output.

6.4.2 Structured Evaluation of the Evaluative phase

In order to be able to consistently evaluate the method in each phase, the same aspects of participation and outcome as shown in table 3.1 are assessed in each phase. Table 6.1 shows the results for each measure in this phase. Broadly, the outcome satisfied the goal and novel insights were gathered in order to specify the right concept. It is however unsure how useful the final concept is, since this was the last phase of the project. In terms of participation, the impact of the participant was big, since without his participation certain insights would have been impossible to gather. He did however not make any decisions in this phase, his involvement was the smallest compared to the other two phases.

Method aspect	Measure	Dimensions
Outcome	Goal reached	The goal of specifying a final concept was reached.
	Novelty	There were no specific expectations for this phase, so the results are novel. There were new insights key to the development of the concept that would not have been produced without the co-design approach.
	Usefulness	The concept seems promising, however since this was the last phase in this project, it is unclear what the actual usefullness will be if it is further developed.
Participation	Impact	The information gathered with the participant was key to the direction of the project. There was not a lot, but what was gained from working together was valuable. Technical information was gathered in a traditional, but that is not necessarily specific to this context, so that makes sense.
	Influence	No decisions were made directly by the participant. However the decisions were made depending on the insights he provided.
	Agency	This phase had the least involvement of the participant in terms of time spent. He however still seemed motivated and engaged with the project.

Table 6.1. Evaluation of the evaluative phase according to table 3.1.

6.4.3 Conclusions from Evaluation of the Generative phase

Prototypes are highly valuable in co-designing with locked-in individuals. Throughout the process it has been clear that having something talk about that is tangible helps drive conversation when it is harder for one party to initiate topics. The prototypes make complex concepts more intuitive to understand. However in this case the prototypes were only made by the designer. It would be interesting if the participant could contribute to this more.

The work was still done in close collaboration with the participant. This meant that at key decision point the participant could voice his opinion and in that way the chance of developing something completely wrong was highly diminished. The unique perspective of the user was very valuable.

Chapter 7

A tangible co-design method for Locked-in individuals

This chapter gives an overview of the proposed co-design method. The approach, process and tools & techniques are summarized and the overarching theme of tangibility is explained in relation to these aspects of the method.

7.1 A tangible approach

Co-design methodology is characterized by its focus on reality as opposed to theory. Instead of theorizing about user needs when making design decisions, users are included in the process and influence such decisions directly. Likewise, the proposed co-design method is characterized by an approach centered around tangibility. An essential feature of the proposed method is that clients are visited in their own home in every phase of the design process. Since users cannot verbally provide a context of their wishes and concerns and other communication is difficult, particular effort should be made by designers to observe and interact with clients in their own homes.

The presence of something tangible at the center of conversation leads to more efficient communication, since it allows for communication relative to the context. With the subject matter present in the room, it is possible to form closed questions in an informed manner. Additionally, a tangible approach facilitates novel lines of inquiry to emerge due to unexpected observations within the context, and allows them to be pursued immediately.

Engaging with the context both directly and indirectly through the participant builds intuition. A tangible approach means going to the context, bringing design outputs to the context and engaging with the user through that context and those design outputs.

7.2 Tangible tools & techniques

The proposed co-design method employs three techniques with a tangible approach to map the context as the participant sees it and to communicate ideas about the solution. The tools used with these techniques extend the participants tangible interaction abilities, and make hypothetical solutions and situations more concrete and tangible.

7.2.1 Probing

The first technique is probing. In the proposed method probing is applied as a day in the life exercise [8]. This allows different layers of information about the context and participant to be obtained.

First, a probing tool is installed in the participants home. This tool allows the participant to make photos and takes a photo every thirty minutes. The picture is then stored in a secured cloud (e.g. Google Drive) such that they can be processed remotely. Such a tool is described in section 4.2.1. The tool is enabled from three days up to a week in order to obtain enough pictures to get an impression of the participant's day to day life. From these pictures a selection is made into a timeline, representing one day in the life.

The timeline is then discussed face to face with the client, who can rate the pictures with an emotion. A tool like the SpeakUP soundboard can be used to efficiently communicate the emotions. Such a soundboard can be programmed with sounds fitting emotions. The participant can scan through these sounds and play the sound corresponding to the emotion he rates a picture.

Afterwards, the client is invited to comment on the picture and his rating. To get a clear overview the information is combined into one graphic. Figure 4.6 shows an example of a timeline with the pictures, rating and comments combined. The graphical elements to create such a timeline can be found in appendix B.

7.2.2 Enacting scenarios

The second technique is enacting scenarios. The enacting of scenarios is done to enhance awareness of the context and generate insights that lead to potential solutions, both for designers and participants. First, a scenario has to be created. This scenario should be representative of the problem and context. It should highlight possibilities and impossibilities.

Once a scenario has been established, it can be enacted in a generative session. This session should take place with the locked-in participant and at least two other stakeholders. The stakeholders are ideally people that interact with the participant regularly and span the type of interactions as much as possible to get input from different perspectives. The session should be led by the main designer and other designers can participate as well, but should take care not to dominate the discussion. The session should take place in the context of the problem to maximize the effectiveness. Participants are stimulated to explore.

To generate different types of insights participants are asked to enact the scenario in three different time frames: present, past and future. The present gives insight into the current situation, the past gives insight into the fundamentals of the context and the future stimulates the imagination. After each enactment the participants are encouraged to discuss their insights and after the last enactment can transition into a brainstorm session to collect ideas for a solution concept.

7.2.3 Prototyping

The third technique, prototyping, is used mainly as a form of communicating ideas. Prototypes are used to make ideas tangible, both for the designer and the participant. Ideas translated into tangible three-dimensional objects facilitate a different way of understanding the underlying concepts.

Once research into the realization of the concept idea is done, the new directions that emerged can be explored using prototypes. The prototypes can then be discussed with the participant and the prototypes can be adapted according to insights gained from the participant. Initially the prototypes should be diverging, however after at least one discussion with the participant the prototypes can be more focused on one approach to the concept idea, eventually leading to a final concept. One evaluation is the minimum, however two or more rounds of prototyping will allow more customization to the participants needs.

7.3 A tangible process

A multi-step process is proposed structure the tangible method. The end goal of the design process is to design a final concept solution to a problem. Breaking this process into steps with sub goals makes that challenge more approachable and makes sure no crucial steps are missed. The proposed design process consists of three main phases, each consisting of several steps. In the first phase, the pre-design phase, a problem statement is defined. In the second phase, the generative phase, a concept idea is generated. In third and last phase, the evaluative phase, a final concept is specified. Figure 7.1 shows the entire process, including sub-steps consisting mainly of the techniques explained in the previous section, section 7.2.

The time required to go through all the steps can vary. An example of a two month timeline is shown in table 7.1. The timeline assumes that a participant has been recruited, there is a maximum of one visit a week and that two rounds of prototyping take place before the concept specification. The method can be altered to a shorter timeline by combining visits, or extended by adding more rounds of prototyping or spreading out visits over a longer period of time.

Week 1	Preparation Desk research
Week 2	Introduction and probe placement* Organizing incoming probe data into a timeline
Week 3	Discussion of the timeline* Synthesis of discussion insights
Week 4	Discussion of probing insights* Problem statement definition Scenario creation
Week 5	Generative session with scenario enacting and brainstorming* Synthesis of session insights Concept idea specification
Week 6	Research into concept Prototyping
Week 7	Discussion of prototypes and concept* Further prototyping and research
Week 8	Discussion of prototypes and concept* Concept specification

Table 7.1. An example timeline going through the tangible co-design process in two months with six visits to the participant, indicated by a *.

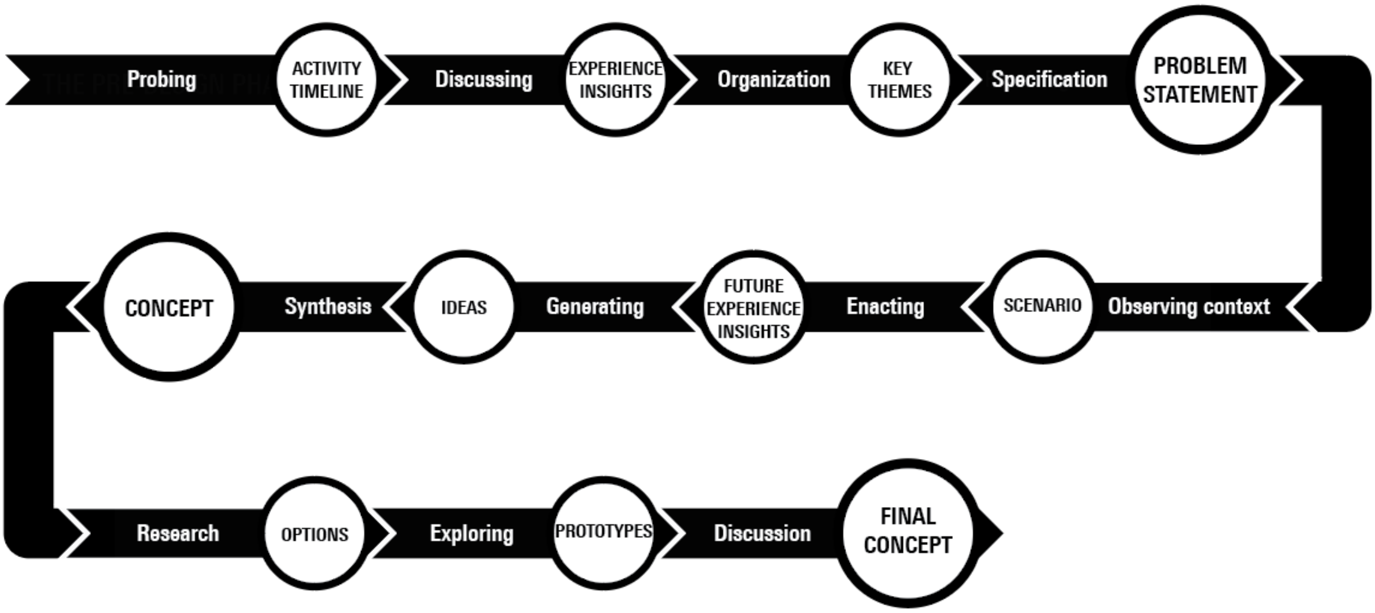


Figure 7.1. The complete tangible co-design process, employing the techniques from section 7.2.

Chapter 8

Discussion

This pioneering study set out to apply co-design methodology to design a technical solution with locked-in individuals. Existing tools and techniques were adapted to form a co-design method suitable for working with locked-in individuals face to face in their own context. That method was subsequently applied to design the technical solution with a single locked-in individual. After qualitative evaluation of the method and design output it can be cautiously concluded that a focus on tangible interaction is beneficial to the application of co-design methodology with locked-in individuals.

8.1 Tangibility in Co-design with verbal and physical impairments

Tangibility is one of the characterizing aspects of co-design, besides communication. Co-design involves interacting with your environment, with people, with co-design tools. Many of those interactions are tangible, i.e. perceptible by the senses.

The communication aspect of co-design overlaps with the tangible aspect of co-design. Wilson et. al. have used tangible design language to facilitate co-design with aphasia patients, who's verbal communication is limited similarly to that of locked-in individuals. They successfully used images, gestures, demonstration and physical artifact to replace verbal communication in design activities [18]. However, such implementations cannot directly translate to locked-in patients, since in addition to a limited ability for verbal communication, they have a limited ability to produce tangible language. This makes tangibility one of the most challenging aspects to incorporate when working with Locked-in individuals. Yet, the ability to have this type of interaction means being in control and being independent, both highly valued by locked-in individuals. Consequently, tangibility may also be one of the most rewarding aspects to incorporate while working with locked-in individuals.

Therefore this research aimed to incorporate tangibility in the developed co-design method. We were able to create ways of using the tangible languages in a way that worked for locked-in individuals. The two outputs of this research, the co-design method and the solution concept, both aim to enable the participant to be more in control and have a bigger sense of independence through enabling tangible interaction. In the co-design method, his abilities for such interactions during co-design activities are extended, and the abilities he does have are enabled to the fullest extent by doing the co-design activities face to face, in his context. The context was used similarly to Wilson's physical artifact, as mediator for relative communication, in which the minimal gestures and language the locked-in individual was able to produce make were highly valuable. By visiting the participant in his context, he was able to demonstrate his way of life instead of having to explain it in a conference room. In a similar way, a tool that allowed him to create images was developed to enable him to show his life from day to day. To conclude, the use of a tangible approach successfully facilitated co-design with a locked in individual.

8.2 Tangible co-design tools and techniques

The tangible co-design approach is reflected in the tools and techniques that were adapted for this research. The three techniques, probing, enacting scenarios and prototyping each used tools that facilitated communication through tangible languages.

Probing is a technique characterized by its use of ambiguous prompts and often tangible tools to gain insight into user experience. Since Gaver et. al. introduced probing in 1999 [14], many tools have been developed [5]. However, locked-in individuals are not able to interact with common probing tools like camera's and diaries. Therefore we developed a tool that allows the participant to take photos in his home environment and that takes photos at regular intervals, aiding the participant in gathering tangible image data. These images serve as the first layer of information in Sanders and Stappers' day in the life exercise [8]. The second layer of information is produced by letting the participant rate the photos on an emotional scale. In order to facilitate this process a soundboard tool was adapted to allow the participant to communicate six emotions efficiently. The last layer of sanders and Stappers' exercise is obtained by discussing the emotional ratings and factual information, in this case the images, with the participant. A graphical template was created to display all three layers of information together, which allows patterns to be observed and gives a clear overview.

These tools made the well known co-design technique of probing accessible and efficient for locked-in individuals. However, the camera tool did not function entirely as expected, so the interval in which it takes pictures can still be further explored. The prompting of the user was very broad, so this can be expanded upon as well. The camera behavior and prompts determine what type of raw data is gathered, so specific topics could be targeted through the adjustment of these aspects.

The enactment of scenarios is used to test a future product concept with users [39]. Similar to Iacucci and Kuuti [40] we focused on the enactment of the scenarios in the actual use context, the participants home. The context again serves as a tangible mediator for communication as well as a source of information for additional stakeholders that participate. In addition to enacting the future, the participants enacted the present and the past. This was done to get them familiar with the current situation and the fundamental processes going on, respectively. The different time perspectives generated different types of insights. However, the participants could have been guided more, since it seemed hard for them to get truly immersed. A more elaborate story could be used as well as specific props to help stimulate the participants imagination.

Prototyping is a design technique that not only allows designers to explore ideas and evaluate them, but also helps communicate these ideas to users according to Gill [41]. In accordance to Gill we used prototypes not only for evaluating a complete solution, but to communicate the ideas behind these solutions to the participant. This corresponds to the physical artifact tangible design language proposed by Wilson [18]. Additionally, we used the presence of these prototypes to guide the conversation with the participant into higher level ideas about the system. Some of the prototypes were able to convey the principles behind complex mechanical systems that would have been hard to explain verbally. The prototypes used in this study were conceptual prototypes, since the realization stage was not reached. Prototypes with a higher fidelity could have different uses when co-designing with locked-in individuals, which would be interesting to explore.

8.3 Design outcome

During the design process the application of the adapted co-design tools and techniques resulted in the definition of a problem and a concept specification to solve that problem. The identified problem was determined to be that the locked-in participant's ability to interact with his tangible home environment is too limited and that the help he needs prevents him from working uninterrupted. The need for solving this problem emerged both from the probing activity and specific wishes expressed by the participant.

The final concept for a solution to this problem was a modular system of mechanical actuators that can be controlled trough the existing environment control. This solution would not only solve the participant's current problems but would serve as an expandable platform upon which future solutions could be build thanks to the modular aspect. The system would also serve as a bridge between the limited environment control and existing IoT solutions incompatible with that system. However, the mechanical aspect would have to be explored further in order to assess the full feasibility and accessibility of the system. The portability of the system would require further engineering taking power consumption into mind. The co-design process could be extended, involving more stakeholders like the stakeholders that would install such a system.

8.4 Scope and scale of the Research

The design process during this research was based on sanders and Stappers' four phase co-design process [1]. Due to time limitations on three of these phases were implemented. Arguably, the last phase was not completed since it did not result in a working product. The phases that were implemented guided the process sufficiently and logically, as the output of each phase fed into the next. The incompleteness of the process leaves room for the exploration of co-design during g the later stages of the design process, concerning the realisation of the solution. The tangible approach as proposed in this research could be continued, for example using the prototyping techniques and rating tools from earlier phases.

This study mainly involved a single locked in participant with the addition of two non-locked-in participants during one session. Such a low number of participants is not uncommon in co-design processes. Even though no statistical conclusions can be drawn, the low number of participants does allow much deeper interaction. Especially with the face to face approach taken in this research, being able to take the time for a participant seems highly valuable, especially when dealing with a locked-in individual. However in order to solidify the findings the method should be applied to more participants.

To evaluate the method measures proposed by Segalowitz [29] regarding outcome and participation have been used. Three measures for each of the two aspects guided a structured qualitative evaluation. This assessment method covered many aspects of co-design. However, the assessment was informal, based upon observations of the researcher. A more formal evaluation could be performed in order to confirm the conclusions in addition to repeating the process with multiple participants.

Lastly, the pioneering nature of the research led to a mostly abductive process, which means that more approaches to co-design could potentially work with locked-in individuals. However, the tangible approach seems to be a great starting point.

Bibliography

[1] E. B-N Sanders and P. Jan Stappers, “Co-creation and the new landscapes of design,” tech. rep., Maketools LLC, Delft University of Technology, 2008.

[2] F. S. Visser, P. J. Stappers, R. van der Lugt, and E. B.-N. Sanders, “Contextmapping: experiences from practice,” *CoDesign*, vol. 1, no. 2, pp. 119–149, 2005.

[3] E. Brandt, T. Binder, and E. B.-N. Sanders, “Tools and Techniques: Ways to Engage Telling, Making and Enacting,” in *Routledge international handbook of participatory design*, pp. 145–181, Routledge Handbooks, 2013.

[4] E. B. Sanders, E. Brandt, and T. Binder, “A Framework for Organizing the Tools and Techniques of Participatory Design,” in *PDC 2010*, p. 88, 2010.

[5] T. Mattelmäki, “Applying probes-from inspirational notes to collaborative insights,” *CoDesign International Journal of CoCreation in Design and the Arts*, 2007.

[6] E. B. Sanders and P. J. Stappers, “Probes, toolkits and prototypes: Three approaches to making in codesigning,” *CoDesign*, vol. 10, no. 1, pp. 5–14, 2014.

[7] K. Tai MASc, S. Blain BASc, and T. Chau PEng, “A Review of Emerging Access Technologies for Individuals With Severe Motor Impairments,” *Assistive Technology*, 2010.

[8] E. B. N. Sanders and P. J. Stappers, “From Designing to Co-Designing to Co-Designing to Collective Dreaming: Three Slices in Time,” *Iteractions*, vol. 21, no. 6, pp. 24–33, 2014.

[9] S. Laureys, F. Pellas, P. Van Eeckhout, S. Ghorbel, C. Schnakers, F. Perrin, J. Berré, M. E. Faymonville, K. H. Pantke, F. Damas, M. Lamy, G. Moonen, and S. Goldman, “The locked-in syndrome: What is it like to be conscious but paralyzed and voiceless?,” *Progress in Brain Research*, vol. 150, no. 05, pp. 495–511, 2005.

[10] Y. Man Law Lan Fang Feng Qui Liang Li Jiao Meng Peng Shen Shuai Jiang Yu Wing Yi Pao and Y. Man Law, “Effect of Exercise on Physical Recovery of People with Locked-In Syndrome after Stroke: What Do We Know from the Current Evidence? A Systematic Review E X T R A E X T R A Law et al.: Effect of Exercise on Physical Recovery of People with Locked-In Syndrom,” *Cerebrovasc Dis Extra*, vol. 8, pp. 90–95, 2018.

[11] D. Lulé, C. Zickler, S. Häcker, M. A. Bruno, A. Demertzi, F. Pellas, S. Laureys, and A. Kübler, "Life can be worth living in locked-in syndrome," *Progress in Brain Research*, vol. 177, no. C, pp. 339–351, 2009.

[12] P. J. Stappers and E. Giaccardi, "Research through Design," 2017.

[13] E. Sanders and C. T. William, "Harnessing People's Creativity: Ideation and Expression through Visual Communication," *Focus Groups: Supporting Effective Product Development*, 2001.

[14] B. Gaver, T. Dunne, and E. Pacenti, "Design: Cultural probes," *Interactions*, vol. 6, no. 1, pp. 21–29, 1999.

[15] A. Crabtree, T. Hemmings, T. Rodden, K. Cheverst, K. Clarke, G. Dewsbury, J. Hughes, and M. Rouncefield, "Designing with Care: Adapting Cultural Probes to Inform Design in Sensitive Settings," in *Ergonomics Society of Austral*, pp. 4–13, 2003.

[16] P. J. Stappers, "Prototypes as a Central Vein for Knowledge Development," in *Prototype*, Bloomsbury Publishing Plc, 2013.

[17] J. Galliers, S. Wilson, A. Roper, N. Cocks, J. Marshall, S. Muscroft, and T. Pring, "Words Are Not Enough: Empowering People With Aphasia In The Design Process," in *Proceedings of the 12th Participatory Design Conference, ACM International Conference Proceedings Series*, pp. 51–60, 2012.

[18] S. Wilson, A. Roper, J. Marshall, J. Galliers, N. Devane, T. Booth, and C. Woolf, "Codesign for people with aphasia through tangible design languages," *CoDesign*, vol. 11, no. 1, pp. 21–34, 2015.

[19] F. Hamidi, M. Baljko, and I. Gómez, "Using Participatory Design with Proxies with Children with Limited Communication," in *Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility*, pp. 250–259, 2017.

[20] U. Konnerup, "Engaging people with aphasia in design of rehabilitation through participatory design: A way to learn what hey really want," *Participatory Design & Health Information Technology*, no. August, pp. 148–157, 2017.

[21] M.-c. Bernatchez, C. Poirier, E. Morales, and D. Maltais, "Rethinking the Bathroom for Adolescents with Cerebral Palsy: An exploratory pilot study. Addressing privacy and independence," *Journal of Accessibility and Design for Allll*, vol. 7, no. 2, pp. 218–235, 2017.

[22] E. Morales, V. Gauthier, G. Edwards, F. Courtois, A. Lamontagne, and . A. Guérette, "Co-designing Sex Toys for Adults with Motor Disabilities," *Sex Disabil*, vol. 36, pp. 47–68, 2018.

[23] K. Krishnaswamy, "Participatory Design: Repositioning, Transferring, and Personal Care Robots Kavita," in *Proceedings of the Companion of the 2017 ACM/IEEE International Conference on Human-Robot Interaction*, pp. 351–452, 2017.

[24] B. Daveler, J. Candiotti, and H. Wang, “Participatory design and validation of mobility enhancement robotic wheelchair Assistive Robotic Manipulator Evaluation Tool View project Mobility Enhancement roBot (MEBot) View project,” *Article in The Journal of Rehabilitation Research and Development*, 2015.

[25] G. Lesher, B. Moulton, and D. J. Higginbotham, “Techniques for augmenting scanning communication,” *Augmentative and Alternative Communication*, vol. 14, no. 2, pp. 81–101, 1998.

[26] L. Fernando Batista Loja, R. de Sousa Gomide, F. Freitas Mendes, R. Antonio Gonçalves Teixeira, R. Pinto Lemos, and E. Lúcia Flôres, “A concept-environment for computer-based augmentative and alternative communication founded on a systematic review,” *Research on Bomedical Engineering*, vol. 31, no. 3, pp. 257–272, 2015.

[27] G. Dornhege, J. Millan, T. Hinterberger, and D. Mcfarland, *Towards Brain-Computer Interfacing*. MIT Press, 2007.

[28] “The Design Process: What is the Double Diamond? | Design Council, Available:https://www.designcouncil.org.uk/news-opinion/design-process-what-double-diamond, Visited: 2019-07-19.”

[29] M. Segalowitz, *”Participation” in Participatory Design Research*. PhD thesis, 2012.

[30] J. A. Garde and M. C. Van Der Voort, “Participants’ view on personal gains and PD process,” in *PDC ’14 Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts*, pp. 79–82, 2014.

[31] J. Trischler, S. J. Pervan, S. J. Kelly, and D. R. Scott, “The Value of Codesign: The Effect of Customer Involvement in Service Design Teams,” *Journal of Service Research*, vol. 21, no. 1, pp. 75–100, 2017.

[32] “Problem Definition | University IT, Avaible: https://uit.stanford.edu/service-management/toolkit/problemdefinition, Visited: 2019-07-19.”

[33] A. Trossèl, P. Trossèl, and L. van der Burgt, *Oogwenk : ineens kan de vader van een jong gezin alleen nog met zijn ogen knipperen*. Uitgeverij Water BV, 2017.

[34] I. Anggreeni and M. C. van der Voort, “Tracing the Scenarios in Scenario-Based Product Design: A Study to Understand Scenario Generation,” *Design Principles and Practices: An International Journal—Annual Review*, vol. 2, no. 4, pp. 123–136, 2008.

[35] A. Sools and J. H. Mooren, “Towards Narrative Futuring in Psychology: Becoming Resilient by Imagining the Future,” *Graduate Journal of Social Science*, vol. 9, no. 2, pp. 203–226, 2012.

[36] A. Ion, J. Frohnhofen, and L. Wall, “Metamaterial Mechanisms,” in *UIST*, pp. 1–5, 2016.

[37] E. A. Peraza Hernandez, D. J. Hartl, and D. C. Lagoudas, "Introduction to Active Origami Structures," in *Active Origami*, pp. 1–53, Cham: Springer International Publishing, 2019.

[38] "About Compliant Mechanisms | Compliant Mechanisms, Available: https://www.compliantmechanisms.byu.edu/about-compliant-mechanisms, Visited: 2019-07-19."

[39] W. Odom, J. Zimmerman, S. Davidoff, J. Forlizzi, A. K. Dey, and M. K. Lee, "A fieldwork of the future with user enactments," in *Proceedings of the Designing Interactive Systems Conference on - DIS '12*, (New York, New York, USA), p. 338, ACM Press, 2012.

[40] G. Iacucci and K. Kuutti, "Everyday Life as a Stage in Creating and Performing Scenarios for Wireless Devices," *Personal and Ubiquitous Computing*, vol. 6, pp. 299–306, sep 2002.

[41] C. Gill, E. Sanders, and S. Shim, "Prototypes as inquiry, visualization and communication," *International Conference on Engineering and Product Design Education*, no. September, pp. 672–677, 2011.

Appendix A

Generative session briefing

Introduction

Hello everyone, thank you for your participation. Today we are going to explore a problem that Paul (the locked-in participant) has and hopefully we can end up with a few ideas on how to solve that problem. I will first introduce the problem and give an impression of the context. Then you are going to enact a couple scenarios to get familiar with the problem and context. After discussing the insights gained from the enactment a brain storm session will take place where those insights can be translated into solutions.

Problem

The problem Paul has is that he doesn't have enough control over his home environment. This prevents him from being independent.

Scenarios

In the scenarios you will enact there are a number of goals that have to be reached. It is up to you to help Paul reach those goal, where cannot of has difficulty reaching it on his own. We will do this with three different time perspectives. After each perspective you will have some time to discuss your insights.

First we will go through the scenarios in the present time. Paul uses his current technology as much as possible. The second perspective is in the past, where the goals have to be completed without technology. The last way of enacting the scenario is in the future, where you have access to any technology you can imagine. Try to imagine, describe and enact the scenarios. You can discuss what you are going to do in advance or just improvise. In how many ways can the goal be reached?

Appendix B

Graphical elements to create a day in the life timeline

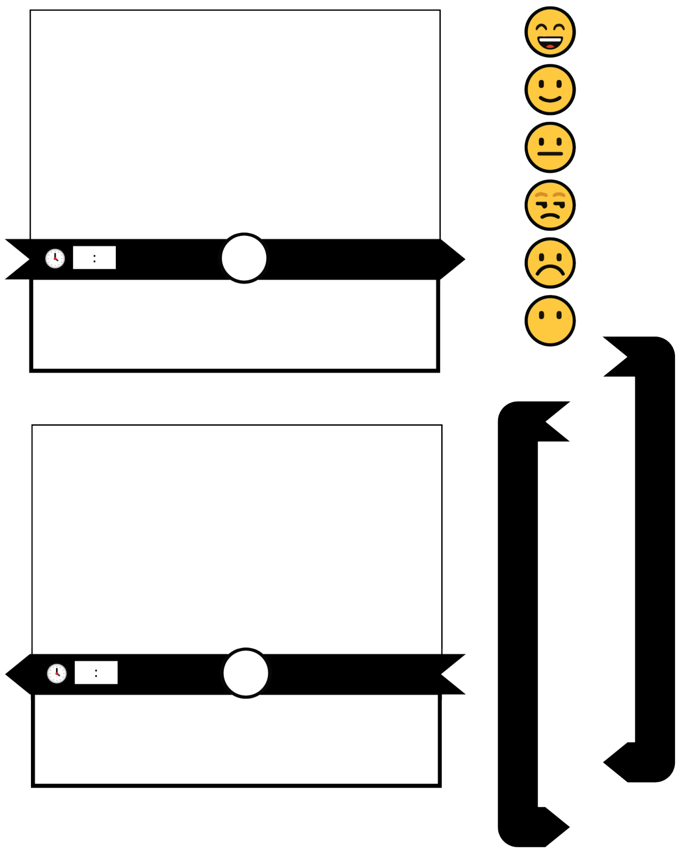


Figure B.1. Graphical elements to create a day-in-the-life probing outcome timeline.