Department of Informatics
University of Oslo

Participatory Design & Aphasia:

The Digital Food Diary *Sunnere* – Designed with and for Patients with Aphasia at Sunnaas Hospital

Robin Alexej Pettersen
Master's Thesis – Spring 2016

Robin Alexej Pettersen
2016
Participatory Design & Aphasia: The Digital Food Diary *Sunnere* – Designed with and for Patients with Aphasia at Sunnaas Hospital
http://www.duo.uio.no
Printing: Reprosentralen, University of Oslo

ABSTRACT

Avoiding malnutrition is a vital aspect of physical medicine and rehabilitation at Sunnaas Hospital. However, understanding personal nutritional requirements and enabling informed dietary decisions can be difficult for aphasic patients. Aphasia impairs the ability to produce and comprehend language, which complicates social processes and the use of ICT. This thesis presents the prototype design of the digital food diary *Sunnere,* designed with and for aphasic patients employing Participatory Design, and investigates the implications of aphasia to participation in the design process using ethnographic methods. The study found that the *Sunnere* prototype accommodated the requirements of the aphasics involved, but that there is a need to involve future aphasic users since a degree of customisation is almost always needed. Having a pedagogical mindset was instrumental in supplementing Participatory Design, and teaching the aphasics to be co-designers through optimal learning, and in supporting the aphasics through instructional scaffolding.

ACKNOWLEDGEMENTS

First and foremost, I would like to thank all of the kind and professional people at Sunnaas Hospital for providing me with the opportunity to conduct my research within such an inspiring and progressive work environment; most notably Hanne, Sonja, Eli Anne, Bjørn, Kristin, and Silje. I would also like to thank all the patients that were involved in the design of the Sunnere app prototype – your opinions have been invaluable and essential to this thesis.

Tone – you have my dearest gratitude and utmost respect for being a fantastic supervisor. Our meetings have been important in keeping my feet on the ground: your calming presence, and insightful recommendations have been thoroughly appreciated.

Thank you to my employer TeleComputing; to all my awesome colleagues that have generously put up with my absence. In particular, my boss Erling, for showing support from the start, and allowing me to juggle work and studies – and for generally being a cool and inspiring boss.

My fellow Snippeteers – Christopher and Bente, you have been great friends and invaluable discussion partners in my time of need (in regards to everything from British comedy, coffee, and keming, to academic matter). Rebekka, Martine, and Peter, you are awesome – undoubtedly the best team members I could have ever wished for (no dating).

Mum – you are a superstar, and the world needs more people like you. Your pedagogical perception has helped me see exciting links between design and pedagogy (some of which are central to this thesis!). You are absolutely right: "livet før og etter master'n".

Aiysha – your unfaltering love and endless encouragement deserves the most appreciation of all: you are an immeasurable source of inspiration and determination, which is unquestionably interweaved with this thesis. I am forever grateful that we met – I love you.

Robin Alexej Pettersen
Bærum, 01.05.2016

TABLE OF CONTENTS

1 INTRODUCTION

Den som spiser pølsemat og kjøttmat hele dagen,
han blir så doven og så lat og veldig tjukk i magen.
Men den som spiser gulrøtter, knekkebrød og peppernøtter,
tyttebær og bjørnebær og kålrot og persille.
Han blir sånn passe mett i magen, glad og lystig hele dagen
og så lett i bena at han ikke kan stå stille.

–Grønnsakspisersang, Thorbjørn Egner[1]

Knowing what we eat is in our best interest. Nutrition plays a vital part in our lives, whether we choose to think about it or not – and a healthy diet, as encouraged by Thorbjørn Egner in his 'grønnsakspisersang' ('herbivore song'), can make the difference between feeling on top of the world, bursting with energy, or feeling tired and unhappy.

This thesis presents the design of a digital food diary prototype – the *Sunnere app* – for Sunnaas Hospital, the largest hospital in Norway specialising in physical medicine and rehabilitation. The clinical staff at Sunnaas Hospital spend a significant amount of time registering the meals that the patients consume in order to ensure that they have appropriate diets that complement their rehabilitation plan – an important part of ensuring that the rehabilitation of the patient is as efficacious as possible. Not only was the Sunnere app intended to off-load some manual routines performed by the clinical staff, but also to give the patients an active role in managing their own diet by allowing them to register what they had eaten themselves. Also giving them insight into the contents of the food and drink items at the Sunnaas Hospital cafeteria, ultimately informing dietary decisions.

The design was intended to accommodate the patients at Sunnaas Hospital with aphasia. Aphasia impairs the ability to produce and comprehend language in often unique ways, and can result in difficulties with filtering important information from noise. When designing for user groups that have unique and non-binary requirements such as aphasia, the user's involvement in the design process becomes critical in order to ensure that the design accommodates their requirements. Paradoxically, aphasia limits the individual's ability to participate in the design process.

This thesis presents the process in which the Sunnere app prototype design unfolded. The process is grounded in past design cases involving aphasic individuals as users, and in two related pilot studies that were completed in the months before the work for this thesis began. The design process builds on the experiences of these pilot studies, and uses a Participatory Design approach to both directly and indirectly involve the future users of the Sunnere app in the decisions that eventually made up the Sunnere app prototype design.

---

[1] English translation in Appendix G.

1.1 Motivation and Purpose

The idea that sparked the collaboration between Sunnaas Hospital, and Department of Informatics at the University of Oslo, was motivated by an increased focus on appropriate nutrition and healthy foods in hospitals in Norway (Pasientsikkerhetsprogrammet, 2015). This has received increasing amounts of attention in the media in recent years (e.g. Fuglehaug, 2015 & Westerveld, 2012) – 76 incidents related to inappropriate nutrition were reported[2] in hospitals in Norway between June 2012 and December 2014. Some have even argued that food is just as important as the surgeon, in terms of the patient's well-being, because malnutrition can inhibit the body's ability to heal itself (Sæland, 2015). *The Norwegian Directorate of Health* stresses the importance of ensuring that patients receive sufficient attention in regards to their nutrition, and suggest implementing simple procedures like *nutritional screening* (Lindahl & Saastad, 2015, p. 12). At Sunnaas Hospital, nutritional screening was a manual task performed by the dietician and other clinical staff (such as nurses) – a process that involved tediously taking details from the patients about what they had eaten through handwritten diet records.

This is the context in which the Sunnere app design was conceived. The design had two goals:

- Enable the patients to make informed decisions in regards to their own dietary requirements by being able to get an overview of how the different food and drink items in the Sunnaas Hospital cafeteria correspond to their own recommended diet plan, and to easily log consumed food and drink items in a 'food diary' (diet record).
- Enable the dietician (and other clinical staff) to use the patients' food diaries (diet records) to alleviate some of the manual work involved in registering food and drink items consumed by the patients at Sunnaas Hospital, and to allow monitoring of the patients' dietary habits.

Even though it was envisioned that the Sunnere app could eventually be used by all the patients at Sunnaas Hospital, the design process presented in this thesis is concerned with the patients with aphasia at Sunnaas Hospital. These patients have difficulties communicating what they have eaten due to the communicative impairment brought on by their aphasia. By allowing these patients to use a digital food diary, it was imagined that it would be easier for them to engage in their own dietary habits. Furthermore, due to the communication requirements of aphasia, the Sunnere app would necessarily need to be simple to use – an incentive to involve other people with a variety of other impairments as well.

---

[2] As required by regulation *§ 3-3.Meldeplikt til Helsedirektoratet* in *Lov om spesialisthelsetjenesten m.m. (spesialisthelsetjenesteloven)* available at: http://lovdata.no/lov/1999-07-02-61/§3-3

1.2 Personal Motivation

In my relatively short career, I have worked as a software developer – something that I have and will always thoroughly appreciate. I am fascinated by both human and computer languages. In the work carried out as part of this thesis, I have had to take a step away from the 'developer mindset', and think very differently about how ICT is designed, developed, and situated within a socio-technical perspective. I have become absolutely captivated by the complexity of human language, and frightened of the impact aphasia has on one's life. I am very happy to have been able to work towards helping some of these people – even if it is just a tiny contribution.

1.3 Research Questions

There are fundamentally two aspects of this thesis: the process and the product – the research and the design. The two research questions (RQs) presented, aim to deal with each of these aspects, and were used to guide my position as a designer and researcher. In regards to the design, RQ1 aims to discover the most appropriate way to present nutritional information to aphasic users. RQ2 deals with exploring what implications aphasia has to participation in the design process. These two RQs are inevitably intertwined, and the methods applied contribute to the discussion of both RQs.

> *RQ1: How can nutritional information be represented in a way that it is understandable by a wide range of aphasic users, thus enabling informed dietary decisions?*
>
> *RQ2: How does aphasia affect the individual's ability to contribute in the design process, and how can they be empowered in communicating their needs and requirements?*

1.4 A Reader's Guide

The list of figures and tables, abbreviations, references, & bibliography are found at the end of this thesis.

In **chapter 2**, the thesis' background is presented. It features the importance of appropriate nutrition to physical rehabilitation at Sunnaas Hospital, and describes related manual routines and challenges for patients that have aphasia. The chapter concludes with presenting Sunnaas Hospital's request for an app for these patients, intended to make nutritional information accessible and enabling informed dietary decisions based on their personal requirements.

In **chapter 3**, aphasia is presented; its implications in terms of communicative ability and participation in social situations, and how this translates to the use of Information and Communications Technology. The chapter concludes with a literature review that explores past design projects involving aphasic users in terms of both design guidelines, and the design process.

In **chapter 4**, designing Information and Communications Technology with and for humans is explained, through the Human-Centred Design philosophy. There is a focus on the Participatory Design approach employed in this thesis, and the process in which the future user can learn about the design process, and through this process become empowered within it.

In **chapter 5**, the research design and strategy is explained. This gives an account of the qualitative nature of the research conducted in this thesis, aims to position it within the elements of research, and outlines how qualitative research can be conducted in a trustworthy manner. Furthermore, the Participatory Design approach and the applied design and research methods and their rationale are accounted for. The chapter concludes with a discussion of how the ethical issues of working with patients as users have been handled.

In **chapter 6**, the design process for the Sunnere app is presented. It opens with recognising the project work that inspired the thesis as pilot studies, and acknowledges their results and limitations as considerations for the design process. Following this, the ethnographic study that informed the design process is described, highlighting important considerations in both designing for aphasic users, and communicating with aphasic participants in the design process itself. The chapter concludes with presenting the participatory workshops conducted in detail – both using participation by proxy, and direct participation – and the two resulting prototype iterations, the last of these being the final prototype of the Sunnere app.

In **chapter 7**, the final prototype and the contributions through different types of participation in the workshops are discussed in relation to the research questions, and the theory presented throughout the thesis. There is a focus on how the aphasic participants can be supported to participate in a design process, and have a say in the design. The final prototype is analysed through heuristic evaluation, and thus positioned in relation to existing aphasia design research.

In **chapter 8**, a conclusion of the thesis is presented: the findings, analysis, and discussion are reiterated to highlight the potential contributions, which focuses on how the aphasics participated in this design process. The chapter concludes with identifying limitations and further work.

2 NUTRITION AT SUNNAAS HOSPITAL

Let food be thy medicine and medicine be thy food.

–Hippocrates

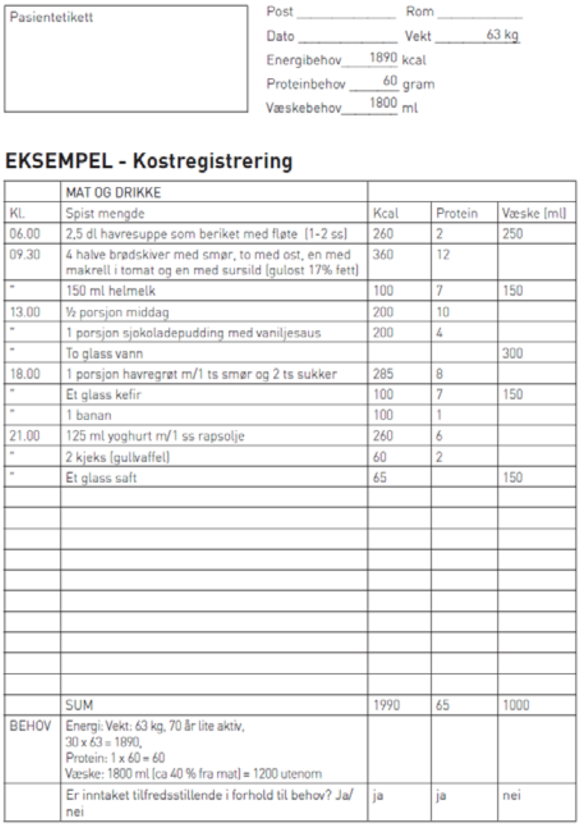
Sunnaas Hospital is the largest hospital in Norway specialising in *physical medicine and rehabilitation*; typically applying competence from multiple fields in the rehabilitation of patients with complex functional loss following illness or injury (Sunnaas sykehus HF, 2015). Sunnaas Hospital accommodates patients with a wide range of physical conditions. Some common causes for rehabilitation include physical trauma to the spine or the brain (including stroke), cerebral palsy, and various motor disorders, such as difficulties with swallowing. Ensuring appropriate nutritional intake through tailored diet plans is an essential aspect of *any* rehabilitation process (Helsedirektoratet, 2012, pp. 59–61), one that may change with the condition of the patients. Some of the patients at Sunnaas Hospital experience difficulties with their short-term memory, or motor skills, often resulting in an unbalanced diet that can cause malnutrition, or other metabolic diseases such as diabetes. For this reason, patients are involved in a **nutritional screening process**, where the objective is to find patients that are vulnerable to malnutrition so that they can get recommended diet plans that correspond to the requirements of their conditions (Helsedirektoratet, 2012, p. 80).

Sunnaas Hospital uses a nutritional screening procedure called *Malnutrition Universal Screening Tool* (MUST) (Stratton, Green, & Elia, 2003; The British Association for Parenteral and Enteral Nutrition, 2016). In the MUST[3] screening process, patients are asked questions in three steps about *Body Mass Index* (BMI), abnormal change in weight, and recent dietary habits related to illness. Each of these steps result in a score, which are all aggregated into a **malnutrition risk level** value that indicates the criticality of the patient's current nutritional habits.

If the risk level is 0 (low risk), the patient is rescreened on a weekly basis. If the risk level is 1 (medium risk), a **diet record** is completed over three days, and the patient regularly re-evaluated, and observed for signs of malnutrition. A diet record is a detailed account of the food and drink intake of a patient, and involves registering information regarding the time of consumption, and amounts of the various food and drink items consumed (an example of a diet record is shown in Figure 2-1). In addition, a diet plan is tailored according to the patient's nutritional requirements. If the risk level is 2 or more (high risk), the patient is subject to more intensive treatment, but is at the very least, observed, and recommended a tailored diet plan.

---

[3] The steps in the MUST screening process is described in detail in Appendix C.



Pasientetikett

Post ______________ Rom ______________
Dato ______________ Vekt 63 kg
Energibehov 1890 kcal
Proteinbehov 60 gram
Væskebehov 1800 ml

EKSEMPEL - Kostregistrering

	MAT OG DRIKKE			
Kl.	Spist mengde	Kcal	Protein	Væske (ml)
06.00	2,5 dl havresuppe som beriket med fløte (1-2 ss)	260	2	250
09.30	4 halve brødskiver med smør, to med ost, en med makrell i tomat og en med sursild (gulost 17% fett)	360	12	
"	150 ml helmelk	100	7	150
13.00	½ porsjon middag	200	10	
"	1 porsjon sjokoladepudding med vaniljesaus	200	4	
"	To glass vann			300
18.00	1 porsjon havregrøt m/1 ts smør og 2 ts sukker	285	8	
"	Et glass kefir	100	7	150
"	1 banan	100	1	
21.00	125 ml yoghurt m/1 ss rapsolje	260	6	
"	2 kjeks (gullvaffel)	60	2	
"	Et glass saft	65		150
	SUM	1990	65	1000
BEHOV	Energi: Vekt: 63 kg, 70 år lite aktiv, 30 x 63 = 1890, Protein: 1 x 60 = 60 Væske: 1800 ml (ca 40 % fra mat) = 1200 utenom			
	Er inntaket tilfredsstillende i forhold til behov? Ja/nei	ja	ja	nei

Figure 2-1 Example of diet record showing the degree of detail involved in completing such a record (Helsedirektoratet, 2012, p. 87).

The diet record is central to dieticians, and has multiple purposes (Helsedirektoratet, 2012, p. 87):

- Document efficacy of diet plan (as mentioned above);
- Assess to what degree the patient is adhering to the recommended diet plan;
- Create opportunities for conversation with the patients in regards to dietary habits and therefore;
- Create a foundation for tailoring a diet plan to the patient.

The manual and paper-based nature in which these routines were completed by clinical staff at Sunnaas Hospital, was the main motivator for the request that started a collaboration between Sunnaas Hospital and the Institute for Informatics at the University of Oslo as part of the course *Interaction Design* (INF4060) – a request for a digital food diary prototype, or a 'nutrition app'.

The target user group for the app was determined to be the **patients with aphasia** at Sunnaas Hospital. Aphasia is a cognitive impairment that impacts the use and comprehension of language, and therefore also the use of traditional user interfaces (aphasia and its implications are presented in chapter 3.1). This specific user group was chosen because at the time, few innovation projects were directed at these particular patients, and because it was thought that by creating an app that accommodated the needs and requirements of aphasic users, one could also accommodate a variety of other patients with various impairments.

2.1 Requirements Specification

The request for the Sunnere app from Sunnaas Hospital was made part of the coursework for the Interaction Design (INF4060) course, and the work was conducted by nine students during the autumn semester of 2014. The purpose of the request was to invite the students to propose a prototype app design that would allow the patients to complete their own diet records in an interactive manner (i.e. getting personalised information on food choices), thus engaging them in a participatory role in regards to managing their own diet, raising awareness of the importance of appropriate nutrition during and after the rehabilitation process, and ultimately informing food choices. The diet records created by the patients through the app would in turn provide the dietician at Sunnaas Hospital with supplementary information regarding the patients' dietary habits. In addition, it was thought that such an app would reduce some of the work that was previously carried out by the dietician (and other clinical staff, such as nurses) in manually completing the patients' diet records.

The work required for the app was conceptually broken down into two parts, which was in turn assigned to each of the two student groups:

- **Diet records:** the design and development of a user interface prototype that would allow its users to select food items from the cafeteria at Sunnaas Hospital, and register consumed food and drink items into the app's diet records database. This subproject was nicknamed project **MARTIN** (*Matregistrering på Sunnaas*) (Eide, Li, Simonsen, & Skårberg, 2014).
- **Feedback and motivation through gamification:** the design and development of the 'gamified' feedback mechanism prototype, intending to give motivating feedback on the food choices made by the user based on the diet records, depending on the tailored diet plan for that user. This subproject was nicknamed project **NAM** (*Nutrition-Aware Meals*) (Pettersen, Halvorsen, Vangen, & Odincova, 2014)

Sunnaas Hospital suggested a requirements specification (see Appendix A) as a formal agreement for the deliverable features for the app over that semester. The initial requirements specification specified a finished, production-ready app. The MARTIN and NAM projects were not completed as a production-ready app, but as design suggestion prototypes of various fidelity (see chapter 6.1).

This thesis builds on the work conducted by the MARTIN and NAM projects, and aims to complete the incomplete aspects based on a revised and downsized requirements specification, (see revised requirements specification in Appendix B) to a more appropriate scope in respect to the time and resources available. The revised requirements specification primarily drops the **motivation through gamification** requirement, and emphasises on the completion of the interactive **diet record** requirement of the design. This focuses the design on allowing the patients to effectively use the app as a means of completing their own diet records in an interactive manner based on the food and drink choices available from the cafeteria at Sunnaas Hospital. This was meant to inform dietary choices, and to provide the dietician with diet records to enable monitoring of the patients in regards to malnutrition, and continually adjusting the patients' diets plans. Since the motivation through gamification aspect was dropped from the requirements specification, this was instead acknowledged as further work (see chapter 8.1.2).

2.1.1 The Sunnere App Scenarios

A **scenario** is a readable way of presenting how a system is intended to be used. As Löwgren and Stolterman suggest; "writing stories is a quick and accessible way of contributing to the shaping of a design. The scenario should be made as elaborate and personal as possible, in order to force the design team to pose and answer questions regarding intended users" (2007, Chapter 4, *4.3.2 Techniques for detailed shaping*, para. 3). For the purpose of making the requirements specification more accessible as an input to the design process, I converted the requirements specification to very short scenarios.

2.1.1.1 Main Scenarios

Since the Sunnere app is focused on giving the user a proactive role in regards to their own diet record, I have chosen to the Sunnere app's purpose through three short scenarios (hereinafter the **main scenarios**):

Scenario One (SCN1)

> *The patient (user) picks a cafeteria food or drink item (stored in the Sunnere app), and gets feedback regarding whether this was a good choice or a bad choice based on what the user has been recommended. The meal gets added to the user's diet record.*

Scenario Two (SCN2)

> *The patient (user) picks a cafeteria food or drink item (stored in the Sunnere app) to get information regarding what nutrients this items contains.*

Scenario Three (SCN3)

> *The patient (user) checks his or her own diet records to see if the food or drink items consumed today/yesterday/last week/etc. corresponds to the recommended diet plan.*

The main scenarios necessarily translate into two different **areas** of the Sunnere app: the first area is the **cafeteria menu**, which is the area where the user can select food or drink items from what is available from the cafeteria at Sunnaas Hospital. Items that the user selects get logged in the app's diet records for that user. The second area is the **diet record feedback**, which is the area where the user can get feedback on the diet records that have been registered – for that particular day, or particular week. The scope covered by these scenarios, allows the patients to interact with their own diet records, allowing them to make informed decisions about the food and drink items they consume based on the feedback given by the Sunnere app. The scenarios that are not related to this, are omitted as they are beyond the scope of the Sunnere app design process as presented in this thesis, as per the revised requirements specification. One scenario was left out despite being in the revised requirements specification, as it was deemed out of scope for the initial design suggestion of the Sunnere app:

~~*The user (patient) cannot find a food or drink item and chooses ingredients individually, composing a meal.*~~

The rationale for this, was to primarily focus the Sunnere app on the food and drink items that were available in the cafeteria, not exposing the users to the complexity of searching for ingredients, and specifying quantities.

2.2 Understanding Nutrition with the Sunnere App

This thesis focuses on the design of the Sunnere app as an **interactive diet record**, with the ultimate goal of allowing the patients at Sunnaas with aphasia to *interact* with the food and drink choices available from the Sunnaas Hospital cafeteria, to make informed dietary decisions. For instance, if a patient is facing more than one option, he or she should be able to use the Sunnere app to see which option is more appropriate in regards to their individual diet plan. These diet records would be available to the dietician, who would in turn provide the means to follow up on the patients' recommended diet plans.

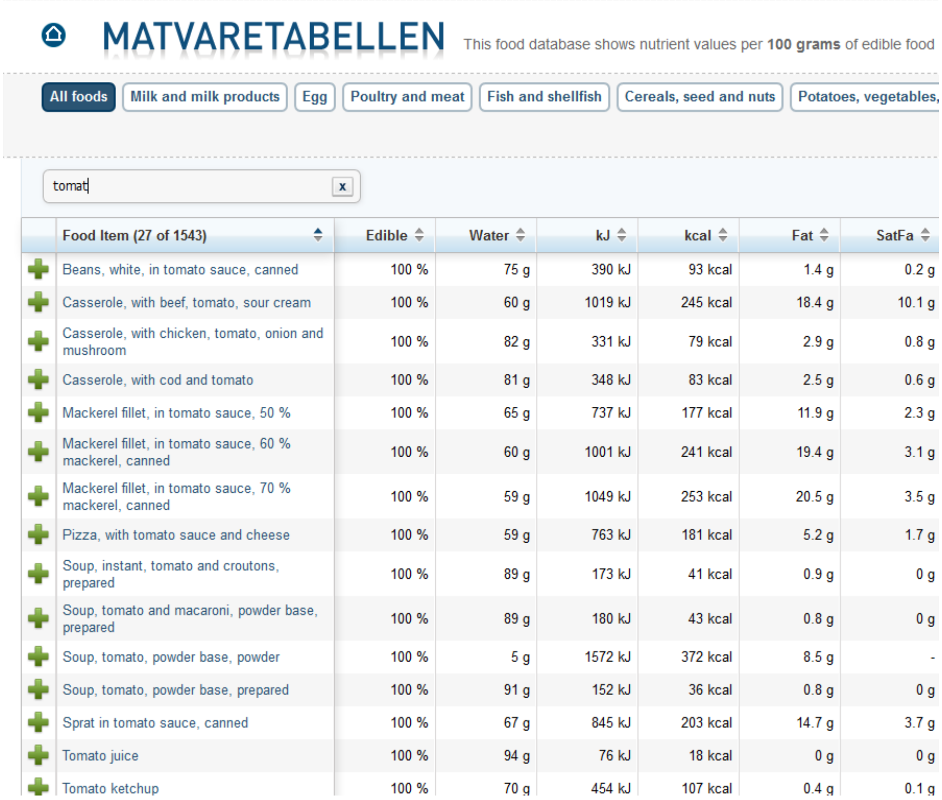
Understanding a patient's dietary requirements requires knowledge about the patient: aspects of health and lifestyle play important roles in determining an individual diet plan. For instance, a wheelchair user, a patient with kidney failure or diabetes, and a professional athlete all have very different nutritional requirements (Helsedirektoratet, 2012, pp. 167–233). In addition, understanding nutrition requires access to information about the nutritional values of the consumed foods and drinks – a substantial amount of detail regarding *macronutrients* and *micronutrients*[4]. Fortunately, in Norway, information regarding macronutrients and micronutrients contained in common ingredients is publically available on the Internet through the *Food Composition Table* (FCT). The FCT contains nutritional information (on 38 macronutrients and micronutrients) of over 1500 of the most common ingredients used in Norway, and was published for use by everyone (either through the Website, or through a downloadable spreadsheet format) in an effort to promote public health through informed decisions in regards to varied and appropriate food choices (Matportalen, 2012).

The FCT is a great step towards promoting awareness of the contents of the foods and drinks that are commonly consumed (and is in fact used by the dietician at Sunnaas Hospital to provide information regarding the meals that are served at the hospital cafeteria), but the problem is that

---

[4] Macronutrients provide the bulk of energy that an individual's metabolic system needs to function (fats, proteins, carbohydrates, etc.). Micronutrients are supplementary, and consist of vitamins and minerals.

the information is not cognitively accessible to individuals with particular cognitive needs. The nutritional information contained by the FCT naturally fits into a tabular form because of its numerous display of macronutrients and micronutrients, and are therefore represented as such (see Figure 2-2):



MATVARETABELLEN This food database shows nutrient values per **100 grams** of edible food

	Food Item (27 of 1543)	Edible	Water	kJ	kcal	Fat	SatFa
✚	Beans, white, in tomato sauce, canned	100 %	75 g	390 kJ	93 kcal	1.4 g	0.2 g
✚	Casserole, with beef, tomato, sour cream	100 %	60 g	1019 kJ	245 kcal	18.4 g	10.1 g
✚	Casserole, with chicken, tomato, onion and mushroom	100 %	82 g	331 kJ	79 kcal	2.9 g	0.8 g
✚	Casserole, with cod and tomato	100 %	81 g	348 kJ	83 kcal	2.5 g	0.6 g
✚	Mackerel fillet, in tomato sauce, 50 %	100 %	65 g	737 kJ	177 kcal	11.9 g	2.3 g
✚	Mackerel fillet, in tomato sauce, 60 % mackerel, canned	100 %	60 g	1001 kJ	241 kcal	19.4 g	3.1 g
✚	Mackerel fillet, in tomato sauce, 70 % mackerel, canned	100 %	59 g	1049 kJ	253 kcal	20.5 g	3.5 g
✚	Pizza, with tomato sauce and cheese	100 %	59 g	763 kJ	181 kcal	5.2 g	1.7 g
✚	Soup, instant, tomato and croutons, prepared	100 %	89 g	173 kJ	41 kcal	0.9 g	0 g
✚	Soup, tomato and macaroni, powder base, prepared	100 %	89 g	180 kJ	43 kcal	0.8 g	0 g
✚	Soup, tomato, powder base, powder	100 %	5 g	1572 kJ	372 kcal	8.5 g	-
✚	Soup, tomato, powder base, prepared	100 %	91 g	152 kJ	36 kcal	0.8 g	0 g
✚	Sprat in tomato sauce, canned	100 %	67 g	845 kJ	203 kcal	14.7 g	3.7 g
✚	Tomato juice	100 %	94 g	76 kJ	18 kcal	0 g	0 g
✚	Tomato ketchup	100 %	70 g	454 kJ	107 kcal	0.4 g	0.1 g

Figure 2-2 Tabular representation of micronutrients and macronutrients contained in various ingredients from matvaretabellen.no.

There are other government initiatives that attempt to make the information represented by the FCT more accessible: '*Kostholdsplanleggeren*[5]' is a free Web application for the planning of meals by providing a user interface (UI) on top of the FCT, allowing for the planning and logging of single or weekly meals based on a profile of preferences (e.g. sex, age, and lifestyle), or simply looking up ingredients in a more accessible manner than looking them up in the FCT directly (Helsedirektoratet & Mattilsynet, n.d.). Although Kostholdsplanleggeren is more accessible in its representation through pie-charts and other visualisations (Figure 2-3), it still relies on the representation of nutritional information in tabular form (Figure 2-4):

---

[5] Kostholdsplanleggeren.no

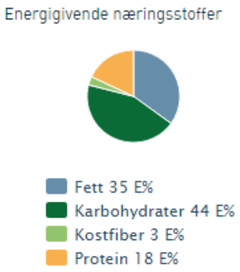
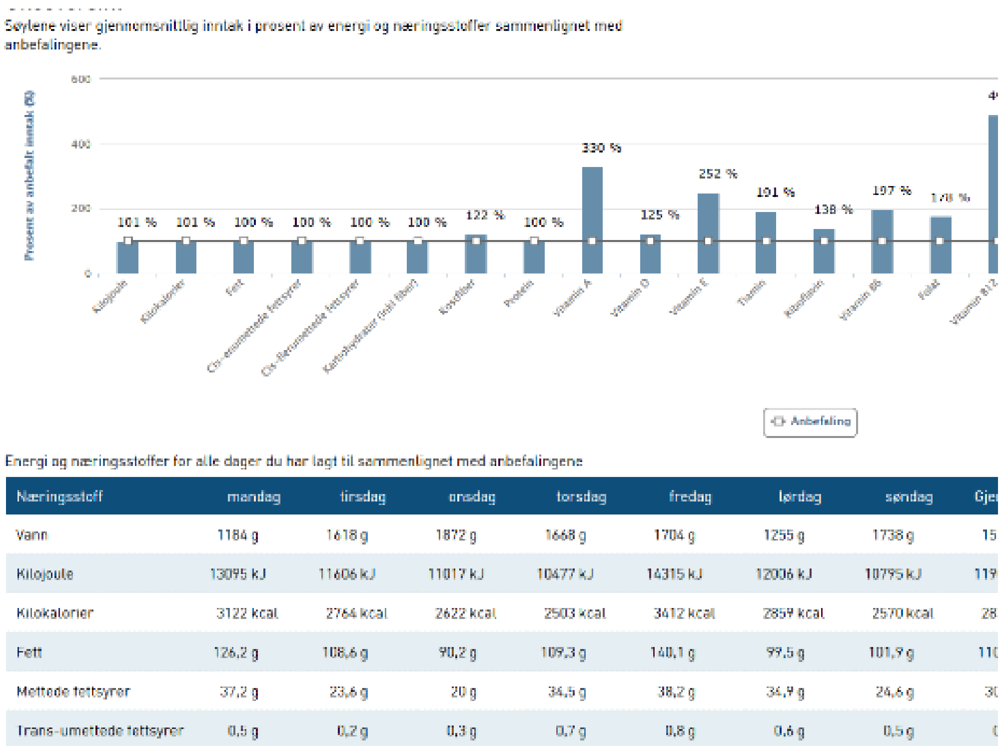


Figure 2-3 Overview of nutritional values as presented by kostholdsplanleggeren.no.


Søylene viser gjennomsnittlig inntak i prosent av energi og næringsstoffer sammenlignet med anbefalingene.

Energi og næringsstoffer for alle dager du har lagt til sammenlignet med anbefalingene

Næringsstoff	mandag	tirsdag	onsdag	torsdag	fredag	lørdag	søndag	Gje
Vann	1184 g	1618 g	1872 g	1668 g	1704 g	1255 g	1738 g	15
Kilojoule	13095 kJ	11606 kJ	11017 kJ	10477 kJ	14315 kJ	12006 kJ	10795 kJ	119
Kilokalorier	3122 kcal	2764 kcal	2622 kcal	2503 kcal	3412 kcal	2859 kcal	2570 kcal	28
Fett	126,2 g	108,6 g	90,2 g	109,3 g	140,1 g	99,5 g	101,9 g	11
Mettede fettsyrer	37,2 g	23,6 g	20 g	34,5 g	38,2 g	34,9 g	24,6 g	3
Trans-umettede fettsyrer	0,5 g	0,2 g	0,3 g	0,7 g	0,8 g	0,6 g	0,5 g	

Figure 2-4 Graphical and tabular representation of micronutrients and macronutrients contained in various ingredients from kostholdsplanleggeren.no.

There are numerous alternative initiatives that bring nutritional management packaged as apps into the pocket of the consumer (as a Web search for 'nutrition app' or 'diet app' reveals). The problem with these tools, is that they generally do not consider the needs of individuals with particular needs (see chapter 3.3). Individuals that are cognitively impaired (for instance, aphasic individuals), face problems using these tools because of their difficulties with comprehending and filtering information (see chapter 3.1.1).

The intended Sunnere app design was to bridge the information in the FCT, the patient's individual diet requirements, and the cognitive requirements of the patient – providing an 'intelligent' tool that could be adapted to the patient using a *user profile* – allowing the Sunnere app to present nutritional information in a relatively comprehensive manner. Digital tools, such as apps and other Internet and Communication Technologies (ICT), are in fact highly adaptable in nature – for instance, it is unlikely that the user needs to see *all* 38 micronutrients and macronutrients when deciding between two different food or drink items. For example, if the Sunnere app had a user profile, and thus 'knew' that the user had diabetes, perhaps showing only 'sugar' as an ingredient in meals would be the solution for that particular user.

3 APHASIA AND LANGUAGE

A word devoid of thought is a dead thing,
and a thought unembodied in words remains a shadow.

–Lev S. Vygotsky

3.1 Aphasia

The concept of *aphasia* as we know it today is no modern phenomenon: Benton and Joynt (1960) reviewed early descriptions of aphasia before the nineteenth century, and found references to *aphonia* (translating to ‘speechless’ or ‘loss of speech’) in Hippocratic writings dating back to 400 BC. Loss of speech is also recorded in the *Edwin Smith Surgical Papyrus;* an ancient Egyptian medical treatise named after an American (studying Egyptian science) that acquired the papyrus in Luxor in 1862. The papyrus shows indications of being a textbook on surgery, and contains descriptions of clinical cases of head injuries, though the nature of these cases remain unknown. Supposedly, the papyrus originates back to 3000 BC (“Edwin Smith papyrus | Egyptian medical book,” n.d.; Goodglass, 1993, p. 13). In their historical review, Benton and Joynt (1960, p. 122) mention numerous medical references to early aphasia scattered throughout history, the earliest clear reference in 1481 by Guaineiro (as cited in Benton & Joynt, 1960) where a patient could only recall three words. Their review concludes with suggesting that almost all the clinical forms of aphasia had been recorded and described before 1800.

Modern aphasia[6] is an umbrella term used to describe a multiplicity of deficits involving one or more aspects of language use related to injury in the left hemisphere of the brain[7] (Goodglass, 1993, p. 3), and it can affect any combination of the language modalities (reading, listening, speaking, or writing). The most common cause for aphasia is stroke occurring in older individuals, but other causes that have a wider demographic impact include brain lesions caused by e.g. trauma, tumours, and infections. Difficulties to communicate that are not related to brain lesions in the left hemisphere of the brain (e.g. paralysis that inhibits communication, motor disorders like apraxia[8] and ataxia[9], and vision impairment, apathy, depression, and euphoria), and dyslexia are not aphasia, but may impose difficulties with diagnosis: an individual may unknowingly have aphasia, due to aphasic symptoms being overshadowed by other conditions or impairments caused by the same brain injury (Goodglass, 1993, pp. 2,7–8; Goodglass & Kaplan, 1972, p. 5).

Since aphasia can be the result of even a minor brain injury, it can affect any individual of any nationality. The *National Institute of Neurological Disorders and Stroke* (NINDS) and the *National*

---

[6] Individuals with aphasia are referred to as *aphasics*.

[7] One type of *cognitive impairment*.

[8] Difficulty with the motor planning to perform tasks or movements.

[9] Incoordination of musculature related to speech and writing.

Health Service (NHS) estimate respectively that in the US, there are over one million people living with aphasia, while in the UK, the number is just under 400,000 (NHS, 2015). While there are no official numbers available in Norway, international statistics can be used to roughly estimate that there are between 2,800 and 5,700 new aphasics every year (Becker, 2008).

The term aphasia is purposefully vague because no case of aphasia is the same; its definition needs to encompass the vast landscape of heterogeneous aphasia cases. This makes the definition and boundaries harder to grasp, for instance, as Jordan and Kaiser point out, "occasional word-finding problems and Spoonerisms [(i.e. the both non-intentional and intentional swapping of the first sounds of a word, for instance saying *well-boiled icicle* instead of *well-oiled bicycle*)], are not seen as 'abnormal', or taken as evidence of underlying impairments. Such minor occurrences may be 'laughed off' or put down to fatigue, but might equally be understood as minimal aphasia" (1996, p. 4, definition and example added). By this, they mean that even struggling to remember *that word on the tip of your tongue*, or innocent mistakes such as Spoonerisms, can be understood as aphasia.

Depending on the degree of aphasia, there is almost always some amount of improvement, and it is not unusual that the condition will transform into another type of aphasia, making the rehabilitation trajectory unpredictable. Even if rehabilitation is successful, most aphasic individuals are left with *some* degree of life-long impairment which can affect the quality of living due to the ubiquitous requirement of communication in daily life. The implication of this requirement essentially defines aphasia as extremely pervasive in that it has the potential to exclude aphasics from various aspects of life (Jordan & Kaiser, 1996, p. 14). Aphasia rehabilitation attempts to deal with the social isolation aphasics experience because of the implications of aphasia on 'keeping up' with communication. Since "communication is the key to social participation, […] the main goal of aphasia rehabilitation is a social goal: to optimise the communication between the person with aphasia and his or her environment" (van de Sandt-Koenderman, 2011).

3.1.1 Classification

Aphasia is a non-binary condition, affecting individuals in different ways, depending on the magnitude of the brain injury. In addition, the way in which aphasia affects the individual can vary on a daily, monthly, or yearly basis (Jordan & Kaiser, 1996, p. 13). The nature of which individuals are affected uniquely in such a multivariable manner, makes the classification of aphasia challenging at best, leaving certain degrees of aphasia in a grey area where no *formal* classification exists. Classically, the most widely adopted classification model is the Boston model[10], which groups together commonly occurring symptoms into an array of classifications – a *symptomatic* approach. The clearest distinctions that this model presents, are the *fluent*, and *non-fluent* aphasias,

---

[10] The Boston model emerged from the Boston School of Aphasiology, and is based on revised typology based on discoveries made by Wernicke in the 19th century (Goodglass, 1993, p. 209).

and the most predominant aphasias in each of the fluent and nonfluent categories are *Wernicke's/motor* (fluent) and *Broca's/sensory* (nonfluent) aphasias (Goodglass, 1993, pp. 75–76). The symptoms of these two aphasias are described in the following sections to provide an example of how aphasia can affect an individual.

Individuals with Broca's (sensory/expressive) aphasia are nonfluent in terms of producing speech; only the most important words in a sentence are uttered (usually based on a restricted vocabulary), and short, grammatical words are omitted[11]. Articulation, and repetition is hesitant and awkward. Auditory comprehension is however, preserved for simple conversation, while reading is less preserved. Individuals struggle with naming words that are *on the tip of the tongue* – which is also referred to *anomia* (FRCP, 2012, pp. 179–180; Goodglass, 1993, pp. 209–210; Jordan & Kaiser, 1996, pp. 40–41).

Individuals with Wernicke's (motor) aphasia are fluent in terms of producing speech, but can yield abnormal language content due to paraphasic speech[12], causing nonsensical sentences or words with no relationship with the intended message (severe cases are referred to as *jargon aphasia*). Naming, repetition, reading, writing, and auditory comprehension are reflected by this. Sometimes, speech output is at a very fast pace, resulting in an individual's unawareness of mistakes. This results in speech production that *sounds* like the individuals intended language, but that is incomprehensible (FRCP, 2012, p. 180; Goodglass, 1993, pp. 210–211; Jordan & Kaiser, 1996, pp. 40–41). Even though the Boston model contains additional classifications, Broca's and Wernicke's aphasias provides sufficient examples of the varying impacts of aphasia. Two other notable classifications from the Boston model are *global* aphasia, where all language modalities are severely impaired (considered the sum of Broca's and Wernicke's aphasias), and *pure* aphasias, where a single language modality is impaired in isolation (FRCP, 2012, pp. 181–182; Jordan & Kaiser, 1996, p. 40).

It is important to note that while the identification and classification of aphasia is centred around the language production modalities (simply because they are more obvious), there is a strong relationship between all language modalities, and in particular also in *understanding* language. The role of language in filtering information from noise, may cause individuals with aphasia to struggle with comprehending and filtering lots of information. The implication of this is that aphasics can have problems understanding not only spoken words, but also the written ones (Jordan & Kaiser, 1996, pp. 43–44). This relationship is illustrated in Figure 3-1:

---

[11] This is referred to as *agrammatism* and *telegraphic speech* (FRCP, 2012, p. 179).

[12] Paraphasia is divided in *literal* and *verbal* paraphasia, the first being sound substitution (e.g. "sand" instead of "hand"), and the latter being word substitution (e.g. "foot" instead of "hand") (Jordan & Kaiser, 1996, p. 40).

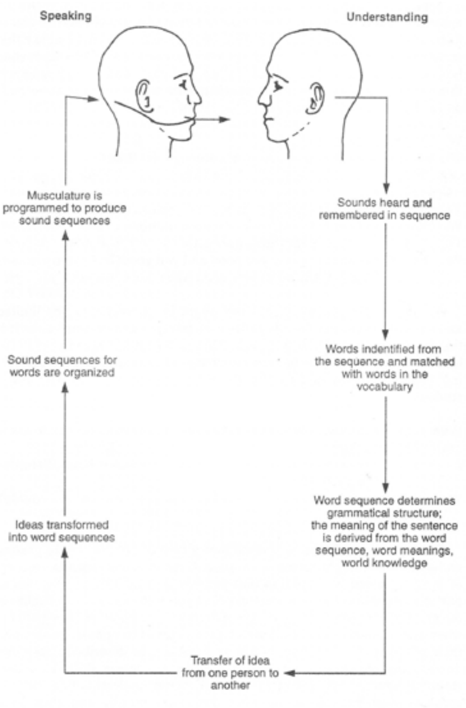


Figure 3-1 "A simple model of understanding and speaking" (Jordan & Kaiser, 1996, p. 42).

Jordan and Kaiser present an example case of what aphasia *feels* like: the case is a nurse who suffered a series of small strokes that resulted in temporary aphasia: "she described having a 'pane of glass' inside her head that prevented words entering her mind. She could hear them but they 'slid off' the glass and she was unable to determine their meaning before the person spoke again. She felt similarly that the pane of glass prevented her from producing the words she wished to say. She was able to feel a response to a question building up in her head, but was unable to get the words past the glass and thus out of her mouth" (1996, p. 2).

3.1.2 Responsibility in Communication: Participant Accommodation

In communication disorders such as aphasia, a conversation entails an imbalance in communicative abilities between the individuals involved (see chapter 3.2). Accommodating the needs of the individual that has impaired communication, is an important responsibility. The active adaption of communication based on the capabilities of the impaired individual, is referred to as *participant accommodation* (Kovarsky, 2014, pp. 69–70). It is also known as *listener adaption* (Glucksberg, Krauss, & Higgins, 1975 as cited in Kovarsky, 2014, p. 69), and *recipient design* (Schegloff. 1979 as cited in Kovarsky, 2014, p. 69).

For example, consider a situation where an individual has, due to language impairment, been reduced to using only the words 'yes' and 'no'. It is the responsibility of those more communicatively capable to adapt their communication so that the individual with impaired communication can communicate – in this case, it would be asking questions that could be answered exclusively with 'yes' and 'no'. With aphasia, participant accommodation can also entail taking advantage of aphasics' ability to better understand words and concepts that have a high degree of concreteness.

3.1.3 The Concreteness Effect: The Efficacy of the Concrete Versus the Abstract

Non-aphasics are generally better at processing concrete words and concepts – or concrete materials – opposed to abstract materials. However, aphasics struggle significantly more with abstract materials than concrete ones (Franklin et al. 1994; 1995; Tyler et al. 1995 as cited in Galliers et al., 2011, 2012; Hagoort, 1997, p. 239; Jessen et al., 2000). This means that the efficacy of using concrete materials is greater for aphasics than it is for non-aphasics. This is referred to as *the concreteness effect*. This suggests that when communicating with aphasics, one should avoid abstract materials. Although true for the majority, there have been recorded cases of aphasic individuals recalling abstract materials better than concrete ones – a reverse concreteness effect (Hagoort, 1997, pp. 239–240).

3.1.4 Dual Coding Theory

One theory that frames the efficacy of the concreteness effect in aphasics opposed to non-aphasics, is the *dual coding theory* (DCT) proposed by psychologist Allan Paivio (Hagoort, 1997, pp. 239–240; Paivio, 1986). In explaining the DCT, Paivio (1986, p. 17) gives a self-proclaimed imperfect but useful explanation of what representations are in a psychological sense:

> *"Representations can also be described as varying in concreteness-abstractness, a dimension that correlates with the distinction between picture-like and language-like symbols. Thus, at one extreme we have highly concrete, iconic, modality-specific representations of objects and events. […] At the other extreme we have completely abstract, amodal (or at least not modality-dependent) representations that are only arbitrarily related to real world objects and events."*

In short, the DCT suggests that when an individual learns new material, the brain stores two separate and distinct representations of this material: one *verbal* (language-like), and one *nonverbal* (picture-like) representation. Likewise, in recalling learnt material, the brain has access to two separate representations that are referentially connected (i.e. the brain knows that the two separate representations refers to the same material), and can use both representations to recall the material (Paivio, 1986, pp. 53–54). The manner in which these representations are stored and recalled to and from the two separate systems according to the DCT, is illustrated below in Figure 3-2:

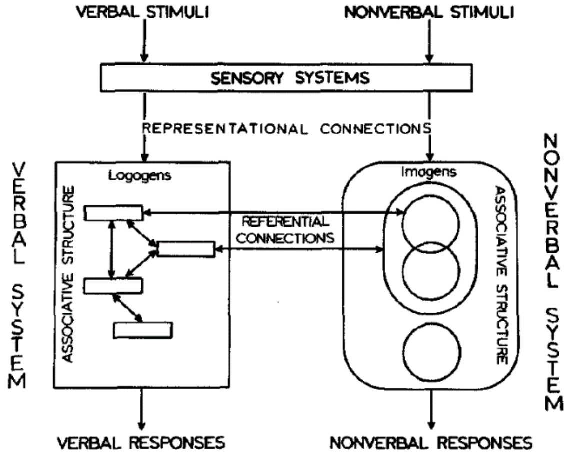


Figure 3-2 A schematic illustration of DCT; the verbal and nonverbal system, showing referential connections between these (Paivio, 1986, p. 67).

The implication of this is, according to the DCT, that words that are represented – or coded – in both the verbal and nonverbal system, have a higher chance of being recalled than if they only exist in one system. Hagoort explains how this can be advantageous to aphasic individuals: "the advantage for concrete words due to the existence of a dual code for this class of words, one verbal and the other nonverbal (imaginable). Abstract words, in contrast, only activate a verbal code" (1997, p. 239).

For example: you learn the meaning of 'car'. According to the DCT, the brain stores two representations of car: a verbal (and thus linguistic) representation of the word 'car', and a nonverbal representation of what a car visually is – what you can imagine the car to be. In recalling 'car', the brain uses both representations; both the verbal and nonverbal. This is possible because 'car' has a high degree of concreteness. Abstract words are often intangible (e.g. 'dream' or 'happy') and may be hard to imagine, and thus do not have any clear referential nonverbal representation.

In aphasia, the verbal representation may not work as intended (for instance with anomia – see chapter 3.1.1), but in recalling the meaning of 'car', the brain can still draw on the nonverbal representation because 'car' has a high concreteness, and is representable by the nonverbal system. Abstract words, on the other hand, may be difficult for an aphasic to understand because they only activate the verbal system – which is not accessible because of the damage caused by aphasia. Thus, the concreteness effect is amplified for aphasic individuals.

I have chosen to highlight the DCT theory because it is useful in supporting one particular anomaly experienced in one of the workshops with an aphasic participant. This is discussed in chapter 7.1.2.1. In addition, the DCT also frames some important findings related to current research (see chapter 3.4.2):

- DCT supports the use of concrete words and concepts over the abstract in communicating with aphasic individuals (see chapter 3.4.2.5).
- DCT supports multi-modality, and the use of visual support (see chapter 3.4.2.3, and chapter 3.4.2.4).

3.2 Communication is Power

Communication is an overloaded and broad term that defines the exchange of information between two or more entities, using some form of medium. Commonly, these different mediums are languages, and this thesis is concerned with human language. In regards to human language, Borden (1993, p. 2) defines a particular language as "a rule-governed communication system composed of meaningful elements, which can be combined in many ways to produce sentences […]". Furthermore, "we use [communication] in many ways: to initiate, build and maintain relationships; to carry out transactions; to achieve status; to project our personalities; to assess other people" (Jordan & Kaiser, 1996, p. 1). Since a language is rule-governed, it can be understood by anyone who is familiar with the rules of that particular language, and are able to communicate normally. Jordan and Kaiser describe **normal** human communication between two individuals in short as "the simultaneous nature of communication, with both partners taking equal responsibility for ensuring that ideas are passed effectively between them" (as illustrated in Figure 3-1). This exchange of ideas happens quickly, with subtleties of meaning not only passed with the intonation of words and grammatical structure of sentences, but through body language such as movement of limbs and microexpressions, which often carry more meaning and emotion than verbal communication (1996, pp. 38–40, 44).

This suggests that any factors that interrupt this balance of responsibility between the individuals, implies a **non-normal** communication process. Goodglass and Kaplan describe this exchange of ideas as a complex one, depending on interaction "between sensory-motor skills, symbolic associations, and habituated syntactic patterns […]" (1972, p. 5), suggesting not only the complexity of such a process, but its variance from one individual to another. The loss of a normal communication can have dire consequences for the individual, and aphasics are often left disempowered and socially isolated without language. Terms like 'impairment', 'disability', and 'handicap' are often used to describe the severity of an individual's difficulties: *The World Health Organization* (WHO) defined these terms as shown below in Table 1:

Impairment	Any loss or abnormality of psychological, physiological, or anatomical structure or function.
Disability	Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
Handicap	A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role (depending on age, sex, and social and cultural factors) for that individual.

Table 1 The WHO classification of disability – adapted from Jordan and Kaiser (1996, p. 4)[13]

These definitions have since received criticisms (Jordan & Kaiser, 1996, p. 5) – not because they are wrong – but because of their stigmatisation of disability. Disability is in itself a socially constructed phenomenon, and therefore, the accountability of discrimination should be placed on the social construction itself – not the individual. This is what the *social model definition of disability* (hereinafter *social disability model*) attempts to address. This model is shown in Table 2:

Impairment	The functional limitation within the individual caused by the lack of part or all of a limb, or having a defective limb, organ, or physical, mental or sensory mechanism of the body. [14]
Disability	The loss or limitation of opportunities that prevents people who have impairments from taking part in the normal life of the community on an equal level with others owing to physical and social barriers. [15]

Table 2 The social model definition of disability – adapted from Jordan and Kaiser (1996, p. 5).

The key difference between the two models, is that the social disability model situates the 'problem' not on the individual, but on the socially constructed phenomenon 'disability' itself – this model is emancipatory in nature, suggesting that the problem must be solved on a societal level, and that it is an issue of equal opportunity. The social disability model aims to maintain 'compatibility'

---

[13] Original source: World Health Organization (1980).

[14] Original source: Barnes (1992), and Finkelstein et al. (1993).

[15] Original source: Finkelstein et al. (1993).

with the model proposed by the WHO in terms of the definition of 'impairment', and disband the term 'handicap' altogether due to its stigmatising history (Jordan & Kaiser, 1996, pp. 3–7).

This thesis uses the definition of disability proposed by the social disability model, because it aligns with the philosophy behind HCD (see chapter 4): design must accommodate the needs and capabilities of the intended users – not vice versa.

3.3 The Digital and Disability Divides

Aphasic individuals are unable to use a lot of off-the-shelf Internet and Communications Technology (ICT) – their access to ICT may be restricted by *cognitive* access, resulting in a digital divide[16] defined by their aphasia. For aphasics, this *disability* divide transcends the digital divide, because if the ICT is available but perceived as an obstacle, it might as well not exist. In regards to the social disability model defining disability (see Table 2), this effectively means that ICT has the power to define some people as disabled, and others as not disabled, and create new forms of exclusion for people with disabilities based on the ICT they can use (Goggin & Newell, 2007, p. 159; Stienstra, Watzke, & Birch, 2007, p. 151). There are initiatives that promote accessibility for all; for instance, the *Web Accessibility Initiative* (WAI) introduced by the W3C (Caldwell et al., 2008), and the *Universal Design* movement, which promotes *inclusive design* – design for everyone (Connell et al., 1997). In Norway, Web pages that are run by the public sector are now obliged by law to follow universal design principles (Tilsyn for universell utforming av IKT, n.d.), and similarly in the United States through the United States Rehabilitation Act (Maskery, 2007, p. 188).

3.3.1 Universal Design

As humans, we are fundamentally different, and thus we have different requirements. The *Universal Design* (UD) movement tackles this very issue. UD is an interdisciplinary movement in design, pioneered by architect, product designer, educator, and founder of *The Center for Universal Design*, Ronald Mace (The Center for Universal Design, n.d.):

> *"He coined the term "universal design" to describe the concept of designing all products and the built environment to be aesthetic and usable to the greatest extent possible by everyone, regardless of their age, ability, or status in life. He was also a devoted advocate for the rights of people with disabilities which is reflected in his work."*

UD is important because it promotes interdisciplinary design solutions that are inclusive in nature – design that discriminates against no one. The seven principles of UD are defined at a high level

---

[16] A *digital divide* is a manifestation of technology and inequality; a "discrepancy between social groups in **access** to, use of, and empowerment by networked computers and other digital tools"(Quan-Haase, 2012, p. 128, emphasis added).

in that it attempts to cater to all design disciplines, and because of this, it is explicitly stated that some principles do not cater to certain designs (Connell et al., 1997):

- "**Equitable Use**: The design is useful and marketable to people with diverse abilities."
- "**Flexibility in Us**e: The design accommodates a wide range of individual preferences and abilities."
- **"Simple and Intuitive Use**: Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level."
- "**Perceptible Information**: The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities."
- "**Tolerance for Error**: The design minimizes hazards and the adverse consequences of accidental and unintended actions."
- "**Low Physical Effort**: The design can be used efficiently and comfortably and with a minimum of fatigue."
- "**Size and Space for Approach and Use**: Appropriate size and space is provided for approach. Reach, manipulation, and use regardless of user's body size, posture, or mobility."

A more detailed implementation of UD, can be found in WCAG 2.0 (part of the WAI, initiated by the W3C), which covers the accessibility of content on the Web. Since WCAG 2.0 is specific to the Web platform, it provides specific guidelines supported by success criteria, and advisory techniques on implementation. The W3C explicitly advises that, even though it attempts to make Web content more accessible for everyone, the guidelines are not suitable for all combinations – again because of its UD nature (Caldwell et al., 2008). The WCAG 2.0 guidelines provides a level of specificity that is not possible through UD, because WCAG 2.0 is, as the name implies, specific to the Web platform.

UD is undoubtedly a critical movement towards narrowing the digital divide, while more discipline-oriented initiatives such as WCAG 2.0 create opportunities for UD in the HCI discipline. However, such high-level heuristics are troublesome because they aim to accommodate *all* users – they are suitable to no one in particular. The reality of this, is that they effectively act as *meta* guidelines, or guidelines *about* guidelines – the specifics disappear in trying to 'explain it all'. These types of guidelines are useful as starting points, but need refinement and focus for users with very particular requirements. An example of such a refinement, is the *Accessibility Requirements for People with Low Vision* – a proposed extension to WCAG 2.0 (Allan, Kirkpatrick, & Henry, 2016). Albeit just a working draft, this document specifies requirements for users with very specific requirements on the Web platform.

There was, at the time of writing, no such guideline frameworks available for the individuals with aphasia – therefore, I conducted a literature review in order to compose such a list to use in the design of the Sunnere app. This is covered in the next section.

3.4 Literature Review: Designing for and with Aphasics

Marshall and Rossman (2010, p. 58) point out three reasons for conducting a literature review: determine whether the study has potential to 'contribute knowledge' – whether it is significant to the ongoing inquiries about the topic; determine and acknowledge the traditions that revolve around the topic; and through critique, identify gaps in knowledge, or point to practices and policies that are not working. The two aspects of the research questions outlined in chapter 1.3; the research, and the design; pose the following inquiries in the context of a literature review:

- What design guidelines have been used both successfully and unsuccessfully in designing user interfaces (UIs) for aphasics? (formulated from RQ1)
- What roles have aphasics previously assumed in the design process, and what were the outcomes of their involvement? (formulated from RQ2)

Since the biggest challenge for aphasic individuals is coping with the requirements of communication in everyday situations, the majority of past design cases focus on the augmentation of remaining communicative ability. These devices are referred to as *Augmentative and Alternative Communication* (AAC) devices – an umbrella term used to describe communicative aids that compensate for an individual's loss of language. AAC devices can be either low-technology (for instance, drawings, written words and messages, and images), or high-technology (for instance, digital aids that support communication using sound, images, and text together) (Beukelman, Fager, Ball, & Dietz, 2007, pp. 230,235–238). Moffat et al. (Moffatt, McGrenere, Purves, & Klawe, 2004, p.407) present a useful distinction clearly inspired by *Maslow's hierarchy of needs* (Maslow, 1943): ICT can fulfil high-level or low-level goals. A low-level goal is one that is critical to the individual in terms of life quality, for instance, by tending to an aphasic individual's ability to communicate and therefore participate in everyday situations. A high-level goal is related to activities that are non-critical in regards to the individual's quality of life; for instance, an organisational aid (such as digital diaries, or a calendar), or a nutritional app that can improve the individual's dietary habits. Moffat et al. (2004) suggests that this may be one reason why there are a limited number of design cases that target high-level goals, intended for aphasic end-users.

While the low-level goals must be prioritised, this leaves room for ICT that target higher-level goals like nutrition. My literature search was guided by two conditions:

- The end-user of the design had to be aphasic users.
- The aphasic individual had to be involved in the design process, either directly, or indirectly.

The design cases that matched these conditions included a recipe book, a calendar, an email client, and four AAC-like devices. The aphasic individuals were involved in the design process both directly, and indirectly:

- The *Enhanced with Sound and Images* (ESI) Planner; a PDA daily planner using sound and images to facilitate the management of appointments (Moffatt et al., 2004).
- The *Visually Enhanced Recipe Application* (VERA); a pen-based tablet application featuring multi-modal recipes, using text, sound, and images to describe cooking instructions (Tee et al., 2005).
- The *Enhanced with Sound and Images* (ESI) Planner II; the further development of the ESI Planner, integrating the communication aid *Lingraphica* into the original ESI Planner (Boyd-Graber et al., 2006).
- *PhotoTalk*; an AAC PDA application designed to support face-to-face communication through the capturing and annotation of images (Allen, McGrenere, & Purves, 2007).
- An email application for aphasic individuals; designed to make email accessible, facilitating input by incorporating AAC into an existing email tool (Al Mahmud & Martens, 2010).
- An AAC application supporting communication through storytelling and manipulation of digital photos (Koppenol, Mahmud, & Martens, 2010).
- *GeST*; a gesture therapy tool, allowing the practice of gestures as an alternative way of communication for individuals with aphasia in an AAC-like manner (Galliers et al., 2011, 2012).

3.4.1 The Role of Aphasic Participants in the Design Process

Involving future users in the design process is paramount in order to achieve a design that aligns with future use – and communication is at the heart of involvement. In regards to designing accessible ICT for users with very particular (and non-binary) requirements such as aphasia, involvement becomes all the more important. In HCD approaches such as UCD and PD (see chapter 4), the future user of a design is involved in the design process, and communicates requirements for the design in some way to the designer. Aphasia manifests as a challenge for the design process, because design practice which puts the user in focus relies so unshakably on communicative ability. Design practice that lets the participant 'speak in their own language' is essential when involving the aphasics directly in the design process. The role an aphasic individual can assume in the design process is largely dependent on retained communicative ability.

Despite the apparent challenges, aphasic individuals have been involved directly in the design process in a multitude of design cases, and their involvement varies from participants in PD approaches (Galliers et al., 2011, 2012; Moffatt et al., 2004), to interviewees (Al Mahmud & Martens, 2010) and usability testers in UCD approaches (Tee et al., 2005). However, in direct involvement in the design process, aphasic participants have generally been 'recruited' on the precondition that they show a relatively high degree of language stability and independence. This implies that these participants and are not in a vulnerable state, and not undergoing rehabilitation.

One of the most prominent challenges in direct involvement of the aphasics in the design process, is effective communication with the participants (Moffatt et al., 2004). For instance, sentences are best split up: Galliers et al. provide an example: “for example, asking ‘Would you like tea or coffee?’ is too difficult. ‘Would you like tea?’ Pause. ‘Or would you like coffee’ allows for a response via a nod or a shake of the head in between questions” (2012, p. 55).

Aphasics generally require a lot of time, so in direct involvement, activities must allow for sufficient time to give the participants the ability to participate (Al Mahmud & Martens, 2010; Boyd-Graber et al., 2006; Galliers et al., 2011; Moffatt et al., 2004). This is complicated by the fact that long sessions can be both physically and mentally exhausting for aphasics, and should be avoided to reduce stress on the participants. Moffatt et al. employed aphasics in workshop-like settings lasting for 90 minutes successfully (2004, p. 411). This is however a timeframe that must be adjusted with the participants at hand. When involving aphasics in the design process, there is strong agreement that assessment of the participants’ communicative abilities provides a huge advantage as “[it] proves insight into the results that would not otherwise have been apparent” (Moffatt et al., 2004, p. 413). In other words, an aphasic individual may have developed compensatory communicative abilities that are not apparent without standardised assessment, which, in turn may mark the ‘real’ degree of aphasia.

3.4.1.1 Proxy Users

In cases where the aphasics have been unable to communicate, *proxy users* have been used in the design process. Proxy users are individuals that act on the behalf of the actual users (Lazar, Feng, & Hochheiser, 2010, Chapter 15, *15.3 Proxy Users*, para. 1). In the case of aphasia, these are usually Speech-Language Pathologists (SLPs) that have first-hand experience with the impairment as primary aphasia therapists, and are able to generally participate in communicative aspects of the design process *on behalf* of the aphasic individuals (Allen et al., 2007; Boyd-Graber et al., 2006; Koppenol et al., 2010).

The various ways in which aphasics are involved in the design process suggests that the aphasic individual’s role in the design process is highly dependent on their ability to communicate, and should be adapted to the case at hand.

3.4.2 Eight Usability Heuristics for Aphasic Users

The following section outlines notable findings in regards to design guidelines that have been used in designing interfaces for aphasic users. They are numbered for convenience:

3.4.2.1 H1 – Deep Customisability

The recurring requirement for all past design cases is rooted in the fact that aphasia affects the individual in such a unique manner. In a majority of the design cases, **customisability** was a key requirement to allow tailoring of the user interface to accommodate the particular requirements of the aphasic individual (Allen et al., 2007; Al Mahmud & Martens, 2010; Boyd-Graber et al., 2006; Galliers et al., 2011; Moffatt et al., 2004; Tee et al., 2005). I have adopted the term “**deep customisability**” (Moffatt et al., 2004), which entails a degree of customisation that allows for incredibly fine-grained adjustments of the UI. Examples of such deep customisability include: making a single button or image larger (Allen et al., 2007; Koppenol et al., 2010), allowing for typographic cues; such as the enlargement or emphasis of important text (Boyd-Graber et al., 2006), or removing content that is deemed 'noise' (unnecessary visuals or sounds).

3.4.2.2 H2 – Quiet Design

Visual and audible **noise** is best avoided as aphasics also can suffer from attention deficits (Murray 1999, as cited in Galliers et al., 2012). A common way in which design can manifest as visual noise is for instance, when user interfaces are cluttered with buttons (Al Mahmud & Martens, 2010), or if they lack **whitespace** between elements in the user interface (Boyd-Graber et al., 2006). Whitespace between elements similarly plays an important role for aphasic individuals that are also affected by motor impairments: when they interact with the interface, the motor impairment may cause them to target elements imprecisely. Having whitespace around such elements facilitates targeting by allowing a 'free zone' around these (Allen et al., 2007; Moffatt et al., 2004). Working memory, which may be impaired accompanying aphasia (Wright & Shisler, 2005), affects the amount of interface elements that should be displayed at any one time – **fewer interface elements are better** (Al Mahmud & Martens, 2010; Galliers et al., 2012).

3.4.2.3 H3 – Multi-Modality

There is general agreement that using a **multi-modality**, i.e. triplets of *text*, *image*, and *sound* is beneficial in conveying information to aphasics. This is based on the employment of such multi-modal approaches in AAC technology (Boyd-Graber et al., 2006; Moffatt et al., 2004; Tee et al., 2005).

3.4.2.4 H4 – Visual Support

There is a consensus that aphasics generally retain their ability to recognise images (Allen et al., 2007; Al Mahmud & Martens, 2010; Boyd-Graber et al., 2006; Galliers et al., 2012; Koppenol et al., 2010; Moffatt et al., 2004; Tee et al., 2005). This suggests that **images and symbols are useful as visual support** in conveying information.

3.4.2.5 H5 – Avoid Abstractions

Individuals with aphasia struggle with **processing abstract concepts** than concrete ones (Franklin et al. 1994; 1995; Tyler et al. 1995 as cited in Galliers et al., 2011, 2012; Hagoort, 1997, p. 239). In some cases, **colour-coding** was used with images to create a correspondence between for instance images and actions, or to distinguish between several options (Al Mahmud & Martens, 2010; Tee et al., 2005). This also corresponds with the efficacy of the concreteness effect for aphasics, presented in chapter 3.1.3.

3.4.2.6 H6 – Reduced Use of Text and Numbers

Designs purposefully avoid large amounts of text due to difficulties with word retrieval and recognition, but **short text and familiar words** can be used in some cases (Koppenol et al., 2010; Tee et al., 2005). Difficulties with understanding numbers (**dyscalculia**) can also be a problem for some individuals (Capelletti & Cipolotti, 2010 as cited in Galliers et al., 2012). Inputting text can be slow and frustrating for aphasic individuals, and can be facilitated through the use of templates; for instance, ready-made short sentences that are commonly used that can be composed together, formulating more complicated information (Al Mahmud & Martens, 2010; Boyd-Graber et al., 2006).

3.4.2.7 H7 – Simple Navigation

Traditional UI navigation through hierarchical menus is best avoided: navigational options should be clear and consistent, and facilitate **findability** (Allen et al., 2007; Al Mahmud & Martens, 2010; Boyd-Graber et al., 2006; Moffatt et al., 2004). For instance, navigation can be indicated by using arrows representing moving actions between screens (Tee et al., 2005). **Task-switching**; moving back and forth between two or more tasks may be confusing for some aphasics: allowing for separate tasks on the same screen might facilitate tasks where task-switching is traditionally required (Al Mahmud & Martens, 2010).

3.4.2.8 H8 – Sufficient Time

Aphasics generally require more time in interacting with the world around them (Al Mahmud & Martens, 2010; Boyd-Graber et al., 2006; Galliers et al., 2011; Moffatt et al., 2004). In the context of apps, this translates to designs that allow for enough time for the individuals to interact with the UI.

4 HUMAN-CENTRED DESIGN

> *It is the duty of machines and those who design them to understand people. It is not our duty to understand the arbitrary, meaningless dictates of machines.*
>
> –Don Norman (2013, p. 6)

There are numerous overlapping disciplines that involve designing technology for humans, and the terminology that attempts to define it all can be confusing. Although not a *formal* definition of their relationships, designer Dan Saffer's (2008) placement of the various disciplines that make up *User Experience* (UX) – the user's perceived experience of a particular design – provides a useful illustration of how the myriad of disciplines may fit together (see Figure 4-1):

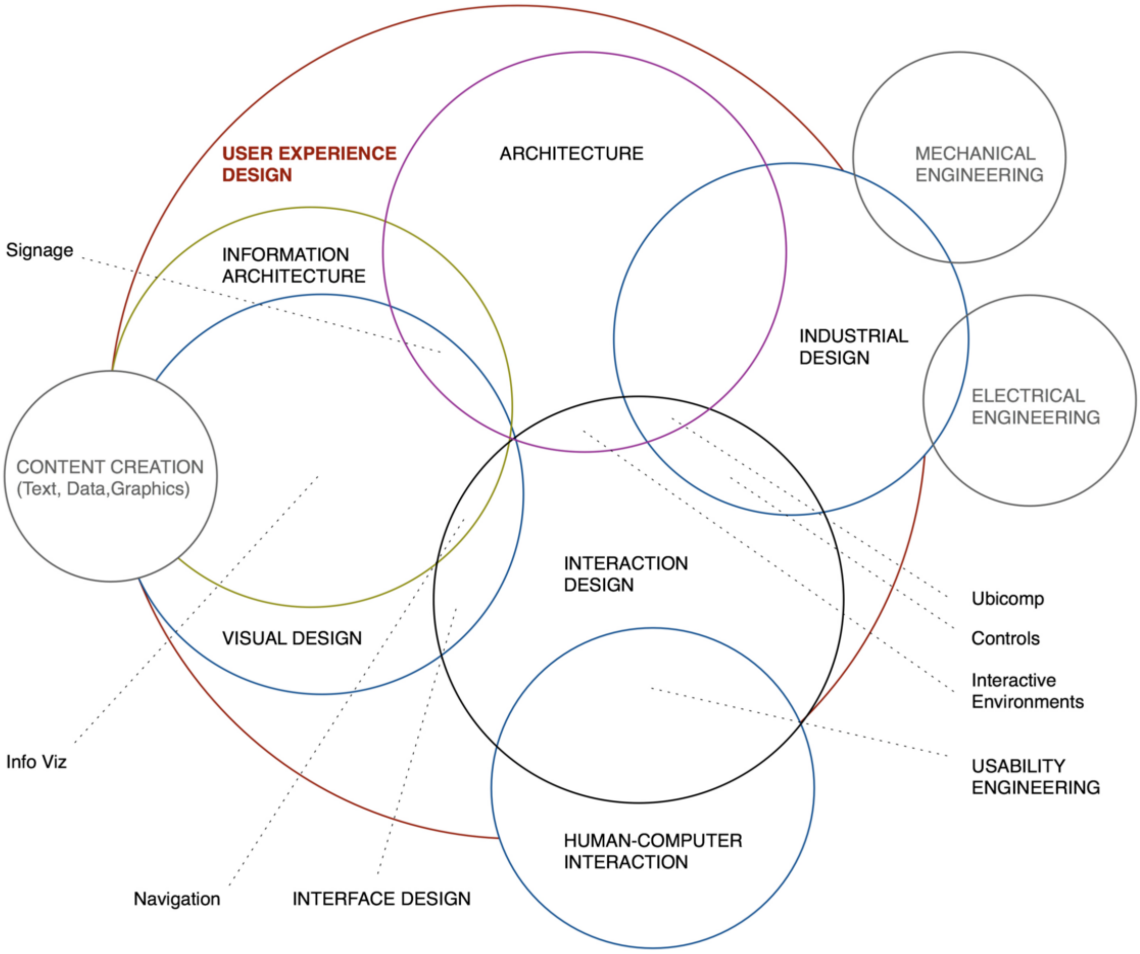


Figure 4-1 An interpretation of how User Experience fits together with various related design disciplines (Saffer, 2008).

Where the figure above outlines the apparent relationships of disciplines, Don Norman proposes *Human-Centred Design* (HCD) as a *design philosophy*, rather than a discipline or "an area of focus" (Norman, 2013, pp. 7–9). Thus, HCD is compatible with all disciplines: "[it is] [t]he process that ensures that the designs match the needs and capabilities of the people for whom they are intended"

(Norman, 2013, p. 7). This thesis is concerned with two areas of focus: *Interaction Design* (IxD), and *Human-Computer Interaction* (HCI) – it is, however, driven by the HCD philosophy.

Interaction Design is described by Löwgren and Stolterman as: "the process that is arranged within existing resource constraints to create, shape, and decide all use-oriented qualities (structural, functional, ethical, and aesthetic) of a digital artefact[17] for one or many clients" (2007, Chapter 1, *1.2 Core Concepts*, para. 1). IxD is inevitably tangled with HCI, the broad academic field relating to the inter-disciplinary study of interaction between humans and computers. HCI has significantly gained momentum since the early days of computers due to the ubiquitous adoption of computers (Lazar et al., 2010, Chapter 1), and is ever-changing as society becomes increasingly entangled with ICT.

4.1 The Landscape of Human-Centred Design

In what they call *the current landscape of Human-Centred Design*, Sanders and Stappers (2008) position two design approaches that involve the future user of the design in the design process, distinguished by the user's role in this: designing *for* the user, and designing *with* the user. These key differences are central to two methodologies that follow the HCD philosophy: *User-Centred Design* (UCD) and *Participatory Design* (PD) respectively. Their positions in relation to each other are illustrated in Figure 4-2:

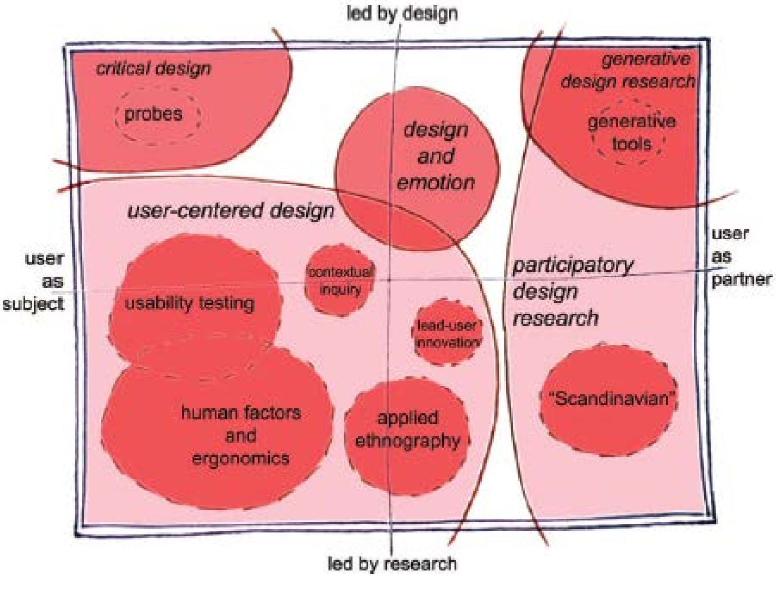


Figure 4-2 The current landscape of HCD, as illustrated by Sanders and Stappers (2008).

UCD has as a goal to design *for* the user, with the objective of ensuring that "the [design] meets the needs of the user" (Sanders, 2002, p. 1). In a typical UCD design scenario, the design team consists of a researcher and a designer. The user's role in the scenario is limited to telling and showing the researcher about their needs: the user is not *really* part of the team, but is represented

---

[17] A digital artefact in this context simply refers to any ICT device.

through the researcher. The researcher relays this data to the designer, whom develops the design. Later user involvement is optional (e.g. usability testing) (Sanders, 2002, p. 1).

PD implies that the user has a *participatory* role in the design process itself; the design is developed *with* the user. Sanders and Stappers (2008, p. 6) refers to this as *co-design*: "collective creativity as it is applied across the whole span of the design process". The distinction between the user and the designer roles blur, and both are considered *participants* of the design process: the "designer strives to learn the reality of the users' situation while the users strive to articulate their desired aims and learn appropriate technological means to obtain them" (Robertson & Simonsen, 2013, p. 2). In addition, the designer and the researcher can be the same person (Sanders & Stappers, 2008, p. 12). This is a dramatic shift away from simply using the user as a means of input to the design requirements specifications; a process where the user and designer have limited correspondence.

4.2 Participatory Design

PD originated in a socio-political context that began in the 1960s and 70s in Scandinavia. The change resulted from the introduction of Information and Communication Technology (ICT) to the workplace, and the computer automation of tasks – a modern day industrial revolution. PD was a reaction to this: a movement with the goal of providing the workers with better tools for their jobs by involving the workers in the design process; designing tools *with* the future users of these tools. This was based on the premise that the workers were, in fact, the domain experts, and that they should *have a say* in the design of the tools that they would eventually use. Not only was it envisioned that this approach would provide better tools for the workers, but also that through automation of tedious and repetitive work, the workers would be able to extend their skills (Robertson & Simonsen, 2013, pp. 1–2).

In PD, participation must be *genuine.* This "[refers] to the fundamental transcendence of the users' role *from* being merely informants *to* being legitimate and acknowledged participants of the design process" (Robertson & Simonsen, 2013, p. 4). Genuine participation is the result of proactivity grounded in the heritage and ethos of PD. Kensing and Greenbaum summarise their interpretation of this as *six guiding principles*, emphasised below (Kensing & Greenbaum, 2013, pp. 32–33):

- **Democratic practices** that promotes this equality and allows "educated and engaged people acting on their own interest and […] the interests of the common good".
- **Equalising power relations,** which means actively engaging hegemonies and striving to make all voices carry equal weight in regards to decisions that will influence the design (e.g. a manager should not have the final say over an employee of lower organisational rank in regards to making a decision that will influence the design that the employee will use).
- **Situation-based actions** allow for the designer to "work directly with people in their workplace or homes to understand actions and technologies in actual settings, rather than through formal abstractions".

- **Mutual learning** which is enabled through establishing common ground for participation through the sharing of expert knowledge.
- **Tools and techniques** that allows the participants to express their visions, eventually resulting in **alternative visions about technology**.

PD methods are used to set the scene for practical application, and therefore "refers to a coherent set of organising principles and general guidelines for how to carry out a design process from start to finish – within a Participatory Design perspective". The method is applied as a set of general guidelines, and must be adapted to the project at hand (Bratteteig, Bødker, Dittrich, Holst Mogensen, & Simonsen, 2013, p. 118). There are three core perspectives for *all* methods in PD: *having a say*, *mutual learning*, and *co-realisation*.

A fundamental perspective not only in methods, but in PD as a whole, is **having a say**: "Having a say means having something to say as well as affecting the outcome of an activity with what you say – i.e. having an influence" (Bratteteig et al., 2013, p. 129). Having an influence does not happen without effort, and requires that the participants are both empowered and informed through mutual learning throughout the design process. Models of power (e.g. programmer/user, designer/programmer, manager/employee) must be challenged as all stakeholders' knowledge should have an equal weight, be it use-oriented or technical knowledge. Through this foundation, a decision-making process in regards to design problem-solving should be shared between *all* participants (Bratteteig et al., 2013, pp. 129–131).

PD considers the users as the *domain experts* of the systems that they (will) use: "the 'designers' know about technical issues and design processes, while the 'users' know the domain and use context, i.e. the activities and practices into which the new technology will be introduced" (Bratteteig et al., 2013, p. 132). Since competencies can vary between the participants (e.g. users, managers, designers, and other stakeholders) they should all be considered experts in their respective professional contexts. This is essential to create a common understanding of how the different participants reason their own professional logic in the context of the design project. Furthermore, the resulting trust and respect between all the participants opens up for **mutual learning** between these participants (Bratteteig et al., 2013, pp. 132–133).

Co-realisation, the final perspective, is achieved using prototyping as the most important technique (see chapter 5.3.2.1): "a tangible artefact makes it easier to imagine the consequences of a design suggestion than would an abstract description" (Bratteteig et al., 2013, p. 133). In practice, this means creating low-fidelity prototypes (e.g. paper prototypes) together in workshop-like settings, co-realising a design solution. Bødker argues that the choice of materials or artefacts chosen for such collaborative processes play an important role in "mediating different kinds of relationships in user activities as well as between users and designers" (Bødker, 2009). This is important because it means it should be expected that the researcher's choice of workshop content, may impact the way in which the participants share their knowledge. The notion of *boundary* *objects* (Star & Griesemer, 1989, p. 393) is important in this context: they act as artefacts that are relatable to all participants, yet mediate a common space of understanding. These are either abstract (e.g. language), or concrete artefacts (e.g. physical objects), which are 'plastic yet robust', allowing them to convey some universally relatable identity across diverse competencies that the participants may have, therefore creating a common space of understanding within their use (Brandt, Binder, & Sanders, 2013, pp. 147–148).

4.2.1 Participatory Design in Practice

The tools and techniques used (e.g. prototyping) should be carried out with a *participatory mindset* (Brandt et al., 2013, p. 145; Sanders & Stappers, 2008). Simply put, this means that participants must be engaged and supported in activities, more specifically in *telling*, *making*, and *enacting*: "the making of things, the telling of stories and the enactment of possible futures together provide the basis for forming a temporary community in which the new can be envisioned" (Brandt et al., 2013, p. 145,149). It is important to support the various levels of creativity that the participants may have, as Sanders and Stappers argue: "all people are creative but not all people become designers" (2008, p. 12). They present four different levels of increasing creativity: **doing**, **adapting**, **making**, and **creating**, which are reliant on expertise, interest, and effort. The 'doing' activity represents the least amount of expertise, interest, and effort, while 'creating' represents the most. All participants have the potential become part of the design team as the "experts of their experiences" (Sleeswijk Visser et al., 2005, as cited in Sanders & Stappers, 2008, p. 12).

However, this is dependent on tools that allow them to express their own creativity – regardless of their creativity level. With each level of increasing creativity, less involvement of the designer should be required. Sanders and Stappers suggest that at the 'doing' level the participants must be **led**; at the 'adapting' level they must be **guided**; at the 'making' level they must be supported by **scaffolds** (see chapter 4.2.2.1); and at the 'creating' level, they must be offered a **clean slate** (Sanders & Stappers, 2008, p. 14). It is important to understand that participation in the creative process may take on such different forms – and need different types of support.

PD is grounded in the belief that a designer cannot infer the 'use practice' of an artefact – the manner in which the artefact will be used by the user – without the participation of the users themselves (Bratteteig & Wagner, 2014, p. 29). Thus, PD is about creating design choices, and selecting among these – together with the future users of the design. Central to this, is the sharing of power in the decision-making process of the design choices that eventually make up the design. Knowing about *how* these choices manifest, helps to clarify *how* participation in the design process can happen. Bratteteig and Wagner (2014, pp. 30–31) suggest that in order to know *what* the participant is participating in; it is useful to be aware of the of decisions that can be made: creating, selecting, concretising, and evaluating design choices – often in an overlapping and parallel manner. Furthermore, Bratteteig and Wagner (2014, p. 32) emphasise that full participation –

participation in *all* of these decisions is not necessary to produce a 'participatory result' – but is important to the participants so that they recognise their contributions.

In design, the degree in which the designer stays open to changes in the design, is often described with the expressions *divergence* and *convergence*. Divergent thinking refers to the expansion of design space – to be explorative and ever-open to suggestions and alternatives through a divergent design process. Contrariwise, convergence is the 'coming together' of the design process – where the design process focuses in creating a final design solution. Divergent thinking is important because by having multiple suggestions to what a design could be, the designer can avoid the possibility of 'falling in love' with a design, and subconsciously defending this as a matter of pride; an aspect that is paramount to the thoughtful designer to not do (Löwgren & Stolterman, 2007, Chapter 2, *Exploring Design Possibilities*) – and the involvement of the future users of the design in the design process can help dispel this predisposition.

4.2.2 Mutual Learning and Pedagogy

An important part of PD is the process in which a user 'becomes' a designer through guidance on the design process from the designer, and in turn is able to teach the designer about their own requirements through the design – this is referred to as **mutual learning**. Thus, the challenge for designers is to teach the user *become* a designer. Naturally, this process involves some degree of pedagogy, and as a useful frame to think about how someone can become what they not yet are, I will use Lev Vygotsky's *zone of proximal development* (ZPD). The ZPD originated in educational psychology, but is relevant in any situation where learning occurs – for instance, in the mutual learning process of PD.

Vygotsky defined the ZPD as "the distance between a child's '*actual developmental level as determined by independent problem solving'* and the higher '*potential development as determined through problem solving under adult guidance or in collaboration with more capable peers'*" (Vygotsky, 1978, p. 86; Wertsch, 1985, pp. 67–68, citation from Wertsch, italics represent citations from Vygotsky). In other words, this means that the ZPD is the zone of development that is between what the learner can do alone, and what the learner cannot do at all. In this area, exists what the learner can do with the guidance of adults, or what Vygotsky calls "more capable peers" (MCP) (Vygotsky, 1978, p. 86). The ZPD is illustrated below in Figure 4-3:

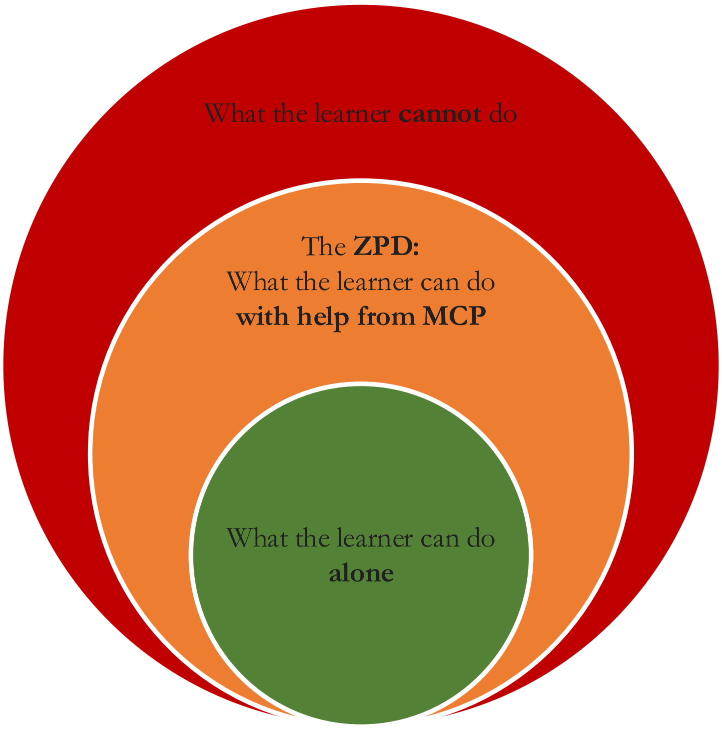


Figure 4-3 Vygotsky's zone of proximal development (ZPD) illustrated.

The ZPD attempts to grapple with how learners (originally children) can become what they not yet are – skills that the learner one day will have the potential to do alone. In practice, this means that the learner has an active role in learning through guidance from a MCP, in what Vygotsky calls an ‘internalisation’ of these skills (Vygotsky, 1978, p. 86; Wertsch, 1985, p. 67). The ZPD is essentially concerned with *how a child can become what he or she not yet is* (Bronfenbrenner, 1977, p. 528; Wertsch, 1985, p. 67). This is significantly different from a traditional learning situation, where the teacher lectures, and thus transmits information to the learner. In the context of PD, this applies to mutual learning in the sense that the user should be able to design with the guidance of an MCP (the designer), but also vice versa – the designer should be able to learn about the user’s needs and requirements – and the ZPD provides a frame for thinking about how this can be achieved.

4.2.2.1 Scaffolding

The term *instructional scaffolding* (or just scaffolding) comes from cognitive psychologist Jerome Bruner’s notion of scaffolding in a pedagogical context: scaffolding is when an adult supports a child in a “process that enables a child or novice to solve a problem, carry out a task or achieve a goal which would be beyond his unassisted efforts. This scaffolding consists essentially of the adult ‘controlling’ those elements of the task that are initially beyond the learner's capacity, thus permitting him to concentrate upon and complete only those elements that are within his range of competence” (Wood, Bruner, & Ross, 1976, p. 90). Bruner’s theory of scaffolding is clearly inspired by Vygotsky’s ZPD: *scaffolds* are implementations of guided learning, continually adapted to fit the cognitive needs of the learner, and are thus situated in the ZPD.

Thinking about the ZPD, and scaffolding is crucial to the mutual learning process. And will be discussed in chapter 7.2.4.

5 RESEARCH DESIGN

If you have met one person with aphasia –
well, then you have met one person with aphasia.

–SLP at Sunnaas Hospital (2015)

This chapter gives an explanation of the research design employed in this thesis, in order to address the RQs presented in chapter 1.3. The RQs aim to investigate the intertwined nature of how the Sunnere app was designed to enable informed dietary decisions for aphasic users, and how qualitative research methods were used to investigate the implication of aphasia on the design process. The applied methods; even though contributing to *both* the research process, and the design process; are described in this chapter.

The chapter starts with an account of qualitative research, and a positioning of the research conducted as part of this thesis in relation to the elements of research. In addition, I present some strategies in how qualitative research can be conducted in a trustworthy manner. Furthermore, the applied research methods, and their rationale for application is presented. The chapter concludes with outlining predominant ethical issues encountered in this study, especially in regards to interacting with patients as users.

5.1 Positioning Research

5.1.1 Qualitative Research

Empirical research is generally divided into *quantitative* and *qualitative* research approaches, and the researcher adopts either (or both) approaches depending on the topic of inquiry. The quantitative approach was intended to gain empirical knowledge relating to natural phenomena, using methods like surveys, laboratory experiments, and mathematical modelling. Contrariwise, the qualitative approach was intended to gain empirical knowledge of *social* phenomena; dynamic social contexts and individuality best explored through methods such as ethnography, participant observation, and case studies (Myers, 1997, *Overview of Qualitative Research*). The research conducted in this thesis is of qualitative nature, and thus, a short account of qualitative research is given in the following section: Marshall and Rossman describe both qualitative research, and the qualitative researcher as:

Qualitative research...

- "Takes place in the natural world"
- "Uses multiple methods that are interactive and humanistic"
- "Focuses on context"
- "Is emergent rather than tightly prefigured"
- "Is fundamentally interpretive"

The qualitative researcher…

- "Views social phenomena holistically"
- "Systematically reflects on who she is in the inquiry"
- "Is sensitive to his personal biography and how it shapes the study"
- "Uses complex reasoning that is multifaceted and iterative"

(Rossman & Rallis, 2003, pp. 8, 10 as cited in Marshall & Rossman, 2010, p. 3)

The characteristics outlined above demonstrate that qualitative research emphasises that which is human, and accepts that there are multiple truths in social context. Accordingly, the qualitative researcher must exercise active awareness of this view, and acknowledge that the researcher him or herself will also 'bring something' to the research process. The difference in perspectives between the participant and the researcher is, in anthropology, conveniently distinguished by etic (the researcher's), and emic (the participant's) perspectives[18]. An assumption that is fundamental to qualitative research, is that "the participant's perspective on the phenomenon of interest should unfold as the participant views it (the emic perspective), not as the researcher views it (the etic perspective)" (Fetterman, 2008; Marshall & Rossman, 2010, p. 144).

5.1.1.1 Thick Description

'Thick description', as adopted by Geertz (1973) in the context of qualitative studies (and more specifically, in ethnographic methods – see chapter 5.3.1), is the idea that a phenomenon described from an emic perspective has sufficient supporting context around it to enable it to be understood true to its intended meaning from an etic perspective. For instance, the researcher, or someone foreign to a culture or social context.

To illustrate the complexity associated with understanding complex social phenomena, Geertz (1973, pp. 2–3) provides an example based on anthropologist Gilbert Ryle's notion of thick description: two girls are rapidly contracting their eyelids. The first girl has an involuntary twitch; the second one is sending a secret signal to her friend. To anyone observing, the 'winking' is identical, but the context decides what is *actually* happening – the second girl is deliberately sending a particular message to a particular friend, according to an agreed upon signal. Imagine a third girl appears, and starts copying the first girl – or if, the second girl, was in fact, initially faking the signal. The intricacies appear to be infinite.

Marshall and Rossman suggest that researchers determined that the qualitative approach is appropriate for their inquiry, and should justify this by making "a case that 'thick description' […] and systematic and detailed analysis will yield valuable explanations of processes" (2010, p. 11).

---

[18] See Fetterman (2008).

5.1.2 Four Elements of Research

Research, either quantitative or qualitative, can be carried out in numerous ways, all leading to different paths, affecting the research process and its outcome. Crotty outlines four basic elements of *any* research process (1998, Chapter 1, *Four Elements*, para. 1):

- **Methods**: "the techniques or procedures used to gather and analyse data related to some research question or hypothesis"
- **Methodology:** "the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcomes"
- **Theoretical perspective:** "the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria"
- **Epistemology:** "the theory of knowledge embedded in the theoretical perspective and thereby in the methodology"

These four elements and their relationships are depicted in Figure 5-1:

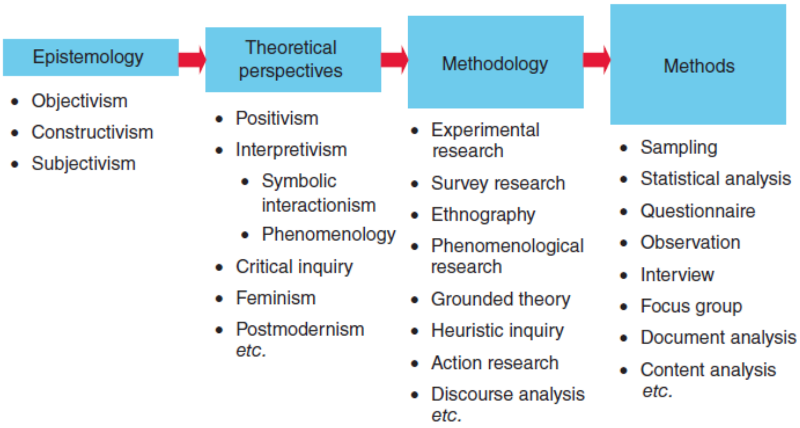


Figure 5-1 The relationship between epistemology, theoretical perspectives, methodology, and methods (Gray, 2013, p. 19).[19]

The four elements provide the researcher with a frame for thinking about the research process. But what are their practical implications to the research process? By reflecting on and thinking about these elements, the researcher thinks about his or her assumptions about what knowledge is and how to understand it: this is called **epistemology**, and "is a way of understanding and explaining how we know what we know" (Crotty, 1998, Chapter 1, *Four Elements*, para. 1). For instance, what the epistemology *constructivism* tells us about knowledge, is that "all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an

---

[19] Original source: Crotty (1998).

essentially social context" (Crotty, 1998, Chapter 3, para. 1). This sets knowledge in a relativist perspective, saying that no truth is absolute, but rather a construction of a given social reality, indicating that *meaning* (and knowledge) can be constructed differently, "even in the relation to the same phenomenon" (Gray, 2013, p. 20). This view of knowledge is in opposition to the epistemology *objectivism*, which is closely linked to the theoretical perspective *positivism*: "reality exists external to the researcher and must be investigated through the rigorous process of scientific inquiry" (Gray, 2013, p. 20) – it has an absolute reality.

Linked closely to the epistemology, the **theoretical perspective** encompasses underlying assumptions about knowledge (Crotty, 1998, Chapter 1, *Theoretical Perspective*, para. 1). For instance, in positivism, it is assumed that "ideas only deserve their incorporation into knowledge if they can be put to the test of empirical experience […]. For positivists, then, both the natural and social worlds operated within a strict set of laws, which science had to discover through empirical inquiry" (Gray, 2013, p. 21). As a contradistinction, the theoretical perspective *interpretivism*, which is closely related to constructivism, "asserts that natural reality (and the laws of science) and social reality are different and therefore require different kinds of method" (Gray, 2013, p. 23). This difference of theoretical perspective is summed up by Crotty (1998, Chapter 4, *Roots of Interpretivism*, para. 1):

> *"Our interest in the social world tends to focus on exactly those aspects that are unique, individual and qualitative, whereas our interest in the natural world focuses on more abstract phenomena, that is, those exhibiting quantifiable, empirical regularities"*

Epistemology and theoretical perspectives are important because the they significantly alter the researcher's assumptions about knowledge in the research process, and change the way that **methodology** – the researcher's strategy – is informed, and how **methods** are used to interact with this knowledge, all the while guided by qualitative or quantitative inquiry. Thinking about the four elements of research, helps guide the researcher dealing with the **research design**, and shows how to *find* and *interpret* the knowledge encountered. The researcher's **theoretical perspective** will, in turn, assume *something* about this knowledge. For instance, to investigate social phenomena, one must focus on the qualitative – one cannot employ the same methods as one would to investigate the natural world, an assumption that belongs to the theoretical perspective interpretivism.

Naturally, the manner and extent to which the researcher thinks about this is largely based on the researcher's experience and background – the researcher's personal subjectivity – what does the researcher 'bring' to the research process? It is important to acknowledge one's own subjectivity, as Crang and Cook (2007, Chapter 2, *'Subjective' Conclusions?*, para. 1) argue: "we might therefore say that the task for *all* researchers is to recognise and come to terms with their/our partial and situated 'subjectivity' rather than aspire to an impossibly distanced 'objectivity'. Once this is done, 'subjectivity' is much less a problem and much more a resource for deeper understanding". Actively and continually thinking, and engaging in one's own subjectivity, and how it affects the researcher's interaction with the world, is in qualitative research referred to as *reflexivity* (Dowling, 2008).

5.1.3 Positioning this Study

It is evident that the epistemological stance, and theoretical perspective assumed by the researcher will guide the methodology, affect application of the methods, and most certainly outcomes of the research undertaken. Naturally, whether the researcher acknowledges these four elements or not, the researcher's actions will in some way be positioned within these four elements – however, thinking actively about these elements may aid in the research design.

Since aphasia affects language in such a unique manner, understanding the individual aphasic's 'world' – their reality, is essential to understanding how to design for (RQ1), and with (RQ2) the individual (see chapter 1.3). This is grounded in the notion that communication largely revolves around constructing contextual and situated meaning – and thus is best understood from the perspective of the individual. This is essentially epistemologically constructivist with an interpretivist theoretical perspective in that this meaning is constructed individually and differently in the relation to the *same* phenomenon. The implication of this is that the results of interpretivist research is only 'valid' in the cases investigated.

As a counterexample to this constructivist understanding of aphasia, we could put the understanding of aphasia in an objectivist position from a linguistically scientific standpoint: in linguistics, language is separated in to discrete components (*morphology*, *phonology*, *syntax*, etc.) in which language capabilities are assessed. In a case study presented by Damico (1988), a language-impaired young girl failed to receive therapy due to language assessment based on the linguistic model failing to account for how language is used depending on the contexts. The objectivist position was not wrong – but the *interpretation* that it brought with it was problematic in assessing appropriate therapy, in that it was missing fundamental constructivist nuances. This phenomena was referred to as a *fragmentation fallacy* – i.e. the fragmentation of language into its linguistic components, resulted in an unrepresentative construction of the girl's language (Kovarsky, 2014, pp. 58–59).

This example is important, because it highlights that the young girl's reality – *her* construction of language – was significantly different than the reality of language positioned in clear-cut linguistic terms. This is also evident in the traditional classifications of aphasia – there exists aphasic individuals that do not fit one particular classification (see chapter 3.1.1).

Using Damico's case describing this failed therapy, I will argue that adopting a constructivist epistemology with a theoretically interpretivist perspective is well suited to the inquiry posed by the RQs (see chapter 1.3), as it offers a nuanced view – one that is *pragmatic* (in that it deals with the individual's reality of language – *their* constructions) and *synergetic* (in that all the experiential, social, and contextual parts is the *gestalt* of the individual's language – greater than its individual parts) (Kovarsky, 2014, pp. 58–59).

5.2 Trustworthiness

Traditionally, quantitative research has been the benchmark of ensuring *trustworthiness* of the research process, and results, through the concepts *reliability*, *validity*, *objectivity*, and *generalisability*. These concepts were historically 'borrowed' in qualitative research as an effort to give qualitative research similar trustworthiness as quantitative research (Marshall & Rossman, 2010, p. 39). Lincoln and Guba (1985, as cited in Marshall & Rossman, 2010, p. 40) criticised the manner in which qualitative research borrowed quantitative concepts of validity, and suggested a transformation of the quantitative concepts of trustworthiness (reliability, validity, objectivity, and generalisability) to better fit the nature of qualitative research: *credibility*, *dependability*, *confirmability*, and *transferability*. In addition, they proposed strategies that the researcher could use to work towards qualitative trustworthiness (Lincoln & Guba, 1985, as cited in Marshall & Rossman, 2010, p. 40):

- **Prolonged engagement:** a notion that is traditionally from anthropological studies; the researcher should be engaged in the qualitative research for a long period of time as this enables the researcher to immerse, develop congenial relationships, and understand the various constructions of reality encountered (Lundy, 2008).
- **Member checks**: interpretations and data should be shared with the participants to affirm it; that the researcher 'gets it right' (Sandelowski, 2008).
- **Triangulation**: a broad concept suggesting multiple perspectives, ranging from data collection methods, theoretical perspectives, to simply involving multiple researchers. The fundamental idea is that the phenomena under study can be better understood through multiple perspectives (Rothbauer, 2008).
- **Peer debriefing**: also called 'analytical triangulation'; results should be discussed with a disinterested peer in a manner of probing the researcher's thinking regarding the research process to ensure that analysis is grounded in the data, *not* the researcher's interest or values (Thi Nguyen, 2008).

These suggestions have been supported, and expanded since they were proposed by Lincoln and Guba (1985, as cited in Marshall & Rossman, 2010, pp. 40–41), and some additional suggestions include:

- **Searching for disconfirming evidence, and alternative explanations:** the researcher should actively look for evidence that is either disconfirming, or provides an alternative explanation.
- **Engaging in reflexivity:** the researcher should continually engage in her own subjectivity, and question how it influences her research.

- **Developing an audit trail:** a detailed account of the steps undertaken in the research process. The audit trail is important because it enables 'retroactive assessment', and justification of the emergent choices that appear in qualitative research (Rodgers, 2008).

An alternative terminology to Lincoln and Guba's suggested strategies for ensuring validity, is that of **transactional validity**, suggested by Cho and Trent (2006, as cited in Marshall & Rossman, 2010, p. 41). The key characteristic of transactional validity, is the involvement of participants in the research process as a means of validating its research results. This is primarily achieved through member checks and triangulation.

There are ongoing controversies in how validity applies to qualitative research (Marshall & Rossman, 2010, p. 41). For instance, it can be argued that the epistemologically constructivist and interpretivist theoretical perspective challenges the notion of validity as a whole, as Corbin and Strauss inquire: "[…] if findings are constructions and truth a 'mirage', aren't evaluative criteria also constructions and therefore subject to debate?" (Corbin & Strauss, 2007, p. 297, as cited in Marshall & Rossman, 2010, p. 41). Even though Corbin and Strauss pose a compelling conundrum in regards to validity for constructivist research, questions regarding ethical aspects of the research process, the quality of the results of the research, and contributions to the field of study ought to be asked.

Trustworthiness of this study will be discussed further in chapter 8.1, together its limitations.

5.3 Applied Methods

5.3.1 Ethnographic Methods

The qualitative study of human behaviour using methods like *interviews* and *observations* in combination, is central to ethnography, which, in its sociological and anthropological roots addresses the positivist unconcern for the individuality and complexity of human experience. Ethnography and its methods therefore aim to allow the researcher to "understand parts of the world more or less as they are experienced and understood in the everyday lives of people who 'live them out'" (Crang & Cook, 2007, Chapter 1, *Introduction*, para. 1). Even though these methods are central to ethnography, they are primary methods for qualitative inquiry in general (Marshall & Rossman, 2010, p. 137). Crang and Cook suggest that there is value in familiarising oneself about both (participant) observations and interviews *even when one does not intentionally plan on explicitly using these methods*, because "all social research involves learning through conversation" – and therefore these methods play their roles both formally *and* informally (Crang & Cook, 2007, Chapter 5, para. 2).

5.3.1.1 Interviews

Interviews provide the researcher and the subject with a temporary space that allows 'in-depth' exploration of a topic of mutual interest (Kvale & Brinkmann, 2009, as cited in Marshall &

Rossman, 2010, p. 142). Their structures vary: *unstructured* interviews are comparable to serendipitous, spontaneous, and informal conversations with no predetermined strategy of inquiry; *semi-structured* interviews are guided by some predetermined questions of interest, but in which divergence is encouraged; and *fully structured*, where predetermined questions are adhered to, and follow-up questions are principally avoided. Interviews can be carried out as a one-to-one interaction (as a one-off event, or in a series of events, allowing for 'deeper' inquiry) between the researcher and subject, or as a *focus group* (or group interview), where the researcher has potential to investigate multiple opinions, though at the mercy of well-functioning group dynamics (Lazar et al., 2010, Chapter 8; Marshall & Rossman, 2010, pp. 142–146).

Crafting the right questions to ask, can be difficult. The goal of the questions (at least in ethnographic research), is to allow the interviewee to give an account of their own knowledge and experience – *in their own words*. One caveat the researcher should be aware of, is *directive* (or *leading*) questions: these questions are loaded with presumptions about the answer. For instance, the question 'how good is this button?', should be rephrased to 'what do you think about this button?'. It is worth noting that directive questions may lead to interesting answers in some cases – but the researcher should be aware of this choice, and should certainly not bombard the interviewee with such questions (Crang & Cook, 2007, Chapter 5, *Asking The 'Right' Questions*).

When conducting a focus group, group dynamics, as mentioned above, are paramount, and there are hegemonic concerns which may upset the group dynamic. A good example of such influence, is a 'groupthink', where a 'leading figure' in the group establishes an opinion early on which is adopted by the other participants, which may become difficult to disagree with by some participants (Crang & Cook, 2007, Chapter 6, *Group Dynamics*, para. 4).

Interviews are central to HCI, and are employed in a variety of roles throughout the design process: initial exploration of the needs and challenges of a particular situation, avoiding functional and design details that may cause confusion (Lazar et al., 2010, Chapter 8, *8.2.1 Initial exploration*); requirements gathering – specific details about the user goals, and identification of frustrations with current tools, that can be used as input for the design process as a requirements specification (Lazar et al., 2010, Chapter 8, *8.2.2 Requirements gathering*); and towards the end of the design process in evaluation of the design (see chapter 5.3.3).

5.3.1.2 Observation

Observation is paramount in supplementing other qualitative inquiry (such as interviewing) with data that comes from complex interactions, or the periphery of the situation; body language, tone of voice, and affect being a few examples that will likely provide sources of insight to the inquiry (Marshall & Rossman, 2010, p. 140). There are two extremes of roles that the researcher can assume in regards to the observation method. The first is that of complete passiveness, where the researcher acts as a 'complete observer', and there is no interaction between the researcher and the subject. The other extreme is when the researcher 'goes native' as a 'complete participant' – an undesirable identity reaction that may impair the researcher's ability to research. The trade-off when assuming an observer role, is that of losing perspective in moving towards the 'complete participant' role, and risking misinterpreting observations towards the 'complete observer' role (Gold, 1958 as cited by Lazar et al., 2010, Chapter 9, *9.4.2 Participating: choosing a role*). *Participant* observation is an adopted role to observation that exists between these extreme roles. It generally focuses on immersion in the setting studied in order to provide insight into how the subjects experience their reality, at the cost of prolonged engagement required to enable such immersion (Marshall & Rossman, 2010, pp. 140–142). The data gathered from observations, is that which is recorded as *field notes*, taken during the observation (Crang & Cook, 2007, Chapter 4, *Constructing Information*, para. 1; Marshall & Rossman, 2010, p. 139).

Observations are important to HCI research because they provide the researcher with means to study the context surrounding the use of an existing or future system *in situ*. The importance of such *situated action*, was exemplified by Lucy Suchman (1987) in her ethnographic study of a photocopier, where she developed an understanding that "differences between the human model of the copier and the expert system's model led to communication breakdowns and task failures" (Lazar et al., 2010, Chapter 9, *9.3 Ethnography in HCI*, para. 6).

5.3.1.3 Application and Rationale

I used the ethnographic methods observation and interviews in conjunction both formally and informally throughout this study; formally in the ethnographic background study (see chapter 6.2), and a part of the design process throughout the workshops (see chapter 6.3). As social research involves learning through conversation, these ethnographic methods were employed informally as part of the research process as a whole. I acknowledge that the informal application of ethnography was of value to me as a researcher as they continually provided insight into the context surrounding aphasia, thus shaping my own subjectivity. The rationale for employing ethnographic methods *formally*, was grounded in the fact that aphasia affects the individual in such a unique manner, and impairs communication in unpredictable manners. Using participant observation enabled me to gain a better understanding of the implications this had for the individual, as I could take advantage of both talking to and observing the aphasic participants directly.

One important advantage of using ethnographic methods in conjunction, is that the information collected from interviews and observations can be used to supplement each other (Marshall & Rossman, 2010, p. 145). This is particularly true when involving subjects that have impaired communication. Communication is often highly context-dependent, and by employing ethnography, exploration of the context surrounding the subject is encouraged (Kovarsky, 2014, pp. 55–60).

From a PD perspective, ethnography can play various roles in conjunction with PD (Blomberg & Karasti, 2013, p. 94). In this study, PD was used as a component of the design process itself in a similar way to how it is employed in the *MUST* PD methodology: "provide context for learning about the users' present work in particular work settings with a special emphasis on gaining an understanding of practitioners' concrete experiences" (Blomberg & Karasti, 2013, p. 91).

However, in the context of this study, ethnography was employed as a background study to gain insight into communication strategies (opposed to work experiences, which are central in the application outlined above) in order to better enable me to communicate with, and thus involve the aphasic participants in the design process (see chapter 6.2).

I conducted three interviews; one as part of the ethnographic background study with one of the SLPs that were present during the participant observation sessions, with the purpose of asking follow-up questions that I did not get the opportunity to ask during the participant observation sessions (see chapter 6.2.3). The two other interviews were conducted as part of the participatory usability workshop with the aphasic participants, using an interview format tailored to the aphasic participants to get feedback on the design presented (see chapter 6.3.2). In addition, I had the opportunity to partake as a participant observer in four language therapy sessions lasting for an hour and a half each, and one session lasting for an hour, as an ethnographic background study as the initial stage of the design process (see chapter 6.2). The first four sessions were set in a therapy group setting involving multiple SLPs and aphasic individuals (see chapter 6.2.1), while the last one was set in a session involving acute language therapy with one SLP and one aphasic individual (see chapter 6.2.2).

5.3.2 Prototyping

Making prototypes is a fundamental technique, integral to the any design process (albeit 'prototypes' have different meanings in various disciplines). Within design practice, prototypes allow of the exploration and expression of possible design ideas and solutions (Houde & Hill, 1997, p. 1), and are usually described in their degree of completeness and interaction opportunity - *fidelity*. Prototypes can be anything from quick-to-make *low-fidelity* prototypes, hand-drawn on a piece of paper, to a *medium-fidelity* PowerPoint presentation with simple interaction opportunities such as navigating between screens, to a more time-consuming and intricate *high-fidelity* Web application with rich interaction opportunities such as buttons and input fields (Houde & Hill, 1997, p. 2).

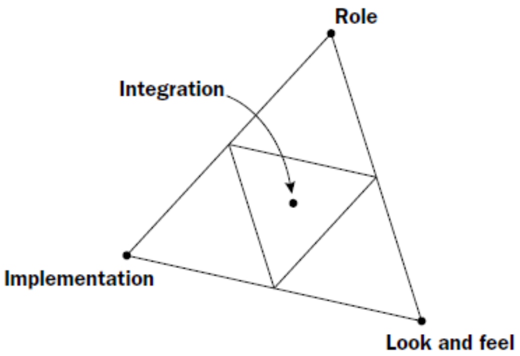


Figure 5-2 "A model of what prototypes prototype" (Houde & Hill, 1997, p. 3).

Houde and Hill (1997) propose moving away from technical terms like *fidelity*, which to a participant of a design process with limited technical experience or knowledge, gives little value in terms of understanding *what* the prototype is. Instead, a model is proposed (Figure 5-2) in explaining 'what a prototype prototypes'; in other words, a visualisation of the focus of exploration into three *dimensions* of inquiry: "**implementation** usually requires a working system to be built; **look and feel** requires the concrete user experience to be simulated or actually created; **role** requires the context of the artefact's use to be established" (Houde & Hill, 1997, p. 3, emphasis added).

The model depicted is askew to emphasise that there is no dimension that is more important than the other; the prototype can seek to explore both a single dimension, or a combination of dimensions. Of equal importance, positioning a prototype within this model gives some indication of what the model *is not* intended to explore: a positioning that is naturally relative, given the designer's subjectivity (Houde & Hill, 1997, p. 3). On the extremes of the model, it is also suggested that one can create pure role, implementation, or look and feel prototypes, or a prototype that equally explores the extreme dimensions; an implementation prototype which represents the total user experience of an artefact (Houde & Hill, 1997, p. 12). Therefore, if it is desired to explore the total user experience of a design, an implementation prototype suggests that the prototype must equally explore role, implementation, and look and feel, and the effort to do so must be split between the three dimensions. If the purpose of the prototype is to solely explore the look and feel of an artefact, one can ignore what role the artefact being prototyped would play in the user's life, and the limitations of practical implementation (Houde & Hill, 1997, p. 9). The model provides a useful scope for completing a particular prototype: as Houde and Hill so eloquently put it: "by focusing on the purpose of the prototype – that is, on *what it prototypes* – we can make better decisions about the kinds of prototypes to build" (1997, p. 1).

5.3.2.1 Prototyping with a Participatory Mindset

While prototyping is a fundamental part of the design process, it is also important to make sure that the prototype represents its future users. How does one involve the users in this process? PD is committed to ensuring involvement of future users of a design in the design process through *genuine participation* (see chapter 4.2.1). The prototyping technique is fundamental to this commitment because it makes the design process accessible to non-designers through allowing "design-by-doing" (Robertson & Simonsen, 2013, p. 6). This is rooted in PD's pledge to allow the participants to 'speak their own language' – to allow true participation in the design process without the need for design language (Bratteteig et al., 2013, pp. 133–134). This is best accomplished through creating a common ground – a temporary community – through the use of boundary objects (see chapter 4.2). This temporary community is the space in which participation in the design process can happen – supported by the activities: telling, making, and enacting – within a participatory mindset. Prototypes are central to PD, because they are used to intertwine the design and the analysis process: "understanding the use context and the technical possibilities better – and for design – trying out ideas for new technical solutions" (Bratteteig et al., 2013, p. 134).

Löwgren and Stolterman argue for hand-drawn paper prototypes in that they allow “simple direct manipulation technique”; “[…] anybody can cut a piece of paper in the shape of a button as well as the designer can” (2007, Chapter 4, *4.3.2 Techniques for Detailed Shaping*, para. 24). Prototyping with paper also extends to more expressive prototypes like *storyboards*, which combine *interface sketching* and *scenarios* to provide rich enactments of how a scenario could play out, all the while being accessible to the participants. *Dynamic* paper prototypes can be used to take storyboards to an interactive level: participants interact with the paper prototype, and the designer ‘responds’ on behalf of the prototype, adding sticky-notes or swapping out the screen to simulate the rich interaction (2007, Chapter 4, *4.3.2 Techniques for Detailed Shaping*). The argument for using low-fidelity prototypes over more high-fidelity prototypes is that simple, direct manipulation techniques that are possible with paper, enable the participants to get involved without needing to understand technical language (Löwgren & Stolterman, 2007, Chapter 4, *4.3.2 Techniques for Detailed Shaping*, para. 24). In addition, low-fidelity prototypes, and their ‘unfinished’ appearance, are more prone to criticism from participants as they may seem less invested in than their higher-fidelity counterparts, which may come across as ‘final solutions’ (Löwgren & Stolterman, 2007, Chapter 4, *4.3.2 Techniques for Detailed Shaping*, para. 2).

5.3.2.2 Application and Rationale

I used prototyping as the primary means of involving the participants in the design process, and it was intended that the prototypes would focus on the ‘look and feel’ of the design, as suggested by Houde and Hill (1997, p. 4) (Figure 5-2). I decided to use low-fidelity paper prototypes in the workshop settings to take advantage of the benefits of paper prototypes: simple and cheap to create, accessibility in terms of ease of engagement, and susceptibility to criticism (Snyder, 2003, as cited in Lazar et al., 2010, Chapter 10, *10.4.1 Types of usability testing*, para. 1; Löwgren & Stolterman, 2007, Chapter 4, *4.3.2 Techniques for Detailed Shaping*, para. 1). According to Houde and Hill, “[look and feel prototypes] simulate what it would be like to look at and interact with, without necessarily investigating the role it would play in the user’s life or how it would be made to work. […] They ask users to interact with them to see how the look and feel could be improved” (Houde & Hill, 1997, p. 9).

As a ‘formalisation’ of the prototypes, I created the prototypes presented in this thesis (P0, P1, and P2) in *Balsamiq Mockups 3*, a rapid wireframing tool used to create low and medium-fidelity prototypes (Balsamiq Studios LLC, 2016).

5.3.3 Usability Testing

Usability is a high-level term used to describe how well a certain design fits a certain user group – how *usable* it is. Even though usable stands relative to the individual user, there are certain standard sets of heuristics one can use to assess the usability on a high level – these are often referred to as *usability* heuristics. For example; one can agree that all users would benefit from a user interface

(UI) that offered informative feedback in the case of failure – that the UI did not just become unresponsive.

Usability *testing* is all about “representative users attempting representative tasks in representative environments, on early prototypes of computer interfaces” (Lewis, 2006, as cited by Lazar et al., 2010, Chapter 10, *10.1 What is usability testing?*, para. 1)[20]. This definition is purposefully broad to allow a variety usability testing methods. However, regardless of the method, these all share one common goal: improving the quality of the interface by uncovering flaws that create problems for the users, and equally important, identify what is working well in the interface. Note that usability testing is not about the user’s preference: if a user does not like the colour of a button, this is not related to the domain of usability testing. However, if the colour of the button is interfering with the user’s ability to *use* the button (e.g. colour blindness), this affects the button’s usability (Lazar et al., 2010, Chapter 10, *10.1 What is usability testing?*, para. 2). In other words, usability testing is the process in which the interface is ‘made better’. Lazar et al. emphasises that “users are testing interfaces, but users are not being tested” – it is about how well the UI fits the user, not how well the user fits the interface (Lazar et al., 2010, Chapter 10, *10.3.2 User-based testing*, para. 1). There are two notable distinctions of usability testing, *formative* and *summative* tests. Formative testing involves the evaluation of low-fidelity prototypes, usually hand-drawn paper prototypes or wireframes: “there is more of a focus on how the user perceives an interface component rather than on how well the user completes a task” (Rubin & Chisnell, 2008, as cited in Lazar et al., 2010, Chapter 10, *10.4.1 Types of usability testing*, para.1). Summative testing takes place later in the design process, usually with more functional high-fidelity prototypes, where “the goal is to evaluate the effectiveness of specific design choices” (Lazar et al., 2010, Chapter 10, *10.4.1 Types of usability testing*, para.1).

In practice, usability testing can be carried out in numerous ways, both in a quantitative manner using experimental design based on task lists, or qualitative approaches involving a handful of users, explorative testing (with no instructions or task lists) and methods such as observation, and interviewing (see chapter 5.3.1). In terms of *measuring* the degree of usability, it is generally agreed “[…] that earlier, formative usability tests tend to focus more on qualitative feedback, moderator observation, and problem discovery, whereas summative usability tests tend to focus more on task-level measurements, metrics and quantitative measurements” (Lewis, 2006, as cited in Lazar et al., 2010, Chapter 10, *10.4.1 Types of usability testing*, para.4). Even though measurement is done quantitatively, qualitative measurement remains paramount as supplementing data, as methods like observation might reveal frustration, or joy – qualitative data that is not well expressed through numbers (Lazar et al., 2010, Chapter 10, *10.4.7, The testing session*).

---

[20] Although usability testing can be performed not only by the users, but also by interface experts, and by machines in automated processes, this thesis is concerned with *user-based* usability testing, and uses the term accordingly (Lazar et al., 2010, Chapter 10, *10.3 Types of usability testing or usability inspections*, para. 1).

5.3.3.1 Heuristic Evaluation

One type of usability testing (also known as *usability engineering method*) is a *heuristic evaluation* (or heuristic review), which is a review of an interface conducted by usability 'experts'. The interface is usually judged against a set of usability principles (also known as usability *heuristics*). Although it can be performed by one evaluator, it is generally recommended to have more than one evaluator, keeping in mind that more evaluators do not necessarily uncover a higher amount of flaws. A heuristic evaluation can be conducted both in a formative manner, on low-fidelity prototypes early in the design process, or in a summative manner at later stages of the design process. The fidelity of the prototype may limit what heuristics can be used. For instance, a heuristic that is concerned with animation, is not suitable for low-fidelity paper prototypes (Lazar et al., 2010, Chapter 10, *10.3.1 Expert-based testing*; Nielsen, 1995). Nielsen refers to a heuristic evaluation as "discount usability engineering"; which yield good results from few resources, due to the use of expert knowledge – however, it is not a thorough account, especially with few testers (Nielsen, 1995). Figure 5-3 gives an approximation of usability flaws found – naturally, this depends of which usability heuristics are employed, and the experience of the testers:

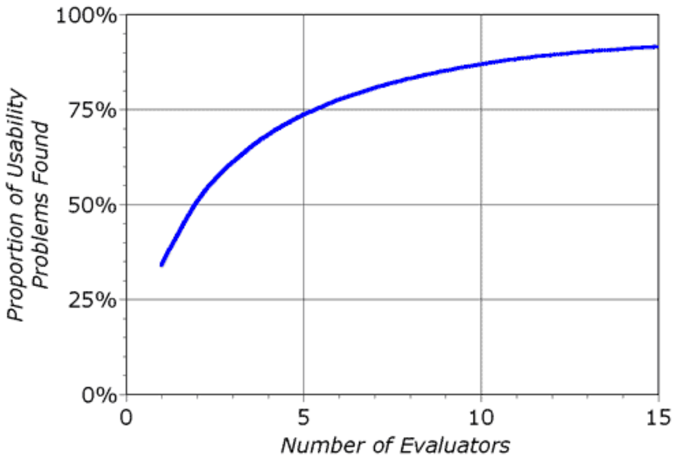


Figure 5-3 "Curve showing the proportion of usability problems in an interface found by heuristic evaluation using various numbers of evaluators. The curve represents the average of six case studies of heuristic evaluation." (Nielsen, 1995).

5.3.3.2 Application and Rationale

Usability testing was used in an informal manner with the aphasic participants in two workshops as an effort to evaluate the design suggestions that had been implemented in the Sunnere app prototype up to that point (see chapter 6.3.2). Usability testing was also used in a heuristic evaluation of the final Sunnere app prototype as an effort to determine to what extent it compared to the past design cases involving aphasic users, identified as part of the literature review (see chapter 7.1.1).

The usability testing was conducted as a *usability workshop* as a final step of the Sunnere app design process as a means of assessing the design, but also to stay divergent and open to design suggestions. In order to accommodate this, the usability testing was done on low-fidelity paper prototypes, to allow impromptu changes. The usability workshop combined elements of a participatory prototyping workshop, and with a semi-structured interview in an effort towards participant accommodation (see chapter 3.1.2).

The rationale for choosing a workshop structure primarily builds on the experiences of the MARTIN and NAM projects for two reasons in particular: the usability testing was generally perceived as oversimplified due to our expectations of the aphasic participants being different than expected; and some of the participants suggested improvements. In the evaluation of the NAM prototype, the layout of the evaluations did not accommodate 'on the fly' changes of the prototypes tested because the testing was done on a high-fidelity prototype, and so the suggestions made by the participants were seemingly dismissed, whereas a lower-fidelity prototype could have been changed in an impromptu manner (see chapter 6.1.3.1). Furthermore, such a structure also promotes a participatory mindset in that it allows the participants to actively engage in the design process.

I chose to employ the use of *dynamic* paper prototypes in the usability workshop: these are a simple way to mock the more dynamic and interactive aspects of an otherwise static paper prototype. It requires that the designer prepares a number of interface cards representing the screens that the participant may end up on, basing this on what is being tested. The designer is actively involved in performing the role of a 'window manager', reacting to the interactions of the participant. For instance, when the participant presses a button on the paper prototype, the designer reacts on behalf of the prototype by adding sticky-notes, or other cut-outs to the current 'screen', or by swapping out the screen entirely with a new one. This technique is akin to role-playing, in that it requires some imagination to envisage the interactions represented by the designer to 'be part' of the prototype. The benefits for using dynamic paper prototypes naturally draws on the benefits for using regular paper prototypes, but are limited in representing complex interactions (2007, Chapter 4, *4.3.2 Techniques for Detailed Shaping*).

5.4 Ethical Considerations

Working with users that are vulnerable necessitates a rigorous ethical approach, which is an important part of my rationale for employing a PD approach. The core of PD revolves around an ethical commitment to giving the future users of a design a say in shaping it: "perhaps the core principle of Participatory Design is that people have a basic right to make decisions about how they do their work and indeed any other activity where they might use technology" (Robertson & Wagner, 2013, p. 65). However, the implication of using a participatory approach to involve the user in the design process when the user has communicative impairments, escalates the ethical concern. As outlined in chapter 3.2, communicative ability often translates to power – and aphasics are often left disempowered and socially isolated because of their loss of communicative ability. This is no different when considering participation in a design process – a consideration that was perhaps the most important rationale for choosing to employ a PD approach in the first place.

Newell et al. (Newell, Gregor, Morgan, Pullin, & Macaulay, 2010) highlight some ethical concerns that are prominent in user-centred and participatory approaches when the users have disabilities. Below, I have highlighted a selection of their concerns that were most prominent in this thesis:

- Consenting participation may be difficult to obtain.
- The user may be unable to communicate their thoughts.
- The user group may have requirements that are uncommon, or even conflicting within the same user group.

In what they call "User-Sensitive Inclusive Design", Newell et al. suggest that when designing for users that have disabilities, the designer has to be sensitive, and consider that users are primarily humans. Therefore, the designer should develop a real and empathetic relationship with the user (2010, p. 237). They continue by emphasising that this view aligns more with PD than with other design disciplines, such as UCD (Newell et al., 2010, p. 237). This notion of inclusion inevitably touches on the same domain as Universal Design. While UD is a critical movement in closing the digital and disability divides (see chapter 3.3.1), Newell et al. argue that the notion of sensitivity better aligns with the needs of the disabled in that the 'Universal' in 'Universal Design' is problematic because universality conflicts with opposing requirements (2010, p. 237). In other words; one cannot design for universality when the users have very different requirements that can even be contradictory to each other. Such sensitive consideration has been paramount throughout my interactions with aphasic participants, because they are fundamentally different as users – and humans.

5.4.1 Meeting the Human, Protecting the Patient, Representing the User

Marshall and Rossman (2010, pp. 44–51) suggest that ethics must be an integral part of the research process – not just a set of forms completed at various stages of the research process (Davies & Dodd, 2002, p. 281 as cited in Marshall & Rossman, 2010, p. 47). They stress that three concepts central to ethics; **respect for persons**; **beneficence**; and **justice**, are often reduced to just informed consent. Furthermore, they argue that a solid ethical embodiment of the research process contributes to the trustworthiness of the research as a whole. In the following section, I describe some of the strategies that I employed as an effort to consider ethics and the research process not as separate processes, but as inevitably intertwined processes, embodying respect for persons, beneficence, and justice to my best ability.

Meeting the Human

Losing the ability to communicate to the degree that aphasics often experience, is losing the ability to participate in many of the activities that are deemed 'normal'. As exemplified by the stigmatisation that became a side effect of WHO's definition of 'impairment', 'disability', and particularly 'handicap' – that people often *become* their difficulties in the eyes of others*:* he or she **is** handicapped. I have adopted the view advocated by the social model of disability (see chapter 3.3), which suggests that the accountability of stigmatisation is located on a societal level and that disability is a result of a system that does not work towards equal opportunity. This emancipatory view places ‘disability’ on a societal level – *not* on the individual. Thus, meeting the human in accordance with this view involves respect for persons at a very basic level: meeting the human, not their difficulties. At a practical level, this involves explaining the purpose of the research, why the research is important to you, that the opinions of the participants are important, and engaging in small talk.

Protecting the Patient

The aphasic patients at Sunnaas Hospital are mostly recent victims of aphasia, or individuals that severely struggle with language, and need linguistic or physical therapy – they are vulnerable. With impaired language, quality of life is severely affected, and naturally this can cause depression and frustration – sorrow over losing a big part of who you are (see chapter 3.2). With regards to beneficence, it was a primary concern for me as a researcher that the aphasic patients at Sunnaas Hospital were not exposed to anything that may put them under stress or worsen their situation. I used SLP proxies (stand-ins) as an integral part of the design process as an effort to protect the aphasics as much as possible – to avoid exposing them to ‘full participation’ (discussed in chapter 7.2.3).

Representing the User

Representing the user in the design through participation in the design process is central to PD. This represents ‘bringing justice’ (or emancipation) to the user through a design that represents the *actual* needs and requirements of the user (see chapter 4.2). More importantly, when dealing with communicatively impaired individuals that have lost the ability to participate in many activities, it is important that both the design process and the resulting design does not become *yet another thing they cannot cope with* (see chapter 6.2.4).

All three perspectives; meeting the human, protecting the patient, and representing the user; have required *scaffolds* as a central component (discussed in chapter 7.2.4).

5.4.2 Consenting Participation

Perhaps the biggest challenge with involving aphasic participants in the research, is informed consent, and consenting participation. To ensure that the aphasic participants knew what they were participating in, I created specially made consent forms that focused on presenting the purpose of the workshop in very short sentences. I made two versions identical in content one with a normal font, and one using a font specifically made for dyslexia[21], as this frequently accompanies aphasia (these consent forms can both be found in Appendix E). In the workshop, the consent forms were presented to the aphasic participants, and they were asked which version they understood better. Instead of asking the participants to read it on their own, I supported them in guided reading (see chapter 6.3.2).

---

[21] The font is called OpenDyslexic, and is free for commercial and personal use: http://opendyslexic.org/.

Even though measures were taken to ensure that the aphasic participants understood what they were participating in, there was a very real possibility that the aphasic participants did not understand the consent form, and signed it to avoid confronting not understanding it. This puts a huge amount of responsibility on the researcher in either ensuring that the participants understand what they are consenting to, or relying on next of kin to give informed consent – preferably the former.

6 DESIGN PROCESS

Tell me, I forget.
Show me, I remember.
Involve me, I understand.

– Chinese proverb

This chapter presents the implementation of the design process; starting with a description of the two projects that inspired this thesis, which are recognised as pilot studies as they obtained valuable experiences and covered important design groundwork. Ethnography (see chapter 5.3.1) was employed as what I have called a 'background study' – an effort to inform myself as a participatory designer; to learn about the milieu at Sunnaas Hospital in regards to clinical staff and patients, how to communicate with aphasics, and thus gaining insight into how workshops could be planned to enable participation. Prototyping (see chapter 5.3.2) was used as the primary means of making the design process available to the participants. The design process involved the use of workshops to complete the development of two prototypes; the first one involving SLPs as proxy users to complete the 'broad strokes' of the design, and the second one involving aphasic participants directly to complete the prototype. Elements of usability testing (see chapter 5.3.3) were used in the workshop with the aphasics to assess the usability of the prototype iteration developed with the SLPs.

I chose to employ the PD approach primarily because of PD's agenda for empowerment of the future users of a design: due to aphasia's impact on language, aphasics are left disempowered in most social situations (see chapter 3.2). Furthermore, PD – in accordance with the HCD philosophy – ensures that the design accommodates the requirements of the intended users, and aligns with future use – a goal that is enabled through the user's active involvement in the design process, and shared power in the decision-making processes that eventually make up the design (see chapter 4.2).

6.1 Pilot Studies

The fieldwork completed, lessons learnt, and the data collected during the MARTIN and NAM projects provide a substantial amount of groundwork and background information, and the project reports present various challenges and limitations uncovered in the design processes (Eide et al., 2014; Pettersen et al., 2014). In an effort to address these challenges and limitations, the MARTIN and NAM projects were recognised as pilot studies for the Sunnere app design process. A pilot study is a "small-scale implementation of a larger study" (Schreiber, 2008); useful in helping to determine feasibility, or to uncover flaws or limitations in the research design, and furthermore to argue for why a certain strategy fits a certain research topic (Marshall & Rossman, 2010, pp. 95–96). Additionally, they are particularly valuable when working with participants that have impairments. This is because expectations of working with these participants may be drastically different than reality, but also because access to users with impairments may be limited (Lazar et al., 2010, Chapter 15, *15.6 Pilot Studies*, para. 1).

Even though the MARTIN and NAM projects were limited in some aspects, the design choices made in the projects' prototypes were valuable because they were grounded in the fieldwork conducted at Sunnaas Hospital, and evaluated by aphasic individuals. Thus they are considered as part of the prototype evolution presented in this thesis, and described in chapter 6.1.4.

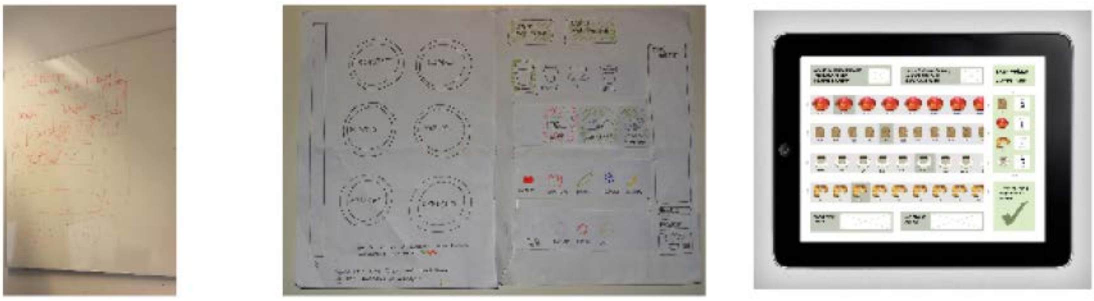
6.1.1 MARTIN

The goal of the *Matregistrering på Sunnaas* (MARTIN) project, was to "develop [a Web application prototype] that can help increase patients' motivations and raise their awareness of food choices" (Eide et al., 2014): the MARTIN project focused on the experience of presenting food choices to the users, with the ultimate goal of enabling informed decisions in regards to the user's nutritional requirements. One of the recommendations from Sunnaas Hospital was to use traffic-light colour coding in the presentation of food, with the purpose of indicating the appropriateness, or 'healthiness' of food and drink items (see Figure 6-1), based on the user's recommended diet plan.

Figure 6-1 Traffic-light colour coding indicating the 'healthiness' of the food or drink item from the MARTIN prototype.

The student group focused heavily on prototyping, iterated through five different prototypes ranging from low-fidelity paper prototypes, to the final high-fidelity interactive Web application (see prototype evolution on Figure 6-2). These prototypes were used in usability tests with a variety of hospital staff, and two aphasic patients.

The MARTIN project's prototype was notable for navigating the menu using an interactive image catalogue with the various categories of foods sorted horizontally, and the use of traffic-light colours to indicate the appropriateness of choice, corresponding to what has been recommended to the user. These features are evident in the evolution of the prototypes, as shown below in Figure 6-2:



Prototype 1 Prototype 2, page 1 and 2 Prototype 3

Prototype 4 Prototype 5, page 1 Prototype 5, page 2

Figure 6-2 Prototype evolution of the MARTIN project prototypes.

6.1.2 NAM

The goal of the *Nutrition-Aware Meals* (NAM) project – my project group – was to "develop a high fidelity prototype using UDC principles in which the purpose was to aid patients in understanding relevant personal nutritional goals, and motivate better eating habits through gamification models and techniques[22]. The high-fidelity prototype [would] also provide the [clinical] staff with relevant cumulative data to be used for analysis of patient eating habits" (Pettersen et al., 2014, p. 3). My group adhered to UCD, and it involved a conceptual design (see Figure 6-3), and ultimately the development of a high-fidelity Web application prototype (see Figure 6-4) to be used for usability testing with the patients. The first part of the design process – the low-fidelity prototype design of feedback on the patient's meal choices – was developed based on the recommendations from our assigned psychologist, who suggested using Universal Design guidelines for cognitive impairment (see chapter 3.3.1). In addition, our assigned sign-language specialist suggested using easily relatable and generally understood symbols, such as 'thumbs' and 'smileys', as these types of symbols were generally relatable by most aphasics.

---

[22] Since gamification was omitted from the scope of this master thesis, these results are not discussed in the following section.

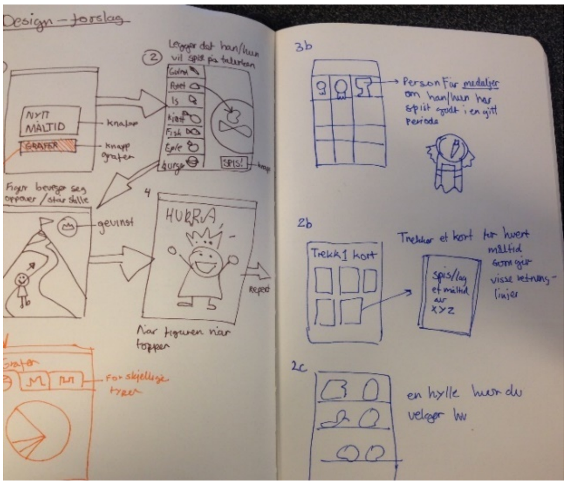


Figure 6-3 Conceptual design of the NAM project prototype.

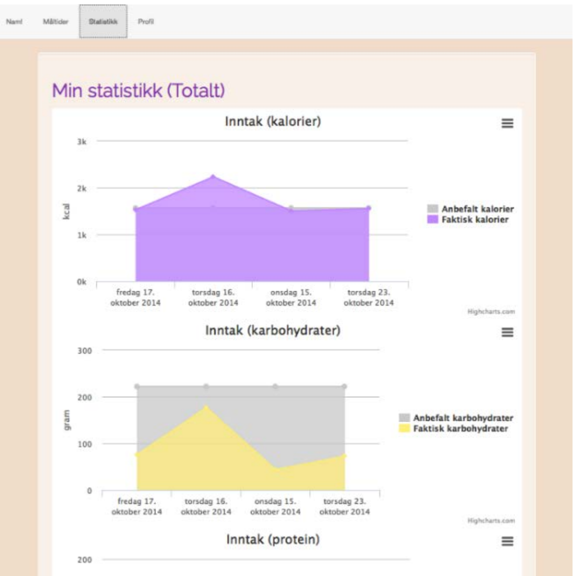


Figure 6-4 Screenshot from the high-fidelity NAM project Web application prototype.

The purpose of the design process was to develop feedback mechanisms – or *symbols* – that could represent different complexities of feedback depending on the choices of the users, and their cognitive ability, that then could be used in the high-fidelity prototype. These feedback mechanisms intended to give feedback in reaction to the diet records, on a per-meal, daily, weekly, or monthly basis. The NAM project work consisted of designing various feedback mechanisms to suit different kinds of users. We developed four feedback mechanisms, starting with simple, binary feedback (good/bad), increasing in complexity, with the most complex feedback mechanism being direct visualisation of nutritional intake in the form of graphs:

- **Thumbs**: binary feedback model; thumbs up or down (Figure 6-5).
- **Cat**: three-tiered smiley scale using a cat character (Figure 6-6).
- **Smiley**: five-tiered smiley scale (Figure 6-7).
- **Graphs:** direct data visualisation; the most complex form of feedback (Figure 6-8).

Figure 6-5 'Thumbs' feedback model from the NAM project prototype.

Figure 6-6 'Cat' feedback model from the NAM project prototype.

Figure 6-7 'Smiley' feedback model from the NAM project prototype.

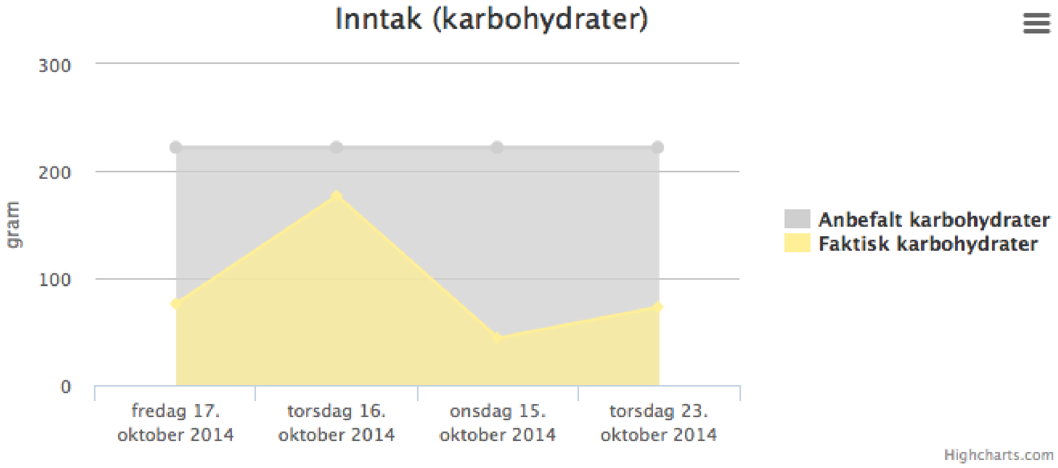


Figure 6-8 'Graphs' direct data feedback model from the NAM project prototype.

6.1.3 Results and Limitations of the MARTIN and NAM Projects

The results from the MARTIN and NAM projects represent a substantial amount of groundwork, and received mostly positive feedback from the aphasic participants involved in the evaluation of the prototypes. The highlights of the prototypes are acknowledged as valuable input to the Sunnere app design process:

Feedback Mechanisms

The feedback mechanisms that were the result of the NAM project (see Figure 6-5, Figure 6-6, and Figure 6-7), were well understood by all the aphasic participants. One of the participants even suggested a new type of graph, showing more complex data – demonstrating a high degree of language independence and comprehension (Pettersen et al., 2014, p. 12). The thumbs up and thumbs down feedback mechanism, was a recommendation from Sunnaas Hospital as they are interpreted correctly by most patients (Pettersen et al., 2014, p. 10).

Image Catalogue for Navigating Food and Drink Items

The MARTIN project used an image catalogue as a central approach to navigating food and drink items – a recommendation from the clinical staff at Sunnaas Hospital. This was well understood by all aphasic participants (Eide et al., 2014, p. 2).

Colour-Coding of Food and Drink Items

The MARTIN project used a traffic-light coloured theme to indicate the 'healthiness' of food and drink items shown in the image catalogue. Even though the evaluating aphasic participants managed to choose 'the healthy options' both with and without the traffic-colour coding, they expressed that the it was useful as a moral guide (Eide et al., 2014, p. 16). The same colour coding was also used by the NAM project in the feedback mechanism, as per recommendation by Sunnaas Hospital, as this was "almost universally understood by the patients" (Pettersen et al., 2014, p. 10).

6.1.3.1 Limitations

In acting the role of pilot studies for the Sunnere app design process, the MARTIN and NAM projects were essential in uncovering challenges when designing for individuals with aphasia. The following points from the reports (Eide et al., 2014; Pettersen et al., 2014) were noted as points for improvement for the Sunnere app design process:

Inexperience in Communicating with Aphasics

Both the MARTIN and NAM project groups misjudged the capabilities of the aphasic participants assigned for the evaluation of their prototypes, resulting in oversimplified prototype evaluations. This was identified as a lack of experience in dealing with aphasic individuals, and because the theoretical descriptions of how aphasia affects the individual, vary from its reality (see chapter 3.1.1).

Selection of Participants

Neither the MARTIN nor the NAM project groups had influence in choosing participants. The participants were chosen based on who was available at Sunnaas Hospital at the time, with the condition that they were able to understand the consent forms presented by the groups.

Inflexible Degree of Participation

During the evaluation of the NAM project group's prototype, one of the aphasic participants suggested improvements to the design. This was not expected, and therefore not dealt with as well as it could have been if the NAM project group had planned the session to accommodate this. The suggestion was simply noted, instead of explored further. This was mostly due to the fact that the evaluation was conducted on a high-fidelity prototype. Had the evaluation been carried out on a lower-fidelity prototype, the suggested changes could have been made ‘on the fly’, together with the participants.

6.1.4 Prototype Zero (P0)

The prototypes resulting from the MARTIN and NAM projects were initially supposed to be combined into a single prototype as a final stage of the design process. This was, however, never completed as part of the original project work, but instead completed as part of this thesis as a combined conceptual prototype. This prototype is referred to as *prototype zero* (P0) because it was not a result of the design process presented in this thesis, but acknowledged as input to the design process presented in chapter 6. The different prototypes essentially focus on the two different areas that are relevant to the main scenarios (see chapter 2.1.1.1): the cafeteria menu (MARTIN), and the diet record feedback (NAM).

Cafeteria Menu (MARTIN)

Figure 6-9 shows the menu screen, horizontally categorised, and colour coded. It was imagined that the prototype would know the time, and could ‘intelligently’ predict the time of day, and therefore suggest meals relevant to that time (breakfast, lunch, dinner, snack).

Figure 6-9 P0: cafeteria menu.

Cafeteria Menu – Magnified View (MARTIN)

Figure 6-10 shows the state of the prototype when the user has selected a food or drink item, and is asked to confirm or deny the choice, to enter it in the diet record. It shows a bigger image of the food item, its name, and an indication of whether this is a healthy choice according to the user’s recommended diet plan.

Figure 6-10 P0: cafeteria menu – magnified view.

Diet Record Feedback – Day View (NAM)

Figure 6-11 shows daily feedback based on the diet records using the 'thumbs' feedback model. At the bottom part of the screen, consumed food and drink items that were 'bad' (in regards to the user's recommended diet plan) are shown on the left, while the 'good' choices are shown on the right. An alternative feedback model using the 'smiley' feedback model is shown in Figure 6-12. The user can toggle between different units of time by using the buttons; 'dag' ('day') 'uke' ('week'), 'måned' ('month'), and 'totalt' ('total').

Figure 6-11 P0: daily diet record feedback using the 'thumbs' feedback model from the NAM project.

Figure 6-12 P0: daily diet record feedback using the 'smiley' feedback model from the NAM project.

Diet Record Feedback – Week View (NAM)

Figure 6-13 shows weekly feedback based on the diet records using the ‘cat’ feedback model. Essentially the same as the day view described above.

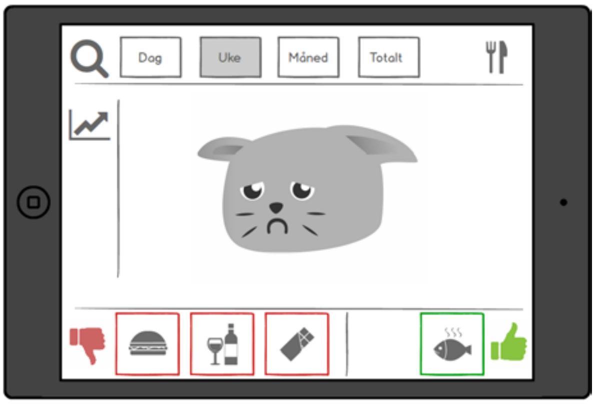


Figure 6-13 P0: weekly diet record feedback using the 'cat' feedback model from the NAM project.

Miscellaneous – Bar Charts (NAM)

Figure 6-14 shows direct visualisation of the nutritional values by using a bar chart to represent the nutritional values contained in the diet records for that day.

Figure 6-14 P0: direct data visualisation as a bar chart.

6.2 Ethnographic Background Study

Lack of experience in interacting with aphasic individuals was the main problem during the MARTIN and NAM projects (see chapter 6.1.3.1). In addition, the review of past cases with aphasic individuals revealed that effective communication with the aphasic participants was a significant challenge (see chapter 3.4.1). The ethnographic background study was planned and conducted as a component of the design process in order to gain insight into what aphasia is and how it affects the individual's ability to communicate, to observe the interaction between the SLPs and the aphasic participants, and thus strengthen my experience in interacting with aphasics.

6.2.1 Participant Observation: SunCIST Therapy

SunCIST is an intensive language therapy course offered by Sunnaas Hospital to aphasic individuals that need language rehabilitation. It involves a manifold of activities that aim to stimulate language, and get the participants involved in conversation with the SLPs, and each other. The core of SunCIST is based on a therapy method called *Constraint-Induced Therapy* (CIT), which simply involves restricting healthy or functioning features. For instance, consider this physiotherapy example: an individual has damaged muscles in his or her right arm, and the body has automatically compensated by making the left arm stronger. In CIT, the left arm is then constrained, forcing rehabilitation on the right arm. At Sunnaas Hospital, this is used similarly with aphasia: *Constraint-Induced Language Therapy* (CILT) is used to constrain language modalities that are functional, or in a similar manner, restrict compensatory techniques such as gestures, or technological aids, in order to rehabilitate the language modalities that are less functional (Kirmess, 2010).

I got the opportunity to act as a participant observer during a SunCIST session, lasting two days. Over the course of the two days, I participated in four group therapy sessions that were an hour and a half each. The groups consisted of two SLPs and two/four aphasic participants. There were two sets of groups of aphasic participants; one *fluent* group (four aphasic participants) and one *non-fluent* group (two aphasic participants). Both groups played a game that involved both the SLPs and the aphasic participants: the game was reminiscent of 'Memory' in that it had a card deck consisting of pairs of images. The gameplay was centred around picking an image card from the deck, keeping it hidden, and asking whether any of the other participants had the corresponding matching card, using only words (thus constraining communication to solely speaking and listening).

I had intended to act the role as a complete observer as I did not want to intrude on the therapy session, but was offered a part in the game by the SLPs, allowing me to participate in the gameplay. This is something that proved to be of great value in understanding how to communicate with aphasic individuals of varying impairment levels. At the end of the last day, one of the SLPs (also being a very talented musician) engaged the aphasics in a singsong. I got to witness one of the more severely impaired aphasics that would normally struggle even with uttering single words, to my surprise, sing *the entire first verse* of the Norwegian national anthem *without flaw and effort*. This provided an excellent example of how complex an instance of aphasia can manifest.

6.2.2 Participant Observation: Acute Aphasia Therapy

During one of my visits to Sunnaas Hospital, I had the opportunity to observe a one-on-one hour-long session between an SLP, and a younger-to-middle-aged recent stroke victim that showed signs of non-fluency. This individual was undergoing language therapy only two weeks post-stroke. The language therapy consisted of the SLP showing images of people performing some arbitrary actions, inquiring the aphasic participant about the actions and items depicted in the images. Again, I intended to act the role as a complete observer, but was involved in the language therapy process: the SLP asked me similar questions to the ones asked to the aphasic participant in order for my answers to facilitate the answering for the aphasic participant. The use of images in even acute aphasia rehabilitation, shows yet another example of the ubiquity of the use of images to communicate ideas to aphasic individuals, regardless of aphasia degree.

6.2.3 Interview with Speech-Language Pathologist

I got the opportunity to interview one of the SLPs that was part of the SunCIST therapy sessions. I used a semi-structured interview that was focused on observations made during my participation in the therapy session. The transcript of this interview can be found in Appendix D – its findings are discussed in the following section.

6.2.4 Findings

Notable field notes from participant observations

- **Participant accommodation** is a central component of communication: for every aphasic, communication is adapted and supported to fit the needs of the individual. It was evident that the SLPs were pedagogical in their approach – slowing down rate of speech, and using simple words; **giving *one* message at a time**. This is fundamentally different than talking 'down' to someone, and these should not be confused.
- Give aphasics **enough time** to communicate themselves. Aphasics often struggle with naming words. Giving enough time is a critical aspect of respecting their needs.
- **Visual support through images** is valuable for any degree of aphasia.

Notable points from SLP interview transcript

- **Aphasics are fundamentally different**; not only the impairment itself, but also the context surrounding who they were before – age, personality, and profession, all contribute to making each case of aphasia unique since an individual's language depends on all of these factors, and more. ICT should present content based on the competence of the individual.

- **Multi-modality** (i.e. using sound, text, and images together) aids comprehension of information. Even aphasics with difficulties reading can benefit from *seeing* the word in text, if it is accompanied by images or sound. However, there should be flexibility in using these – some aphasics may not benefit from certain modalities.
- **Images** were used as a central component of the SunCIST therapy because images generally 'reach' all aphasics. Some images were small, and often intricate. However, this was frequently used as a hook for discussion: for instance; 'what do *you* think this is an image of?'. Outside therapy, images should be clear and concise – especially since aphasia can be accompanied by vision impairment, apraxia, etc. (see chapter 3.1.1).
- At Sunnaas Hospital, they use 'Norsk grunntest for afasi' ('Norwegian base aphasia test'), which is based on the Boston model (see chapter 3.1.1). However, according to the SLP, such assessment may position the aphasic individual inappropriately in terms of social rehabilitation – besides, no aphasic fully fits a particular classification. At Sunnaas Hospital, they tend to use a more social approach which focuses on what matters *to the patient*. For instance, if the patient does not like to read, there is no point focusing on rehabilitation of reading skills.
- There exists an open database with 1600 Norwegian words, categorised by average frequency, and imageability which can be used to identify how easy a word is to recall, on average:
    - **High-frequency and low-frequency words** are words that the aphasic has used frequently, and not so frequently. Rehabilitation primarily focuses on high-frequency words as these are words that the patients are more likely to remember. However, 'high-frequency' is relative: a chef may have a vocabulary that consists of very different high-frequency words than a mechanic.
    - **Imageability refers to the concreteness** (the opposite of abstract) of a word: for instance, the word 'ærlig' ('honest') has a low imageability, whereas the word 'strømpe' ('stocking') has a high imageability. Words with high imageability are easier to recall – this is again, relative to the individual's background.
- Even though **most aphasics use smartphones** as an aid in everyday life, there are some that choose not to have one, because it becomes **yet another thing they cannot do**. Aphasia rarely comes on its own, and other impairments may, in combination with the aphasia, restrict to what degree the individual can use certain technologies.

6.3 Participatory Workshops

Since aphasia and its impairment of language limits an individual's ability to participate in the design process, I wanted to take advantage of the SLP proxies' ability – due to their unimpaired communication – to participate on a higher level as a first step in the design process. The purpose of the workshop with the SLPs was thus to give them 'a clean slate' in which they, with my design assistance, could use their professional knowledge and experience to create something that could potentially accommodate the needs of the aphasic users – a rough design suggestion. Furthermore, by creating a 'protected' design suggestion (i.e. one that had been suggested by experts), it was intended that this would protect the aphasics in not presenting them with the overwhelming nature of a ‘clean slate’. Instead, the workshops with the aphasic participants would focus on refining the design suggestions proposed by the SLPs, and to confirm or deny the appropriateness of these – within a safe frame of design suggestions.

6.3.1 Prototyping Workshop with Proxy Participants

The rationale for using the prototyping technique with a participatory mindset, was to put the knowledge and experience of the SLPs into design practice through a mutual learning process. There were three SLPs involved in the process (SLP1, SLP2, and SLP3). I had met with all of them during the ethnographic background study. I gave them all a printout of the main scenarios SCN1, SCN2, and SCN3 (see chapter 2.1.1.1). The workshop was planned to last for an hour.

I spent a few minutes talking about the Sunnere app, and how its primary goal is to provide a way for the aphasic patients to register consumed meals from the cafeteria at Sunnaas Hospital – and to thus take a proactive role in regards to their own nutritional requirements and recommendations. I told them that the purpose of the workshop was to imagine how this scenario could play out with an app, and that the focus should be on ‘look and feel’ – what such an app would need look like in order to accommodate aphasics. The idea was to engage them in telling, making, and enacting (see chapter 4.2.1). I wanted to make it clear that nothing we did was ‘final’, but merely explorations of ways that the scenario could play out, utilising low-fidelity prototyping to its full potential, allowing ‘anything that comes to mind’.

I brought paper, pencils in a variety of colours, scissors, and glue as the main tools for creating low-fidelity paper prototypes – tools that enabled ‘direct manipulation’ (see chapter 5.3.2.1). In addition, I brought the following items to augment the paper prototypes:

- Pictures of food in various sizes.
- Cut-outs of various mobile devices that the Sunnere app could potentially run on.
- Printouts of how nutritional information is displayed on *matvaretabellen* and *kostholdsplanleggeren* (see chapter 2.2), to illustrate how inaccessible such presentation is to aphasics.
- The smiley and thumbs feedback models from P0 and the NAM project (see chapter 6.1.2) to prompt discussion regarding the appropriateness of these.

Figure 6-15 Workshop with the SLPs - overview of the table.

During the workshop, we completed three design suggestions focusing on various aspects of the main scenarios. The first two design suggestions focused on simple ideas for registering food or drink items as diet records (SCN1). These two prototypes varied in conceptual complexity. Since images are so important in conveying information, the SLPs all agreed that an image catalogue would be the most appropriate way for locating items (meals or ingredients) for most degrees of aphasia. The third design suggestion focused on the diet record feedback (SCN3). We completed no design suggestions for SCN2, but the SLPs agreed that directly showing nutritional values should be reserved for aphasics that *want* to see this – and that it should focus on what the aphasic *needs* to see.

Design Suggestion One

Design suggestion one (Figure 6-16) simply had two buttons, 'sulten!' ('hungry!'), and 'tørst!' ('thirsty!'). It was discussed that the Sunnere app would then, depending on which button was pressed, use the user's recommended nutritional values, the time of day, and the user's diet records to suggest a selection of the image catalogue of food and drink items (see *Design Suggestion Two* below) that intelligently matched these criteria. For instance, if it was morning (e.g. time between 06.00 and 11.00), pressing 'thirsty' would suggest coffee, or orange juice, while pressing 'sulten!' would suggest a bowl of cereal, eggs, bacon, and bread. In addition, the user's history would be used in conjunction with the user's recommended nutritional values to ensure that, for instance, if the user had already had a cup of coffee that morning, or if the user was recommended not to have coffee, the Sunnere app would suggest tea instead, and mark coffee as 'not recommended'. A variant of this prototype (Figure 6-17) that I suggested as a counterexample to the suggestion described above, would be 'less inteligent', and allow the user to select the type of meal manually; for instance 'frokost' ('breakfast') or 'lunsj' ('lunch'), but would work similarly to the first variant after this step. The SLPs agreed that both solutions could work – but we settled on the simplest one, suggested by the SLPs (Figure 6-16).

Figure 6-16 Workshop with the SLPs - design suggestion one, with two buttons indicating 'hungry' and 'thirsty'.

Figure 6-17 Workshop with the SLPs - design suggestion one, with five buttons indicating the names of different meal times.

Design Suggestion Two

Design suggestion two (Figure 6-18) was the result of a discussion regarding how the aphasics would find the food and drink items: the most accommodating way for an aphasic to find a food or drink item, would be through an image catalogue. However, another suggestion involved the use of a keyboard, and would allow the user to manually type in the item being searched for. Whereas *design suggestion one* (see above) relied on a fair amount of behind-the-scenes prediction to figure out what the user was looking for, this design suggestion would allow the user to access a food or drink item directly by searching for it via text, aided by text and image predictions (i.e. images would appear as the user typed in letters). Concerns were raised by the SLPs in regards to categories: some aphasics struggle with naming categories, therefore, finding the right category may prove difficult. In addition, *literal or verbal paraphasia* (see chapter 3.1.1) can confuse words, resulting in a variety of situations where the aphasic user searches for something, but means to find something else. They proposed that the Sunnere app could suggest items that were in the same category as the item being searched for. For instance, if the user searched for 'kiwi', the Sunnere app would suggest other fruits like 'apple', and 'banana' as well, in an effort accommodate paraphasia in the searching process. There was also a suggestion to recommend items across categories; for instance, if the user searched for 'kiwi', the Sunnere app would suggest 'bacon', or 'yoghurt', because the app 'knew' that this was a commonly made mistake for that particular user. I argued that his would be difficult to set up for every user; the SLPs agreed, and thus we decided on the image catalogue as the most appropriate solution for navigating food and drink items.

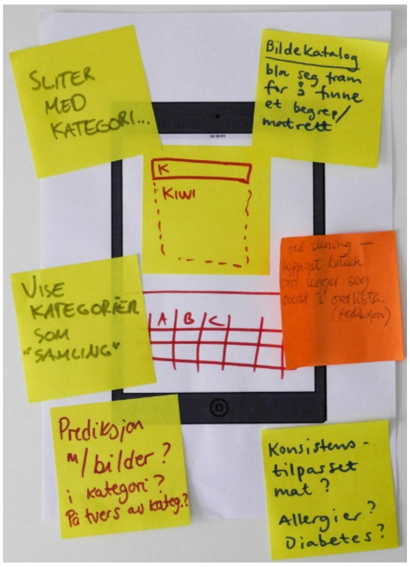


Figure 6-18 Workshop with the SLPs - design suggestion two, showing various interesting ideas like, text (using the device keyboard) and image prediction, and browsing food and drink items through an image catalogue.

Design Suggestion Three

Design suggestion three (Figure 6-19) was focused on how the user would receive feedback on consumed meals, given a one day, week, or monthly timeframe. For instance, if the user wanted to check what they had consumed against what was recommended for them last week, they would have to have some way of finding that 'portion of time' in the diet record. One of the SLPs suggested, that since aphasics can usually recognise day names if they are lined up next to each other like in a calendar, that such a format would likely work. Two views were discussed: a week view, where the days of the week were lined up horizontally at the top, and the time of day, categorised by meal, were lined up vertically below the days. Each meal would have an icon showing to what degree that meal conformed to the recommended nutritional scheme; for instance, a smiley face, or a thumbs up icon. The user could then tap one of these to get more information about *what* food items were good or bad for that particular meal. The second view, a month view, would look very similar to the day view, but instead of showing the meals for a particular time, each meal would be a particular date instead, giving a day-average value of conformance to the recommended nutritional scheme.

The SLPs agreed that the smiley-face feedback model (Figure 6-20) was appropriate for the majority of the aphasic users, but that this should be to customisation per user due to the large degree of individuality among aphasics. I suggested traffic-light colour themed indications on 'healthy'(green) and 'unhealthy' (red), and an alternative thumb feedback model, both which were well received by the SLPs – whom commented that these are generally well understood by aphasics.

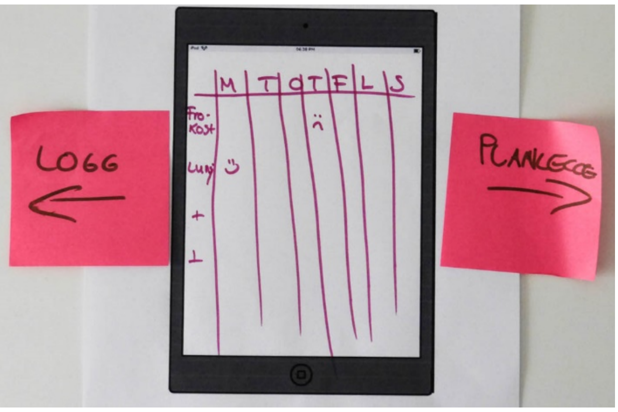


Figure 6-19 Workshop with the SLPs - design suggestion three, showing a calendar-like grid with days laid out horizontally, and meals laid out vertically.

Figure 6-20 Workshop with the SLPs - design suggestion three, showing interesting ideas like multi-modality (through sound), and the ability to toggle sound, images, or text on/off. It was also suggested that a three-tiered smiley scale was sufficient.

6.3.1.1 Findings and Prototype One (P1)

In addition to the three design suggestions presented in the previous section, some of the discussions that resulted from the workshop were summarised on sticky-notes (and are shown together with the design suggestions). These sticky-notes represent requirements on a general level, or design ideas that did not fit together with the three presented design suggestions. These are summarised below:

- All SLPs agreed that **images were vital** in conveying information about the content. However, it must be possible to remove images from the interface if the aphasic user is proficient with text, and finds the images distracting (sticky-notes shown in Figure 6-18).
- All SLPs agreed that **using text, images, and sound together** (multi-modality) may benefit the aphasic user's ability to understand content. However, it must be possible to turn each one of these off, based on the individual requirement of the aphasic user (sticky-notes shown in Figure 6-20).
- The **smiley feedback mechanism** from the NAM project (see chapter 6.1.2) was recommended as a robust feedback mechanism that would likely be understood by all aphasics. It was, however, refined to a three-tiered smiley, instead of a five-tiered smiley (stick note shown in Figure 6-20).
- Since aphasia varies from patient to patient, **a high degree of customisation** of the interface is required; examples include (sticky-notes shown in Figure 6-20):
    - Fine-grained control over content presence (i.e. turning various content like sounds, images, and text on and off).
    - Typographic changes (e.g. case, size, colour).
    - Visual changes (e.g. image size, image content).
- Some aphasics have **trouble understanding numbers**, so care should be taken when using numbers (sticky-note shown in Figure 6-20).
- Although more of a 'role' requirement for the prototype (see chapter 5.3.2), the SLPs agreed that the Sunnere app should be in accordance with Sunnaas Hospital's positive vision: 'one way ahead'. The implications this has for the design, is that when using symbols like smileys, care should be taken in not showing smileys that express overwhelming negativity unless representing something dangerous, like an allergy, or a sugar warning for diabetics (sticky-note shown in Figure 6-20).

The three design suggestions from the SLPs were formalised into what is presented in this subchapter as *prototype one* (P1). This included substantial refinement of P0 (see chapter 6.1.4). As a part of this formalisation, the dietician at Sunnaas Hospital took pictures of some of the food and drink items that were served at the cafeteria in order to make P1 a more representative prototype in terms of choices – acting as boundary objects, and promoting *situated-based action* (see chapter 4.2.1). Each screen shows which scenario it corresponds to in parentheses, and changes to the screens that were results of the workshop, are highlighted in **bold**.

Cafeteria Menu (SCN1)

Figure 6-21 and Figure 6-22 show the food and drink item selection menu containing the items from the cafeteria. Items are navigated using an **image catalogue for navigation of food items** and the labels '**sulten**' ('hungry') and **'tørst'** ('thirsty') as filters. The image catalogue shows green borders around some food items; green indicating a healthy choice (according to the user's personal dietary recommendation). **Red borders around the food and drink items were omitted** to adhere to Sunnaas Hospital's positive vision: rather than discourage unhealthy choices, the Sunnere app should encourage healthy ones. The top-left (cutlery) and top-right (human silhouette) icons would navigate to the cafeteria menu, and the diet record feedback page respectively.

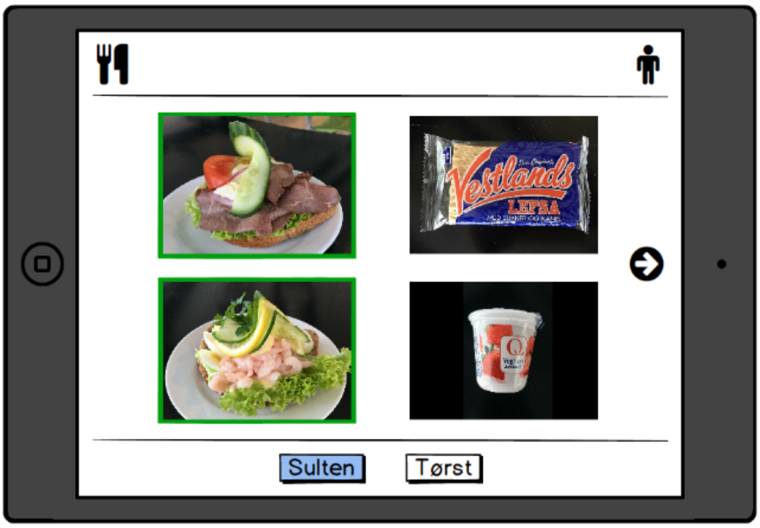


Figure 6-21 P1: cafeteria menu showing food items.

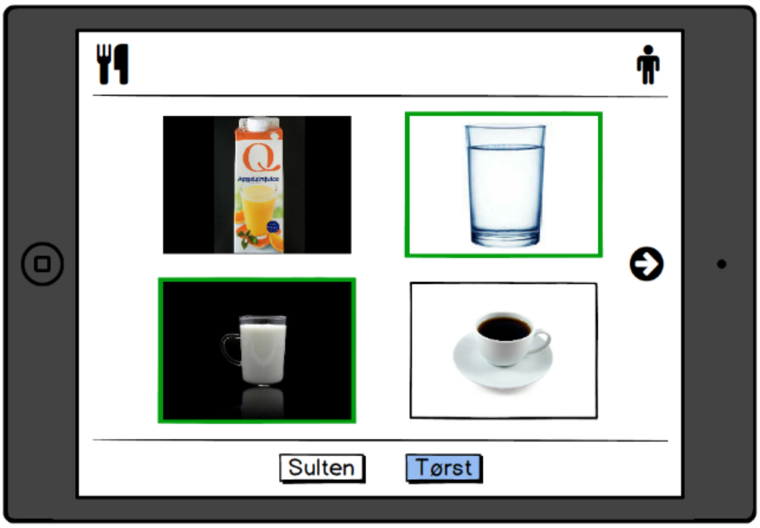


Figure 6-22 P1: cafeteria menu showing drink items.

Cafeteria Menu – Magnified View (SCN1)

Figure 6-23 shows a magnified view; a larger image of a food or drink item, that gave three options: 'go back to the previous menu' (arrow on lower left), 'get more information about this food item' (question mark in the lower middle), and 'register this this meal in the diet record' (checkmark on the lower right). This demonstrates the prototypes ability to make **visual changes such as image size** to accommodate the user's requirements.

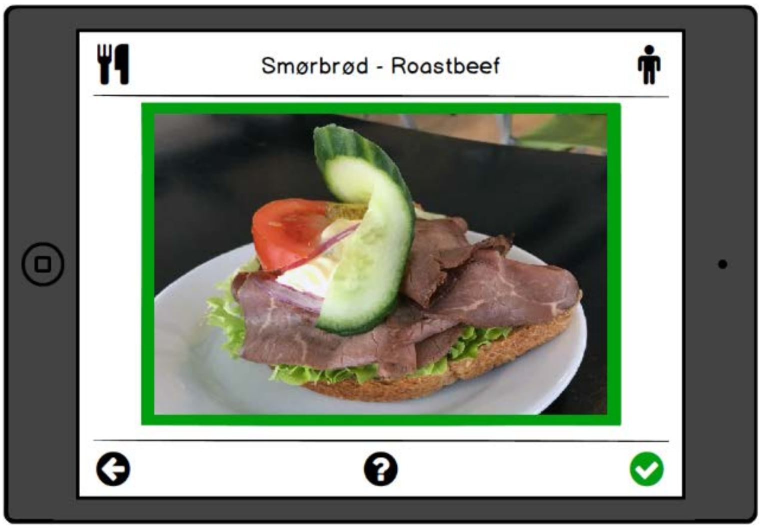


Figure 6-23 P1: cafeteria menu – magnified view.

Cafeteria Menu – Nutritional Details View (SCN2)

Figure 6-24 shows more detailed information about the nutritional content in the food [23]. **Deep customisability of content presence** suggests that displaying *all* nutritional stats is not viable, and thus only the nutritional values that are relevant could be 'picked' for that particular user. For instance, for a user with diabetes, one could choose to omit all values but the 'sukker' ('sugar') value. This screen is largely a simplification of P0's overly complicated bar chart (see chapter 6.1.4). This simplified bar chart **avoids the use of numbers** to represent the nutritional content of a food or drink item, and instead uses traffic-light colours to indicate how the values correspond to the user's recommended diet plan.

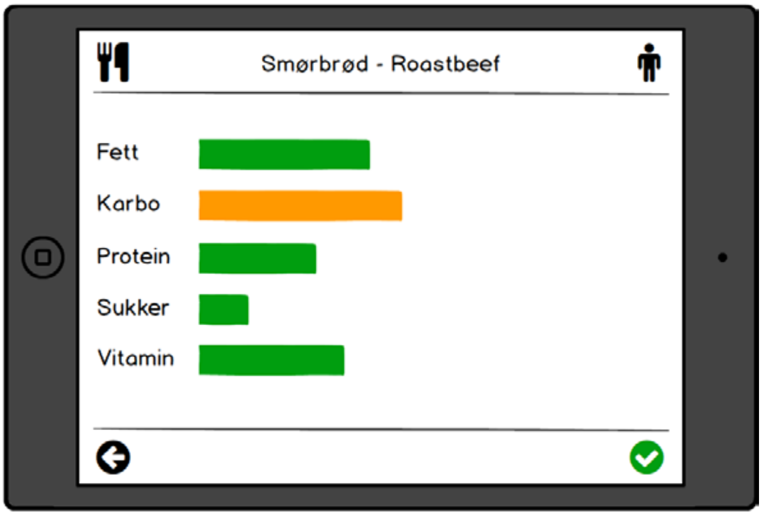


Figure 6-24 P1: detailed view of nutritional values in food item.

Diet Record Feedback – Day View (SCN3)

---

[23] Note that the nutritional values are not accurate, simply rough estimations.

Figure 6-25 shows the daily feedback based on the diet record using the smiley feedback model. **The smiley scale was reduced from five values** (as originally designed as part of the NAM project – see chapter 6.1.2) down to three, as a result of discussion with the SLPs. The user could toggle between a day view, and a week view using the buttons 'dag' ('day') and 'uke' ('week') respectively. Figure 6-26 shows the traffic-light coloured theme used in a detailed view, where the user could see how their diet record corresponds to their recommended nutritional values individually. The red colour and 'unhappy' smiley was reserved for representing dangers, such as allergies, or a sugar warning for diabetics. Figure 6-27 shows an alternative view, displaying values horizontally to accommodate visual deficiencies, and to demonstrate the imagined flexibility of the Sunnere app in terms of accommodating different users.

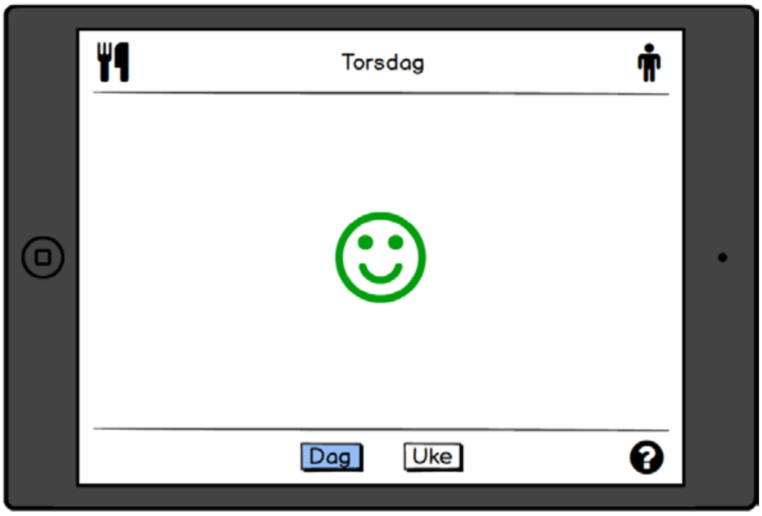


Figure 6-25 P1: daily diet record feedback using a smiley feedback model.

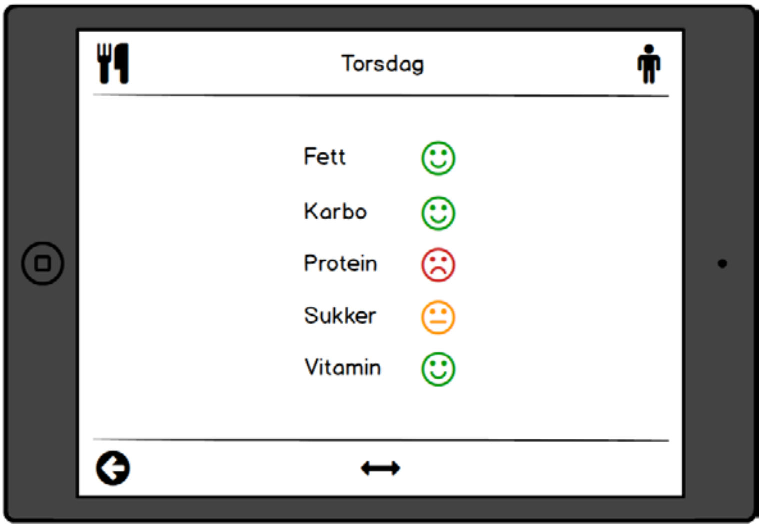


Figure 6-26 P1: daily diet record with feedback on individual nutritional values using a smiley feedback model (vertical)

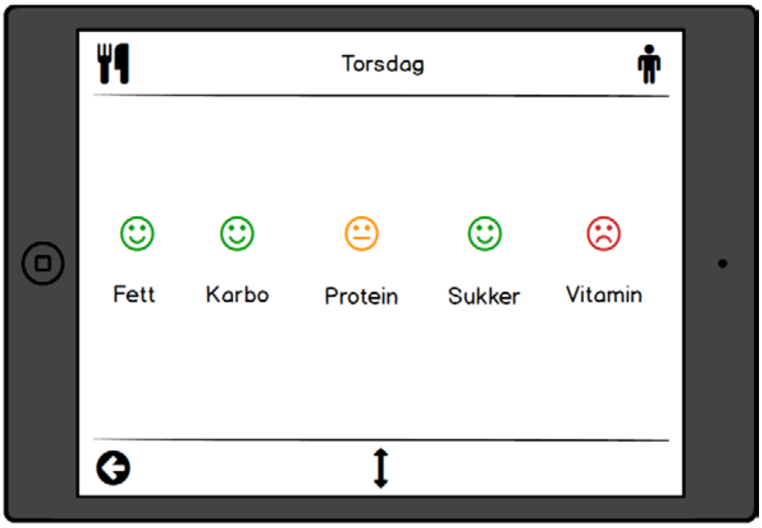
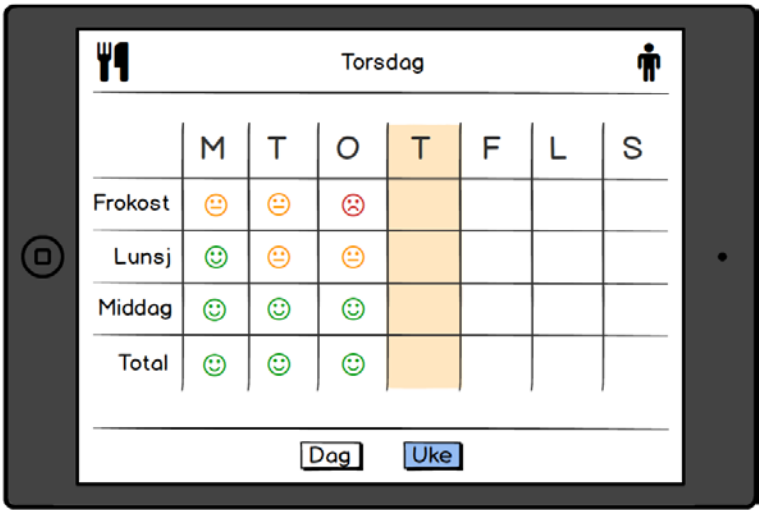


Figure 6-27 P1: daily diet record with feedback on individual nutritional values using a smiley feedback model (horizontal).

Diet Record Feedback – Week View (SCN3)

Figure 6-28 shows the **calendar-like grid** from *design suggestion three* – a suggestion made by the SLPs. It gives a weekly overview of how well the user is following their dietary recommendations.



	M	T	O	T	F	L	S
Frokost	😐	😐	☹				
Lunsj	☺	😐	😐				
Middag	☺	☺	☺				
Total	☺	☺	☺				

Figure 6-28 P1: weekly diet record using a calendar grid layout.

6.3.2 Usability Workshops with Aphasic Participants

Since I did not know which aphasic patients would want to participate in the workshop before the day that I was conducting the workshop, I had to plan the workshop and the tools to accommodate various degrees of participation due to the varying communicative abilities of the aphasics. The usability workshop consisted of two components; drawing on elements from usability testing (see chapter 5.3.3), and participatory prototyping in a similar manner to the proxy workshop. The usability testing component represented the lowest degree of participation in the design process, while the participatory prototyping component represented the highest degree of participation in the design process. This was intended to allow the participants to 'choose' their role as they pleased, a requirement that built on the pilot studies (see chapter 6.1), and the ethnographic background study (see chapter 6.2). The foundation of the workshop was therefore built upon the use of low-fidelity paper prototypes. These were employed in a dynamic fashion in order to mimic the more complex interactions of a higher-fidelity prototype.

The usability testing component of the workshop – the lowest intended degree of design participation – was centred around what I will refer to as the *usability kit*. The usability kit was a collection of printed paper cards which each represented an individual digital interface sketch[24] (hereinafter interface cards) from both P1 (Figure 6-29). The sticky-notes shown in Figure 6-29 were intended to add improvised notes to the cards:

Figure 6-29 Workshop with aphasics – usability kit (P1), and sticky-notes.

The usability kit contained the interface sketches necessary to 'walk through' the main scenarios (see chapter 2.1.1.1). The cards of the usability kit contained a selection of food and drink items from P1 (taken from the cafeteria at Sunnaas Hospital), allowing the scenario to be completed multiple times, with different selections of food and drinks to illustrate different choices. The purpose of the usability kit was not only to demonstrate the Sunnere app to the aphasic participants, but also to identify aspects of the design that were working well, or not working well.

While walking through the various instances of the main scenario (i.e. picking different food and drink items, and receiving feedback on these choices), I planned to use an unstructured interview (see chapter 5.3.1.1) to ask the aphasic participants usability questions about the interface. The exploratory nature of this method, was intended to allow me to use this observation to change the questions to address issues not covered by the questions in an impromptu manner. The rationale for choosing an unstructured interview, was that no aphasic individual is the same, and there is no

---

[24] The interface sketches were made in Balsamiq Mockups 3 – see chapter 5.3.2.2.

single interview format that would accommodate all aphasic individuals. I prepared the following questions[25] as possible questions to ask in the usability interview – a formative approach (see chapter 5.3.3):

- Would you make the text bigger?
- Would you make the text smaller?
- Would you make the images bigger?
- Would you make the images smaller?
- How well do you understand the text?
- How well do you understand the images?
- Would you change anything else?

The questions had to be simple and atomic[26], and care was taken in making sure that the questions were not directive (see chapter 5.3.1.1). For instance, I would not ask questions like 'do you like this?', or 'would you make anything bigger, or smaller?' – the first question being directive, and the second one composed of multiple questions. Such a question would be broken down and rephrased into its atomic questions: 'would you make the text bigger?', 'would you make the text smaller?', 'would you make the images bigger?', and 'would you make the images smaller?'. In order to ensure that the participants would be able to communicate their answer to these questions even with impaired speech, I prepared a sheet with the 'thumbs up' and 'thumbs down' icons in green and red, accompanied by 'Ja' ('Yes') and 'Nei' ('No'), respectively (hereinafter **yes/no sheet**). I intended this to be a communicative aid that could be used if the participants struggled with communicating these phrases (Figure 6-30):

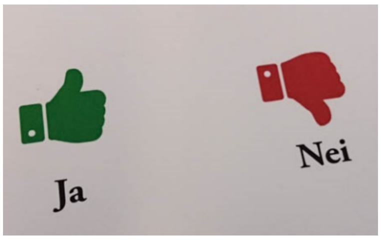


Figure 6-30 Workshop with aphasics –yes/no sheet.

I wanted to avoid the very real possibility that the aphasic participants would be unable to answer any of the questions. Since interviews on their own are limited very much to verbal communication, I employed observation and field notes in an ethnographic manner as an integral part of the workshops as an effort to reveal qualitative data regarding the aphasic participants' experiences of the prototypes, and to guide the flow of the workshop. Body language revealed important insight regarding the experience of the prototypes: for instance, if I saw that the

---

[25] The reason why this was not a semi-structured interview, was that the questions were asked wholly dependent on the observations.

[26] Atomic in the sense that the question is irreducible into smaller questions.

participant was struggling with a button, this would prompt me to ask questions about this button. It was critical to the success of the workshop that the participants could 'speak their own language': the questions were asked so that they could be answered with 'yes' or 'no', ensuring that they could be answered in whatever way the participants were capable of; for instance, with gestures, body language, or words.

The exploratory usability testing represented the lowest degree of involvement in the design process, but was intended to serve as a 'gateway' to higher degrees of participation in the design process, by the questions imposing critique on the prototypes. Accommodating a higher degree of participation, was the purpose of what I shall refer to as the *prototyping kit*. The prototyping kit consisted of laminated cards with the illustration of a blank tablet screen, and was intended to be a **modular** approach to prototyping (opposed to the **static** usability kit): cut-out elements of the prototype (images of food, stat bars of various sizes and colours, smileys etc.) were attached to the laminated cards with sticky-tack, allowing them to be moved or removed, or changed for other elements. The laminated surface of the cards also allowed for whiteboard markers to be used to draw directly on them. Some of the modular prototyping cards are shown below in Figure 6-31, Figure 6-32, Figure 6-33, Figure 6-34, and Figure 6-35:

Figure 6-31 Workshop with aphasics – prototyping kit with sticky-tack and whiteboard markers.

Figure 6-32 Workshop with aphasics – prototyping kit

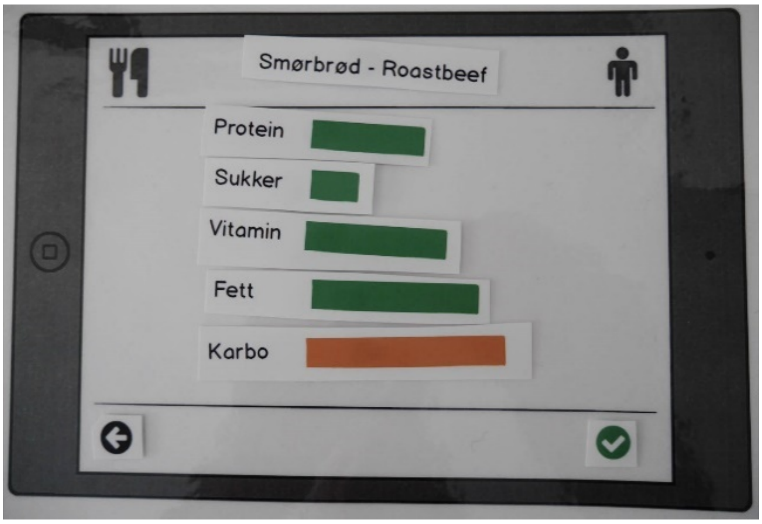
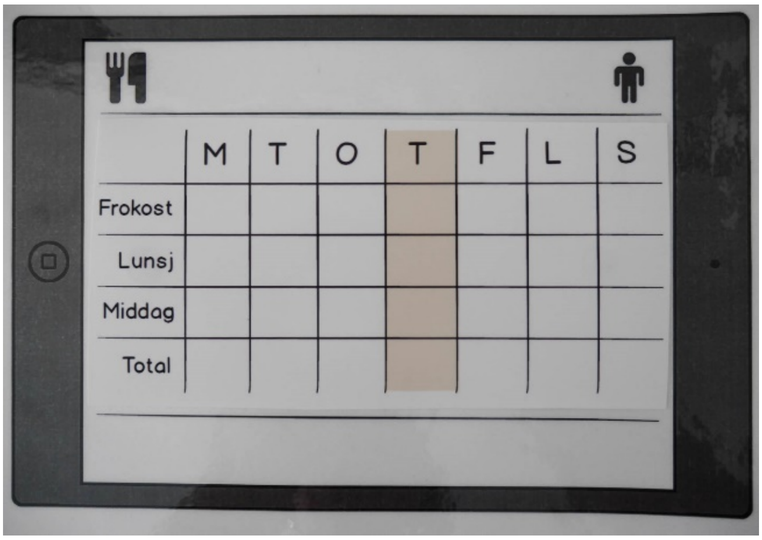


Figure 6-33 Workshop with aphasics – prototyping kit.



	M	T	O	T	F	L	S
Frokost							
Lunsj							
Middag							
Total							

Figure 6-34 Workshop with aphasics – prototyping kit.

Figure 6-35 Workshop with aphasics – prototyping kit, various components.

If the participant disagreed with the design decisions made in the prototype, the static usability kit card could be swapped for the corresponding modular prototyping kit card, which allowed for elements of the interface to be changed. These changes were supposed to 'open up' for new ideas in the design space between the prototypes. For instance, the answer 'yes' or 'maybe' to the question 'would you make the text bigger?', would prompt me to ask 'OK – text how much bigger?' or 'OK – let us compare', then subsequently change the modular prototype, and ask the questions again; iterating until the participant agreed that the change was better than the original design. The purpose of this process was to create alternative suggestions of what the design could be – an important part of PD (see chapter 4.2.1).

The usability workshop was inspired by *Situated and Participative Enactment of Scenarios* (SPES) as proposed by Iacucci, Kutti and Ranta (2000): they used a block of wood to imagine a 'magic' technological artefact, as a way of engaging in the telling, making, and enacting of all possible (and impossible) ways in which the artefact could be designed. SPES is useful in PD because the enactment of scenarios is carried out in the context of which the imagined artefact would be used (Brandt et al., 2013, p. 168). However, envisioning that a block of wood is an incredible piece of technology requires imagination, but more importantly, the participant's ability to communicate these abstract ideas to the designer.

Relying on the participant's ability to communicate ideas based on such abstraction was unlikely. Instead, I employed the enactment of scenarios using the interface cards as a less abstract medium than the nondescript wooden block. That which I employ in a similar manner to SPES, however, was *situation-based action* (see chapter 4.2): the workshop was carried out in the patients' rooms, and the interface cards contained representative images of the food and drink items served in the cafeteria at Sunnaas Hospital.

The usability component of this workshop, led in a SPES-inspired manner, intended to provide the participants an opportunity to 'act out' the main scenario in which the Sunnere app would be used, and to encourage critique of the current state of the prototype. The prototyping component was intended to allow adapting of the prototype design into something more appropriate, using the modular prototyping kit – a tool intended to adhere to a participatory mindset.

I spend the better part of a day at the nurse's station at Sunnaas Hospital. I got the opportunity to talk to the nurses about their roles, and about the patients. I addition, I was able to observe the environment in which I was situated. By the end of the day, I had completed two instances of the usability workshop with two aphasic participants (AP1 and AP2). I was initially going to conduct the workshop with a third aphasic individual (AP3), but AP3 had a very tight schedule, and I thus missed my time window to conduct the workshop with AP3.

In preparation for the workshop, I created forms for informed consent and participation in the workshop. These were specifically made considering the challenges aphasic individuals face, and the participants were asked to choose the forms they understood best (these are discussed in chapter 5.4.2 – and can be found in Appendix E). Crang and Cook suggest that in order to ease into an interview situation, the interviewer should take care to exchange pleasantries, introduce him or herself, ask where to sit, and give a thorough explanation of the purpose of the interview. This should be followed by an ethics protocol, such as a consent form (2007, Chapter 5, *Asking The 'Right' Questions*). This was the process in which I started the workshops.

6.3.2.1 Aphasic Workshop One

AP1 had global aphasia – global aphasia affects all language modalities, and is considered the sum of Broca's and Wernicke's aphasia (see chapter 3.1.1). In other words, a severely aphasic participant with practically non-existent verbal communication. Adhering to the workshop plan, I was aware of the participant's assessment before starting the workshop, and planned on using the yes/no sheet (see Figure 6-30) as a communication aid for the participant (i.e. they could answer my questions pointing at the corresponding message). Due to global aphasia's effect also on comprehension of spoken language, I knew that my questions should be reduced to very few, slow-spoken, or if possible, single words. AP1 did, however, nod when asked 'kan du lese?' ('can you read?').

Following this, I showed AP1 the specially made consent form, reading it with AP1's assessment in mind; slow, and with longer than normal breaks between words and sentences, using guided reading; I pointed to each word as I was reading it to support AP1's reading. In terms of giving consent, it was paramount that AP1 understood who I was, how AP1 could help me, and that I would write about the workshop in this thesis, but I would not disclose AP1's identity. AP1 signed AP1's name on the consent form. I observed that AP1 had a smartphone, and assumed that AP1 would understand the paper-prototype-to-app abstraction.

After this, I walked AP1 through the paper prototype using the main scenarios pretending that I was 'doing' it myself. After a few minutes, I prompted AP1 to interact with the paper prototype, i.e. 'pressing' the various 'buttons', something AP1 followed willingly. I walked through the scenarios again, picking a different item from the food item menu (see Figure 6-21). AP1 appeared to be understanding the interface in that AP1 was not hesitating in interacting with the 'buttons' on the paper-prototype.

The paper prototype proved to be limiting when I asked AP1 to pick a drink: I asked AP1 to pick the orange juice from the drink menu (Figure 6-22) interface. Instead of picking the orange juice, AP1 picked the glass of milk. I asked if AP1 did not like orange juice: 'liker ikke?' ('do not like?') while pointing at the orange juice – AP1's body language indicated that this was true.

After walking through the scenario, I asked AP1 whether it was alright if I asked some questions regarding the paper prototype: 'kan jeg spørre deg? [pause] om appen?' ('can I ask you? [pause] about the app?'). I pointed to my Yes/No sheet, indicating that AP1 could use this to answer the questions. AP1 scoffed, and made a dismissing gesture towards the Yes/No sheet. It was evident that AP1 did not want to use the sheet, and that observation would be the key to interpreting answers from the questions. AP1 was enthusiastic, so I assumed this would not be a challenge.

I asked AP1 about the 'sulten' ('hungry') and 'tørst' ('thirsty') filter buttons on the food/drink item menus – 'kan du lese?' ('can you read?'), while pointing at each of the buttons. AP1 nodded, indicating that the **text on the buttons were fine**. This was consistent with AP1's indication that AP1 could read, as established before the signing of the consent form.

I asked AP1 about the quantity of items on the food item menu: 'for mange bilder?' ('too many images?') in an attempt to get AP1's opinion on the quantity of items. I did not get a coherent reply, so I swapped the static usability card with the corresponding modular prototyping card, and removed two of the food items (Figure 6-36):

Figure 6-36 Workshop with aphasics – modification related to quantity of food items made together with aphasic participant (AP1).

I proceeded to ask the question again, and AP1 nodded, and indicated that **the food menu was better with two food items instead of four**.

Even though I had observed that AP1 was pressing the buttons on the paper prototype with little effort, I asked AP1 if the button on the magnified food item view (see Figure 6-23) was 'for stor?' ('too big?') or 'for liten?' ('too small?') while pointing at the button, in order to get AP1's opinion on the button. AP1 did not give a coherent answer, so I swapped the static usability card with the corresponding modular prototyping card, and used a whiteboard marker to draw on a bigger button (Figure 6-37):

Figure 6-37 Workshop with aphasics – modification related to size of button made together with aphasic participant (AP1).

I pointed at each button, asking 'bedre?' ('better?') for each button, while pointing at each. AP1 nodded when I pointed at the bigger button, indicating that **the bigger button was better**.

After that, I asked AP1 about the details page for the selected food item. Again, I asked 'kan du lese?' ('can you read?'), while pointing at each of the labels to each nutritional value listed (see Figure 6-24). AP1 nodded again. I asked AP1 'for mange?' ('too many?') while pointing at each of the nutritional values. I did not get a coherent answer. I swapped the static kit card with the corresponding prototyping kit card, and started removing the nutritional values in an attempt to reduce the amount of values shown (Figure 6-38):

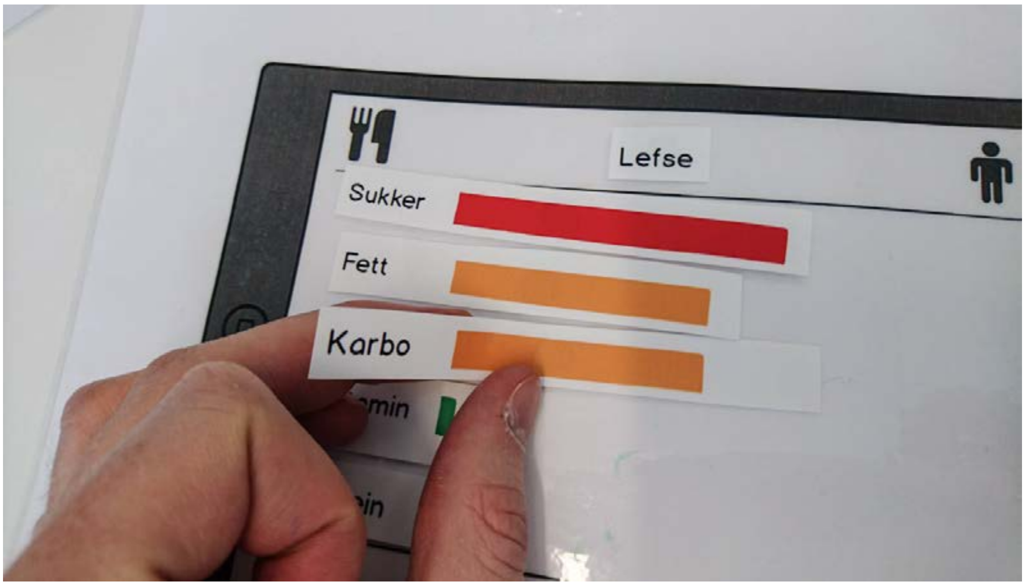


Figure 6-38 Workshop with aphasics – modification related to quantity of nutritional detail bars rejected by aphasic participant (AP1).

AP1 immediately made a gesture, and a non-coherent vocal sound. I stopped removing the values, and asked AP1 'OK?'. AP1 nodded, indicating that **five nutritional values** were comprehensible to AP1. I asked AP1 about the colours, to reveal whether AP1 could understand the traffic-light colours used to indicate the impact of the nutritional values (e.g. *too much* sugar is *bad*, therefore the bar is red – see Figure 6-38): 'rød er ikke sunn' ('red is not healthy'), while pointing to the 'sukker' ('sugar') stat. AP1 nodded, and pointed to the 'vitamin' stat. I said 'grønn er sunn' ('green is healthy'), and AP1 nodded. I pointed at the orange stat, which indicates that the stat is average – somewhere between unhealthy and healthy, as I stated 'mellom' ('between'), AP1 nodded again. This indicated that AP1 understood the **traffic-light abstraction as unhealthy-healthy**.

Finally, I showed AP1 the week feedback card (see Figure 6-28). I pointed at the letters of the days in the grid ('M', 'T', etc.), while speaking out 'mandag' ('Monday'), 'tirsdag' ('Tuesday'), and so forth. I repeated this for the name of each meal; 'frokost' ('breakfast'), 'lunsj' ('lunch'), and so forth. AP1 nodded. It appeared AP1 had no problem understanding the grid, as predicted by one of the SLPs in the proxy workshop.

At this point I concluded the workshop, and I thanked AP1 for AP1's time – the workshop lasted 20 minutes.

6.3.2.2 Aphasic Workshop Two

AP2 either had expressive aphasia, or apraxia of speech (see chapter 3.1.1), AP2's assessment was unclear. AP2 had replaced vocal communication with thumbs-up and thumbs-down gestures; unable to produce coherent speech. I was aware of AP2's condition before the workshop started, and so I decided to discard the use of the yes/no sheet, as AP2 was self-capable of using these gestures to communicate. AP2 showed a high degree of awareness of AP2's surroundings – more than AP1.

I started with asking AP2 whether AP2 could read: 'kan du lese?' ('can you read?'). AP2 gestured 'no' (thumbs down). I proceeded with reading AP2 the consent form to give AP2 an idea of who I was, and how AP2 could help me. I read it slow, and with exaggerated pauses. AP2 appeared to understand my words, as AP2 would ever so often gesture 'yes' (thumbs up) when I caught AP2's attention to assess the communication. I made it clear that I would write about the workshop in this thesis, and that I would not disclose AP2's identity by repeating each of these statements twice. AP2 responded with a 'yes' gesture, and proceeded to sign the consent form. As with AP1, I observed that AP2 had a smartphone, and was confident that AP2 understood that the paper prototype was *supposed* to 'be an app'.

Similarly, to the workshop with AP1, I walked AP2 through the paper prototype using the main scenarios.

AP2 seemed uninterested in interacting with the paper prototype when I asked. AP2 gestured 'yes' for every part of the scenario walkthrough, indicating that AP2 seemed to grasp the concept well.

I repeated the scenarios with a different food item, and then a drink item, with the same answer from AP2.

After walking through the scenario, I asked AP2 whether it was alright if I asked some questions regarding the paper prototype: 'kan jeg spørre deg? [pause] om appen?' ('can I ask you? [pause] about the app?'). AP2 gestured 'yes'.

I asked AP2 about the 'sulten' ('hungry') and 'tørst' ('thirsty') filter buttons on the food/drink menus (see Figure 6-21 and Figure 6-22): 'kan du lese?' ('can you read?'), while pointing at each of the buttons. AP2 gestured 'no'. The manner in which AP2 so promptly gestured 'no', made it apparent to me that AP2 was not afraid to 'disagree' with things that were not understandable, or wrong. I swapped the static usability card with the corresponding modular prototyping card, and removed the two filter buttons from the interface. I used a whiteboard marker to draw on two buttons, one with a chicken club inside it, and one with a glass of water inside it (poorly drawn by myself) (Figure 6-39).

Figure 6-39 Workshop with aphasics – modification of buttons made together with aphasic participant (AP2).

I explained to AP2 that the first button was supposed to be 'kylling' ('chicken'), and the second one 'glass vann' ('glass of water'). I quickly followed with 'jeg kan ikke tegne godt!' ('I cannot draw well!'). AP2 snickered. I asked AP2 'bedre?' ('better?'), while pointing to each of the newly drawn buttons, and AP2 gestured yes, while snickering again. The fact that AP2 **preferred my drawn buttons to the text**, confirms AP2's expressed inability to read.

I also asked AP2 about the quantity of items on the food item menu: 'for mange bilder?' ('too many images?') in an attempt to get AP2's opinion on the quantity of items. AP2 gestured 'no'. I reduced the amount of food items to two (instead of the original four), just like with AP1, and re-asked the question to AP2. AP2 promptly gestured 'yes', indicating that, similarly to AP1, **the food menu was better with two items instead of four**.

AP2 had problems understanding the image of the 'Vestlandslefsa' (a Norwegian soft flatbread), and quickly gestured 'no' when AP2 saw the picture. In hindsight, AP2 may have meant that AP2 could not understand the writing in the picture as the main text was written in script – this is however, purely speculative.

As with AP1, I asked AP2 about the buttons: the magnified view (see Figure 6-23) contained three buttons. First I asked about the checkmark button; 'stor nok?' ('big enough?'), which AP2 hesitantly gestured 'yes' to. I repeated the same with the two other buttons, with the same answer from AP2. Since AP2 was generally quick to gesture a response, I decided to ask AP2 further about the buttons. I asked 'vet hva knappen gjør?' ('know what the button does?'). AP2 quickly gestured 'no'. I swapped the static usability card with the corresponding modular prototyping card, and took the buttons off. I asked AP2 'vil du tegne?' ('do you want to draw?'), but AP2 gestured dismissively towards the pen. I was unable to find a non-textual (due to AP2's inability to read) button design that would convey the meaning of the buttons.

I moved on to the daily feedback card (see Figure 6-25), and said to AP2 'i dag. er torsdag' ('today is Thursday'). Then I pointed at the green smiley, and said 'spist bra' ('eaten well'). AP2 gestured 'yes'. I pressed the 'week' button, and moved to the weekly feedback card (see Figure 6-28). I pointed at the letters of the days in the grid ('M', 'T', etc.), while speaking out 'mandag' ('Monday'), 'tirsdag' ('Tuesday'), and so forth. I repeated this for the name of each meal; 'frokost' ('breakfast'), 'lunsj' ('lunch'), and so forth. AP2 gestured 'yes'. It then became evident to me that AP2 understood the text when supplemented by reading the text out loud – AP2 was most likely unable to understand the 'sulten' ('hungry') and 'tørst' ('thirsty') buttons previously because I had not read the text out loud.

After suspecting that AP2 understood text if it was supplemented by reading the text out loud, I decided to investigate this further. I showed AP2 the static card of the drink item menu, and asked AP2 to select the orange juice; 'velg appelsin juice?' ('choose orange juice?'). AP2 pointed at the orange juice, and I swapped the drinks menu card for the magnified view card of the orange juice. I said 'mer informasjon' ('more information'), as I pointed to the question mark button that indicated navigating to the details view (that AP2 had trouble understanding), and swapped the magnified view card with the details view card. This view listed the nutritional stats for the orange juice, all listed by name, accompanied by a traffic-light coloured bar indicating the corresponding value of the stat. I read the names of the nutritional values out loud as I pointed at them; 'sukker' ('sugar'), 'fett', ('fat'), and so forth, looking at AP2 between each stat, awaiting a response. AP2 gestured 'yes' for each of the stats read out loud. On the last two stats; 'protein', and 'vitamin', I did not read out loud, but instead, asked 'forstår du?' ('do you understand?'). AP2, gestured 'no', as I had suspected – also consistent with AP2's stated inability to read. I pointed at the two stats again, while reading them out loud, pausing between each, looking at AP2 awaiting a response. AP2 gestured 'yes' to each of the stats when read out loud, indicating that AP2 **understood text when read out loud**.

At this point I concluded the workshop, and I thanked AP2 for AP2's time – the workshop lasted approximately 20 minutes.

6.3.2.3 Findings and Prototype Two (P2)

During the workshop, it was important to identify not only what could be improved upon in the interface, but also to identify things that were working well. The following points were either observed as well-functioning, or confirmed by the aphasic participants as appropriate design through the questions asked:

- **The images were understood** (with the exception of AP2's inability to identify the image of 'Vestlandslefsa' – which may have been due to unfamiliarity with this food item). Both AP1 and AP2 agreed that displaying four images was too much in the food and drinks menus – both participants agreed that displaying two images at a time was better.
- The abstractions of **traffic-light colours** to represent healthy (green), average (orange), and unhealthy (red) choices, were understood by both participants. Furthermore, the symbols, like **smileys, or thumbs up and thumbs down** accompanied by colour-coding posed no apparent difficulties for the participants to understand.
- Both AP1 and AP2 **understood the grid view** representing days of the week, a suggestion proposed by one of the SLPs in the proxy workshop.
- Both AP1 and AP2 **understood the simple bar chart** accompanied with traffic-light colours representing how the detailed nutritional values corresponded to their own dietary recommendations (see Figure 6-24). There were no numbers used directly in the interface.
- The text that was used in P1 represented **single words, or short descriptions** of food or drink items: **AP1 understood these, and AP2 understood these when the text was accompanied by reading the text out loud**.
- When I asked AP2 'ville du brukt en slik app?' ('would you have used such an app?'), AP2 shrugged, showing disinterest.

The following changes were made to the prototype using the modular prototyping kit during the workshop:

- AP1 and AP2 both agreed that displaying **two images of food and drink items** at a time in the menus, was better than displaying four items.
- AP1 indicated that the **buttons were too small**, and agreed that bigger buttons were better.
- AP1 and AP2 both appeared to understand the detailed nutritional stat view (see Figure 6-24), but AP2 had the need to accompany the name of each stat with audible support, suggesting the need for **multi-modality**.
- AP2 could not understand the symbols of various buttons – I suspect that the symbols could have been replaced by text and audible support together (as worked in the detailed nutritional view, described above. However, I did not think to try this at the time).

- In attempting to use the prototyping kit to find a new representation for a button that AP2 did not understand the text of, this failed, and the **button ended up being blank as we could not find a visual representation for its purpose**.

The changes suggested by AP1 and AP2 were formalised into what is presented in this subchapter as *prototype two* (P2). Each screen is appended with what scenario it corresponds to, and changes that were results of the workshop, are highlighted in **bold**.

Cafeteria Menu (SCN1)

Figure 6-40 and Figure 6-41 show the food and drink item selection menu containing the items from the cafeteria. Compared to P1 (see chapter 6.3.1.1), there is a **reduction of the number of items in the food and drink item menu**, and the introduction of **multi-modal buttons**, displaying both text *and* a symbol. The size of the text was increased, to demonstrate the Sunnere app's imagined flexibility in accommodating different users. The cafeteria menu and diet record buttons (top left and right, respectively), were displayed as buttons (opposed to just icons) in an effort to make the interface more consistent.

Figure 6-40 P2: cafeteria menu showing food items.

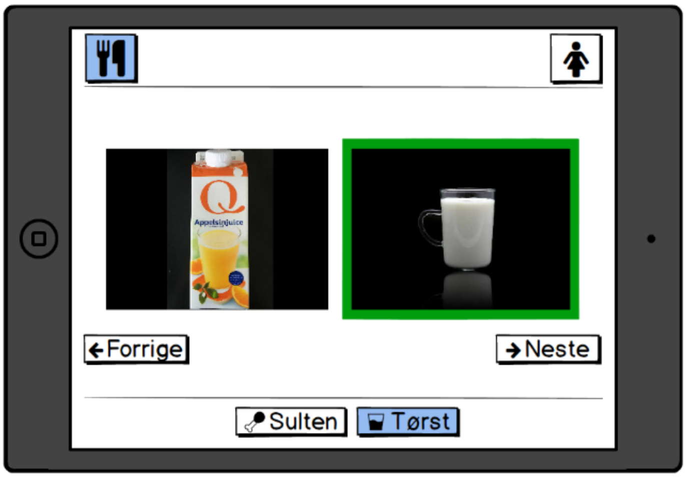


Figure 6-41 P2: cafeteria menu showing drink items.

Cafeteria Menu Item – Magnified View (SCN1)

Figure 6-42 and Figure 6-43 show the same changes as Figure 6-40 and Figure 6-41. Other than that, this screen remained unchanged.

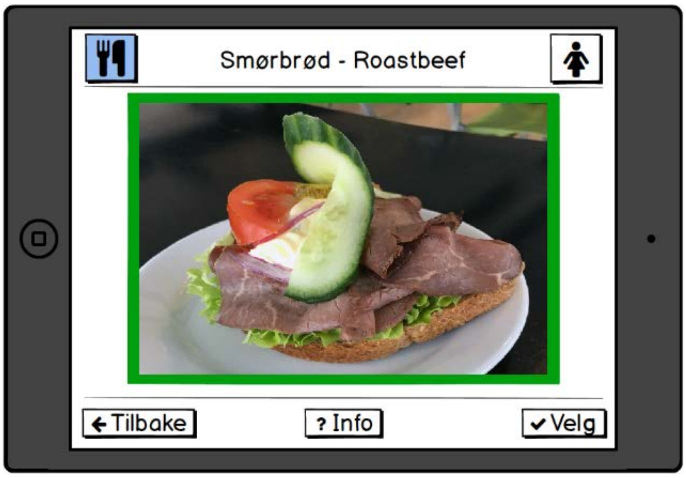


Figure 6-42 P2: cafeteria menu - magnified food item view.

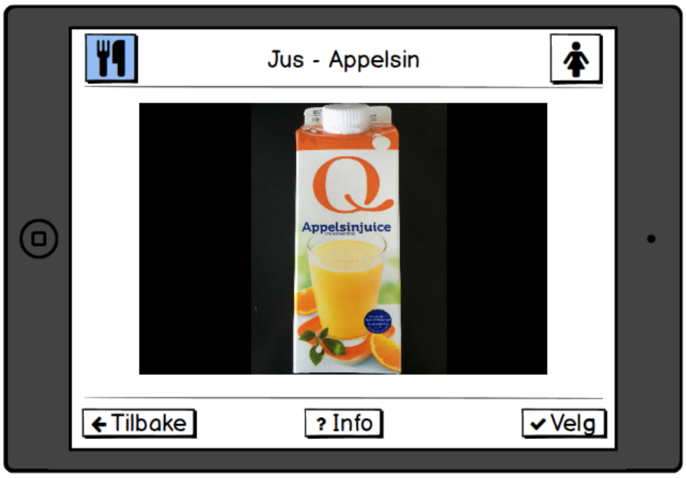


Figure 6-43 P2: cafeteria menu - magnified drink item view.

Cafeteria Menu Item – Nutritional Details View (SCN2)

Figure 6-44 shows the same changes as Figure 6-40 and Figure 6-41. Figure 6-45 shows a **reduction in the number of nutritional values** displayed in the detailed view. Figure 6-46 shows a horizontal display of nutritional values, and Figure 6-47 shows **further reduction of the number of nutritional values** to demonstrate the Sunnere app's imagined flexibility in accommodating different users.

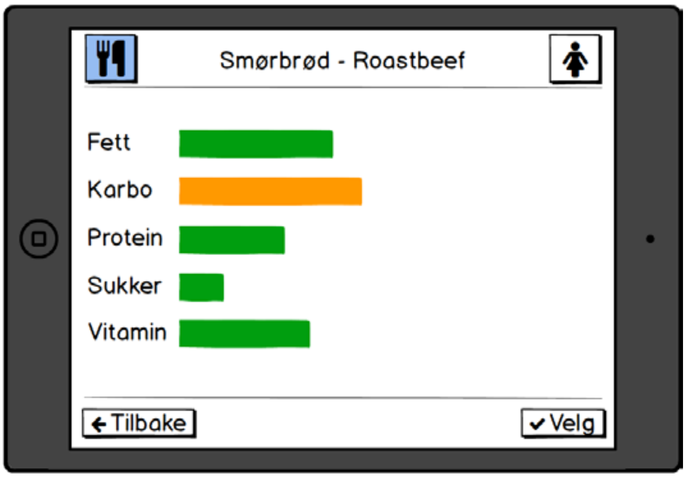


Figure 6-44 P2: detailed view of nutritional values in food item.

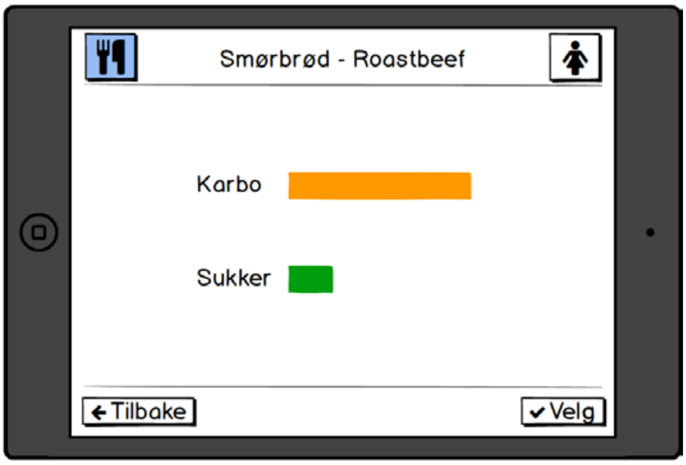


Figure 6-45 P2: reduced detailed view of nutritional values in food item.

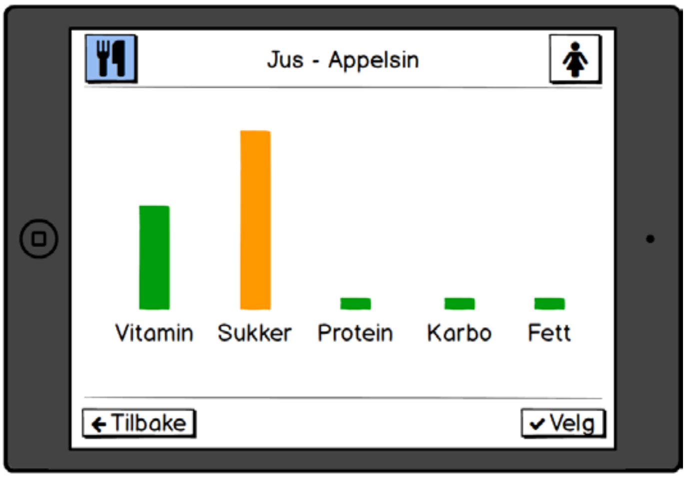


Figure 6-46 P2: detailed view of nutritional values in drink item.

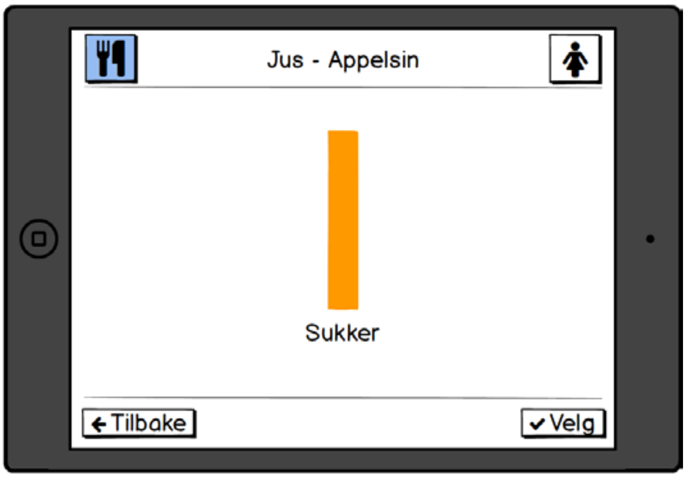


Figure 6-47 P2: reduced detailed view of nutritional values in drink item.

Diet Record Feedback – Day View (SCN3)

Figure 6-48 shows the same changes as Figure 6-40 and Figure 6-41 – however, we were unable to find a multi-modal representation of 'dag' ('day'), and 'uke' ('week'). Figure 6-49 and Figure 6-50 show vertical and horizontal displays of nutritional values to demonstrate the imagined flexibility of the Sunnere app in accommodating different users.

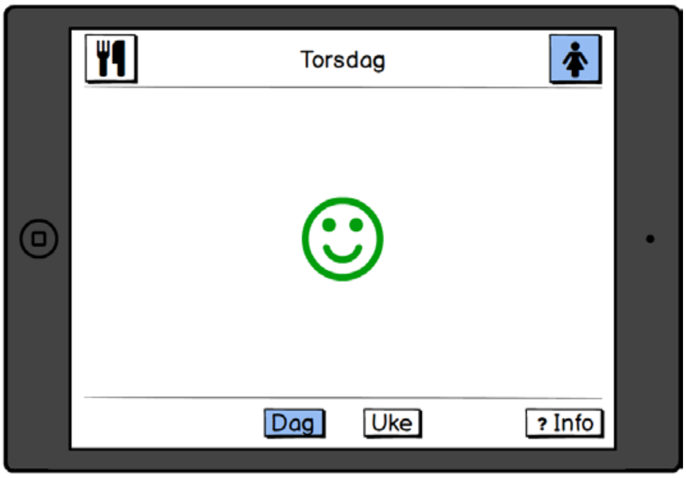


Figure 6-48 P2: daily diet record feedback using a smiley feedback model.

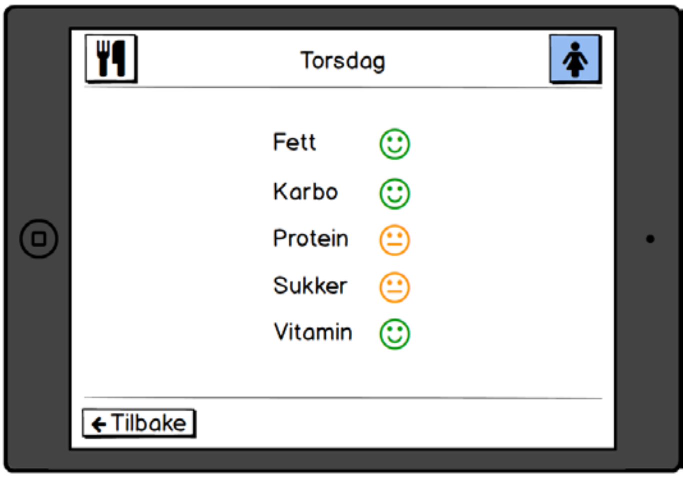


Figure 6-49 P2: daily diet record with feedback on individual nutritional values using a smiley feedback model (vertical).

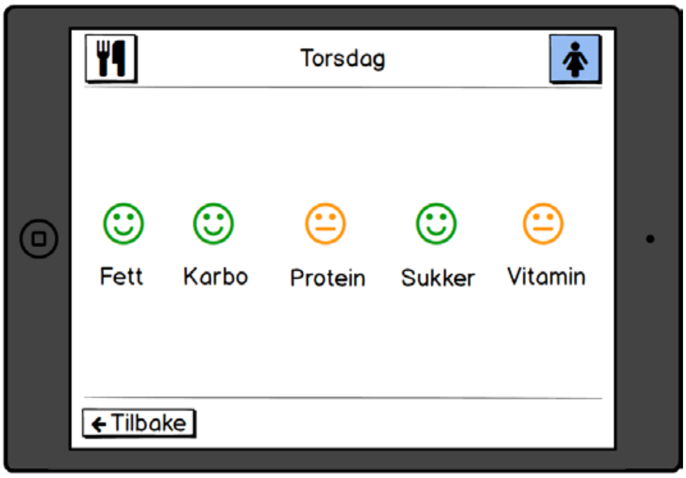
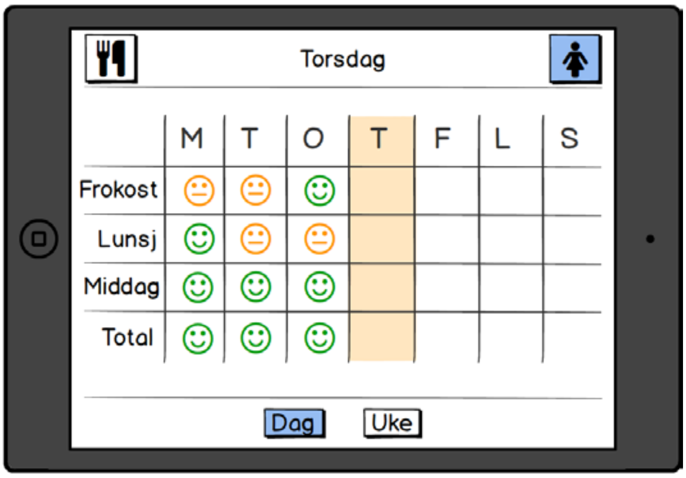


Figure 6-50 P2: daily diet record with feedback on individual nutritional values using a smiley feedback model (horizontal).

Diet Record Feedback – Week View

Figure 6-51 shows the same changes as Figure 6-40 and Figure 6-41 – however, we were unable to find a multi-modal representation of 'dag' ('day'), and 'uke' ('week'). Other than that, this screen remained unchanged.



	M	T	O	T	F	L	S
Frokost	😐	😐	☺				
Lunsj	☺	😐	😐				
Middag	☺	☺	☺				
Total	☺	☺	☺				

Figure 6-51 P2: weekly diet record using a calendar grid layout.

7 ANALYSIS AND DISCUSSION

We do not learn from experience - we learn from reflecting on experience.

–John Dewey

In this chapter, an analysis of my findings is presented, followed by a discussion of my RQs in the context of the theory and related work presented in this thesis. I have divided the chapter into *Designing for Aphasic Users* (RQ1), which firstly discusses the design itself. Secondly, *Designing with Aphasic Participants* (RQ2) discusses how aphasic participants were involved in the design process.

7.1 Designing for Aphasic Users

This section revolves around discussion regarding the design, and the resulting Sunnere app prototype:

> *RQ1: How can nutritional information be represented in a way that it is understandable by a wide range of aphasic users, thus enabling informed dietary decisions?*

In this section, I will put the final prototype (P2) in the light of a heuristic evaluation using usability heuristics identified from past design cases involving aphasic end users, as an effort to put P2 in the light of current research. The purpose of this was to identify whether or not there were design guidelines that could reach a wide range of aphasics – and more importantly, what these are.

7.1.1 Heuristic Evaluation

As presented in chapter 5.3.3.1, a heuristic evaluation is a usability testing method that aims to evaluate a prototype or user interface (UI) against a set of predetermined usability heuristics, employing one or more usability experts. I conducted a heuristic evaluation of P2 using the eight usability heuristics for aphasic users (see chapter 3.4.2). Although not a direct part of the evaluation, an illustration of the prototype evolution (see Appendix F) was used to supplement the heuristic evaluation because it provides insight into how the prototype has developed with the different involvements along the way: P0 involved aphasics that were relatively independent in terms of language; P1 involved SLP proxies; and P2 involved severe aphasics with almost non-existent verbal language.

A heuristic evaluation is ideally conducted by several usability experts. However, even one evaluator will yield results in uncovering the biggest usability flaws. I conducted the heuristic evaluation on my own, and can according to Nielsen's approximation, assume that I have uncovered 25% of the usability flaws (see chapter 5.3.3.1).

The usability heuristics and their sources are described in detail in chapter 3.4.2, and are summarised below:

- H1 – Deep customisability
- H2 – Quiet design
- H3 – Multi-modality
- H4 – Use images
- H5 – Avoid abstractions
- H6 – Reduced use of text and numbers
- H7 – Simple navigation
- H8 – Sufficient time

The heuristic evaluation was conducted on a low-fidelity prototype in a formative manner, and therefore, some aspects of the usability heuristics requiring higher-fidelity prototypes were omitted. This is noted for relevant heuristics.

H1 – Deep Customisability

See detailed description in chapter 3.4.2.1.

The most prominent requirement for aphasic users, is rooted in the fact that aphasia affects the individual in unique ways. The implication of this is that even if there are some design guidelines that apply to a wide range of aphasic users, there will most likely be a need to tailor the design to the individual aphasic user.

Since deep customisability requires a higher-fidelity prototype, there was no way to include this heuristic in the evaluation. However, there is consensus that this is an absolute requirement for aphasic users (Allen et al., 2007; Al Mahmud & Martens, 2010; Boyd-Graber et al., 2006; Galliers et al., 2011; Moffatt et al., 2004; Tee et al., 2005). This corresponded to my findings from the ethnographic background study (see chapter 6.2.4), the proxy workshop, and the adjustments that were made in the aphasic workshop. An example of this, was the button sizes on P1: AP1 and AP2 had different opinions of their sizes (see chapter 6.3.2.3) – the need to do such changes and tailor the UI to the individual, was predicted in the proxy workshop (see chapter 6.3.1.1).

H2 – Quiet Design

See detailed description in chapter 3.4.2.2.

The design became progressively more 'quiet' as it evolved from P0 to P2. The most notable example of this, is the reduction in the number of food and drink items in the cafeteria menu (twelve in P0, four in P1, and two in P2), illustrated in Figure 14-3 (Appendix F). This change is also evident in the reduction (from five in P1, to two in P2) of the number of nutrition values in the detailed view shown in Figure 14-7 (Appendix F).

Judging from P0, which involved evaluations using relatively independent aphasic participants (and received positive feedback), and P2 which resulted in a reduction of the quantities of interface elements, I can assume that fewer interface elements are better suited to more severe aphasic users (see chapter 6.3.2.3). This corresponds with the findings of Al Mahmud and Martens (2010), and Galliers et al. (2012).

H3 – Multi-Modality

See detailed description in chapter 3.4.2.3.

Even though *sound* is an important part of multi-modality, it requires a higher-fidelity prototype. This meant that evaluation of multi-modality was reduced to the use of text and images together.

The use of multi-modality became more prominent as the design evolved from P0 to P2. This is most evident in Figure 14-4 (Appendix F): buttons evolve from being symbols only, to including symbols *and text* (in a higher fidelity prototype, there could also be an option to incorporate sound). There are some aspects of P2 that are missing multi-modality; for instance, the smiley faces, or the top menu buttons missing text, displayed in Figure 14-5 and Figure 14-6 (Appendix F). Furthermore, the 'dag' ('day') and 'uke' ('week') buttons are missing visual support. This was the result of a breakdown of the scaffolding, which is discussed further in chapter 7.2.4 – imageability. The nutritional value names in Figure 14-6, Figure 14-7, Figure 14-8 (Appendix F), are missing visual support, as I was unable to find visual representation of these values.

There is general agreement that multi-modality is effective in conveying information, as the aphasic can utilise multiple language modalities for a synergy effect in comprehending it (Boyd-Graber et al., 2006; Moffatt et al., 2004; Tee et al., 2005). However, as recommended by the SLPs, if any modality is perceived as noise to the aphasic user, it should be possible to turn off (see chapter 6.3.1.1) – or simply if they do not benefit from certain modalities, they should be turned off (see chapter 6.2.4). Thus, multi-modality is subject to deep customisability.

H4 – Visual Support

See detailed description in chapter 3.4.2.4.

There is consensus that visual support through images and symbols will generally be understood by all aphasics (Allen et al., 2007; Al Mahmud & Martens, 2010; Boyd-Graber et al., 2006; Galliers et al., 2012; Koppenol et al., 2010; Moffatt et al., 2004; Tee et al., 2005). This was supported by the findings from the ethnographic background study where images were central in the SunCIST therapy (see chapter 6.2.4), the SLP proxy workshop (see chapter 6.3.1.1), and the aphasic workshop (6.3.2.3).

The use of visual support was integral to the Sunnere app prototype as a whole. Navigation of food and drink items (see Figure 14-3 in Appendix F), and feedback on the diet record (see Figure 14-6 in Appendix F), revolved around visual support using images and symbols respectively. However, on one occasion during the aphasic workshop, I experienced that one of the participants was unable to recognise one of the food items in the cafeteria menu; the 'Vestlandslefsa' (see chapter 6.3.2.3). It was clear that the participant was unfamiliar with this particular food item, and did not recognise it (this is discussed further in chapter 7.1.2.1).

H5 – Avoid Abstractions

See detailed description in chapter 3.4.2.5.

Concrete words and concepts are preferred over their abstract counterparts in conveying information to aphasics (Franklin et al. 1994; 1995; Tyler et al. 1995, as cited in Galliers et al., 2011, 2012). This was also recommended by an SLP in the ethnographic background study, in the form of words with high imageability (see chapter 6.2.4).

The Sunnere app prototype, did however use one arguably abstract concept successfully: traffic-light colour coding together with the feedback mechanisms (smileys) representing the 'healthiness' of a food or drink item choice, according to user's recommended diet plan. The colour coding is shown as borders around food and drink items in the cafeteria menu in P2 (see Figure 14-3 in Appendix F), and as part of the diet record feedback in combination with the smiley feedback mechanism (see Figure 14-5 or Figure 14-6 in Appendix F). Colour-coding was also used successfully by Al Mahmud and Martens (2010), and Tee et al. (2005). The smiley and thumbs feedback mechanisms from the NAM project (see chapter 6.1.2) were comprehended well by both aphasic participants (see chapter 6.3.2.3).

Another abstraction, the grid view on the weekly feedback screen (see Figure 14-2 in Appendix F), appeared to be well understood by both aphasic participants (see chapter 6.3.2.3), as recommended by the SLPs in the proxy workshop (see chapter 6.3.1.1).

H6 – Reduced Use of Text and Numbers

See detailed description in chapter 3.4.2.6.

Since aphasics generally struggle with text and numbers, this should be kept to a minimum, or as part of multi-modality. This was central to the Sunnere app prototype. It was essential that the user could complete their own diet records without being overwhelmed by text and numbers. Koppenol et al. (2010) and Tee et al. (2005) successfully used short sentences and familiar words in their UIs. The ethnographic background study revealed that high-frequency words, and words with high imageability and concreteness can be used (see chapter 6.2.4). The findings from the proxy workshop supports avoiding the use of numbers, if possible (see chapter 6.3.1.1). The aphasic workshop showed that text was problematic when unaccompanied by visual support or sound (through my guided reading) (see chapter 6.3.2.3).

The most important example of this, is the transformation of nutritional values into traffic-coloured bars, showing visual representations of the nutritional values according to the user's dietary recommendations (see Figure 14-6, Figure 14-7, Figure 14-8 in Appendix F). Moving away from the traditional display of tabular data (see chapter 2.2), and finding alternative representations of these values (for instance the numberless bar chart), was key in enabling informed decisions.

H7 – Simple Navigation

See detailed description in chapter 3.4.2.7.

An integral part of the Sunnere app prototype, was that it would be easy to navigate through food and drink items – promoting findability through the image catalogue – in order to allow the aphasic users to quickly complete their own diet records based on the choices from the cafeteria at Sunnaas Hospital. However, this solution gives little help if the user cannot find the food or drink item they are looking for.

In respect to task-switching, the buttons that allowed the user to switch between the food and drink menu, and the diet record feedback, were consistently available from the top left and right (e.g. P2 in Figure 14-3 in Appendix F).

H8 – Sufficient Time

See detailed description in chapter 3.4.2.8.

Due to the low-fidelity nature of the Sunnere app prototypes, this usability heuristic could not be evaluated. However, there is consensus that this is an absolute requirement for aphasic users (Al Mahmud & Martens, 2010; Boyd-Graber et al., 2006; Galliers et al., 2011; Moffatt et al., 2004). This was also confirmed by the ethnographic background study (see chapter 6.2.4).

7.1.2 Enabling Informed Dietary Decisions

Critical to enabling informed dietary decisions, was ensuring that the information presented in the Sunnere app was understandable by its aphasic users. The pilot studies proved valuable insight into how nutritional information could be presented in a comprehensible manner and the MARTIN and NAM projects combined prototype (P0 – see chapter 6.1.4) received positive feedback from the aphasic participants. However, the aphasic participants involved in the MARTIN and NAM projects demonstrated a relatively high degree of language independence comprehension compared to the participants involved in the Sunnere app design process, who suffered from significantly worse degrees of aphasia. AP1 had global aphasia, and AP2 had no vocal language (see chapter 6.3.2). In contrast, one participant from the NAM prototype evaluation, requested a new type of graph, displaying more complex nutritional information (see chapter 6.1.3). Thus, the workshops with AP1 and AP2 became opportunities for insight into how usable the features from the P0 prototype would be for more severe aphasics. The usability aspect of the aphasic workshops showed that the Sunnere app prototype generally fits the needs of AP1, and AP2 (see chapter 6.3.2.3).

In addition, the heuristic evaluation showed that there are overlaps between the design choices made for the Sunnere app prototype, and past design cases involving aphasic end users (see chapter 7.1.1). I will argue that usability heuristics presented in chapter 3.4.2 are useful in providing a starting point for a design, because they are based on the findings of numerous past design cases involving aphasics as end users (see chapter 3.4).

In the following sections, I elaborate on two notable findings that resulted from the design process: a discussion on an important experience regarding visual support (see chapter 7.1.2.1), and a discussion on how informed dietary decisions can be enabled for the aphasic users I interacted with (see chapter 7.1.2.2). I will conclude with highlighting the importance of deep customisability to accommodate the aphasic individual (see chapter 7.1.2.3).

7.1.2.1 Visual Support – An Anomaly

There is consensus that visual support will almost universally cater for aphasia (Allen et al., 2007; Al Mahmud & Martens, 2010; Boyd-Graber et al., 2006; Galliers et al., 2012; Koppenol et al., 2010; Moffatt et al., 2004; Tee et al., 2005). This was also confirmed through the image catalogue for navigating food and drink items in the MARTIN project (see chapter 6.1.3), and by the SLPs in the proxy workshop (see chapter 6.3.1.1). However, in the aphasic workshop, I experienced that AP2 was unable to understand the image of the food item 'Vestlandslefsa' (see Figure 7-1). AP2 could not read, and was unable to read the text on the image of the food item:

Figure 7-1 The 'Vestlandslefsa' food item that AP2 was unable to understand.

I have interpreted this occurrence in the frame of the DCT presented in chapter 3.1.4. I will assume AP2 had never seen a 'Vestlandslefsa' before. Thus, according to the DCT, seeing the image of the food item did not activate a nonverbal representation, and AP2 was unable to activate the verbal system because of AP2's aphasia. In addition, AP2 could not read the text on the image of the food item, nor the supplementing text above the image. This resulted in an image of a food item that did not activate either the verbal system, or nonverbal system.

Although this is speculative, it proposes that visual support is only useful when it is accompanied by an *existing* nonverbal representation. Therefore, I will argue that visual support counts for nothing if it represents something abstract, or does not have a nonverbal representation. In other words, if the individual has never seen it before, they will likely have no benefit from seeing it.

This has implications to the design because the Sunnere app prototype relies heavily on images to represent the food and drink items from the cafeteria at Sunnaas Hospital. Examples like these will possibly manifest as 'noise' to users like AP2, that do not recognise certain abstract images.

7.1.2.2 Representing Healthy Choices

In the Sunnere app prototype, a central part of the diet record, was providing feedback through the feedback mechanisms that resulted from the NAM project: the smiley, and thumb feedback mechanisms (see chapter 6.1.2). These were understood by all aphasic participants, both during the pilot studies (see chapter 6.1.3), and during the aphasic workshops (see chapter 6.3.2.3). The smiley feedback mechanism was refined by the SLPs during the proxy workshop from a five-tiered scale, to a three-tiered scale to represent clearer feedback (6.3.1.1), as shown below in Figure 7-2:

Figure 7-2 The refinement of the five-tiered smiley feedback mechanism to three tiers.

Traffic-light colours from the MARTIN project (see chapter 6.1.1) were incorporated in P1 to represent the degree of healthiness, combined with the refined three-tiered smiley feedback mechanisms from the NAM projects (see chapter 6.1.2). Examples of this can be seen in Figure 14-6, Figure 14-7, and Figure 14-8 (Appendix F).

The combination of the feedback model and traffic-light colours were well received by both severely aphasic participants (see chapter 6.3.2.3), and by the less severe aphasic participants from the MARTIN and NAM projects (see chapter 6.1.3), and did not prompt any further refinement from either of the severe aphasics involved in the workshops. However, as identified in the NAM and MARTIN projects, some less severe aphasics may benefit from more complicated and 'direct' feedback mechanisms, such as graphs (see chapter 6.1.3).

In regards to the simple bar chart in the detailed view (see Figure 7-3), AP1, who could read, could understand the single words accompanied by the traffic-coloured bars indicating how well a nutritional value corresponded to the user's recommendation.

Figure 7-3 The simple bar chart in the detailed view, representing how the values correspond to the user's dietary requirements.

AP2, could understand the single words when they were accompanied by my guided reading, suggesting that multi-modality – more specifically the inclusion of sound that was left out due to the low-fidelity nature of the prototype – may make these values accessible for aphasics like AP2, that could not read the text without guidance. Both AP1 and AP2, despite being severely aphasic, understood the 'traffic-light colour' *to* 'healthiness' abstraction, and showed no difficulties understanding the smiley feedback mechanism that was accompanied by the traffic-light colours.

Moreover, these representations were understood by both the less severe aphasic participants in the MARTIN and NAM projects, and the more severe aphasic participants AP1 and AP2. This suggests that these representations may also be appropriate for different types of aphasia not explored in this study, seeing as the span between the aphasics in the MARTIN and NAM projects, and AP1 and AP2, was quite extreme. In addition, I will argue that these representations at the very least would *enable* the aphasic participants AP1 and AP2 to make informed decisions in regards to their personal dietary recommendations.

7.1.2.3 A Need for Deep Customisability

There may be potential in the representation of healthy and not healthy food and drink choices through the traffic-light colours, smiley feedback mechanism, and simple bar charts. However, there is a consensus that a degree of customisation is almost always required in accommodating the nuances of requirements for the individual aphasic user (Allen et al., 2007; Al Mahmud & Martens, 2010; Boyd-Graber et al., 2006; Galliers et al., 2011; Moffatt et al., 2004; Tee et al., 2005). This consensus corresponds with aphasia's non-binary nature: an aphasic can have a small degree of aphasia (such as the participants involved in the MARTIN and NAM projects), requiring only small design adjustments, or an aphasic can be severely impaired (such as the participants involved in the aphasic workshop), and require major design adjustments.

The implication of this individual difference, is that that *H1 – Deep Customisability* – see chapter 3.4.2.1 – is reflected to some extent as a requirement for all other aspects of the design. For instance, H2 (Quiet Design – see chapter 3.4.2.2) suggests a minimal approach to the interface, with few UI elements present at any one time – just how minimal, depends on the needs of the aphasic individual. *H3 – Multi-Modality*; see chapter 3.4.2.3) suggests that a multi-modal approach should be used to convey information (i.e. use sound, images, and text together); but audible noise may not be appropriate for some aphasics; and so forth. For instance, in the workshop, it was uncovered that AP1 and AP2 had different opinions on the sizes, and design of the various buttons (see chapter 6.3.2.3).

This indicates that the usability heuristics presented in chapter 3.4.2, and those used for the heuristic evaluation in chapter 7.1.1 are all subject to customisation in order to accommodate the needs of the individual aphasic user. However, the notion of flexibility through such deep customisation, is nothing new, and is according to Don Norman (2013, p. 245) the ultimate solution:

> *"The best solution to the problem of designing for everyone is flexibility: flexibility in the size of the images on computer screens, in the sizes, heights, and angles of tables and chairs. Allow people to adjust their own seats, tables, and working devices. Allow them to adjust lighting, font size, and contrast. Flexibility on our highways might mean ensuring that there are alternative routes with different speed limits. Fixed solutions will invariably fail with some people; flexible solutions at least offer a chance for those with different needs."*

Since the consensus suggests that some degree of customisation is almost always necessary in order to accommodate the individual needs and requirements of the aphasic user, this makes a strong argument for involving the individual in the design process. Thus, even though the Sunnere app prototype generally fits the needs of AP1, and AP2, this proposes that customisation is necessary to accommodate other aphasic users.

7.1.3 Recap

I conducted a heuristic evaluation to put the Sunnere app prototype (P2) in the light of current research, and the result showed that there are overlaps between what aphasics have required in past design projects, and the Sunnere app prototype. The consensus regarding how to design for aphasic users, is that while there are some commonalities between what different aphasics need in a UI, there is almost always a need to tailor it to the particular needs of the individual aphasic user.

In enabling informed dietary decisions for aphasic users, it was paramount to make sure that the Sunnere app prototype had representations of nutritional information that its aphasic users could understand. The aphasic participants involved in the workshops indicated that they understood the nutritional representations presented by the Sunnere app prototype, even though they had slightly different needs. Thus, there is a strong argument for the involvement of the aphasic in the design process in order to secure a design that aligns with the needs and requirements of the aphasic user.

7.2 Designing with Aphasic Participants

This section revolves around discussion regarding the process:

> *RQ2: How does aphasia affect the individual's ability to contribute in the design process, and how can they be empowered in communicating their needs and requirements?*

Depending on its severity, aphasia affects various aspect of language, often to the degree where the aphasic is unable to follow the flow of 'normal' conversation. In some cases – like with global aphasia – the aphasic is left with severe impairment of all language modalities, and is left with very limited ways of communicating. An aphasic's instance of aphasia is often unique – a characteristic that translates to design requirements that can vary between individuals, as outlined in the chapter 7.1.2.3.

7.2.1 Uncovering Communication Strategies with Ethnography

The rationale for using ethnography as a background study for the design process, was primarily rooted in the biggest challenge in the MARTIN and NAM projects: inexperience in communicating with aphasics (see chapter 6.1.3). The need for experience in communicating with aphasics became clearer during the literature review, one reviewed case explicitly stated: "[t]he most difficult challenge in this work was communicating effectively with participants" (Moffatt et al., 2004, p. 413). Without effective communication, the ability to involve the participants in the design process may be hindered. Thus, the purpose of the ethnographic background study was for me to gain insight into how to communicate with aphasics, through observing interactions between SLPs and aphasic patients, and directly communicating with the aphasics – learning how to adapt my communication to fit the needs of each aphasic participant.

As a participant observer in the SunCIST therapy sessions (see chapter 6.2.1), and later in the acute one-on-one language therapy (see chapter 6.2.2), I gained first-hand experience in interacting with aphasics. In both scenarios, I intended to be a complete observer, but was involved by the SLPs in the therapy activities – which were very insightful experiences. I learnt that aphasics often develop compensatory communicative abilities to make up for being unable to communicate normally. This could be substituting words for a 'thumbs-up', or using a smartphone with images to convey a message. Sometimes, it is subtler, and requires knowledge about *how* the particular aphasic compensates for lacking communication. A story I was told about an aphasic individual by one of the SLPs, illustrates this point: imagine an aphasic individual that can only say the word 'yes' – even when he or she means 'no'. Information about this particular individual's ability to communicate, and the context surrounding him or her becomes all the more important in deciphering the intended meaning of the word 'yes' uttered in a particular situation.

I kept imagining a workshop situation in which I would ask an aphasic individual about whether or not he or she liked a particular feature of the Sunnere app prototype, and would misguidedly accept the individual's 'yes' as praise for the design – when maybe the aphasic meant 'no'. This example parallels the example of 'thick description' presented in chapter 5.1.1.1, and advocates the importance of contextual inquiry.

7.2.1.1 Strategies for Communication

During my interview with one of the SLPs, I was able to follow up on my observations, and gained insight into the SLPs strategies for communication with aphasics (see chapter 6.2.4). In the following section, I will present how these relate to my findings from the reviewed cases.

The SLP suggested that in communicating with an aphasic individual, it is important slowing down communication and conveying single messages at one time, combined with giving the aphasics enough time to communicate themselves, and reducing surrounding noise. These strategies were evident in a large number of the cases I reviewed (Al Mahmud & Martens, 2010; Boyd-Graber et al., 2006; Galliers et al., 2011; Moffatt et al., 2004).

The SLP revealed that abstract concepts are best avoided, an argument also made by Galliers et al. (Franklin et al. 1994; 1995; Tyler et al. 1995, as cited in Galliers et al., 2011, 2012). However, the SLP also revealed that in addition to concreteness, one should use high-frequency words, and/or high imageability words. It is generally accepted that *concrete words* are processed faster and more accurately by humans, than their *abstract* counterparts. In aphasic individuals, the efficacy of using concrete words over abstract ones – *the concreteness effect* – is amplified, both for the production and comprehension of words (see chapter 3.1.3).

The use of visual support through images was central to the SunCIST sessions, and the SLP suggested that images 'reach' all aphasics – a notion supported by a majority of the cases reviewed (Allen et al., 2007; Boyd-Graber et al., 2006; Koppenol et al., 2010; Moffatt et al., 2004; Tee et al., 2005). Thus, images can be useful in supporting communication.

However, the most important consideration in communicating with aphasics, according to the SLPs, was adapting communication to fit the needs of the individual – what is referred to as participant accommodation (see chapter 3.1.2).

From the ethnographic background study, I could conclude that when communicating with aphasics, conversation is not enough. In conveying information, it is critical to adapt to the needs of the individual, but general strategies include slowing down, single messages, visual support, and the use of concrete words and concepts – utilising the concreteness effect (see chapter 3.1.3). In interpreting information, observation becomes critical in revealing clues in body language as to what the intended meaning of a message is. In addition, knowing about the aphasic assessment of the individual (i.e. *how* their language is impaired), will help shape the understanding of how that particular individual communicates; an argument supported by Moffatt et al. (2004). The use of ethnography has been advocated in qualitative inquiry with aphasics due to the contextual dependency of communication (Kovarsky, 2014, pp. 55–60), but was absent as an explicit method from the past design cases reviewed as part of this research (see chapter 3.4).

From my experience, ethnographic inquiry was instrumental in gaining insight into how aphasia can affect the individual's ability to communicate in sometimes seemingly unpredictable ways, only to become evident through thick description. Central to PD, is creating a temporary community in which the participants can speak their own language – and I will argue that *correctly* interpreting their language is critical to this. Bratteteig et al. (2010, pp. 23–25) uses the *Sisom* project to argue that involving 'weak' participants in the PD process challenges true representation, because participant opinions may have to be represented and voiced by others – a challenge evident in the Sunnere app design process as well. This approach – participation by proxy – has been frequently adopted when involving aphasics directly in the design process (see chapter 3.4.1).

7.2.2 Direct Versus Proxy Participation

The purpose of using PD as an integral part of my design process, was to empower the voice of the 'weaker' aphasic users, and give them a say in the design decisions that eventually make up the design. Why use proxies? Can the real users *accurately* be represented by someone else? From an epistemologically constructivist and interpretivist stance, the answer is generally 'no' – the individual and their future use-practice can only be *truly and accurately* represented by him or herself (Bratteteig & Wagner, 2014, p. 29). However, as with the *Sisom* project (Bratteteig et al., 2010, pp. 23–25), this becomes complicated when representing oneself is a challenge, as is the case with aphasics.

The aphasic patients at Sunnaas Hospital represent the aphasics that are most severe – they are at Sunnaas Hospital for that particular reason; usually because they have recently acquired aphasia, or because they need rehabilitation (either physically, or linguistically). Either way, they represent a vulnerable group, and my primary concern was to protect them against unnecessary stress. The arguments for using proxies for vulnerable groups are ethically convincing: the SLPs provide access to the aphasic users through experiential and professional knowledge, all while protecting the real aphasic users – an issue that is absolutely paramount (see chapter 5.4.1). SLP proxies have been used successfully in a number of design cases as aphasic stand-ins, resulting in design that was representative of the real aphasic users, albeit often with minor adjustments (Allen et al., 2007; Boyd-Graber et al., 2006; Koppenol et al., 2010).

Contrariwise, Moffatt et al. (2004) and Galliers et al. (2011, 2012) argue for involving aphasic participants directly in the design process in order to ensure a design that truly aligns with the requirements and needs of the real aphasic users (opposed to an approximate design that participation by proxy yields). However, it is worth noting that in these cases, the aphasic participants involved directly in the design process were employed with the precondition that they were stable in terms of health and rehabilitation (Moffatt et al., 2004, p. 411), and were physically able and sufficiently independent to travel to and from the workshop from their homes (Galliers et al., 2011, p. 140, 2012, p. 53). The aphasic participants (AP1 and AP2) that participated in my workshop, did not demonstrate independence nor stability: recent victims of aphasia, AP1 had global aphasia, and AP2 was still in a vulnerable state.

Participation is multi-faceted: Bratteteig and Wagner (2014, pp. 30–31) suggest that participation through shared decision-making can manifest as several types of choices: creating, selecting, concretising, and evaluating design choices. The proxy workshop consisted of creating an approximate design (what ended up being P1) – a design that would *likely* accommodate varying degrees of aphasia, based on the knowledge and experience of the SLPs, mediated into the design process through my facilitation as a designer. This is based on Bratteteig and Wagner's (2014, p. 31) argument that "even with a process with limited – not 'full' – user participation can result in a design that increases the 'power to' of users. […]. On the other hand, a participatory result always depends on and refers to user participation in the process.".

Thus, since protecting the aphasic participants was my primary concern, I did not want to expose them to a workshop focused on 'clean slates' like with the SLP proxies, as such a setting would probably would be demanding and overwhelming for AP1 and AP2. Instead, I wanted to empower AP1 and AP2 in making design choices *within* the approximate and protected design space created by the SLP proxies and myself – and thus have their 'say' represented in the design through lower-effort and higher-impact choices.

The approximate and protected design space represents the SLP proxies' experiences and knowledge embodied into the design – what the SLPs *thought the aphasic users would need* from the Sunnere app (P1). Within this design space, there are certainly overlaps with *what the aphasic user* *actually needs*. However, there are also needs that cannot be represented by the SLP proxies. In Figure 7-4, I have illustrated the placement of P1 and P2 in the space of designs that are inappropriate, and possibly appropriate to the aphasic user:

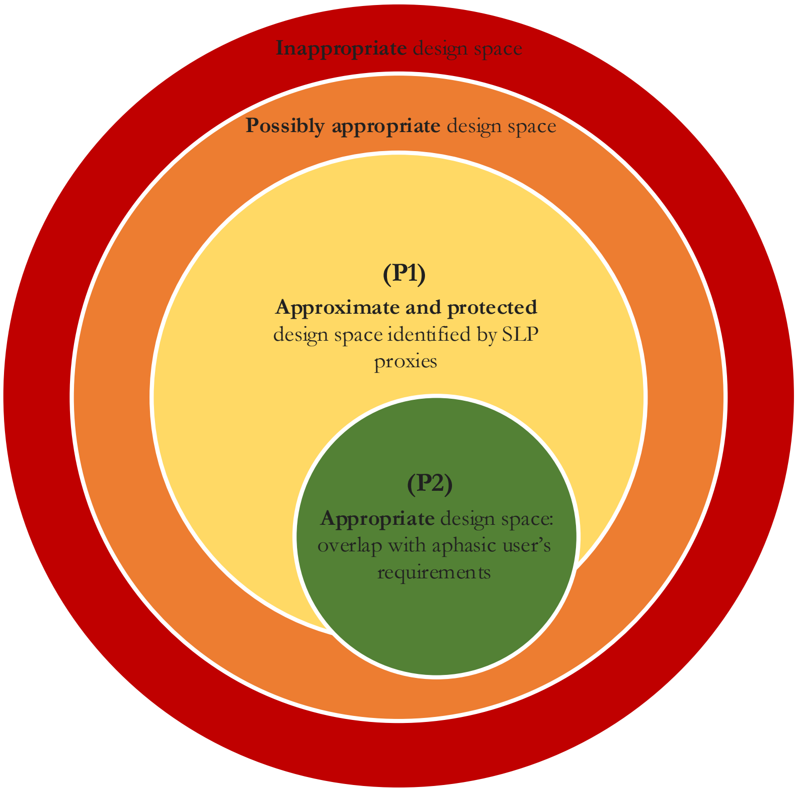


Figure 7-4 P1 and P2 represented in the design space of what is inappropriate and possibly appropriate.

Figure 7-4 attempts to illustrate that the P1 design represents 'broad strokes' of the design – design features that are rough and approximate, yet represents a design that is situated within what is possibly appropriate – based on the SLP proxies' experiences. P2 represents the adaption of the design – design features that are appropriate as identified *only* through involvement of the aphasic users in the design process. An important point to make, is that while there were overlaps between P1 and P2, there were design features that only could be revealed through involvement of the aphasic users in the design process (see chapter 7.1.2.1 and chapter 7.1.2.2)

The two different kinds of involvements that the workshops that resulted in P1 and P2 entailed, led to two different contributions and participations in the design process, and this is discussed in the next section.

7.2.3 Analysing Participation – Participation in *What?*

7.2.3.1 The Proxy Workshop

The SLPs were given 'clean slates' in the form of low-fidelity paper prototyping tools. The main scenarios were intended to act as language boundary objects (see chapter 4.2.1) between the requirements specification and the SLPs' knowledges and experiences about how these scenarios would play out in practice. The purpose was to engage in telling, making, and enacting – three activities central to the participatory mindset (see chapter 4.2.1). In the proxy workshop, the three SLPs engaged in different activities throughout the workshop.

SLP1 had a hands-on approach to the 'making' activity – the paper prototypes. SLP1 was independent in using the prototyping to concretise the ideas that were spoken around the table. SLP2 and SLP3 had stronger participation in the 'telling' and 'enacting' activities; by providing examples from their own experiences, and retelling them to both myself and the other SLPs. I engaged SLP2 and SLP3 in the 'making' activity whenever they had a good idea, or suggestion, by encouraging them to put the idea on paper – but they both preferred discussing the ideas, instead of engaging in the paper-prototyping activity (although they did on a few occasions). Thus, I assumed the role as a 'prototyper' together with SLP1, being supported by the ideas and discussions with SLP2 and SLP3.

In addition, my role consisted as both a 'technical advisor' to the ICT aspect, and as a facilitator for the design process. The former consisting of providing guidance in terms of what an app could and could not do. The latter consisted of informing the SLPs that the workshop was simply brainstorming, and that they should not discard any ideas as not relevant – a mindset I attempted to embody by frequently drawing down all ideas not matter how small, and discarding them by crumpling paper with mediocre ideas on it.

The SLPs had a seemingly well-functioning dynamic between them, being colleagues. They were not completely unfamiliar to who I was either – I had been engaged with all of them in my ethnographic background study. However, designing in groups is unpredictable. Before the workshop, I assumed that everyone would participate on an equal level – but people are different, both in experiences, creativity, and motivation to participate. Bratteteig and Stolterman (1997) use the metaphor of a musical *jazz group* to illustrate that the way in which various musical 'voices' must be coordinated in order to create good music, is similar to the way that a group of different individuals participate in the design process to create good designs. In addition, the jazz metaphor emphasises that predetermining the way in which the group interacts, is difficult. Even though the SLPs and myself adopted roles that were different – and unexpected on my own account, the outcome was positive, evident in the three design suggestions, and the elaborate discussions on what the Sunnere app prototype would have to be to accommodate various degrees of aphasia (see chapter 6.3.2.3). Even though SLP2 and SLP3 were hesitant in engaging with the paper prototyping, I believe that it was necessary to use this technique because it made the design process 'accessible' through direct manipulation (see chapter 5.3.2.1).

As a concluding remark, there is an important limitation to using the SLP proxies to create an approximate and protected design space within P1: upon being presented P1 in the usability workshop, the participants may have been, as Bratteteig and Wagner puts it in regards to the children in the *Sisom* project, "'seduced' into making and confirming certain choices [made by the designers]" (2014, p. 30).

7.2.3.2 The Aphasic Workshops

When aphasics are involved directly in the design process, the primary challenge for designers is effective communication with the aphasic participants (see chapter 3.4.1). Communication is not straightforward, and requires a certain degree of communicative adaptation to the aphasic at hand – what is known as participant accommodation (see chapter 3.1.2). In addition, aphasics usually require a lot of time, and fatigue easily.

Since I did not know who my aphasic participants were until the day, the aphasia workshop was planned so that it allowed a varying degree of participation; the usability kit (representing a low degree of participation), and the prototyping kit (representing a high degree of participation). This configuration of tools was grounded in Sanders and Stappers' (2008, pp. 12–14) proposed levels of creativity: they suggest that people are different in terms of how creative they are – more specifically, at what creative level they can contribute (doing, adapting, making, and creating) – and the higher levels return a greater degree of participation (see chapter 4.2.1). The static usability kit represented a level of 'doing' creativity – walking through the main scenarios of the Sunnere app, simply imagining its intended use. The modular prototyping kit represented the 'adapting' creativity level – the prototype was adapted to fit the needs of the particular user.

AP1 and AP2 were significantly more language impaired than the aphasic participants that were part of the evaluations for the MARTIN and NAM projects. Due to the high degree of language impairment in both AP1 and AP2, the participants were unable to use vocal communication in the two workshops, and so they were completed with the participants using body language as communication. AP1 was severely aphasic, and had extremely limited language and comprehension all around. AP2 had better comprehension, could understand phrases relatively well when read out loud, and reply with thumbs up and thumbs down. AP2, being younger than AP1, was notably quicker in responding to my questions than AP1. In the workshops with AP1 and AP2, their participation was limited to body language. However, it is central to PD that the participants can speak their own language as they are participating.

I planned the workshop to avoid the very real possibility that the aphasic participants would be unable to answer any of the questions: body language does not restrict an individual in smiling, frowning, pointing, nodding, shaking their head, or even drawing. Therefore, the questions I asked regarding the usability of the prototype, were questions that could be answered using body language (or the yes/no sheet). Observation of situations in which the participants indicated struggle with understanding the prototype was used as a central driver for when to ask questions, and when to use the prototyping kit to initiate participation.

In regards to the usability questions, asking the right questions is difficult – and so is asking them in the correct way. Directive questions are loaded with power relations, and imply that the questioner already knows the answer (for instance, 'how great do you think this button is? I think it's pretty great. I made it.'). Actively equalising power relations through democratic practices, is critical to the participatory mindset (see chapter 4.2.1). This is especially relevant when dealing with aphasic individuals that are unable to verbally communicate their disagreement, and are forced to accept something they disagree with (similar to the 'groupthink' phenomenon – see chapter 5.3.1.1). I took great care in asking questions that were not directive.

The usability kit and prototyping kit combination was successful in that it enabled the participants, together with myself, to identify things that were good about the interface, and things that were not good about the interface, and to be able to change these in an impromptu manner.

However, the paper prototyping approach had its limitations: during the workshop session with AP1, AP1 wanted to select a drink item that was an interaction I could not support with the interface cards I had at hand (i.e. I could not show AP1 the corresponding response to the selection of that drink using the interface cards). The paper prototype also proved to be limiting in the AP2 workshop session, when the participant and I were unable to find a design suggestion that AP2 was happy with – we ended up with a blank button; a useless design. In both workshop sessions, there were occasions where I fumbled with the interface cards because I had too many at hand, and could not find the 'next' card; a problem that is non-existent in using a higher fidelity prototype. The choice to use paper prototypes was a deliberate one, building on the restricting participatory experience using a high-fidelity Web application prototype in the evaluation of the NAM prototype, that was part of the pilot studies (see chapter 6.1.3).

7.2.4 A Pedagogical Mindset to Supplement Mutual Learning

In the previous section, I outlined that the SLP and aphasic participants represented different levels of communicative ability, and thus *what* they could participate in. Central to both levels of participation, however, is mutual learning. In PD, mutual learning is the process in which the designer teaches the user about the design process so that the user can contribute their needs and requirements *through* participating in the design process. During the workshops, the biggest challenge by far, was enabling the aphasic participants to partake in the designer role, and this is what I will discuss in the following section.

In discussing this challenge, I will use two theories central to pedagogy: Vygotsky's theory of the *zone of proximal development* (ZPD) presented in chapter 4.2.2, and Bruner's idea of instructional scaffolding presented in chapter 4.2.2.1. My rationale for using these related theories, is that the process in which PD emphasises *how* the user 'becomes' the designer through mutual trust (Bratteteig et al., 2013, p. 132), parallels any learning situation. The ZPD theory provides a frame in thinking about how someone in a learning situation can learn new skills through being supported by what Vygotsky calls a *more capable peer* (MCP) in tasks that are just out of reach of what the learner can do on his or her own. In the context of PD, addressing the ZPD, essentially addresses how the user can become what he or she not yet is – a co-designer.

My intention with the proxy workshop, was to create an approximate and protected design space by embodying the experiences and professional knowledge of the SLPs into the design of the first prototype (P1). Thus, the purpose of the approximate and protected design space incorporated in P1, was to represent something that the aphasic participants knew, or at the very least, could relate to – a situation that could be safe and comfortable with my facilitation in the design process.

Furthermore, it was intended that the aphasic participants could make adaptions to P1 based on their requirements, and thus be empowered as designers *within* the approximate and protected design space of P1.

As outlined by Bratteteig and Wagner (2014, pp. 30–31), participation is multi-faceted, and can manifest as different types of decisions throughout the design process (see chapter 7.2.3). The ZPD was important because it allowed me to think about these decisions, and what decisions the participants could partake in as contribution to the design process in a straightforward manner:

- What decisions could the aphasic participant make on their own?
- What decisions could the aphasic participant not make?
- What decisions could the aphasic participant make *with my guidance?*

The last point represents the range of tasks that Vygotsky's theory considers the ZPD, and thus the optimal spot in engaging the learner in learning something new with the help of the MCP. In the aphasic workshop, I assumed the role as a MCP in regards to the design process – facilitating the design process, providing scaffolds that allowed the aphasic participant to complete the design tasks that were in their ZPD. This is important because it aligns with co-realisation – another core perspective in PD (see chapter 4.2): it is the process in which the 'user' and 'designer' together *co-realise* the design. This was the purpose of the usability kit and the prototyping kit as described in chapter 6.3.2: allow the aphasic participants to assume the degree of participation they felt comfortable with – and in this role, supporting them in sharing their needs and requirements through the design process (this process is described in detail in chapters 6.3.2.1, and 6.3.2.2). In other words, it is the sum of the whole situation. In my experience as a participatory designer, I had to 'become' a scaffold.

A noteworthy example of how my scaffolds broke down in the workshop, was when AP2 indicated that AP2 did not understand one of the buttons, and I intended to use the prototyping kit together with AP2 to find a new representation for the button. As shown in Figure 7-5, the button ended up being blank:

Figure 7-5 The blank button – a result from scaffoldings 'breaking down'.

Put in the context of the ZPD, changing the button thus represented a design task that was out of reach for the participant – outside the participant's ZPD – leaving me unable to guide the participant through the task.

In my experience, scaffolds were complicated, because they were not any single effort. Scaffolds were a combination of how I met the aphasic patients as humans – with a respect for their loss and sorrow (see chapter 5.4.1); it was the way in which communication and engagement was adapted and paced to fit their needs through participant accommodation (see chapter 3.1.2) – both verbally and through body language; it was the support of varying degrees of participation through the usability and prototyping kit (see chapter 6.3.2); and it was the protection from 'full' participation, by using the SLP proxies to create an approximate and protected design space in which the aphasic participants could partake in making decisions that affected the design – through co-realisation. In addition, scaffolding entailed taking advantage of the efficacy of the concreteness effect for aphasics (see chapter 3.1.3), and by using boundary objects (see chapter 4.2.1) as a part of the design process: most notably the images of food and drink items taken at the cafeteria at Sunnaas Hospital (see chapter 6.3.1.1).

Instrumental to my interaction with the aphasic participants, was thinking about the ZPD in terms of what design decisions the participants could not make; what decisions they could make on their own; and what decisions they could make with guidance. This was important because it helped identify how to provide scaffolds. Thinking about how the user could 'become' the designer in the 'temporary community' (see chapter 4.2.1) of the workshop supports the mission of mutual learning in PD. The ZPD and scaffolding needs for each individual are different, and the ethnographic background study was influential in enabling me to understand what types of scaffolds aphasics would need – most importantly in uncovering strategies for communication (see chapter 7.2.1).

These pedagogical theories extended my repertoire in terms of thinking about and supplementing the mutual learning process that is integral to PD, something that was particularly important because the severe aphasics had limited opportunities to participate. By having a 'pedagogical mindset' and thinking about how I could support the participants as learners, and to be the best that they could be through optimal learning, I felt that I took responsibility as a participatory designer in giving the participants *a say* in the design of the prototype.

7.2.5 Recap

In the design of the Sunnere app prototype, I involved both SLP proxies, and severe aphasic participants directly in the process. These two types of participants contributed differently to the design: the SLP proxies completed the 'broad strokes' of the design, while the aphasic participants adapted the design to fit their own needs and requirements.

In supporting the aphasics in the workshop, I used communication strategies uncovered by the ethnographic background study as a central part of providing instructional scaffolds. However, my experience showed that scaffolds were the sum of my interaction with the aphasics. Thinking about how the aphasic participants could optimally learn about the design process with a 'pedagogical mindset', was instrumental in supplementing the mutual learning process that is at the heart of PD.

8 CONCLUSION

The purpose of this thesis, was to investigate the following research questions employing a Participatory Design (PD) approach, and using prototyping and qualitative methods for the inquiry:

> *RQ1: How can nutritional information be represented in a way that it is understandable by a wide range of aphasic users, thus enabling informed dietary decisions?*
>
> *RQ2: How does aphasia affect the individual's ability to contribute in the design process, and how can they be empowered in communicating their needs and requirements?*

This thesis and its research questions were motivated by Sunnaas Hospital's request for a digital food diary prototype – the Sunnere app – that could enable aphasic patients to make informed dietary decisions regarding the food and drink choices from the cafeteria at Sunnaas Hospital; a critical aspect of physical rehabilitation. Essential to enabling informed dietary decisions, is to visualise how nutritional information contained in food and drink items correspond to the patient's individual diet plan. Aphasia impairs the ability to produce and comprehend language in often unique ways, and can result in difficulties with filtering important information from noise.

Participation in the design process is crucial when designing for users that have aphasia, because the non-binary nature of the impairment translates to design requirements that can vary even for users that are seemingly similar. Paradoxically, aphasia complicates participation in the design process – especially with severe aphasics, since communicative ability is often reduced to a bare minimum. In past design cases where aphasics have been involved directly in the design process, they have generally shown a degree of language comprehension and independence. Speech-Language Pathologists (SLPs) have frequently been used as proxy users when the aphasics are unable to communicate themselves. In contrast, the aphasics at Sunnaas Hospital are usually there because they are in need of physical or linguistic rehabilitation and because of this, represent a vulnerable group of aphasics that are generally not independent in language comprehension.

Through involving both SLPs as proxy users, and severe aphasics directly, I have used participatory prototyping informed by ethnography as the main method for refining representations of nutritional information, using valuable groundwork from two pilot studies (P0). The SLPs were used to protect the severe aphasics from 'full' and taxing participation in the design process, and to complete the 'broad strokes' of the design (P1). The severe aphasic participants were then involved in adapting the design, and shaping it to fit their own requirements (P2) – a goal that yielded a prototype evidently different from its predecessor.

A heuristic evaluation was conducted, and revealed that there were overlaps between the design suggestions made in the Sunnere app prototype, and other similar design cases involving aphasic users. However, the high degree of uniqueness in the aphasic user makes a strong argument for direct involvement in the design process in order to secure a design that aligns with the needs and requirements of the individual. The implication of this, is that even though the Sunnere app prototype was understood by the aphasic participants involved in this study, it is likely that it would need customisation to fit other aphasic users.

The biggest challenge encountered in the design process, was empowering the aphasic participants as designers within the temporary community of the workshops. Much of the rationale for employing the PD approach, was rooted in its commitment to pulling the various power relations that exist in decision-making processes, into equilibrium. This challenge was particularly evident in the extreme differences in communicative ability between the aphasic participants and myself.

The mutual learning process in which the user becomes empowered as a co-designer within a temporary community of mutual trust, is central to PD: it enables the future user to communicate their needs and requirements *through* the design process. Decisive to enabling such participation for the severe aphasics involved in the workshops, was thinking about the mutual learning process with a pedagogical mindset. It was important because pedagogy addresses how to best achieve optimal learning – how can the learner best become what they not yet are? How can the user *best* become a co-designer?

Participation in the design process is multi-faceted, and can manifest as different types of choices. Thinking about these choices with a pedagogical mindset allowed me to identify what design decisions the aphasic participants could not make; what decisions they could make on their own; and what decisions they could make with my guidance. Furthermore, a pedagogical mindset supports the notion of instructional scaffolding – making sure that the tasks the participant is engaged in, are not too difficult – and not too easy. In my experience, scaffolding manifested as the totality of how I interacted with the severe aphasic participants; it was not reducible to any single effort. In addition, the ethnographic background study was instrumental in learning what scaffolds aphasics may need – especially in regards to communication strategies.

The unshakable reliance on communication to the design process offers a real challenge in involvement of severe aphasic participants. However, the successful engagement of the two severe aphasics in this study, suggests the usefulness of a pedagogical mindset for engaging in participation in the design process with an extended repertoire, supplementing the mutual learning process that is at the heart of PD; perhaps especially when dealing with users that have severe aphasia. However, the concern with involvement of someone that cannot communicate is: what have they participated in? Have the participants been 'seduced' into confirming certain choices already made by the designer?

By thinking about the most optimal way in which the user can learn about the design process, we take action towards giving the users a better chance at making their own choices in the design process. We have responsibility in learning about our users, and committing to teach them to become co-designers within the temporary communities in the design process – and support those that are have difficulties participating – something that in my experience was facilitated by having a pedagogical mindset, and *becoming* a scaffold.

8.1 Concluding Remarks

8.1.1 Towards Trustworthiness

In chapter 5.2 I outlined some strategies that can be used to work towards trustworthy qualitative research, and I will present three strategies that I have actively pursued: providing an audit trail; engaging in prolonged engagement in the research; and searching for disconfirming evidence and alternative explanations.

First, I will argue that the result of a PD process carried out in accordance with its guiding principles (see chapter 4.2), provides a foundation for arguing for transactional validity due to the active and equal involvement of the user in the design process. Although transactional validity is usually achieved through member checks and triangulation (see chapter 5.2), I will argue that the involvement of the future users in the design process offers transactional validity through different means in that the result is a product of the co-realisation process that is one of the core perspectives of PD.

However, the primary concern for trustworthiness, is situated in the involved severe aphasic participants' powerlessness to disagree with or argue against the research that I have presented on their own. Therefore, by providing an **audit trail** (i.e. a detailed account of the steps carried out as part of the research process) I hope to increase the trustworthiness of qualitative inquiry – and allow others to disagree on the behalf of the aphasic participants. I have paraphrased narrative of the workshops with aphasic participants; who are not themselves able to argue against anything that I have done (see chapter 6.3.2.1 and 6.3.2.2). Paraphrasing is arguably not the best way to provide an audit trail: in order to develop a stronger audit trail, the workshop should have been video recorded, or at the very least, audio recorded to provide a *verbatim* account of my questions and flow, and the participants' participations.

I have been fortunate enough to be involved in working with the development of the Sunnere app prototype in collaboration with Sunnaas Hospital through both the MARTIN and NAM projects, and in my thesis, in which I employed an invaluable ethnographic background study that provided instrumental insight (see chapter 6.2). Therefore, I feel I can confidently say that I have grounded this study in **prolonged engagement** to my best extent; continually learning about aphasia, and gaining insight into the reality of language that aphasics experience, over the course of two years.

Finally, I would like to point out that **searching for disconfirming evidence, and alternative explanations**, can be attributed to the heuristic evaluation (see chapter 7.1.1) – which was central in evaluating the Sunnere app prototype against the status quo of design cases that have been completed for aphasic users.

I hope that these measures will be acknowledged as steps *towards* the trustworthiness of my research and design process.

8.1.2 Limitations and Further Work

An important limitation that I would like to address – which is related to the role of the Sunnere app in implementing it as a tool for the patients and clinical staff – is one uncovered in the final aphasic workshop: I asked whether or not the participant would want to use the Sunnere app when it was completed. The participant simply shrugged in disinterest (see chapter 6.3.2.3). This addresses an important point that was cut from the requirements specification when I took the project on as my thesis: gamification as a motivational aspect as an integral part of the design (see chapter 2.1). Motivation would be critical in order for the Sunnere app to fulfil its role: if not used, the Sunnere app would have no value. Thus, implementing gamification (or something similar) as a motivational component of the design, would be a natural step forward.

The biggest limitation to the research and design work conducted in this thesis, is most likely the manner in which the aphasic participants were only involved in *one* workshop *once* – for a relatively short duration of time. The implication of this, is that getting into the flow of prototyping is difficult – and whether or not I have engaged the aphasic participants to their full creative potential, is arguable. Conversely, the short duration was both a result of the aphasic participants' tight schedules, but also a matter of protecting the participants as patients by not exposing them to overly taxing participation in the workshops. However, a series of short workshops with the same participant may have been beneficial in terms of engaging interest and motivation through better rapport, and would have perhaps revealed some different results as to what was presented in this thesis.

The way that I have approached this research from an interpretivist theoretical perspective, has implications for the generalisability of the results. The Sunnere app prototype was shaped only after the needs and requirements of the aphasic participants involved in the workshops: this suggests that in order to be usable by other aphasics, they should also be involved in the design process. However, even though there is almost always a need to customise a UI to fit the needs of the individual aphasic user, there are design guidelines that can accommodate more than one aphasic user. Thus, the most important work that lies ahead, is the involvement of more aphasics directly in the design of various ICT using PD supplemented by pedagogical approaches in order to uncover the landscape of design for and with aphasics.

As a final remark, I would like to address the nature in which aphasia affects language. It would be interesting to see how a design that accommodates the reduced language capabilities of aphasic users accommodates user groups with *undeveloped* language; for instance, children, or people with other communication impairments.

9 REFERENCE LIST

Allan, J., Kirkpatrick, A., & Henry, S. (2016, March 17). Accessibility Requirements for People with Low Vision. Retrieved March 26, 2016, from https://www.w3.org/TR/low-vision-needs/

Allen, M., McGrenere, J., & Purves, B. (2007). The Design and Field Evaluation of PhotoTalk: A Digital Image Communication Application for People. In *Proceedings of the 9th International ACM SIGACCESS Conference on Computers and Accessibility* (pp. 187–194). New York, NY, USA: ACM. http://doi.org/10.1145/1296843.1296876

Al Mahmud, A., & Martens, J.-B. (2010). Re-connect: Designing Accessible Email Communication Support for Persons with Aphasia. In *CHI '10 Extended Abstracts on Human Factors in Computing Systems* (pp. 3505–3510). New York, NY, USA: ACM. http://doi.org/10.1145/1753846.1754009

Balsamiq Studios LLC. (2016). Balsamiq. Rapid, effective and fun wireframing software. Retrieved March 4, 2016, from https://balsamiq.com/

Barnes, C. (1992). *Disabled People in Britain and Discrimination: A Case for Anti-discrimination Legislation*. London : Calgary, Alta: C Hurst & Co Publishers Ltd.

Becker, F. (2008). *Auditory perception and language comprehension in aphasia – An event-related brain potentials (ERP) study* (Doctoral thesis). University of Oslo. Retrieved from http://urn.nb.no/URN:NBN:no-21436

Benton, A. L., & Joynt, R. J. (1960). Early descriptions of aphasia. *Archives of Neurology*, *3*(2), 205–222. http://doi.org/10.1001/archneur.1960.00450020085012

Beukelman, D. R., Fager, S., Ball, L., & Dietz, A. (2007). AAC for adults with acquired neurological conditions: A review. *Augmentative and Alternative Communication*, *23*(3), 230–242. http://doi.org/10.1080/07434610701553668

Blomberg, J., & Karasti, H. (2013). Ethnography: Positioning ethnography within Participatory Design. In J. Simonsen & T. Robertson (Eds.), *Routledge International Handbook of Participatory Design* (Kindle Edition, pp. 86–116). New York: Routledge.

Bødker, M. (2009). Artifactual Relations in UCD, 4.

Borden, L. J. R., Katherine S. Harris Gloria J. (1993). *Speech Science Primer: Physiology, Acoustics, and Perception of Speech: 3rd (Third) edition*. Lippincott Williams & Wilkins.

Boyd-Graber, J. L., Nikolova, S. S., Moffatt, K. A., Kin, K. C., Lee, J. Y., Mackey, L. W., … Klawe, M. M. (2006). Participatory Design with Proxies: Developing a desktop-PDA System to Support People with Aphasia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 151–160). New York, NY, USA: ACM. http://doi.org/10.1145/1124772.1124797

Brandt, E., Binder, T., & Sanders, E. B.-N. (2013). Tools and techniques: Ways to engage telling, making and enacting. In J. Simonsen & T. Robertson (Eds.), *Routledge International Handbook of Participatory Design* (Kindle Edition, pp. 145–181). New York: Routledge.

Bratteteig, T., Bødker, K., Dittrich, Y., Holst Mogensen, P., & Simonsen, J. (2013). Methods: Organising principles and general guidelines for Participatory Design Projects. In T. Robertson (Ed.), *Routledge International Handbook of Participatory Design* (Kindle Edition, pp. 117–144). New York: Routledge.

Bratteteig, T., & Stolterman, E. (1997). Design in groups—and all that jazz. Retrieved from http://dl.acm.org/citation.cfm?id=270318.270329

Bratteteig, T., & Wagner, I. (2014). Design Decisions and the Sharing of Power in PD. In *Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium Papers, and Keynote Abstracts - Volume 2* (pp. 29–32). New York, NY, USA: ACM. http://doi.org/10.1145/2662155.2662192

Bratteteig, T., Wagner, I., Morrison, A., Stuedahl, D., & Mörtberg, C. (2010). Research Practices in Digital Design. In I. Wagner, T. Bratteteig, & D. Stuedahl (Eds.), *Exploring Digital Design* (pp. 17–54). Springer London. Retrieved from http://link.springer.com/chapter/10.1007/978-1-84996-223-0_2

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, *32*(7), 513–531. http://doi.org/10.1037/0003-066X.32.7.513

Caldwell, B., Cooper, M., Reid, L. G., Vanderheiden, G., Chisholm, W., Slatin, J., & White, J. (2008, November 11). Web Content Accessibility Guidelines (WCAG) 2.0. Retrieved April 23, 2015, from http://www.w3.org/TR/WCAG20/

Connell, B. R., Jones, M., Mace, R., Mueller, J., Mullick, A., Ostroff, E., … Vanderheiden, G. (1997). The Principles of Universal Design. Retrieved November 12, 2015, from https://www.ncsu.edu/ncsu/design/cud/about_ud/udprinciples.htm

Crang, M. A., & Cook, I. (2007). *Doing Ethnographies* (Kindle Edition). Los Angeles: SAGE Publications Ltd.

Crotty, M. (1998). *The Foundations of Social Research: Meaning and Perspective in the Research Process* (Kindle Edition). London ; Thousand Oaks, Calif: SAGE Publications Ltd.

Damico, J. S. (1988). The lack of efficacy in language therapy: A case study. *Language, Speech & Hearing Services in Schools*, (19), 51–66.

Dowling, M. (2008). Reflexivity. In L. Given, *The SAGE Encyclopedia of Qualitative Research Methods* (pp. 748–749). 2455 Teller Road, Thousand Oaks California 91320 United States: SAGE Publications, Inc. Retrieved from http://sk.sagepub.com/reference/research/n377.xml

Edwin Smith papyrus | Egyptian medical book. (n.d.). Retrieved March 8, 2015, from http://global.britannica.com/EBchecked/topic/179901/Edwin-Smith-papyrus

Eide, I., Li, Y., Simonsen, L., & Skårberg, J.-R. (2014). *MARTIN - Matregistrering på Sunnaas*. Universitetet i Oslo: Institutt for Informatikk. Retrieved from http://www.uio.no/studier/emner/matnat/ifi/INF2260/h14/presentations/MARTIN%20-MAt%20RegisTrerINg/martin---matregistrering-pa-sunnaas.html

Fetterman, D. M. (2008). Emic/Etic Distinction. In L. Given, *The SAGE Encyclopedia of Qualitative Research Methods* (p. 250). 2455 Teller Road, Thousand Oaks California 91320 United States: SAGE Publications, Inc. Retrieved from http://sk.sagepub.com/reference/research/n130.xml

Finkelstein, V., French, S., & Oliver, M. (1993). Towards a psychology of disability. In J. Swain (Ed.), *Disabling Barriers - Enabling Environments* (pp. 26–33). Sage.

FRCP, V. S. R. M. P. H. (Ed.). (2012). *Encyclopedia of Human Behavior, Second Edition, Volume 2* (2 edition, Vol. 2). Boston, MA: Academic Press.

Fuglehaug, W. (2015, March 13). 73-åring gikk ned 21 kilo på sykehuset, døde kort tid senere - Aftenposten. *Aftenposten*. Retrieved from http://www.aftenposten.no/nyheter/iriks/73-aring-gikk-ned-21-kilo-pa-sykehuset_-dode-kort-tid-senere-7930236.html

Galliers, J., Wilson, S., Muscroft, S., Marshall, J., Roper, A., Cocks, N., & Pring, T. (2011). Accessibility of 3D Game Environments for People with Aphasia: An Exploratory Study. In *The Proceedings of the 13th International ACM SIGACCESS Conference on Computers and Accessibility* (pp. 139–146). New York, NY, USA: ACM. http://doi.org/10.1145/2049536.2049562

Galliers, J., Wilson, S., Roper, A., Cocks, N., Marshall, J., Muscroft, S., & Pring, T. (2012). Words Are Not Enough: Empowering People with Aphasia in the Design Process. In *Proceedings of the 12th Participatory Design Conference: Research Papers - Volume 1* (pp. 51–60). New York, NY, USA: ACM. http://doi.org/10.1145/2347635.2347643

Geertz, C. (1973). Thick description: toward an interpretive theory of culture (pp. 3–30). New York: Basic Books.

Goggin, G., & Newell, C. (2007). The Business of Digital Disability. *The Information Society*, *23*(3), 159–168. http://doi.org/10.1080/01972240701323572

Goodglass, H. (1993). *Understanding Aphasia* (1 edition). Academic Press.

Goodglass, H., & Kaplan, E. (1972). *The Assessment of Aphasia and Related Disorders*. London: Henry Kimpton Publishers.

Gray, D. E. (2013). Theoretical Perspectives and Research Methodologies. In *Doing Research in the Real World* (Third Edition). London: SAGE Publications Ltd.

Hagoort, P. (1997). The shadows of lexical meaning in patients with semantic impairments. In P. Stemmer & H. Whitaker (Eds.), *Handbook of neurolinguistics* (pp. 235–248). New York: Academic Press.

Helsedirektoratet. (2012, January 10). Kosthåndboken: Veileder i ernæringsarbeid i helse- og omsorgstjenesten. Helsedirektoratet. Retrieved from https://helsedirektoratet.no/retningslinjer/kosthandboken-veileder-i-erneringsarbeid-i-helse-og-omsorgstjenesten

Helsedirektoratet, & Mattilsynet. (n.d.). Kostholdsplanleggeren. Retrieved December 5, 2015, from https://www.kostholdsplanleggeren.no/

Houde, S., & Hill, C. (1997). What Do Prototypes Prototype? Retrieved from http://hci.stanford.edu/courses/cs247/2012/readings/WhatDoPrototypesPrototype.pdf

Iacucci, G., Kuutti, K., & Ranta, M. (2000). On the Move with a Magic Thing: Role Playing in Concept Design of Mobile Services and Devices. In *Proceedings of the 3rd Conference on Designing Interactive Systems: Processes, Practices, Methods, and Techniques* (pp. 193–202). New York, NY, USA: ACM. http://doi.org/10.1145/347642.347715

Jessen, F., Heun, R., Erb, M., Granath, D.-O., Klose, U., Papassotiropoulos, A., & Grodd, W. (2000). The Concreteness Effect: Evidence for Dual Coding and Context Availability. *Brain and Language*, *74*(1), 103–112. http://doi.org/10.1006/brln.2000.2340

Jordan, L., & Kaiser, W. (1996). *Aphasia: A Social Approach* (1st edition). London ; New York : San Diego, Calif: Chapman & Hall.

Kensing, F., & Greenbaum, J. (2013). Heritage: Having a say. In J. Simonsen & T. Robertson (Eds.), *Routledge International Handbook of Participatory Design* (Kindle Edition, pp. 21–36). New York: Routledge.

Kirmess, M. (2010). *The Applicability and Outcome of Constraint Induced Language Therapy (CILT) in Early Aphasia Rehabilitation*. University of Oslo, Department of Special Needs Education. Retrieved from http://urn.nb.no/URN:NBN:no-27838

Koppenol, T., Mahmud, A. A., & Martens, J.-B. (2010). When Words Fall Short: Helping People with Aphasia to Express. In K. Miesenberger, J. Klaus, W. Zagler, & A. Karshmer (Eds.), *Computers Helping People with Special Needs* (pp. 45–48). Springer Berlin Heidelberg. Retrieved from http://link.springer.com/chapter/10.1007/978-3-642-14100-3_8

Kovarsky, D. (2014). The Ethnography of Communication Disorders Revisited. In M. J. Ball, N. Müller, & R. L. Nelson (Eds.), *Handbook of Qualitative Research in Communication Disorders* (pp. 55–78). New York: Psychology Press.

Lazar, J., Feng, J. H., & Hochheiser, H. (2010). *Research Methods in Human-Computer Interaction* (Kindle Edition). Chichester, West Sussex, U.K: Wiley.

Lindahl, A. K., & Saastad, E. (2015, March). Uønskede hendelser ved ernæring i sykehus. (M. Nylenna, Ed.). Nasjonalt kunnskapssenter for helsetjenesten. Retrieved from https://helsedirektoratet.no/publikasjoner/uonskede-hendelser-ved-ernering-i-sykehus

Löwgren, J., & Stolterman, E. (2007). *Thoughtful Interaction Design: A Design Perspective on Information Technology* (Kindle Edition). Cambridge, Mass.: The MIT Press.

Lundy, K. S. (2008). Prolonged Engagement. In L. Given, *The SAGE Encyclopedia of Qualitative Research Methods* (pp. 691–693). 2455 Teller Road, Thousand Oaks California 91320 United States: SAGE Publications, Inc. Retrieved from http://sk.sagepub.com/reference/research/n344.xml

Marshall, C., & Rossman, G. B. (2010). *Designing Qualitative Research* (5th edition). Los Angeles: SAGE Publications, Inc.

Maskery, H. (2007). Crossing the Digital Divide—Possibilities for Influencing the Private-Sector Business Case. *The Information Society*, *23*(3), 187–191. http://doi.org/10.1080/01972240701323614

Maslow, A. H. (1943). A Theory of Human Motivation. *Psychological Review*, (50), 370–396.

Matportalen, M. (2012, May 24). The Norwegian Food Composition Table [Text]. Retrieved December 5, 2015, from http://www.matportalen.no/verktoy/the_norwegian_food_composition_table/#tabs-1-1-anchor

Moffatt, K., McGrenere, J., Purves, B., & Klawe, M. (2004). The Participatory Design of a Sound and Image Enhanced Daily Planner for People with Aphasia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 407–414). New York, NY, USA: ACM. http://doi.org/10.1145/985692.985744

Myers, M. (1997, June). Qualitative Research in Information Systems. Retrieved May 13, 2015, from http://www.qual.auckland.ac.nz/

Newell, A. F., Gregor, P., Morgan, M., Pullin, G., & Macaulay, C. (2010). User-Sensitive Inclusive Design. *Universal Access in the Information Society*, *10*(3), 235–243. http://doi.org/10.1007/s10209-010-0203-y

NHS. (2015, February 2). Aphasia. Retrieved March 8, 2015, from http://www.nhs.uk/Conditions/Aphasia/Pages/Introduction.aspx

Nielsen, J. (1995, January 1). How to Conduct a Heuristic Evaluation. Retrieved April 23, 2015, from http://www.nngroup.com/articles/how-to-conduct-a-heuristic-evaluation/

Norman, D. (2013). *The Design of Everyday Things: Revised and Expanded Edition* (Kindle Revised Edition). New York, New York: Basic Books.

Paivio, A. (1986). *Mental representations: a dual coding approach*. New York : Oxford [Oxfordshire]: Oxford University Press ; Clarendon Press.

Pasientsikkerhetsprogrammet. (2015, October 13). Fire nye innsatsområder i programmet - Pasientsikkerhetsprogrammet, I trygge hender. Retrieved April 29, 2016, from http://www.pasientsikkerhetsprogrammet.no/no/I+trygge+hender/Nyheter/fire-nye-innsatsomr%C3%A5der-i-programmet

Pettersen, R., Halvorsen, B., Vangen, I., & Odincova, A. (2014). *Nutrition-Aware Meals (NAM)*. Universitetet i Oslo: Institutt for Informatikk. Retrieved from http://www.uio.no/studier/emner/matnat/ifi/INF2260/h14/presentations/Nutrition%20Aware%20Meals/index.html

Quan-Haase, A. (2012). *Technology and Society: Social Networks, Work, and Inequality*. Don Mills, Ont: Oxford University Press.

Robertson, T., & Simonsen, J. (2013). Participatory Design: An introduction. In *Routledge International Handbook of Participatory Design* (1 edition, pp. 1–17). New York: Routledge.

Robertson, T., & Wagner, I. (2013). Ethics: engagement, representation and politics-in-action. In J. Simonsen (Ed.), *Routledge International Handbook of Participatory Design* (1st ed., pp. 64–85). New York: Routledge.

Rodgers, B. L. (2008). Audit Trail. In L. Given, *The SAGE Encyclopedia of Qualitative Research Methods* (pp. 44–45). 2455 Teller Road, Thousand Oaks California 91320 United States: SAGE Publications, Inc. Retrieved from http://sk.sagepub.com/reference/research/n25.xml

Rothbauer, P. M. (2008). Triangulation. In L. Given, *The SAGE Encyclopedia of Qualitative Research Methods* (pp. 893–895). 2455 Teller Road, Thousand Oaks California 91320 United States: SAGE Publications, Inc. Retrieved from http://sk.sagepub.com/reference/research/n468.xml

Sæland, M. (2015, March 22). Sykehuskokken er like viktig som kirurgen for pasientens fremtidsutsikter. *Aftenposten*. Retrieved from http://www.aftenposten.no/meninger/debatt/Sykehuskokken-er-like-viktig-som-kirurgen-for-pasientens-fremtidsutsikter-7951499.html

Saffer, D. (2008, December 4). The Disciplines of User Experience. Retrieved from http://www.kickerstudio.com/2008/12/the-disciplines-of-user-experience/

Sandelowski, M. (2008). Member Check. In L. Given, *The SAGE Encyclopedia of Qualitative Research Methods* (pp. 502–503). 2455 Teller Road, Thousand Oaks California 91320 United States: SAGE Publications, Inc. Retrieved from http://sk.sagepub.com/reference/research/n257.xml

Sanders, E. B.-N. (2002). From User-Centered to Participatory Design Approaches. In *Design and the Social Sciences: Making Connections* (pp. 1–9). London: Taylor & Francis.

Sanders, E. B.-N., & Stappers, P. J. (2008). Co-creation and the new landscapes of design. *CoDesign*, *4*(1), 5–18. http://doi.org/10.1080/15710880701875068

Schreiber, J. B. (2008). Pilot Study. In L. Given, *The SAGE Encyclopedia of Qualitative Research Methods* (pp. 625–627). 2455 Teller Road, Thousand Oaks California 91320 United States: SAGE Publications, Inc. Retrieved from http://sk.sagepub.com/reference/research/n320.xml

Speech & Language Pathologist at Sunnaas Hospital. (2015, September 28). Interview regarding job role, therapy, and personal experience with aphasia.

Star, S. L., & Griesemer, J. R. (1989). Institutional Ecology, “Translations” and Boundary Objects: Amateurs and Professionals in Berkeley’s Museum of Vertebrate Zoology, 1907-39. *Social Studies of Science*, *19*(3), 387–420.

Stienstra, D., Watzke, J., & Birch, G. E. (2007). A Three-Way Dance: The Global Public Good and Accessibility in Information Technologies. *The Information Society*, *23*(3), 149–158. http://doi.org/10.1080/01972240701323564

Stratton, R. J., Green, C. J., & Elia, M. (2003). *Disease-related malnutrition: an evidence-based approach to treatment*. Wallingford, UK ; Cambridge, MA: CABI Pub.

Suchman, L. A. (1987). *Plans and Situated Actions: The Problem of Human-Machine Communication* (2 edition). Cambridge Cambridgeshire ; New York: Cambridge University Press.

Sunnaas sykehus HF. (2015, September 1). About Sunnaas Rehabilitation Hospital. Retrieved April 16, 2015, from http://www.sunnaas.no/om-oss/english

Tee, K., Moffatt, K., Findlater, L., MacGregor, E., McGrenere, J., Purves, B., & Fels, S. S. (2005). A Visual Recipe Book for Persons with Language Impairments. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 501–510). New York, NY, USA: ACM. http://doi.org/10.1145/1054972.1055042

The British Association for Parenteral and Enteral Nutrition. (2016, March 7). The “MUST” Toolkit. Retrieved April 22, 2016, from http://www.bapen.org.uk/screening-and-must/must/must-toolkit/the-must-itself

The Center for Universal Design. (n.d.). About the Center - Ronald L. Mace. Retrieved February 28, 2016, from https://www.ncsu.edu/www/ncsu/design/sod5/cud/about_us/usronmace.htm

Thi Nguyen, T. S. (2008). Peer Debriefing. In L. Given, *The SAGE Encyclopedia of Qualitative Research Methods* (p. 605). 2455 Teller Road, Thousand Oaks California 91320 United States: SAGE Publications, Inc. Retrieved from http://sk.sagepub.com/reference/research/n312.xml

Tilsyn for universell utforming av IKT. (n.d.). Krav og regelverk | uu.difi.no. Retrieved November 14, 2015, from https://uu.difi.no/krav-og-regelverk

van de Sandt-Koenderman, W. M. E. (2011). Aphasia rehabilitation and the role of computer technology: Can we keep up with modern times? *International Journal of Speech-Language Pathology*, *13*(1), 21–27. http://doi.org/10.3109/17549507.2010.502973

Vygotsky, L. S. (1978). *Mind in Society: The Development of Higher Psychological Processes*. (M. Cole, V. John-Steiner, S. Scribner, & E. Souberman, Eds.) (Revised ed. edition). Cambridge: Harvard University Press.

Wertsch, J. V. (1985). *Vygotsky and the social formation of mind*. Cambridge, Mass.: Harvard University Press.

Westerveld, J. (2012, December 1). - Min far sovnet ikke stille inn, han tørstet og sultet ihjel. *Aftenposten*. Retrieved from http://www.aftenposten.no/nyheter/iriks/-Min-far-sovnet-ikke-stille-inn_-han-torstet-og-sultet-ihjel-6739876.html

Wood, D., Bruner, J. S., & Ross, G. (1976). The Role of Tutoring in Problem Solving*. *Journal of Child Psychology and Psychiatry*, *17*(2), 89–100. http://doi.org/10.1111/j.1469-7610.1976.tb00381.x

World Health Organization. (1980). International Classification of Impairments, Disabilities and Handicaps. Geneva.

Wright, H. H., & Shisler, R. J. (2005). Working Memory in Aphasia: Theory, Measures, and Clinical Implications. *American Journal of Speech-Language Pathology*, *14*(2), 107. http://doi.org/10.1044/1058-0360(2005/012)

10 BIBLIOGRAPHY

Booth, W. C., Colomb, G. G., & Williams, J. M. (2008). The Craft of Research, Third Edition (3 edition). Chicago: University Of Chicago Press.

Robinson, S., & Sodderland, L. (2016). My Beautiful Broken Brain.

Sørensen, C. (1995). This is not an article: just some food for thought on how to write one (Vol. 782(EN)). Risø National Laboratory.

Bill, M., & Gimmi, K. (2010). Form, Function, Beauty = Gestalt. (P. Johnston, Ed., C. Barrett, Trans.). Architectural Association Publications.

11 LIST OF FIGURES

12 LIST OF TABLES

13 ABBREVIATIONS

Abbreviation	**Definition**
AAC	Augmentative and Alternative Communication
AP1-AP3	Aphasic participant one, two, and three
CILT	Constraint-Induced Language Therapy
CIT	Constraint-Induced Therapy
DCT	Dual Coding Theory
FCT	Food Composition Table
HCD	Human-Centred Design
HCI	Human-Computer Interaction
ICT	Information and Communications Technology
IxD	Interaction Design
P0-P2	Prototype zero, one, and two
PD	Participatory Design
PDA	Personal Digital Assistant
RQ	Research Question
SCN1-SCN3	Scenario one, two, and three
SLP	Speech-Language Pathologist
UCD	User-Centred Design
UD	Universal Design
UI	User Interface
UX	User Experience
W3C	World Wide Web Consortium
WAI	Web Accessibility Initiative
WCAG	Web Content Accessibility Guidelines
WHO	World Health Organization
ZPD	Zone of Proximal Development

14 APPENDICES

Note that some of the transcripts are provided in Norwegian not to alter their meanings through translation.

Appendix A. Initial Requirements Specification from Sunnaas Hospital

Kravspesifikasjon

"Ernæringsapp for pasienter med kognitive vansker"

Beskrivelse av løsningen

Løsningen ("appen") skal gi brukeren mulighet til å velge matvarer fra en liste/oversikt og kombinere disse til et måltid. Når en matvare legges til måltidet, skal appen vise hvor mye av dagsbehovet til brukeren de enkelte næringsstoffene (inkludert kcal) i matvaren utgjør. Den skal indikere hvilke næringsstoffer måltidet - kombinert med tidligere måltider den dagen - brukeren får i seg for lite av, og hvilken han/hun får i seg for mye av.

Det skal være en funksjon/knapp som lar brukeren fortelle appen at måltidet er spist. Dette skal trigge et belønningssystem, som på en underholdende måte gir brukeren en tilbakemelding på i hvilken grad brukeren har vært "flink" og fulgt kostholdsplanen. Dette skal fungere som et slags belønningssystem, og skal virke motiverende for bruk av appen.

Næringsverdien i hver matvare hentes fra en tabell som ligger inne i app'en. Hvor mye av hvert enkelt næringsstoff som er anbefalt for brukeren legges inn i en fil på enheten (f.eks. i et minnekort på et nettbrett), og appen leser informasjonen fra denne filen. En logg over brukerens matinntak skrives til fil, som kan hentes ut av helsepersonell for videre analyse.

Appens brukergrensesnitt skal være utformet for brukere med alvorlige kognitive vansker. Dette innebærer at hele grensesnittdesignet må utformes i etter retningslinjer fra kvalifisert klinisk personell på Sunnaas.

Inndata/utdata

Appen skal lese en datafil med verdier spesifikt for brukeren (brukerverdier). Denne har følgende verdier:

- Anbefalte minimums- og maksimumverdier for næringsstoffer for bruker:

Se matvaretabellen http://matvaretabellen.no/
OG Anbefalinger om kosthold og ernæring og fysisk aktivitet
http://www.helsedirektoratet.no/publikasjoner/anbefalinger-om-kosthold-ernering-og-fysisk-aktivitet/Publikasjoner/anbefalinger-om-kosthold-ernering-og-fysisk-aktivitet.pdf
Her finnes spesifikke og generelle anbefalte verdier for daglig inntak av alle næringsstoffer til befolkningen, delt inn etter alder- kjønn og livssituasjon.
Appen tar utgangspunkt i disse generelle anbefalingene, men har muligheter for å legge inn faktorer som påvirker næringsstoffbehovet (større eller mindre behov).

- ID-nr (se Personvernkrav)

Appen skal skrive en loggfil som viser alle måltider bruker har spist, på formatet:

```
<ID-nr>

Måltid: <Dato><tid>
<ingerdiens 1><mengde><kcal><næringsstoffer...>
<ingerdiens 1><mengde><kcal><næringsstoffer...>
<...>

Måltid: <Dato><tid>
<ingerdiens 1><mengde><kcal><næringsstoffer...>
<ingerdiens 1><mengde><kcal><næringsstoffer...>
<...>
```

Tekniske krav

- Løsningen i denne spesifikasjonen er for aktivt innhold som startes av en annen app, og kan kjøres på Android, iOS og web.
- Løsningen skal tilpasses bruk på nettbrett med 8" skjerm, men skal også kunne brukes på skjermer fra 4" og oppover.

Personvernkrav

Før enheten med appen gis til brukeren, skal helsepersonell legge inn en brukerverdifil, med et identifikasjonsnr. Dette nummeret er et helt anonymt løpenummer, som ikke på noen måte skal kunne knyttes til brukerens egentlige identitet. I bruk inneholder derfor ikke appen noen måte å identifisere brukeren på. Først etter enheten leveres tilbake, når data fra logg hentes ut og legges inn i pasientbehandlingssystem av helsepersonell, vil det foretas en knytning av data mot brukererens identitet.

Appendix B. Revised Requirements Specification for the Sunnere App

Kravspesifikasjon

"Ernæringsapp for pasienter med kognitive vansker"

Beskrivelse av løsningen

Løsningen ("appen") skal gi brukeren mulighet til å velge matvarer fra en liste/oversikt og kombinere disse til et måltid. Når en matvare legges til måltidet, skal appen vise hvor mye av dagsbehovet til brukeren de enkelte næringsstoffene (inkludert kcal) i matvaren utgjør. Den skal indikere hvilke næringsstoffer måltidet - kombinert med tidligere måltider den dagen - brukeren får i seg for lite av, og hvilken han/hun får i seg for mye av.

Det skal være en funksjon/knapp som lar brukeren fortelle appen at måltidet er spist. Dette skal videre gi brukeren en tilbakemelding på i hvilken grad brukeren har vært "flink" og fulgt kostholdsplanen.

Næringsverdien i hver matvare hentes fra en tabell som hentes fra en database over internett. Hvor mye av hvert enkelt næringsstoff som er anbefalt for brukeren legges inn i en database som henters over internett, og appen leser informasjonen fra denne filen. En logg over brukerens matinntak skrives til en database over internett, som kan hentes ut av helsepersonell for videre analyse.

Appens brukergrensesnitt skal være utformet for brukere med alvorlige kognitive vansker. Dette innebærer at hele grensesnittdesignet må utformes i etter retningslinjer fra kvalifisert klinisk personell på Sunnaas.

Appen trenger ikke å være produksjonsklar, men skal være en prototype som kan brukes til å evaluere nyttigheten til appen som et verktøy for relevante pasientene og klinisk personell.

Inndata/utdata

Appen skal lese brukerverdier fra en database over internett. Denne har følgende verdier:

- Anbefalte minimums- og maksimumsverdier for næringsstoffer for bruker:

Se matvaretabellen http://matvaretabellen.no/
OG Anbefalinger om kosthold og ernæring og fysisk aktivitet
http://www.helsedirektoratet.no/publikasjoner/anbefalinger-om-kosthold-ernering-og-fysisk-aktivitet/Publikasjoner/anbefalinger-om-kosthold-ernering-og-fysisk-aktivitet.pdf
Her finnes spesifikke og generelle anbefalte verdier for daglig inntak av alle næringsstoffer til befolkningen, delt inn etter alder- kjønn og livssituasjon.
Appen tar utgangspunkt i disse generelle anbefalingene, men har muligheter for å legge inn faktorer som påvirker næringsstoffbehovet (større eller mindre behov).

- ID-nr (se Personvernkrav)

Appen skal skrive en loggfil som viser alle måltider bruker har spist, på formatet:

```
<ID-nr>

Måltid: <Dato><tid>
<ingrediens 1><mengde><kcal><næringsstoffer...>
<ingrediens 1><mengde><kcal><næringsstoffer...>
```

```
<...>

Måltid: <Dato><tid>
<ingrediens 1><mengde><kcal><næringsstoffer...>
<ingrediens 1><mengde><kcal><næringsstoffer...>
<...>
```

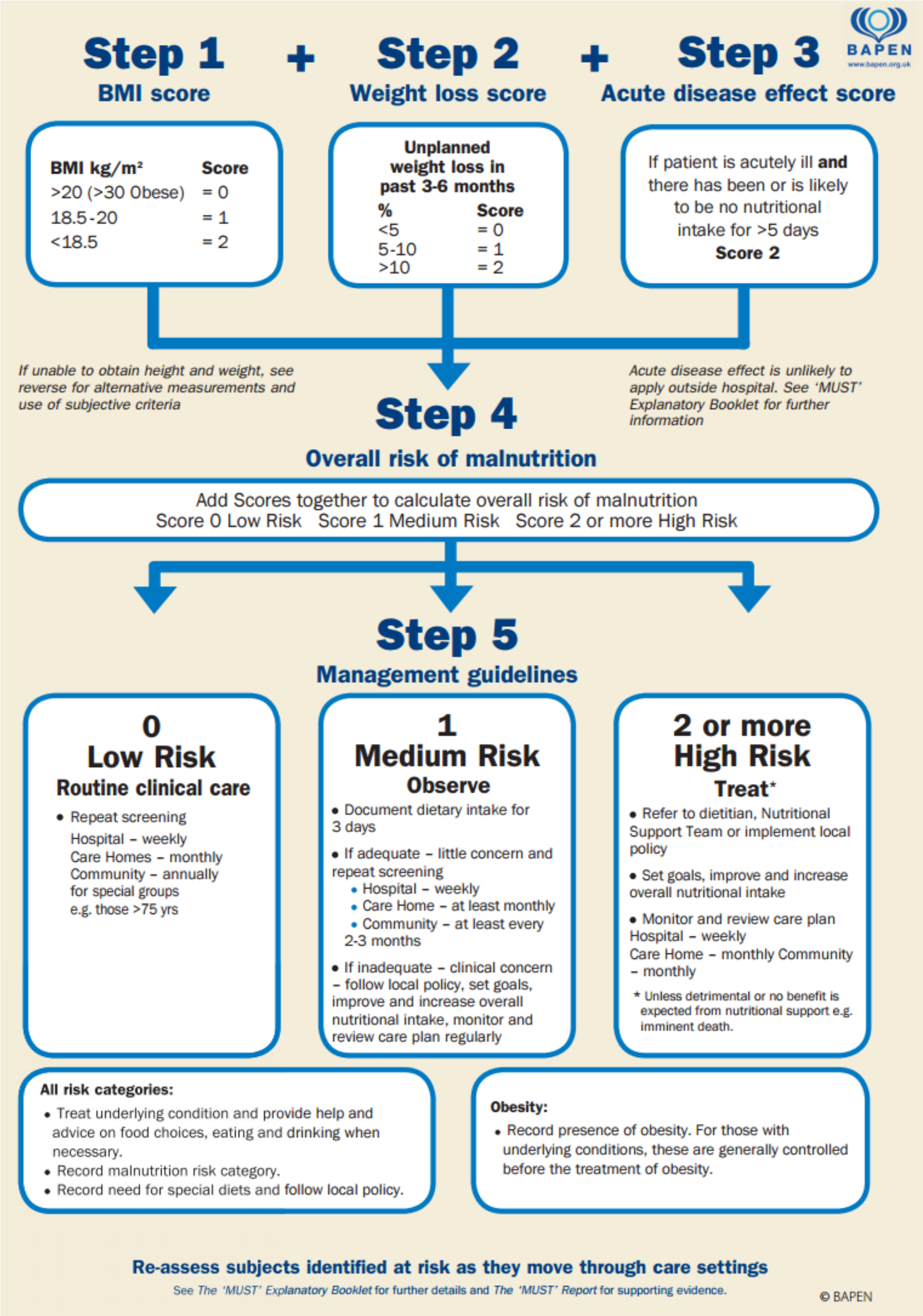
Tekniske krav

- Løsningen i denne spesifikasjonen kan kjøres på Android, iOS og web.
- Løsningen skal tilpasses bruk på nettbrett med 8" skjerm, men skal også kunne brukes på skjermer fra 4" og oppover.

Personvernkrav

Før enheten med appen gis til brukeren, skal helsepersonell legge inn et identifikasjonsnummer som lagres i en database. Dette nummeret er et helt anonymt løpenummer, som ikke på noen måte skal kunne knyttes til brukerens egentlige identitet. I bruk inneholder derfor ikke appen noen måte å identifisere brukeren på. Først ved kobling av identifikasjonsnummer og en koblingsliste som ikke ligger i appen, vil identifikasjon være mulig.

Appendix C. Malnutrition Universal Screening Tool (MUST) Steps



Step 1 + **Step 2** + **Step 3**

BMI score | **Weight loss score** | **Acute disease effect score**

BMI kg/m²	**Score**
>20 (>30 Obese)	= 0
18.5-20	= 1
<18.5	= 2

Unplanned weight loss in past 3-6 months

%	**Score**
<5	= 0
5-10	= 1
>10	= 2

If patient is acutely ill **and** there has been or is likely to be no nutritional intake for >5 days
Score 2

If unable to obtain height and weight, see reverse for alternative measurements and use of subjective criteria

Acute disease effect is unlikely to apply outside hospital. See 'MUST' Explanatory Booklet for further information

Step 4

Overall risk of malnutrition

Add Scores together to calculate overall risk of malnutrition
Score 0 Low Risk   Score 1 Medium Risk   Score 2 or more High Risk

Step 5

Management guidelines

0
Low Risk
Routine clinical care

- Repeat screening
  Hospital – weekly
  Care Homes – monthly
  Community – annually
  for special groups
  e.g. those >75 yrs

1
Medium Risk
Observe

- Document dietary intake for 3 days
- If adequate – little concern and repeat screening
  - Hospital – weekly
  - Care Home – at least monthly
  - Community – at least every 2-3 months
- If inadequate – clinical concern – follow local policy, set goals, improve and increase overall nutritional intake, monitor and review care plan regularly

2 or more
High Risk
Treat*

- Refer to dietitian, Nutritional Support Team or implement local policy
- Set goals, improve and increase overall nutritional intake
- Monitor and review care plan
  Hospital – weekly
  Care Home – monthly Community – monthly

* Unless detrimental or no benefit is expected from nutritional support e.g. imminent death.

All risk categories:

- Treat underlying condition and provide help and advice on food choices, eating and drinking when necessary.
- Record malnutrition risk category.
- Record need for special diets and follow local policy.

Obesity:

- Record presence of obesity. For those with underlying conditions, these are generally controlled before the treatment of obesity.

Re-assess subjects identified at risk as they move through care settings

See *The 'MUST' Explanatory Booklet* for further details and *The 'MUST' Report* for supporting evidence.

© BAPEN

Figure 14-1 The Malnutrition Universal Screening Tool (MUST) Steps (The British Association for Parenteral and Enteral Nutrition, 2016).

Appendix D. Interview with Speech-Language Pathologist

Transcript

[Robin]: «Kan du fortelle kort om hva CIST er?»

[Logoped]: «Det er en veldig spesifisert metode for bedring av talespråk. Det fokuserer utelukkende på den modaliteten av språket. Med basis i tanken at det man skal bli bedre på, må man også trene på. Dette med hjernerns plastisitet er også en av teoriene der; at hjernen trenger stadige 'push' på det den skal bli bedre på. Constraint-Induced har basis i ergo/fysioterapi. Hvis du har lammet høyre arm, vil man begrense den friske, slik at du må bruke den svake. På samme måten er tanken i språk at egentlig ønsker man totalkommunikasjon i generell logopedi; tegn der du ikke kan si, bruk apper [kart etc.], men i CIST er ikke dette lov fordi her vil man pushe på med tale tale tale. En spesifikk metodikk som utelukker alt annet.
Nå vi ikke dette si at dette er noe man vil oppfordre til i en hverdag ellers, men for å få massiv trening i en periode på akkurat det man strever med, så er det dette en metodikk på det. Så den innebærer også da elementet intensitivitet som går på at man da flere timer hver dag innenfor en gitt periode, også innebærer det logopeden som er med på å forme og fasiliteter på den enkelte pasient sitt nivå slik at der som det er en dårlig fungerende gruppe som bare er på ett-ordsnivå, så begynner man der, men etterhvert også fasiliterer og hjelper opp på neste nivå. Det er i tillegg et gruppetreningsopplegg, så det er en litt mer reell setting enn én til én.»

[Robin]: «Har dere brukt noen andre typer opplegg tidligere?»

[Logoped]: «Ja, det er veldig mange ulike type metodikker, men vi tenker hele tiden funksjonell kommunikasjon. Det er ikke et poeng å bli god til noe vis-a-vis en logoped ved et skrivebord. Poenget er jo hva er livet til personen, og hva trenger personen hjemme i samtale med sin ektefelle, så vi gjør jo alltid en bred kartlegging, og da vil språklige være et element av det. Kan du produsere ord? Kan du skrive ord? Kan du forstå hva jeg sier? Men også den helheten med hvem var du før? Hvilke interesser har du? Skal du tilbake i jobb - i så fall hvilken jobb? Men det er klart, at innenfor dette er det mange metodikker for å trene ordmobilisering, for hvordan skal du forstå, også videre.»

[Robin]: [Babler om at jeg forstår, og snakker litt om masteroppgaven, også at jeg forstår at det ikke er likt for noen. Dette speiler jo da også rehabiliteringen.]

[Logoped]: «Det var en kollega av meg som sa 'Har du møtt én person med afasi, ja da har du møtt én person med afasi', fordi de er så forskjellige. Det gjelder ikke akkurat bare språkvansker, men også rammen rundt; konteksten rundt personen. Så er det også det med afasien ikke bare rammer individet, men også de som skal samhandle med personen. Pårørendeundervisning er en viktig ting. Hvordan skal man snakke sammen? Litt tips i forhold til det. CIST er bare en av mange måter å jobber på. Jeg har også vært med på å ha en del språkgrupper som gjør en del andre ting en CIST. Da er det mer som er lov av omfattende bruk; da vil man kanskje oppfordre til det stikk motsatte: beskriv et ord ved å gjøre hva du vil; tegn det, mim det, bruk litt ord, bruk litt handling. Det vil være det motsatte egentlig. Det er en metodikk, for eksempel som heter PACE: Promoting Aphasics Communicative Ability, og det vil være nesten en form for fantasibrettspill hvor man bruker hele den totale kommunikasjon for å formidle noe. En annen metodikk vil for en velfungerende gruppe, ta i tak i en nyhetsartikkel, den ene leser høy, resten av gruppen diskuterer, lage litt spørsmål.»

[Robin]: «Ja, mange metodikker.»

[Logoped]: **«**Dette vil variere på nivå, og pasientens egen motivasjon. Dette kan man jo også drøfte i gruppen.»

[Robin]: «Bruker dere noen digitale verktøy i disse metodikkene i det hele tatt?»

[Logoped]: «I CIST, nei. Nettopp fordi er det er talespråk som utelukkende som skal repeteres og fokuseres på. Men i annen mer funksjonell metodikk vil jeg si ja. Du la merke til den ene pasienten som på eget initiativ som drar opp mobilen sin for å forklare hvor [pasienten] hadde vært da [pasienten] fikk slaget sitt. Så [pasienten] bruker det [pasienten] har tilgjengelig for å vise noe.»

[Robin]: **«**Det høres ut for meg som at det er potensiale for digitale verktøy som telefon.»

[Logoped]: «Ja, men samtidig må det også sies at kanskje for noen, kan det bli enda et problem de ikke mestrer. Men det kommer an på så mange ting. Det kommer ann på førfunksjon; operasjonell kompetanse kalles vel det. Alder kanskje, er man litt eldre er det kanskje vanskelig å lære noe nytt. Også kognitiv funksjon ellers, konsentrasjonsvansker, igangsettingsvansker, nedsatt motivasjon, alt spiller inn. Og du så sikkert på han at han strevde - det tok tid - han ville helt sikkert gjort det raskere før. Dette kan skape frustrasjon, eller det kan være motiverende. Uansett er det mange ting å kartlegge. Men digitale verktøy … Vi bruker et språkstreningsprogram her som heter Lexia (*sp?*) som vil integrere i en typisk én til én logoped-klient setting, som vil hjelpe skriving, mobilisering.»

[Robin]: «Så det er på en måte en setningsbygger hvor man kan bygge setninger basert på for eksempel bilder?»

[Logoped]: «Ja, både bilder og tekst som kan graderes i forhold til et nivå, også kan man også lage et egentreningsoppgavesett på. Velge ut en del oppgaver som er tilpasset pasienten. Men det er jo språktreningsverktøy, ikke et kommunikasjonsverktøy, da. Men ellers er jo stadig flere som kommer med en iPad, mobiltelefon, eller noe, og tar det opp og bruker det.»

[Robin]: «Ja, slik jeg forsto det, så var alle de jeg snakket med eier av en eller annen iPad, mobil eller laptop. Det virker som det er en viss teknisk forståelse blant pasientene?»

[Logoped]: «Ja. Men så var det en på gruppen som vi hadde nettopp som bare hadde begynt å legge bort telefonen, for [pasienten] 'orket ikke det det', eller kjøper seg en enklere variant, som disse 'Doro' telefonene med bare det absolutt mest nødvendige. Mens en annen i gruppa, måtte jeg gjentatte ganger si 'kan du legge bort den der nå?', da [pasienten] satt og surfet fra tid til annen. Så vi er ulike alle. Fysisk funksjon kan også spille en begrensing. Veldig mange av de som har afasi har også høyresidelammelse; og hvis dette er dominant hånd må de kanskje lære seg å swipe og trykke med en andre hånden; finmotoriske aspekter. Veldig ofte er det komplekst da afasi ikke kommer alene.»

[Robin]: «Jeg har lest en del om disse klassiske båsene; Broca og Wernicke, men du har nevnt at dere har deres egen variant her på Sunnaas som er skreddersydd som er dynamisk?»

[Logoped]: «Ja, men jeg vet ikke om jeg vil bruke [dynamisk]. Dette er nok ikke bare på Sunnaas, men at man har gått bort litt generelt i typisk Boston model fordi det ikke er entydig. Det er vanskelig å sette akkurat i bås, og det speiler heller ikke virkeligheten så mye. Det er vanligere nå å tenke litt mer psykolingusitisk; litt mer i forhold til beksrive den reelle språklige fungeringen da… Hvordan er tilgang til ord? Hvordan er talehastighet? Hvordan er forståelsen? Også derfra beskrive helt konkret hva man kartlegger sånn sett. Det finnes noen modeller; [viser modell], som går bort ifra å si at skaden har skjedd på *dette* området i hjernen, men heller en type flowchart. [Hvert steg av flowcharten evalueres, og man evaluerer videre hvilken sideeffekt dette har for neste steg.] Slik det er med kartleggingen i dag, så er den eneste standardiserte kartleggingenprøven vi har, norsk grunntest for afasi, den er basert på Boston modellen. Så den bruker vi fortsatt. Det kommer nok til å endre seg om ikke så lenge. Men etter denne testen, som er ganske grovmasket, går vi videre da vi trenger å vite mer. Da går vi over på modeller som er litt mer språklige. Så finner vi ut av at det, for eksempel, viser seg at pasienten blander mye meninger i ord mye ord, som forveksle kopp og glass, og da må vi kikke litt mer på det semantiske systemet. Så finnes det et stort antall tester som foreslår hva man kan kikke på, for eksempel PALPA, som sier 'hvis dette, eksaminer dette'.»

[Robin]: «Dette kommer litt innpå et annet spørsmål her; i de klassiske modellene så er det inndelt i fluent og non-fluent, og det var det intrykket jeg fikk av de to gruppene også; an en av dem var veldig ettordsbasert, mens den andre var veldig mye, bruke feil ord etc. Brukes disse inndelingene fortsatt?»

[Logoped]: «Det gjør de nok. Det vil være to av flere andre 'symptomer'. Man kan også snakke om typisk semantiske forvekslinger som er sånn kopp/glass. Fonologiske vansker; plutselig kommer en *koff*. Dette er vansker med lydsystemer i språket. Så kommer det også an på forståelse. Men flytende og ikke flytende er en foretrukket måte å si, framfor den klassiske ekspressiv versus impressiv fordi det er, etter min mening, er litt av begge deler uansett. Mens en ikke-flytende og flytende kan inneholde dette også. Det er ikke bar én måte å klassifisere på. For å trekke litt tilbake på det jeg sa i sta også, den Boston modellen, over til den psykolinguistiske, men også at man oppholder seg i den sosiale kartleggingen; nå, i en mye større grad enn før, tenker man på hele mennesket, og kartlegger også omgivelser, interesser, hvem var du før. Kanskje ikke noe poeng å trene mye på å lese hvis du hater å lese; litt av disse tingene.»

[Robin]: «Dette høres veldig fornuftig ut… Og er i opposisjon til den klassiske approachen med at 'skaden har skjedd her i hjernen'.»

[Logoped]: «Mm. For dette betyr ikke så mye for mennesket. Dette resulterer i at det blir ulike måter å trene på. Det er viktig å trene språk; OK, hva er forskjellen på kopp og glass? Men, OK, er denne pasienten en kelner eller kokk, er dette kanskje en ramme man kan sette dette inn i i tillegg som gjør det mer 'aksessibel' for pasienten. Det å sitte her å trene på kopp og glass har egentlig ingen mening, men mindre man trekker det litt videre.»

[Robin]: «Du snakket litt om høy- og lavfrekvente ord. Hva mener du med dette?»

[Logoped]: «Det er litt vanskelig å forklare; men alt vi har lært av ord…tilegnelse i forskjellige kulturer… Hvordan vi bruker det til daglig har mye å si på hvordan vi henter fram ord, og hvor kjapt vi gjør det. Slik at ord som er høyfrekvente for deg, på grunn av dine interesser, er kanskje ikke høyfrekvente for meg! Så det varierer! Men innenfor en kultur så vil det være noen ord som er høyfrekvente for både deg og meg. Forresten, når jeg tenkte på dette, kom jeg også over dette [viser en artikkel]. Hva er høyfrekvente og lavfrekvente ord *på norsk?* Det er ikke gjort så mye studier rundt dette… Men [presenterer forskning gjort rundt dette, ref materiale gitt]. Det er en forskningsgruppe i anvendt lingvistikk på Blindern som har laget en database med disse ordene som man kan søke opp.»

[Robin]: «Dette er kult! Jeg tenker, sånn, i for eksempel et design, så er det kanskje greit å bruke høyfrekvente ord som et utgangspunkt hvis man skal bruke tekst. Dette er jo kjempekult om dette er en database som er åpen…»

[Logoped]: «Ja, den er åpen… Den ligger på… [viser i brosjyren]. De deler opp i høyfrekvent/lavfrekvent…men det er andre kategorier også, som for eksempel billedlighet; en beskrivelse for et konkret objekt, som strømpebukse. For eksempel ordet ærlig, har ikke høy billedlighet.»

[Robin]: «Dette er jo stilig for et design…når man skal presentere ord, kan man basere dette på denne databasen, slik at høyfrekvente ord brukes som basis, men at man, når pasienten blir bedre, bruker flere lavfrekvente ord.»

[Logoped]: «Mm. Ja, det er basert på 1600 ord, hvis jeg husker riktig.»

[Robin]: «Takk for det. Det skal jeg se videre på!»

[Logoped]: «Vi har også en evaluering som en del av CIST oppholdet for å finne ut om ordene vi bruker er representative; ‘synes du ordutvalget var aktuelle begrepsområder for deg?’. Da får de en mulighet til å si ifra ‘nei, det var banalt, etc.’. For eksempel, vi hadde en kokk i sist gruppe, hvor lavfrekvente ord i matkategorien var høyfrekvente for han. Dette kartleggingsbatteriet er likt for alle. I CIST har vi ikke tid til denne omkringkartleggingen med det sosiale - dette vil vanligvis komme utenom. Men disse som kommer på CIST er jo kronikere. CIST er kanskje litt sært med tanke på helhetlig logopedibehandling.»

[Robin]: «Gjør dere en slik evaluering for å forbedre fordelingen av høy/lavfrekvente ord for neste pasient, eller er det bare for historie for den ene pasienten?»

[Logoped]: «Det er for å, sammen med avdelingen, se på hvordan de har opplevd oppholdet, og hva vi kan gjøre bedre neste gang.»

[Robin]: «Det ble brukt en del bilder under [SunCIST] oppholdet: er det noen spesifikke karakteristikker på disse bildene?»

[Logoped]: «Det er ikke noe sånn, CIST-sett, som sier at det er *dette* bildematerialet som brukes. Egentlig kan alle typer bilder brukes.»

[Robin]: «Det er greit å vite at alle bilder kan brukes. Kanskje andre ting som motorisk svikt i øyet vil spille en større rolle i hvilke bilder som velges?»

[Logoped]: «Ja, da vil det være logopedens rolle å definere nivået slik at en lavere fungerende bare vil få oppgave å si [her går logopeden inn i ‘pedagogikkmodus’ og snakker veldig sakte]*:* ‘[Logoped] . har du hatt ‘; og kanskje ikke ta hensyn til at det er en rød hatt med en sløyfe som henger halvveis ned til ryggen. Mens en bedre fungerende vil oppfordres til å bruke mer beskrivelse, og ta hensyn til mer som er på bildene.»

[Robin]: «Ja, jeg la merke til dette i kortspillet vi spilte, at bildene var ofte ganske små og utydlige.»

[Logoped]: «Ja, det er jeg enig i. Det bildene er nødvendigvis ikke gode. Det ble bare sånn fordi [en annen logoped] brukte de slik i sin doktorgradavhandling. Men vi bruker også andre bilder enn de; jeg vet ikke om du kjenner color cards?»

[Robin]: «Ja, [en annen logoped] brukte de i den individuelle logopedtimen…og her er det jo store, fine bilder.»

[Logoped]: «Noen av de i boksen er greie, men noen er litt sånn vanskelige å definere… Men det kan også være litt av diskusjonen! At vi sammen drøfter hva det er på bildet, at jeg sier 'jeg syntes det ser ut som en…', mens pasienten sier 'men jeg syntes det ser ut som…'. Så lenge det finnes dubletter, så kan egentlig alt brukes av bildemateriell. Men ja, jeg er helt enig med poenget ditt, det beste er om bildemateriellet er visuelt sett klart, for det er jo en del av det komplekse også for mange pasienter fordi noen også har synsvansker.»

[Robin]: «Sånn jeg forstår det er bilder en veldig fin vei til en felles forståelse for språk; at det kanskje går gjennom en annen kanal. Så bilder brukes til alle pasienter?»

[Logoped]: «Ja. Det vil det gjøre. Men det avhenger jo også av … Det man helst også ønsker å kartlegge ved et bilde er tilgangen til leksikon på et vis da. Men da… Det er ulike veier inn [viser til psykolinguistisk flowchart - sier at det er ulike veier inn], og der har man fått en visuell vei. Men du vil også måtte kartlegge de andre veiene… Se et ord, høre et ord. For å kartlegge benevning/beskrivelse, istedet for å vise deg et bilde av f.eks. en paraply, og si 'Kan du si meg hva dette er?', så vil jeg kanskje si 'Kan du fortelle meg hva man bruker for å beskytte seg når det regner?'.»

[Robin]: «Så dette går på semantikken da?»

[Logoped]: «Ja, dette vil være en semantisk oppgave. På en måte leksikon av ord… Det kan nok også tenkes at man i CIST også vil bruke skrevne ord for bedre fungerende. Det har ikke jeg gjort ennå da. Det tror jeg det står litt om i [en annen logoped] sin artikkel.»

[Robin]: «Supert. Jeg har noen få spørsmål om pasienter og apper, og du har egentlig svart på dette med at pasienter ofte bruker det som er tilgjengelig; for eksempel [den] ene pasienten som brukte Google maps. Så dette kommer an på hvem du var før osv. Har du noe mer å si på dette?»

[Logoped]: «Nei, egentlig ikke, det er ikke jobbet så veldig mye med dette. Men jeg fant dette [viser til dokumentet på eksempler av apper som en forskningsgruppe har prøvd ut på afatikere]. Men de også skriver også om dette med vanlige ting, og hvordan ta i bruk, fasilitere, og forenkle vanlige strukturer. For eksempel, sånne templates for å skrive tekstmeldinger; forhåndsprogrammerte setninger som de enkelt kan sende.»

[Robin]: «Det er kjempefint å lese om dette da jeg skal gjøre mye av det samme selv…»

[Logoped]: «Men dette er nok mer klinisk og ikke forskningsmessig artikkel, altså.»

[Robin]: «Det tror jeg er helt greit. Men det er fin informasjon uansett.»

[Logoped]: «Jeg har dessverre ikke så mye erfaring når det gjelder apper, men når det gjelder alternativ og supplerende kommunikasjon [AAC], så har det vært prøvd ut en del på afasirammede med varierende hell. Men det måtte på en måte vært presisert, obs obs, ta hensyn til kriterier som førfunksjon/operasjonell kompetanse, språkfunksjon, at en viss form for språkforståelse må de ha for å skjønne hva som skjer, og ikke for mange andre kognitive vansker i tillegg. Selvfølgelig også en egen drive og en motivasjon da. Så dette, som du også er opptatt av da, at det skal være enkelt visuelt, og dette med, som jeg også er helt enig med deg i, gjerne bilde, og tekst og mulighet for lyd. Fordi de fleste afasirammede har lesevansker, men likevel stor nytte av støtte i skrift. Ikke nødvendigvis en paragraf, liksom, men enten en enkel setning, eller et helord. Har du også lyd inn, har du fått det fra flere modaliteter som støtter hverandre. Man kunne også sikkert velge til hvilken grad man *ikke* skulle bruke det for noen.»

[Robin]: «Og det er jo dette som er drømmen i en app, å kunne skreddersy det til en pasient. Du har egentlig svart veldig bra på de resterende spørsmålene nå…»

[Logoped]: «Det var forsåvidt også noe med synsvansker; pasienter som har fått slag ikke bare har *redusert visus*; det finnes ulike typer, for eksempel hemianopsi for eksempel, som vil si at man på en måte ikke har redusert syn på venstre øye, men at synsfeltet er *borte*. Du har også pasienter som kan ha… det er mer en oppmerksomhetsvanske, som heter neglekt. Det er derfor viktig å ha sånne ting i mente også. Kanskje vil det ikke være egnet hvis pasienten ikke ser halve skjermen. Såpass konkret vil dette være; at en pasient ikke vil se denne kolonnen, etc, eller vil se den, men ikke annerkjenne den i oppmerksomheten.»

[Robin]: «Ja, jeg husker dette ble nevnt i sammenheng med måltider også; at pasienter bare spiste halve måltidet…»

[Logoped]: «Ja. Dette er også livsfarlig i trafikken; bare det å gå på fortauet blir livsfarlig.
Jeg tenkte også litt på dette med graderbarhet; dette kan være en tanke, at man presenterer ulike varianter basert på språkfunksjon.»

[Robin]: «Ja, dette er mulig. Det er det jeg ønsker å få til; et type progressivt design. Som blir bedre med pasienten. Eller at man bare har mulighet til å justere.»

[Logoped]: «Som du vet, ryddig skjerm, enkel kontekst. Jo! Vi snakket om dette med totalkommunikasjon; skal de selv kunne skrive, eller er dette bare ting som skal velges?»

[Robin]: «La oss si pasienten skal søke opp en rett de har spist for å registrere at de har spist det i dag. I dag, en slik søkeprosess er ganske komplisert, selv for de som har full funksjonalitet [her er logopeden entusiastisk enig], for man er jo ikke alltid sikker på hva man skal søke på. Sånn jeg hadde sett for meg hadde det vært best å hatt et bildesøk så man kan bruke både bilde og tekst. Først brede kategorier (e.g. grønnsaker), og at man da graver seg ned, og finner det man leter etter.»

[Logoped]: «Da er sikkert lurt med noe prediksjon for de som kan skrive litt.»

[Robin]: «Jepp!»

[Logoped]: «Så lurte jeg på muligheten for å tegne! La oss si de ville formidle en banan.»

[Robin]: «Ja…?»

[Logoped]: «De med stor afasi bruker jo ofte dette. Ved hjelp av tegning, vil dette også noen ganger fasilitere deres egen måte å si hele ordet på.»

[Robin]: «[Jeg forklarer kombinasjonen å bruke bilder for å velge en kategori, og deretter bruke prediction for å finne ting under denne kategorien som begynner på f.eks b] Det er jo en viktig del av kostregistrering, det å kunne søke seg frem til det man har spist.»

[Logoped]: «Ja.»

[Robin]: «Ok, da har jeg ikke flere spørsmål. Takk så mye for tiden din.»

[Logoped]: «Bare hyggelig.»

Appendix E. Consent Form for Aphasic Participants

OpenDyslexic 3 Font

Samtykke

Mål

Jeg er student. Jeg lager en app for afasi. Den skal hjelpe deg å velge mat. Og være dagbok for mat. Din mening er viktig.

Hva skal du gjøre?

Jeg viser deg papir modell av appen. Spørre deg om hva du synes. Vi kan endre på papir modellen sammen.

Bruk

Jeg skriver hva du synes i en oppgave. Jeg skriver om din afasi. Jeg må lese om din afasi. Dette er sensitivt.

Jeg skriver ikke hvem du er. Oppgaven kan leses av alle.

Vil du være med?

Navn, dato

Regular Font

Samtykke

Mål

Jeg er student. Jeg lager en app for afasi. Den skal hjelpe deg å velge mat. Og være dagbok for mat. Din mening er viktig.

Hva skal du gjøre?

Jeg viser deg papir modell av appen. Spørre deg om hva du synes. Vi kan endre på papir modellen sammen.

Bruk

Jeg skriver hva du synes i en oppgave. Jeg skriver om din afasi. Jeg må lese om din afasi. Dette er sensitivt. Jeg skriver ikke hvem du er. Oppgaven kan leses av alle.

Vil du være med?

____

Navn, dato

Appendix F. Sunnere App Prototype Evolution

The evolution of the prototypes is shown **horizontally** in chronological order from left to right, while alternative designs are represented **vertically**. The images of the prototypes are displayed sequentially for a rough illustration of how the prototypes evolved – larger images of the prototypes can be found in the respective chapters for P0 (see chapter 6.1.4), P1 (see chapter 6.3.1.1), and P2 (see chapter 6.3.2.3).

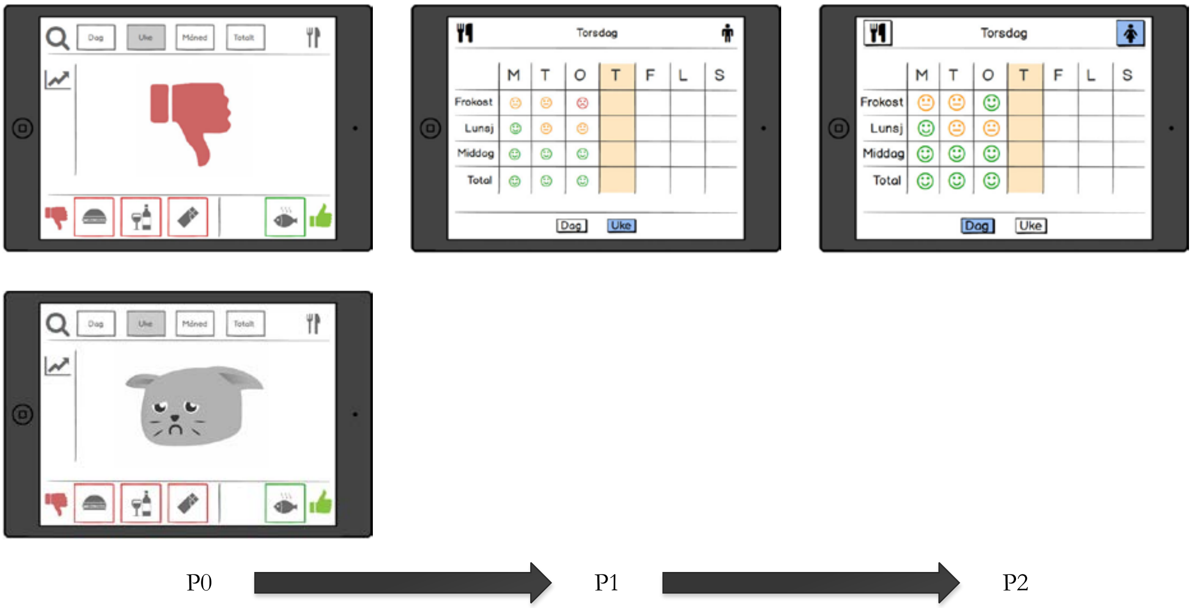


Figure 14-2 Prototype evolution: weekly diet record using a calendar grid layout.

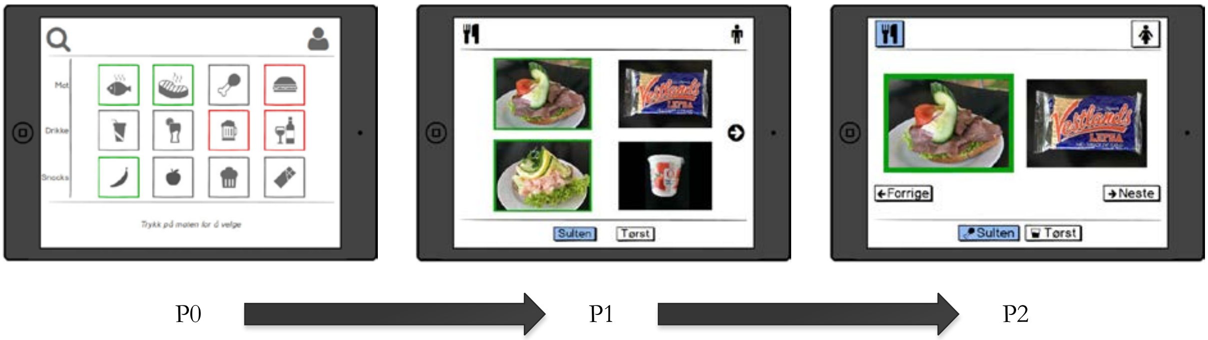


Figure 14-3 Prototype evolution: cafeteria menu showing food items.

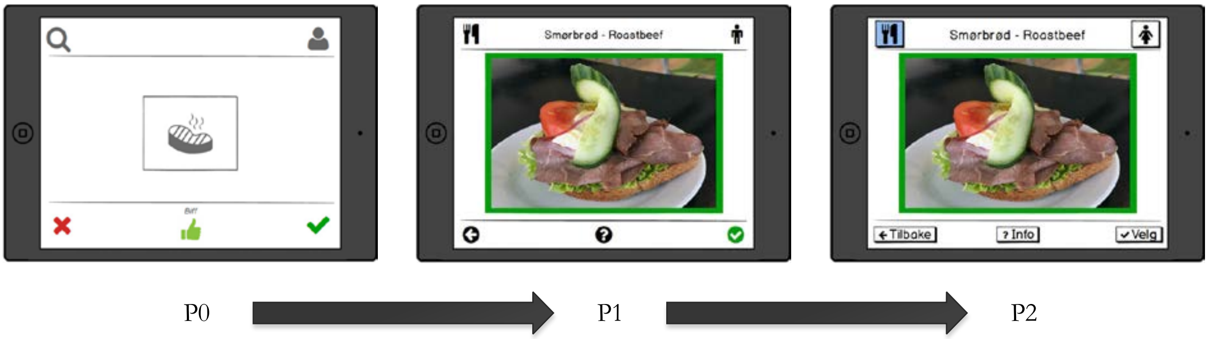


Figure 14-4 Prototype evolution: cafeteria menu – magnified view.

Figure 14-5 Prototype evolution: daily diet record feedback using a smiley feedback model.

Figure 14-6 Prototype evolution: daily diet record with feedback on individual nutritional values using a smiley feedback model. Showing both horizontal and vertical representation alternatives.

Figure 14-7 Prototype evolution: detailed view of nutritional values in food item.

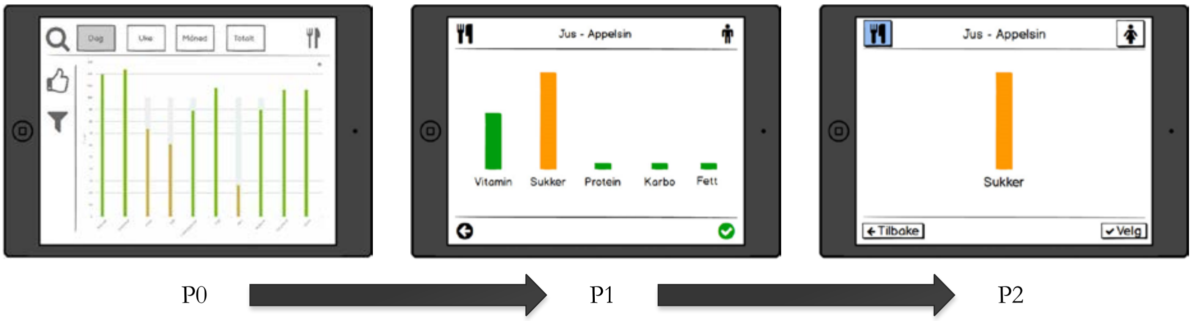


Figure 14-8 Prototype evolution: direct data visualisation as a bar chart.

Appendix G. English Translation of 'Grønnsakspisersang'

If you eat sausages and meat all day,
you will feel slothful, lazy and fat.
If you eat carrots, crispbreads and ginger nuts,
redcurrants and blackcurrants and swede and parsley.
You will feel light and happy all day,
and you will feel like you cannot stand still.