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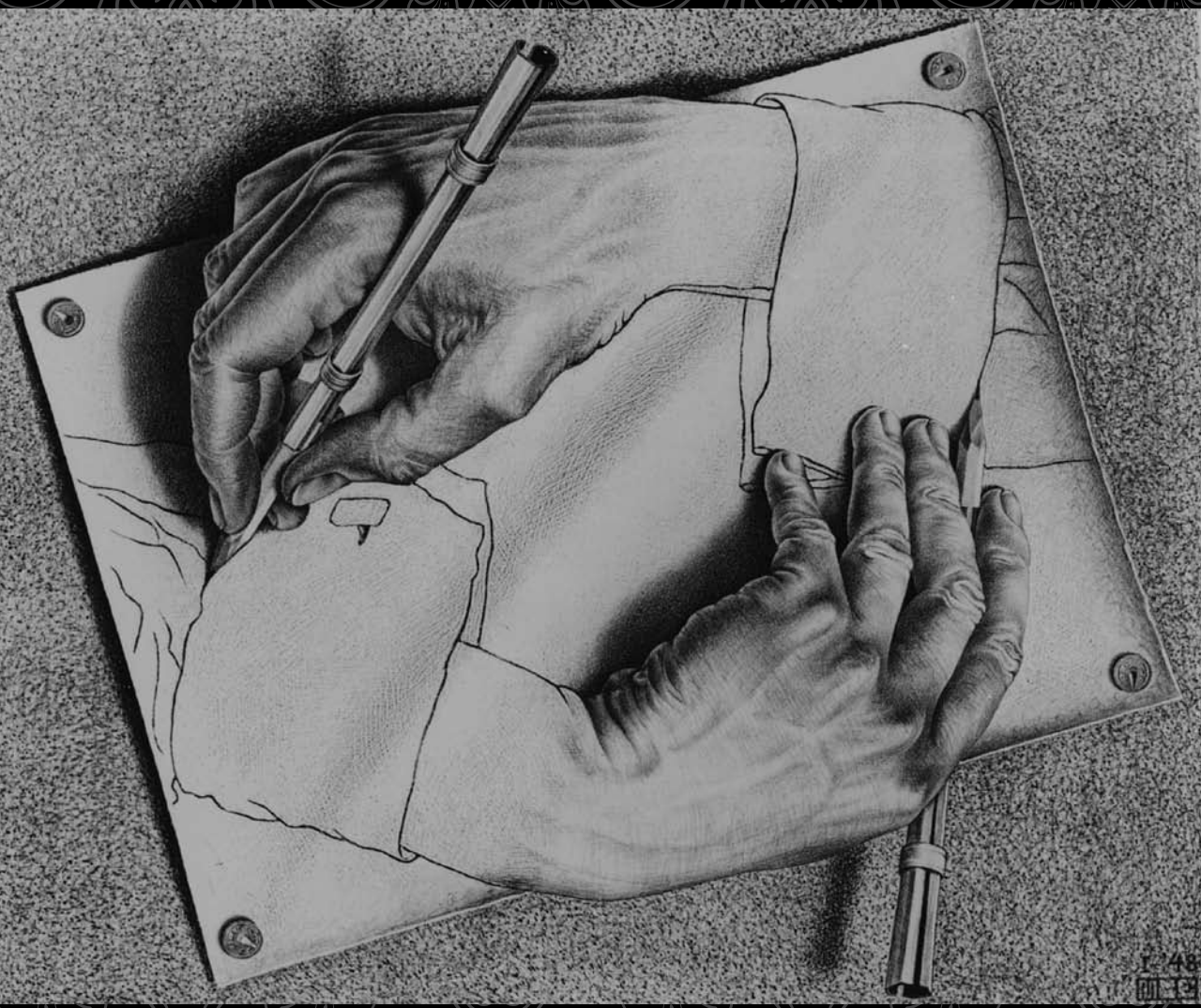
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The I in Design



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The I in Design

Henrik Enquist



LUND UNIVERSITY

Akademisk avhandling/Doctoral Thesis

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The I in Design

Why did I choose this strange subject?
Why don't I write about mobile phones or tattoos instead?
Beckman 2009

Fantasy is what we want, but reality is what we get.
Jason Diakité/Timbuktu 2007

I know you would see it our way because we explained it very fully.
Herbaliser 2002

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Abstract

In this thesis I describe the relations between objects, practices, and individuals. The main objective is to explore the role of artefacts in user-centred participatory design research, specifically for expressing and communicating personal experiences and creating meaning. In a broad sense I draw on experiences from three practices in order to define the scope of the thesis. The first is practice-led research, the second is design research specifically in the user-centred and participatory design traditions, and the third is concerned with the ways lay persons in general express themselves by and through objects and technology. The focus will be on the exchange of knowledge and experiences between two individuals: the researcher and the informant. One issue of interest is how communication can be made possible. Another is the use of artefacts for personal expression. A third is the constant balancing act when using the experiences and knowledge of a single or a few informants in design research.

The first half of the thesis is based on two design cases. The intention of these is to explore how people can introduce their personal perspectives on their health situation into the medical context through the use of expressive artefacts. The first is a study of personal visualisations of experienced health (papers I, II). A future practice of routinely creating and using (instrumental) images based on emotions, meaning and subjectivity in rehabilitation and healthcare is proposed. The second case describes the development of a personal digital device, the Memory Stone used for storing and sharing personal and clinical information (papers III, IV). The case involves pregnant women but the device can be used wherever there is an interest in keeping personal diaries, handling medical information in novel ways, and interacting with information technology at home and in healthcare.

The second half of the thesis is an explorative venture grounded partly in the empirical work described in the first half, partly in reading literature from a range of disciplines. Three main areas have been included to discuss the relationship between humans, objects, technology, and self-narratives: a technology of the self (the self as image and data), a science of the self (autoethnography), and autobiographies. The intention is to set the stage for a critical and productive discussion on how the notion of autobiographic practice can inform and enrich design research methodology.

Papers

Paper I

Bridging the gap between clinical and as patient-provided images.
Enquist, H.
In *Visual Literacy*. Elkins, J. (ed.), pp. 145-163. Routledge, London, 2007.

Paper II

Narcissus's new mirror. Body images and meaning.
Enquist, H.
Crossings – Electronic Journal of Art and Technology, vol. 5.1, 2007.

Paper III

The Memory Stone – a personal ICT device in healthcare.
Enquist, H., and Tollmar, K.
In *Proceedings from the Fifth NordiCHI Conference*,
(Lund, Sweden, 20-22 October, 2008), pp. 103-112.

Paper IV

A socio-material ecology of the distributed self.
Enquist, H.
Design Philosophy Papers, issue 2, 2008.

Paper V

Intuition in Design & Emotion – Transforming raw data into conclusions,
a meta-analysis of the 2006 Design & Emotion Conference papers.
Enquist, H., and Nordgren, C.
In *Proceedings from the 6th Conference on Design & Emotion 2008*. Desmet, P.M.A., Tzvetanova, S.A., Hekkert, P., Justice, L. (eds.). School of Design, the Hong Kong Polytechnic University, (Hong Kong SAR, 6-9 October 2008).

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An artefact like this thesis is the result of the interaction and efforts of many people and it would not have been the same without them. Therefore, I would like to express my gratitude to all of those who have, in one way or another, contributed to the completion of it.

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participating at the visualisation workshop; and the volunteers from Thulehem who shared their life experiences during my exploration of design methodology.

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I would also like to thank all my friends for putting up with my inability and reluctancy to explain what I *really* was doing during all these years. Here is a partial answer to your questions.

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Sammanfattning

Mitt mål med denna avhandling är att tydliggöra hur ting och teknologier bidrar till att skapa och omskapa människors identiteter. Till grund för den ligger en diskussion kring hur människor växelverkar med saker i sin omvärld i en ömsesidig påverkan. Detta kan ses som en sorts självbiografisk aktivitet som människor utövar med hjälp av saker i sin vardag. Min avhandling består av fem publicerade artiklar som tillsammans med en kappa utvecklar sammanhang och nya sätt att tänka i en användarcentrerad designforskning.

Ser man ting och teknologier som delar av en persons identitet, dvs. betraktar man människan och de använda sakerna i hennes omvärld som en helhet, blir det ofta flera utspridda 'distribuerade' jag som framträder. I artikel IV exemplifierar jag detta resonemang utifrån en fallstudie. Att föra in eller ta bort en sak i ens liv påverkar inte bara funktion och förmåga utan också självuppfattning och identitet. Därför kan det vara väl så viktigt att studera sakerna som deltagare i en självbiografisk process som att analysera dem som teknik-i-användning.

Det finns designmetoder som låter forskningspersoner uttrycka sig genom att de själva skapar saker eller berättelser. Ett vanligt exempel är att man ber människor berätta om sina upplevelser kring en specifik situation i text eller fotografier. Det insamlade materialet analyseras sedan av forskarna som drar (sannolika) slutsatser som sedan används för till exempel produkt- eller idéutveckling. Det är ett komplext arbete – den information som forskningspersoner tillför ett forskningsprojekt filtreras och tolkas av forskarna, både medvetet och omedvetet. Dessutom finns risken att forskningspersonerna säger det som de tror att forskarna vill höra. Artikel V handlar till stor del om frågor kring förutsättningar för och problem kring den tolkning som är nödvändig i denna typ av designforskning.

Avhandlingen bygger på två fallstudier som handlar om hur människor kan använda sig av ting och teknologier för att uttrycka sig i en rehabiliterings- och sjukvårdsprocess. Den första handlar om medicinska bilder och hur man kan skapa sina egna bilder för att få bättre förståelse för sin situation och hälsa. För en närmare beskrivning av denna fallstudie, se artikel I. Denna studie består av två delar. I den ena delen deltog personer som lever med en långvarig eller kronisk sjukdom. De

skrev dagböcker och skapade bilder av sina upplevelser samt kom med exempel på hjälpmedel som de ville ha för en bättre egen förståelse av sjukdomen. I den andra delen, som var en simuleringsstudie, deltog konstnärer, designers, ingenjörer och konstnärer för att mot bakgrund av sitt yrkeskunnande tillföra vad de kunde tänka sig hade varit bra i motsvarande sjukdomssituationer. I artikel II diskuteras mer i detalj hur kliniska bilder påverkar vår uppfattning av oss själva.

Den andra fallstudien handlar om en speciellt utvecklad digital verktyg (Minnesstenen) som används för att spara och dela med sig av personlig och medicinsk information. Denna studie presenteras i artikel III. I projektet medverkade gravida kvinnor som bidrog med sina upplevelser och önskemål under graviditeten. Dessutom medverkade medicinsk personal (barnmorskor, läkare och medicinska specialister) och berättade hur deras arbete är organiserat och hur Minnesstenen kan användas i deras arbete. Ett syfte var att undersöka hur personlig och medicinsk information kan integreras. En stor del av projektet var inriktad på teknisk utveckling av prototyper vilka användes för att testa idéer i olika scenarier.

Genom att synliggöra sådana självbiografiska processer som människor utövar med hjälp av saker i sin vardag kommer man nära etnografin och etnometodologin. I designforskningen finns emellertid också ett 'borde' – att man genom design vill tillföra något som leder till en förbättring, det vill säga att människor påverkas i en riktning som de själva upplever som positiv.

Min målsättning är att försöka tillföra nya sätt att se på dessa processer och på så vis bidra till användarcentrerad designforskning.

Publikationer

Artikel I

Att överbrygga gapet mellan kliniska och patient-producerade bilder.
Enquist, H.
I *Visual Literacy*. Elkins, J. (red.), s. 145-163. Routledge, London, 2007.

Artikel II

Narcissus nya spegel. Bilder av kropp och mening.
Enquist, H.
Crossings – Electronic Journal of Art and Technology, vol. 5.1, 2007.

Artikel III

Minnesstenen – ett personligt informations-
och kommunikationshjälpmedel i sjukvård.
Enquist, H., and Tollmar, K.
I *Proceedings from the Fifth NordiCHI Conference*,
(Lund, Sverige, 20-22 Oktober, 2008), s. 103-112.

Artikel IV

En socio-materiell ekologi för det distribuerade jaget.
Enquist, H.
Design Philosophy Papers, nummer 2, 2008.

Artikel V

Intuition i Design & Emotion – Transformationen av data till slutsatser,
en metaanalys av artiklar från 2006 års Design & Emotion konferens.
Enquist, H., and Nordgren, C.
I *Proceedings from the 6th Conference on Design & Emotion 2008*. Desmet, P.M.A., Tzvetanova, S.A., Hekkert, P., Justice, L. (red.). School of Design, the Hong Kong Polytechnic University, (Hong Kong SAR, 6-9 Oktober 2008).

1. Background

Considering the theme of this thesis it seems natural, although perhaps a bit unconventional, to provide a short autobiography of my own. This mini-narrative might be helpful for you to understand the motivation and personal history leading up to the research presented here.

1.1 An autobiography

> I've exhausted all hope of defining who or what I am. … I thrive on imagery, it seems to have a laxative effect (DeLillo 1971, 146).

My academic path began at the Faculty of Engineering of Lund University where I received a degree in engineering physics based on a master thesis on medical laser physics. After a brief employment as a researcher, I began studying art at a Swedish folk high school. After that I went on to complete a bachelor degree at the Academy of Fine Art, Bergen University and then entered my current doctoral programme in design, more specifically in rehabilitation engineering at Certec, Lund University. I had come full circle. In the past eighteen years I have travelled thousands of kilometres, only to end up only a stone's throw away from where I started. One of the driving forces which brought me to Certec was my interest in medical images. The simple question I asked myself was whether patients ever get to see these pictures of themselves and if they are of any use to them. I wanted to take advantage of this extensive collection of visual material to develop some of my ideas, including how the image of the deviant body affects one's perception of identity and normality, which I have examined both as an engineer and an artist.

Throughout my carrier, I have looked for challenges and followed my interests. Beforehand, the goal of each step has always been unclear and obscure, but when looking back everything appears to have been carefully planned in advance. This retrospective coherence is, in a way, a result of a re-construction or sense-making. As I have described this development, it gives the impression that the next step in each phase has exerted a kind of attraction – that the whole journey has followed a

deterministic path or design. It is no coincidence that I ended up with this specific combination of technology, art and design. My interest in the unique, individual and, more fundamentally, the abnormal is the basis of everything I do. As an engineer I worked with medical professionals looking for abnormalities inside the body by examining images of disease. As an artist I scrutinised how these images affect the viewer and his or her perceptions of normality. As a PhD candidate in rehabilitation design and engineering I have studied how the individual can use images and technological artefacts for personal expression.

Let us now take a look at this mini-autobiography. Firstly, it is apparent that it is a naive and simplistic account. It is incomplete and only covers a short period and has a very narrow perspective. Secondly, it does not really tell us anything about the personal motivations, emotions, and convictions behind the story – at least not here and now. Thirdly, we are unable to judge if it is true or pure fiction. In order to make use of it we need to suspend disbelief, and take the story's message at face-value. Additionally, it takes on the shape of a narrative. This structure has a timeline – a beginning, a middle, and an end. It implies a progression which in retrospect seems coherent and meaningful. This is one way of describing life experiences. An alternative perspective is to focus on discrete episodes rather than the (virtual) chain of episodes as such. The kind of design research described in the thesis is positioned in between these two perspectives. On the one hand, design researchers acknowledge the entirety of human experience and the holistic sense of the 'self'. On the other, it is only possible to study the single discrete episodes, represented in this thesis by the observations made during field studies, workshops, and interaction tests such as those presented in the case studies and appended papers.

The act of writing (and reading) an account such as the autobiographical one above assumes an intersubjective understanding between informants and researchers. In a scientific context, researchers claim to understand or be able to interpret what people are telling them, and they believe what they say is intelligible. Here I am not only referring to the simple understanding of words and language, although semantic differences can be a real problem. Cultural differences, the time and place where the interaction occurs, and a range of other factors influence the meaning and understanding of what is expressed. This leads us to the general problem of whether it is possible for people to understand each other and if so, how. It is to some extent an existential issue, but also a pragmatic one. I maintain that it is

critical to discuss these issues in design research when making claims based on other people's experiences. It is a matter of credibility. There are potential risks that participants in research projects say what they think the researchers want to hear. At the same time, it is important to remember that the input participants provide is filtered and interpreted by the researchers, both consciously and unconsciously. The bias of design researchers as well as their wishes and pre-understanding affect their usage of the information participants provide.

We see that an overly simplified story, as the one above, is in fact a very complex artefact if we want to use it as material in a research process. The situation is common in design research, and that is why we have to take a more in-depth look at how people are involved in design research and their capabilities for presenting themselves. Using various types of personal artefacts in this activity may be helpful. If you have a look around in your own home, for example, it becomes clear that the number of things and technologies that are used in daily life is very large, including everything from cars and mobile phones to clothing and shopping lists. These things exist in our lives and contribute to defining who we are, either in a concrete and direct manner as we express ourselves through them, or indirectly by affecting how we live and interact with the world. Many people also use a variety of technologies and things to share their personal experiences, such as diaries, blogs, online social networks, and photo albums. We live with our things in a kind of symbiosis, and are dependent on the things and technologies we use. To put it even more dramatically, they have become a part of our 'selves'. The opportunity to make use of these artefacts and activities in design research in order to learn about people's needs, experiences and wishes is both obvious and problematic.

1.2 Aims

The research presented in this thesis has three overall aims in relation to user-centred participatory design research:

The first aim is to investigate the use of autobiographic artefacts, that is technological and visual artefacts for creating and expressing personal meaning and experience. This is the 'I' by design.

The second aim concerns the interaction between two individuals, the researcher and the informant – each an 'I' in design. The intention is to describe this intersubjective understanding and provide suggestions for using autoethnographic and autobiographic practices in design research.

The third aim is to map out concepts, theories, and literature relevant for this autobiographic practice. In a way, this is me in design.

The thesis is based on two separate but interrelated design cases. The common **aim of the cases** is to explore how people can introduce their personal perspectives on their situation into the medical context through the use of expressive artefacts.

1.3 Comments

This thesis is concerned with experiential and human-centred design, in the sense that the unit of analysis is how people perceive themselves in relation to their surrounding environment and the objects they interact with. The description of design and design research in general, and participatory design research in particular, is cursory. Common aspects such as usability, modes of interaction, sustainability, production, and interpretation are not addressed as such although some discussion regarding these issues is included in the papers.

A number of theoretical and methodological frameworks are introduced as relevant for the understanding of the positioning of the thesis but are not addressed in any considerable depth. To mention some: human-computer interaction is one field of design research which is relevant, but not treated explicitly. Actor-network theory

coming from sociology is certainly applicable, but only mentioned briefly. Similarly, activity theory is most relevant to the topic of this thesis but not applied.

Although I use the term 'autobiography', this thesis is not about autobiographies as they are known from literature in general. In this design research context, autobiographies are considered to be shorter, ad hoc and not necessarily written. Naturally, there is much to learn from the confessional autobiographies and other self-narratives in literature, but I have chosen to exclude this discussion. Another form of autobiographic artefact which springs to mind is the (artistic) self-portrait. It is not within the scope of this thesis to deal with self-portraits as such or other forms of artistic self-presentation. I will not go into art specifically, although certain movements such as situationism and community art have similarities with participatory design and user involvement. Also, discussions from the field of practice-led research, which includes artists practising research, are relevant for studying the relation between artefact and knowledge (embodiment/reification/representation) and the interpretation made by the researcher (practitioner/artist). These discussions are included implicitly but not mentioned explicitly. Furthermore, art therapy is one application of creating and using personal visualisations and images in healthcare but is not addressed here.

This thesis covers many topics which run in parallel and are in some respect distributed throughout the thesis. To aid the reader and prove my good intentions, I would like to clarify the relation between the various topics, and the thesis as a whole.

Structurally, there are two parts. The first half (chapter 1-3) deals with the empirical work of this thesis. It includes a section on methodology, and a description of the two case studies. The cases are presented in more detail in the papers I and III, and put into a wider context in papers II and IV.

The second half (chapters 4-7) presents ideas and associations originating from working with the topics presented in the cases. This part includes a possible subjective position in research including a short description of autoethnography; a discussion aiming at framing the cases in terms of technologies of the self; and finally, a presentation of my approach to autobiographies. In the last chapter, 'Coda', I present some reflections on the thesis as a whole.

If I were to classify my thesis in terms of inductive, deductive or abductive, I would say it is abductive. That is why I consider it to be important to account for the range of perspectives taken in this research.

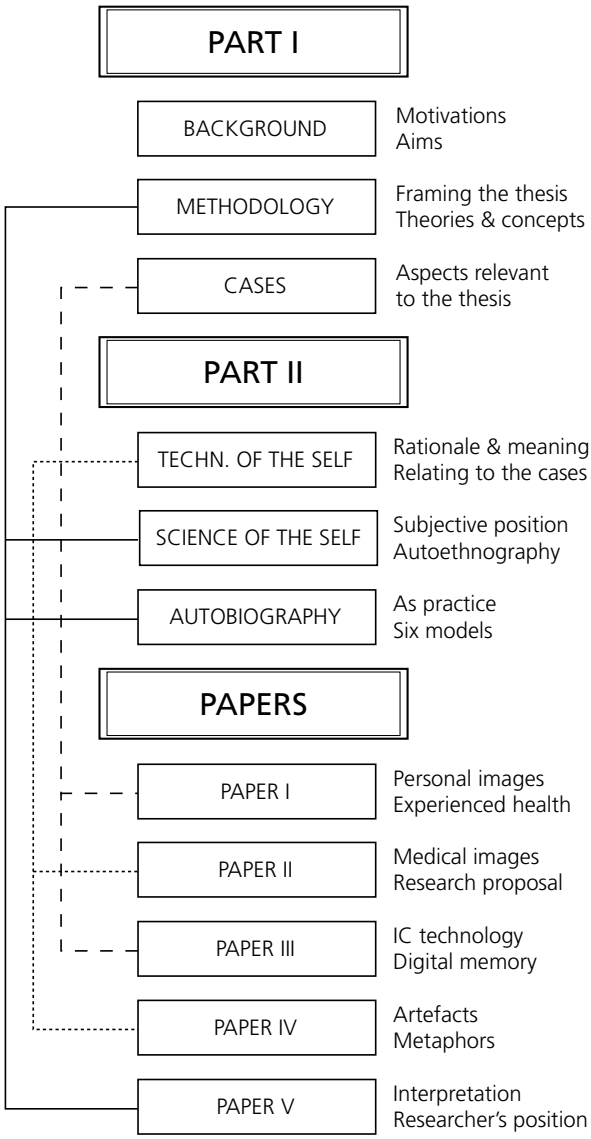


Figure 1. Thesis overview.

2. Methodology

In this chapter I discuss the methodological background of the thesis. Methodology should be understood here as the underlying framework, not the specific methods (and techniques) used in the specific studies. This chapter serves as an introduction to the scientific positioning of the thesis as a whole. It includes a brief description of design research, paradigms and practices as understood in this thesis.

> First, we are discussing methodology, not method. The former refers to the persuasions from which our stories emerge, the latter to the doings of research … Second, methodologies denote different levels of participation on the part of the participant/informant/narrator or narrative subject in the doing of life story research. Third, the authority of the researcher will change according to the methodology. Fourth, methodology enacts an approach to research that combines a commitment to our participants and the generation of theory, alongside and attention to narrative qualities of plot, characterization, and readability (Goodley et al. 2004, 55-56).

2.1 The first person

When working in the field of rehabilitation and disability, classification is almost unavoidable. Although I agree that classification is vital when it comes to legislation, social rights, economic support and personal assistance I argue that it is the circumstances and situations which force a person to call him or herself disabled, not the physical or cognitive capabilities. This is in accordance with the International Classification of Functioning, Disability and Health which is based on functioning rather than disability (WHO 2001). In my approach there is no point in classifying people since such a classification is phenomenological and constructivistic. In other words, it is their right and choice to classify and define themselves, or not to do so. This is an activity of world-making/self-making, and as such it is more a matter of habilitation than re-habilitation, since the individual is different and in some respect new after this process. Since this is common for all people, I do not include an explicit perspective on rehabilitation (design) in

this thesis. The individual is not only seen as the person at the focus of the design activity, but more fundamentally as the origin of this activity. The process begins and ends with the needs, memories, preferences, personality and future dreams of this person. Throughout this thesis I argue for a broader view of the individual, and the implications this perspective has for design in general and design research in particular. Since the aim here is to stress the active participation and perspective of individuals, addressing them as 'users' is definitely not adequate. To find an alternative, I turn to Thackara's commitment to 'the people formally known as users' (Thackara 2001, 43):

> Article 1: We cherish the fact that people are innately curious, playful, and creative. We therefore suspect that technology is not going to go away; it's too much fun.
>
> Article 2: We will deliver value to people – not deliver people to systems. We will give priority to human agency and will not treat humans as a 'factor' in some bigger picture.
>
> Article 3: We will not presume to design your experiences for you – but we will do so with you, if asked.
>
> Article 4: We do not believe in 'idiot-proof' technology – because we are not idiots, and neither are you. We will use language with care, and will search for less patronizing words than 'user' and 'consumer'.
>
> Article 5: We will focus on services, not on things. We will not flood the world with pointless devices.
>
> Article 6: We believe that 'content' is something you do – not something you are given.
>
> Article 7: We will consider material and energy flows in all the systems we design. We will think about the consequences of technology before, not after.
>
> Article 8: We will not pretend things are simple when they are complex. We value the fact that by acting inside a system, you will probably improve it.

> Article 9: We believe that place matters, and we will look after it.
>
> Article 10: We believe that speed and time matter, too – but that sometimes you need more, and sometimes you need less. We will not fill up all your time with content.

Throughout this thesis I use the term 'first person' to denote the people who are the focus of the activity. I choose not to call this actor 'patient' or 'user' or any other such term since this individual has many different aims, means, and roles depending on the specific context and time he or she is currently in and the various opportunities and abilities he or she has. In other words, in a clinical setting the first person is a patient undergoing treatment or consultation, whereas in a private setting the first person could be a user of medication, technological devices, et cetera. Naturally, this term is arbitrary and could be exchanged with similar ones. When talking about first persons in a specific research activity, such as a workshop, I use the words 'participant' and 'informant' interchangeably with the term 'first person'. Researchers are naturally also participants in these activities, but are not included in this term. One can also argue that the informants are researcher into their own experiences, which is in line with the topic of this thesis. However, to avoid terminological confusion, they are not referred to as 'researchers'.

2.2 A position in design research

2.2.1 Design and design research

The word 'design' and its connotations are used in an almost eclectic manner to describe a wide range of activities, both as a professional practice, as a field of research and in everyday life. It is used which includes aspects of creativity, innovation, aesthetics, usability, ergonomics, functionality, form, process development, and much more. To provide an exhaustive list would be difficult, if not impossible or undesirable. The point is that using the word without providing a specific declaration of meaning tends to create more confusion than clarity. Even among individuals in the same area of practice, the word often has no common definition, at least not in day-to-day activities.

Etymologically, design comes from the word 'designare' which means to sketch/draw, but also to create a (visual) conception (Weimarck 2003, 13). It signifies both purpose and arrangement, mode of composition (Dewey 2005, 121). It is used both as a verb, and as a noun. As activity, it is both a manipulative and a cognitive one. The manipulation is focused on change with certain intentions, and to do this requires both skills and knowledge. You can achieve this by utilising different tools to extend your abilities. When we learn to master the tools and instruments, it is as if we extend our own body (Polanyi 1978, 58). As a cognitive activity, design is a knowledge strategy that makes use of both external and internal tools.

According to Herbert Simon, design is an improvement of what is (Simon 1996). This statement implies that design deals with the artificial, that is, what does not come naturally. It also states that designers deal with proposing realisable and possible future artefacts or practices based on the current situation. Design is an instrumental, not an idealistic venture. It does not seek knowledge in its own right, but is directed towards desirable interventions, possibilities, and change. Design (and design research) is an iterative process involving many different steps, which can be illustrated by Kolb's learning circle (Figure 2) (Kolb and Fry 1975).

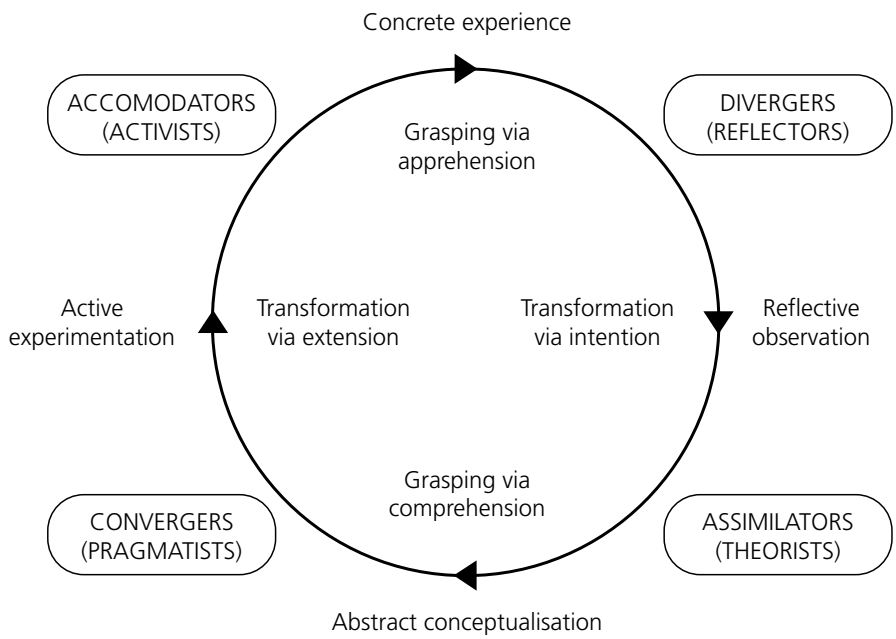


Figure 2. Kolb's learning circle.

The design process also resembles the hermeneutic circle (Gadamer 2004; Heidegger 1962). The production of new knowledge and understanding is based on previous understanding. It is also a matter of alternating between the parts and the whole, and by making the situatedness (being there) explicit. Schön speaks of design as a reflective conversation with the situation (Schön 1992, 3). The design process or activity can start at any point in this iterative process. In unfamiliar situations the designer draws on accumulated 'exemplars': experiences, solutions, and understanding of previous situations used as a ground for the present one. Reversely, by making the familiar strange new ideas can be initiated in known contexts.

The focus of this thesis is not design but design research, so what is design research? Cross distinguishes between two concepts of science related to design: 'Science of design', which is the body of work that attempts to improve our understanding of design through 'scientific' methods of investigation; and 'design science', which is an explicitly organised, rational and wholly systematic approach to design (design as a scientific activity itself) (Cross 2000, 96). To this, Krippendorff adds a third concept, a 'science for design', meaning a systematic collection of accounts of successful design practices, methods, and evaluations filtered through the self-reflective practice of the design community (Krippendorff 2006, 34-35). This thesis, in Krippendorff's terms, is a science for design (research). It is an attempt to reflect on the process and results from two design research cases, and incorporate knowledge and concepts from other disciplines in the process. It also aims at enhancing knowledge in the design community when it comes to understanding the feedback given by research informants.

2.2.2 Participatory design research

> Grudin's law: When those who benefit are not those who do the work, then the technology is likely to fail or, at least be subverted. (Norman 1993, 113)

The research presented here is also human-centred in the participatory design tradition in that it draws on the lives and knowledge of the recipients of design (the 'users', or first persons) in order to increase the validity and applicability of these proposals. An early example of what can be called the Scandinavian participatory design tradition is the Utopia project (Bødker et al. 1987, 1993, 2000). Engineers,

industrial designers, sociologists, historians and others co-operated to create a change in the workplace. What was new was the approach and the methods used. The work was based on two approaches: design-by-doing, which involved low-fidelity mock-ups and prototypes as tools to try out and discuss; and design-by-playing, meaning using design artefacts enacted in situations such as collages, and design games dealing with current and future work practices. Participatory design is about 'design for use before use.' One key aspect of participatory design in this sense is the focus on change, emancipation, and socio-political involvement. It aims at changing things, and openly so. Emancipatory research, such as the work presented in this thesis, has roots in action research paradigms and alliances with feminist research methodologies and disability studies (Goodley 2004, 59-60).

2.2.3 Action research

Action research is a group of research methodologies focusing on change (action) and understanding (research). The term was first introduced in 1946 by the psychologist Kurt Lewin (Lewin 1946). Zuber-Skerritt has developed a theoretical framework of effective action research, known as the CRASP model. In this model, action research is characterised as a 'critical (and self-critical) collaborative enquiry by reflective practitioners being accountable and making the results of their enquiry public, self-evaluating their practice and engaged in participatory problem-solving and continuing professional development' (Zuber-Skerritt 1992, 15). Action research has an interventional intention, a trait it shares with some branches of design research. A common strategy is to introduce prototypes and novel technology into the lifeworld of the participants with the specific aim of changing their behaviour and practices. Co-development of concepts and design, as well as creating personal artefacts in the design research process is another way of dealing with subjective experiences which are difficult to talk about. This approach has its limitations, though. If a design researcher asks the respondent to take a series of photographs portraying daily life, the researcher really has no means of decoding them objectively since the experience of the respondent cannot be shared by anyone else. The epistemic gap of subjectivity is hence even more apparent when it comes to non-semantic communication. Action research proposes an active participation on behalf of the researcher, and acknowledges the impact this presence has on the outcome (Kaptelinin and Nardi 2006). This solves the problem of the absolute need for explicit communication, but only partly. The researcher

gains first-hand experience, but still it is the experience of the researcher, not the respondent. One can argue that these two experiences are similar to such an extent that the insights are good enough to advance the research and/or design at hand. But one can question who is actually the focus of the research: the researcher or the informant? Interpretation is therefore essential.

2.2.4 Ethnography

Ethnography is a methodology that aims to understand culture. This includes both unknown cultures and to look again at cultures we may feel we already know – to make the strange familiar and the familiar strange[1]. It is a matter of turning a social context into a research context. By being present together with the individuals under study – 'going native' – ethnography differs from anthropology in that the impact of this presence is acknowledged. This approach is not without pitfalls. By suggesting that there is commonality between themselves and the others they seek to understand, ethnographers run the risk of creating others in their own image (Shapiro 2003, 193).

Grbich lists some general characteristics which should be fulfilled in order to call a study ethnological (Grbich 1999): (a) The study is undertaken to explore social phenomena, (b) the collected data may be coded before collection is complete, (c) the number of cases studied is small, with the potential for studying only one case, and (d) qualitative analysis is used to interpret the meaning and functions of human practices.

It is not unusual to include ethnographic/ethnomethodological techniques to some extent in design research in order of gain access to the lifeworld of people (Hemmings and Crabtree 2002). One explanation as to why ethnography rarely is applied fully in design research is its cost and time intensive nature. The straightforward approach is to engage ethnographers directly in the research process, which was done in the second case study. This approach, though, introduces (even more) interdisciplinarity and with it a range of potential problems. Another way is to adjust ethnographic methods to suit the specific needs of design researchers in

1 This phrase has been attributed to the German poet Novalis (Georg Philipp Friedrich von Hardenberg, 1772-1801), who declared that the essence of romanticism was 'to make the familiar strange, and the strange familiar'.

the field, often referred to as 'rapid ethnography' or 'quick and dirty ethnography' (Hughes et al. 1995). This essentially involves toolkits of methods providing a 'reasonable understanding of users and their activities given significant time pressures and limited time in the field' (Millen 2000, 280). By combining different design research techniques and methods with ethnographic ones, a triangulation across disciplines is achieved which provides a richer input of data and strengthens the credibility of the material and results. More on ethnographic methods and the issue of different paradigms in chapter 6.

As a whole, the different perspectives on design research taken in this thesis can be summed up as phronetic research. By definition, phronetic researchers focus on values; for example, by taking their point of departure in the classic value-rational questions: Where are we going? Is it desirable? What should be done? (Flyvbjerg 2001, 130).

2.3 In between practices

This thesis, and design research in general, is positioned in between a range of scientific disciplines as well as non-scientific practices. The notion of 'community of practice' is introduced in the first section. Then, three practices are described to define the scope of the thesis – that of practitioners, researchers, and lay people.

2.3.1 Communities of practice

The individuals engaged in a research project can be seen as members of a certain group or community of people who have something in common which separates them from other people. According to Wenger, we are all part of several such communities of practice, at home, at work, in our spare time, et cetera (Lave and Wenger 1991; Wenger 1999). Members of such communities often have an implicit but still real apprehension of who belongs to it, and to what degree. For example, in the second case presented in chapter 3.2, the pregnant women belong to the community of practice of 'pregnant women', whereas the midwives belongs to another, the 'midwives' (although they also can be pregnant and also can be included in the former). These individuals are seen as representatives of a group, and the knowledge gained from these groups are to some extent used to draw

some more general conclusions about the community or other members of that community.

The different communities of practice can organize their interconnections around an artefact – a boundary object – that should be robust enough to transport information between these communities, but at the same time allow for local interpretation (Star 1989). The knowledge, or meaning, 'embedded' in the boundary object cannot be extracted or interpreted locally without prior knowledge within the receiving community.

> (Boundary objects)... are those objects that both inhabit several communities of practice and satisfy the informational requirements of each of them. ... Such objects have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable, a means of translation. The creation and management of boundary objects is a key process in developing and maintaining coherence across intersecting communities (Bowker and Star 1999, 297).

A boundary object is a means for the production of meaning. In Latour's terminology, such an artefact ('actor') can be either a 'mediator' or an 'intermediary' (Latour 2005, 39). In his vocabulary, an intermediary is what transports meaning or force without transformation. The effects of intermediaries are trivial and predictable. Mediators, on the other hand transform, translate, distort, and modify the meaning or the elements they are supposed to carry. Dealing with mediators, it is not possible to foresee the outcome by studying what is given beforehand. In this sense, boundary objects are mediators between different communities of practice.

By connecting 'community' to 'practice', Wenger separates it from other types of human constellations by discussing six aspects of this term (Wenger 1999, 49-50). The first is 'practice as meaning'. Since meaning (and hence, knowledge) production is a social process it is a relevant level of analysis for talking about practice. He uses three concepts for doing this: negotiation of meaning, participation, and reification. The second aspect is 'practice as community'. Practice is what makes a community stable and coherent. Wenger uses three dimensions for describing this: mutual engagement, joint enterprise, and shared repertoires. The third is 'practice as learning'. A practice is a process, developing non-randomly over time. Since it can be subject to discontinuities, it is not inherently a stable entity. The fourth is

'practice as boundary'. As a defined group, a community of practice is separated from other groups. This boundary should not be understood as a simple line separating the inside from the outside, but rather as a complex social landscape of boundaries and peripheries. There can also be exchange across this boundary, for example, by shared artefacts. The fifth is 'practice as locality'. Local variations, routines, and artefacts separate two communities which at first hand look similar or even identical (at some level of analysis). And finally, the sixth is 'knowing in practice', which resonates with Schön's discussion of the reflective practice, and Polanyi's tacit knowing (Polanyi 1967).

Also, by using practice as the unit of analysis, the notion of the person is introduced into the theory without the need to start out with a definition of an individual subject (Wenger 1999, 17). This has similarities to the approach taken in actor-network theory. According to Latour, groups (a parallel to Wenger's communities) are defined and manifested by their actions (Latour 2005, 46). This implies that groups are constantly negotiated and changed by their members (and others) rather than given a priori. If the work (in Latour's terminology) stops, the group is dissolved. To continue the example of the pregnant women, once they give birth, they cease being pregnant and are thus no longer part of the group.



Figure 3. Three practices.

2.3.2 Three practices

I will (explicitly and implicitly) draw on three practices (Figure 3). The first is practice-led research. The second is design research, specifically the user-centred and participatory design traditions, with a special focus on methods involving participant-created artefacts of expression. The third practice is not as easily defined, but is mainly concerned with the ways lay people in general express themselves by and through objects and technology, and how this is utilised in a design research context. I believe that the intersection of these three areas of practice is beneficial for investigating user-created artefacts within design research. This approach is based on a number of general observations.

People engaged in practice-based research, for example artists or designers, express themselves through artefacts. These artefacts are presumed to carry a kind of meaning and knowledge which can be difficult to express in words, or which possess qualities which are specific to a certain medium. The question is how one can argue for the process of expression through artefacts.

Design research in general and participatory design in particular, engage lay individuals (i.e. non-designers/non-researchers) to participate in various parts of the research process. Their active contribution through sharing individual experiences and knowledge is one of the foundations of this tradition. Several research tools and techniques used in this research practice involve different types of artefacts, such as mock-ups, prototypes, and 'cultural probes' through which the participants act creatively as co-producers (Gaver et al. 1999). In other words, the research is performed (in part) through participant-created artefacts.

The average lay design research participant has little or no knowledge of creating artefacts in a design research context. On the other hand, he or she possesses this kind of knowledge in a personal context from writing blogs, keeping diaries, and collecting photographs in family albums, among other things. The main interest here is how design researchers can argue for and use the mechanisms of participant-created artefacts within their scientific practice, and what they come to mean to the participating individuals. The circumstances of the participants' practice in design research are diverse and heterogeneous, but there are several common denominators: They volunteer and hence have some personal interests to express and share their experiences; they are assumed to be able to engage in

and contribute to design research activities; and they have little or no training and education specific for this activity.

This division into three separate practices is in a way artificial. Naturally, researchers use personal experiences, for example from being pregnant or patients, to interpret and understand the input from informants. Similarly, informants use their skills from their professional life when researching their own experiences. All are in some sense members of all three communities of practices described above. One point in using this division is that it makes the multiple practices of the participating researchers and informants explicit.

2.4 In between paradigms

Coming from different backgrounds, using different tools and methods, as well as applying different mental and intellectual models can be a source of confusion, misunderstanding, and failure in multi-disciplinary projects. In this section, I mention some theoretical frameworks, for example critical theory, constructivism, and phenomenology, which are acting as a backdrop for the work done in the case studies and the reasoning in the thesis.

> What rehabilitation engineering can and should affect above all is the lived disability. We have the same goal as medical research: to cure, alleviate and comfort. But our focus is on the principal person's perceptions of what is important for her and what she wants to be able to do. It is the doing rather than the diagnosis that is emphasized (Jönsson et al. 2006a, 122).

Working with medical staff, computer scientists, ethnographers, industrial designers, and other professionals as well as participants with a wide range of backgrounds has been a challenge in the projects. It has led to situations of potential misunderstanding, conflict and made it clear that our actions were based on different paradigms. The issue was not whether we could understand each other as human beings, but that our priorities, languages, and practices made us think and act differently. Agreeing on terminology, methods, and other vital aspects of communication and knowledge production amounted to a considerable part of the total workload in the second case study. This is actually a common position

for a designer/design researcher. Rehabilitation as a design research field balances between medicine, engineering, industrial design, art, humanities, social sciences, and a number of other disciplines (Figure 4). This in-between position makes the clash between paradigms apparent and sometimes a very concrete problem. It can be discussed that design research, in the participatory design and action research traditions adopted here, has one leg in the post-positivistic paradigm (e.g. that it is possible to draw some general conclusions upon which a design can be based) and one leg in the critical theory paradigm (e.g. a research and design focus on the unique experience of single individuals, usage of the designers' personal experiences). To put it simply, this position argues that there is a reality of which we can get a rough and probable picture, but there is also much room left for subjective experience and understanding. There is also a political/social activist side which has some things in common with critical theory and participatory design (power relations, emancipation, etc.). Belonging to two paradigms can create methodological problems. An apparent issue in bridging design research and design practice is the gap between analysis/interpretation and design proposals. This is examined in paper V.

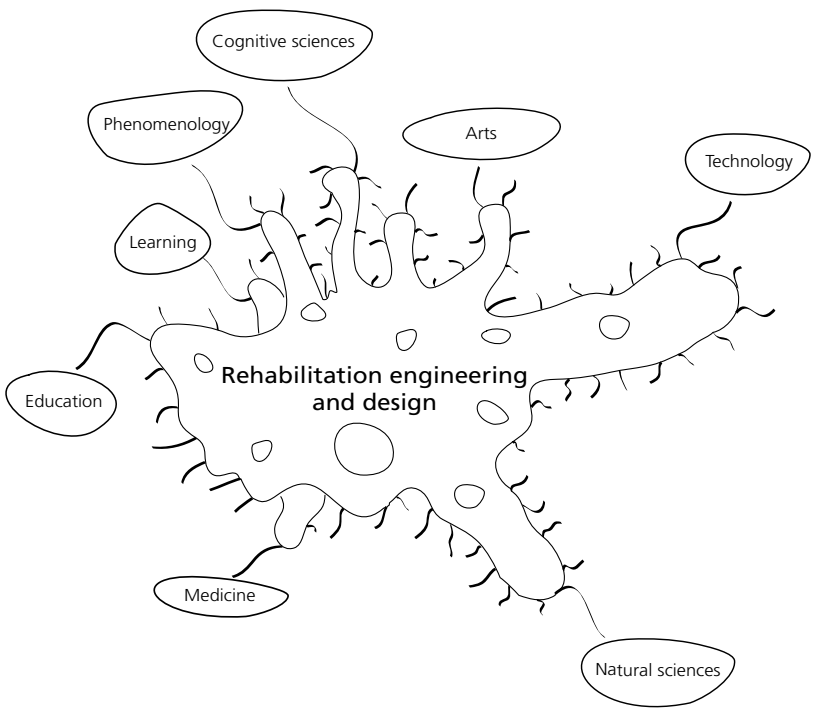


Figure 4. Rehabilitation engineering and design.

2.4.1 Critical theory

> Cultural studies require an interdisciplinary approach that incorporates the sciences, psychology, anthropology, linguistics, psychoanalysis, and the humanities, such as literature, film, and art criticism. In this view…, medicine and experience of the body is not just an objective body of scientific knowledge external to culture but rather a product of media and language (Wilson 2002, 78).

The perspective of the individual is central and for this purpose I make use of a theoretical framework inspired by critical theory and feminist theory (Haraway 1991b; Jones 2007). There are aspects of this framework I want to point out as the most important in my reasoning. First of all, there is a transparency regarding the position of the self as a point of departure of study. It is not only a question of methodology, for example as in research intention and theory, but also a question of the personal incentives of the participants. This means that both the investigator and the person investigated are exposed in the process. It is a matter of a subjective (re-)search rather than a process of unveiling truth, or as Rogoff puts it, talking 'to' people, instead of talking 'about' people (Rogoff 2000, 32).

This process of inquiry is not just a search for answers, but also includes a fundamental questioning, a critical approach both in relation to the material, the methods, and the theories used, as well as the personal conditions for such a practice. Traits such as openness, curiosity, reflexivity and scepticism are essential in a personal way. Spivak argues that it is the questions we ask that produce the field of enquiry, not some body of materials which determines what questions need to be posed to it. She talks about a shift from the old logic-positivistic world of cognition to the new world of representation and situated knowledge (Rogoff 2000, 31). In this way, the position, experience and attention of the investigator will play a crucial role, not only in determining what should be studied, but also regarding the implementation.

2.4.2 Phenomenology

In focusing on experiences and taking the perspective of the individual, phenomenology is another relevant framework for my research. Phenomenology

aims to capture the richness of experience, the fullness of all the ways in which a person experiences and describes the phenomenon of interest (Marton and Booth 1997, 117). In that respect it is a philosophy of experience. In the thesis, phenomenology acts more as a backdrop than an explicit theoretical or analytical framework. Phenomenography, seen as an offspring of phenomenology, can also be of interest for the design researcher due to the somewhat different approach. As Marton and Booth put it: 'Phenomenography and phenomenology differ as to purpose. … Whereas the phenomenologist might ask, "How does the person experience her world?" the phenomenographer would ask something more like, "What are the critical aspects of ways of experiencing the world that make people able to handle it in more or less efficient ways?'" (Marton and Booth 1997, 117). In this sense, phenomenography opens up possibilities for change rather than to focus on description and explanation. Phenomenography is well suited in rehabilitation engineering and design to illuminate differences and variations in the way in which people experience affordances (Jönsson et al. 2006a, 187). For the purpose of this thesis, phenomenography can also be helpful when it comes to explaining learning and understanding in the case studies, as well as the issue of second-order understanding. The fundamental issue is this: When designers ask people to be creative, in one way or another in the context of research, it is crucial to be aware that it is not clear 'who' responds, or what the outcome represents.

2.4.3 Constructivism and existentialism

> As far as men go, it is not what they are that interests me, but what they can become (Sartre 1963).
>
> Man is nothing else but what he makes of himself. That is the first principle of existentialism. (Sartre 1989).

In addition to phenomenology/phenomenography my arguments can be better understood in the light of a constructivist view of knowledge and understanding. Basically there are four aspects of constructivism that are relevant for my line of reasoning. First, knowledge is actively constructed on the basis of already existing conceptions. Nothing comes from nothing, and the activity of teaching/learning is not a matter of transfer but rather making. Second, constructed knowledge is tentative and hypothetical in nature, not final. It is a stepping stone towards

a future understanding which builds on the previous one. Third, although this knowledge is tentative it has to be useful, meaningful, and viable. It has to survive the test of being in contact with the world. The last aspect of the constructivist view on knowledge is its social component. Knowledge is always constructed within a certain social setting in co-operation with other people. Sartre's (in)famous statement 'existence precedes essence' suggests a connection between phenomenology, constructivism and existentialism. Knowledge and our understanding of ourselves is a construction, a 'life making'. This activity is also involving other people in a reciprocal relationship. As we are making ourselves we are making others, and vice versa. A consequence of this is that our understanding of others is based on likeness or similarity.

2.4.4 Constructionism

> Constructionism – the N word as opposed to the V word – shares constructivism's connotation of learning as 'building knowledge structures' irrespective of the circumstances of the learning. It then adds the idea that this happens especially felicitously in a context where the learner is consciously engaged in constructing a public entity, whether it's a sand castle on the beach or a theory of the universe (Papert 1991, 1).

Learning and understanding is not only a matter of thinking but also making and this applies to designers, researchers as well as to first persons. Papert coined the term 'constructionism' as a hybrid between constructivism and construction to explicate this. This approach is to some extent similar to the 'learning-by-doing' advocated by Dewey and other pragmatists (Dewey 1958). Constructionism should not be understood only as a simplistic 'learning-by-making' but, more fundamentally, as 'learning-to-learn', in opposition to instructionism – a pipeline model of learning and communication. Knowledge, according to constructionism, is grounded in situated participation.

> Papert draws our attention to the fact that 'diving into' situations rather than looking at them from a distance, that connectedness rather than separation, are powerful means of gaining understanding. *Becoming one with the phenomenon under study* is, in his view, a key to learning. It's main function is to put empathy at the service of intelligence (Ackermann 1991).

Examples of how a constructionistic approach can be applied in real life are provided in Papert's book Mindstorms where he describes children learning programming by a sort of serious play (Papert 1980).

2.5 In between people

In a research project there are many different stakeholders with different backgrounds, incentives, and goals (Krippendorff 2006, 63-64). This section is about the interaction and communication between two individual stakeholders – the researcher and the informant. A couple of communication models are presented to illustrate the complexity of this activity. Two concepts regarding intersubjective understanding are introduced: second-order understanding and communicative rationality.

The experiences and knowledge of people are desirable objects for a design researcher, but there are some obstacles on the way to capturing them. Methodologically there are several options depending on the intention and prospected outcome. First of all, there is information which could be considered facts such as age, gender, occupation, and data which are measurable objectively such as the time it takes to complete a specific task, physiological responses (skin conductance, heart rate, EEG) and so on. This kind of data is generally indisputable as such, although the means of collecting and interpreting it can be discussed at length. Another kind of information is accessed by asking the person directly. This may seem to be the most straightforward and intuitive way to go about in user-centred design research. In general such methods are largely based on two approaches, or means of communication: language (diaries, interviews, self-narratives) and artefacts (sketches, prototypes).

By using the powerful tool of natural language, deeper insights into the inner life of an individual is possible, and there is no need to learn a specific method, although specific training in interviewing skills, for example, could improve the outcome. On the other hand, this approach poses concerns about semantic differences between the researcher and the individual under study. What terms are used and are they used consistently by both researcher and the first person? Personal values and experiences colour the meaning of words and there is also a risk of touching upon subjects which are not easily described in natural language.

Using artefacts as vehicles for communication also poses questions regarding aspects such as accuracy, the quality and nature of the content, as well as the subjective meaning. An interesting question regarding this subjective position and its 'truth' is what can be said and how it is received by a designer/researcher. This is especially crucial when it comes to people with limited abilities to express themselves. This issue affects the whole design process and its results, and how and what a person *can express*. And in the end, if you agree with my reasoning, what this person *is able to be*. It is necessary to clarify the intersubjective understanding which is a prerequisite for this kind of research.

2.5.1 A transactional model

A communication model can be useful for pointing out some issues concerning interpersonal communication in general, such as complexity and the impact of context. The basic assumption here is that there are two main subjects, the researcher and the first person.

Linear models are the most simple and straightforward, such as the transmission model of communication (Shannon 1948). The message is sent from point A, influenced by distortions and losses along the way, and finally received at point B (Figure 5). A suitable metaphor for this approach is 'the pipeline', or 'the conduit', where communication is seen as a matter of transportation. These linear models were originally developed for describing computer communication and are not practically applicable to human communication in general. One reason for this is that there really is no beginning or end in human communication as is implied by these models. Another is that most human communication is not based on 'data', but on meaning.

The circular model of Osgood and Schramm takes the continual and reciprocal nature of communication into account (McQuail and Windahl 1981; Schramm 1954). The process of interpretation is also included in this model, that is to say, both the sender and the receiver give feedback by decoding, interpreting, coding, and sending messages (Figure 6).

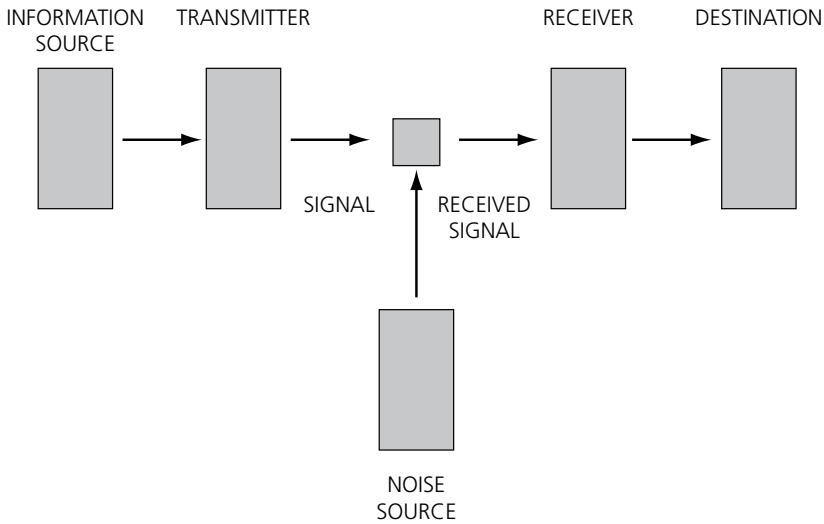


Figure 5. Transmission model (Adapted from Shannon 1948).

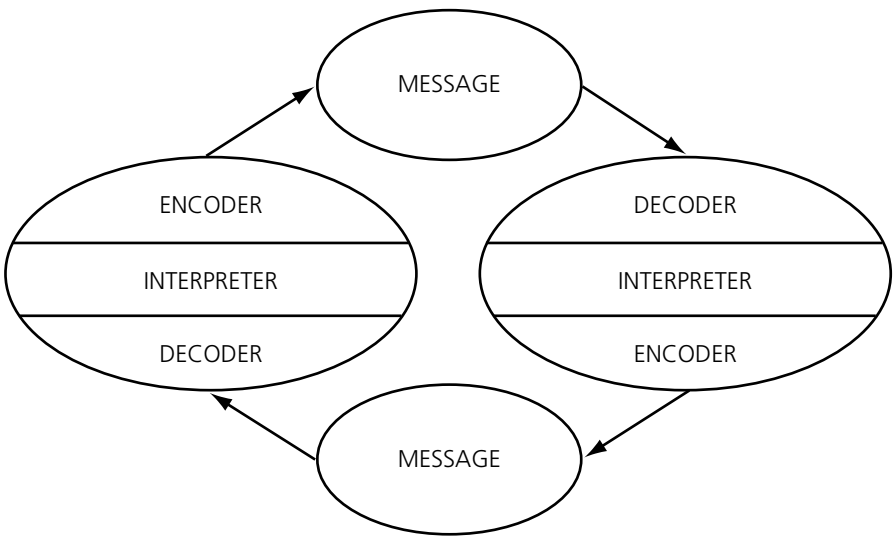


Figure 6. Circular model of Osgood-Schramm.

A model which seems to include many of the aspects covered in this thesis is Barnlund's transactional model (Barnlund 2007). This model takes into account both environmental as well as personal factors, and integrates the coding and decoding of meaning. It is also a non-linear model, and as such there is no definitive beginning or end of the communication process (Figure 7).

Communication, as understood in this model, is hence a complex activity involving a wide range of signs. or cues, which are divided into three types:

1. Public cues are derived from the environment (e.g. the temperature of a room, or furniture). These cues have to be available to others and remain out of the observed individual's control. There are two types of public cues: natural (belonging to the environment), and artificial (belonging to artefacts manipulated by humans.

2. Private cues by their nature are not readily available to other communicants (e.g. feeling pain).

3. Behavioural cues emanate from the individual's observations and reflections of himself. These cues can be manipulated by the individual (e.g. changing posture).

Coding is the process of creating (verbal or nonverbal) cues which are made available to others, whereas decoding is the process of assigning meaning to the various cues available. In this model, the processes of coding and decoding are considered to be closely articulated and interdependent, which is illustrated by the spiral inside the P1 and P2 circles (Barnlund 1970). In this thesis, autobiographical artefacts can be seen as a means of turning private cues into public ones.

One thing that is apparent in this model is that communication has no definitive beginning or end. It is a continuous, circular, and dynamic activity and every communication (cycle) is unique and irreversible. This is an aspect which can also be found in Dance's helical model, where communication is seen as dynamic, accumulative, unrepeatable, and continuous (Dance 1967). The helix metaphor is also often used to describe the design (research) process as a whole, where each turn represents an iteration of, for example, prototype development, user tests,

and feedback. Each iteration builds on the previous and takes the design a step further.

It is also clear that the context influences the message. A verbal cue, such as the question 'How are you?' will have different meanings if uttered in a public place or in a clinical setting. This model takes into account the complex nature of human communication, including power relations, language, social factors, et cetera. This implies that (a) communication is a shared responsibility (clarity, mutual understanding, etc.); (b) that it involves both content (information) and relationship factors (emotions, status); (c) and that meaning (coding/decoding) is based on a personal experience of the world. Here, the terms 'communication' and 'meaning' are interchangeable, which makes it clear that communication requires a certain degree of understanding of the other part, a second-order understanding.

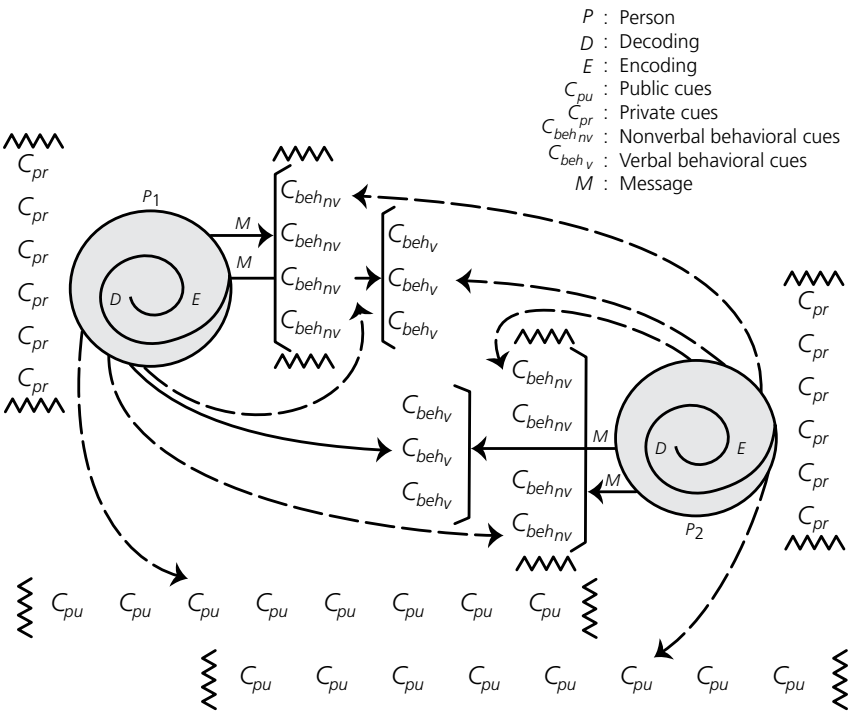


Figure 7. Transactional model (Adapted from Barnlund 1970).

2.5.2 Second-order understanding

In the research context, the distinction between first- and second-order perspectives is primarily a distinction between two kinds of objects of research. In a first-order perspective, experiences are about the physical world. Statements can appear more or less valid or consistent or useful, the acts more or less skilled, the artefacts more or less functional. The second-order perspective, on the other hand, focuses on people's experiences of the world, whether physical, biological, social, or cultural. When adopting a second-order perspective, we have to 'bracket' judgments. We have to look at the statements, acts, and artefacts to find out what ways of experiencing particular aspects of the world they reflect, regardless of their validity, skilfulness, or functionality (Marton and Booth 1997, 119-120).

> A man in the natural attitude, then, understands the world by interpreting his own lived experiences of it, whether these experiences be of inanimate things, of animals, or of his fellow human beings. (Schutz 1932, 108).

Communication is about making statements, acts or artefacts and understanding other people's statements, acts and artefacts. To a certain degree, this involves being able to put yourself in the position of the other. Krippendorff argues that designers have a special ability of second-order understanding, although he seems to use the term somewhat differently than it is used in phenomenology. He means that designers can understand other people's understanding of, for example, an artefact ('understand the understanding of others') (Krippendorff 2006, 66). Language is a very efficient way to share knowledge and meaning, but says Krippendorff, it is through interaction with artefacts that meaning is created. This does not mean that meaning is designed into an artefact or exists in the human mind as a sort of consciousness, but rather that it seems to be created in the activity itself. By acting, we create (our idea) of each other and negotiate our different perceptions of meaning in a given situation – we establish a common ground. In a constructivist view, the first person uses these methods to create an image of him or herself from which the researcher in turn creates an understanding of the first person. This knowledge and identity production is a two-way and reciprocal process, where the two individuals more or less influence each other. Subjectivity here is understood in its positive sense, as an affirmation of human subjectivity against false objectifications: man is not a mere outcome of anonymous natural and social forces (object) but the creator of his self and the subject of human history.

To understand and share meaningful experiences and bridge the subjective gap, the (design) researcher can use a participatory and situated approach. By being exposed to (parts of) the lifeworld of the individual, researchers create a basis of their own experiences. This activity and interaction-based position is also acknowledged by phenomenology. 'Phenomenology has no problem going beyond a single person's private experiencing because experiencing is inherently an interaction process in a situation with other people and things. What appears is neither internal nor external, neither just private nor just interactional. My situation is not just 'subjective' since the others in it are more than I can experience, but neither is it 'objective' since my situation does not exist apart from me' (Gendlin, 1973).

2.5.3 Communicative rationality

According to Schutz we are able to understand others by treating them as reasonable actors with which we share a common reality. This practical and rational assumption has its source in Husserl's notion of the *Lebenswelt,* lifeworld (Husserl 1901). Schutz argues that our understanding of others is essentially based on our own experiences, our own lifeworld:

> All genuine understanding of the other person must start out from acts of explication performed by the observer on his own lived experience (Schutz 1932, 13).

In a similar vein, Habermas talks about 'communicative rationality' or 'communicative action' when discussing rationality and interpersonal understanding (Habermas 1984-87). The main idea is that rationality is based on dialogue and argumentative speech, and that this interaction leads towards agreement when it is understood (Myerson 1994, 9). Depending on the domain of reality, certain claims of validity are necessary. These domains are established based on the function of the speech act, and the intention of the speaker (Table 1).

A speaker, in our case a research informant, engaging in communication can be making one or several of these claims, often implicitly, and it may not be clear which claims are made – if what is said is to be understood as true in a factual sense; if it is normatively right, that is, the right thing to do or say; or if it is a sincere and truthful expression from a personal perspective. This is, among other

things, a matter of context, which means that the researcher must be attentive to not only what is said, but also where, when, and how it is said.

Intersubjective understanding, as a dialogue in the communicative rational sense, seems to be based on a mutual agreement of shared experiences ('con-sensual'). This agreement achieved by the actions and interactions of social beings resolving practical and mundane problems in daily life. Language is used to affirm the degree of probability of this mutual understanding – if what is said and done makes sense according to good reason. In a research context, it is not enough to be 'where the action is', that is, to actively participate in order to have the same of at least similar experiences (Dourish 2001). It requires (implicit or explicit) agreement on a number of other factors, not the least of which are honesty, respect, and empathy.

Domain	**Function**	**Intention**	**Claim**
the external nature	teleological	objectivating	truth
our world of society	normative	norm-conforming	rightness/ appropriateness
my world of internal nature	dramaturgical	expressing	truthfulness/ sincerity

Table 1. Validity claims of speech acts.

3. Two cases

In this chapter I will introduce some aspects of two empirical case studies. Each case will represent one perspective on self-reports and self-expression in participatory design research, and material from the cases illustrating these perspectives are presented here. The methods used in the cases are discussed in the final section of this chapter, including some reflections on practicalities and issues. In the second part of the thesis I will relate to these perspectives and describe them as two different autobiographic practices, or technologies of the self: the self as image (instrumental self-portraits), and the self as data (information handling and digital technology).

Two empirical cases are presented in this chapter. The first deals with personal visualisations in healthcare and relates to medical images and how individuals (patients) can create their own images to gain a better understanding of their situation and health. It consisted of two parts. The first included artists, designers, engineers and artists who created concepts and visual aids intended to be used in dealing with a sudden illness. The second involved people living with a long-term or chronic illness. They wrote diaries and created images of how they perceived their situation and came up with examples of what kinds of tools they wanted in order to better understand their illness. The case is presented in more detail in paper I, and the impact clinical images have on our perception of ourselves and illness is discussed in paper II. The work was conducted at two sessions; one at the School of Arts and Communication, Malmö in late 2004, and the other at Spenshult Hospital for Rheumatic Diseases in early 2005.

The second case presents the design and development of a ubiquitous information and communication device, the Memory Stone, to be used by women during their pregnancies to store and share personal and medical information. The project involved pregnant women who contributed with their experiences and wishes as to how they perceived their pregnancy. Medical personnel (midwives, doctors and medical specialists) also participated, sharing their views on how their work is organised and how a Memory Stone could be used in their current work practice. A large part of the project focused on the technological development of prototypes which were used to test ideas and concepts in a number of different scenarios. This case study is presented in papers III and IV.

The pregnancy case was a part of the Palpable Computing project (PalCom). PalCom was an integrated project in the 6th EU Framework Programme under the proactive initiative the Disappearing Computer in Future and Emerging Technologies, part of Information Society Technologies. The duration of the project was 48 months (01.01.2004 - 31.12.2007) and I participated from February 2006 until the conclusion in December 2007.

The cases may at first appear divergent, since the first is more conceptually driven and the second is technologically driven. The intention of both these case studies is to explore how first persons can introduce their personal perspectives on their situation into the medical context through the use of expressive artefacts. Each case is described in the following sections, focusing on some aspect of the overall theme of the thesis. This presentation overlaps, to some extent, papers I and III.

3.1 Case 1: Personal images in healthcare

This case study investigated how alternative visual aids in healthcare can be of use as a complement to printed and verbal communication between doctor and patient. One fundamental concern was to evaluate the influence and effect images have on patients' experience and knowledge of their personal health. The overall scenario was to examine the potential use of images at different points in time: the first week after diagnosis (investigated by a group of artists who played the role of patients), and for a group of actual patients living with a long-term illness. The task was to create visual representations of health from a patient perspective given certain diagnoses. A cross-disciplinary approach was used involving a range of methods, such as semi-structured questionnaires, interviews, workshops, and cultural probes.

I have four simple points to make:

– That in the near future, the exchange of information in healthcare will take another form;

– that visualisations not only are form and content, but also promote action;

– that the ability to produce visualisations facilitates thinking, learning, and communication as well as the skill to read other images;

– and finally, that there is a wide gap between the clinical images commonly used in healthcare and the proposed patient-provided images – a gap which reflects the differences in interests, perspectives, and means.

3.1.1 Patient group: Everyday life

This part of the case study builds upon two activities. The first was a game played during a visit to a clinic where the participants (approximately 30 persons) stayed during a short period of treatment. This session was used to inform them about the project and recruit people to the second part. Eleven participants volunteered. The second activity involved using a cultural probe at home for a period of three

to five weeks. Of the eleven probes distributed, ten were returned with contents and one was returned empty.

The material provided in the probe package included a single-use camera, a diary, a large sheet of paper, a notebook, some images for inspiration, instructions, information about the study, and a short evaluation form (Figure 8). The instructions for the use of the probe were very simple: 'Use the material provided to describe what is important to you and what affects you and your health in your daily life.' The intention was to provide tools and options to help them express themselves. The outcome of the probe was uncertain, but the hope was that it would originate from the initiative of the participants through their individual selection of what they considered to be important.



Figure 8. Cultural probe content.

An examination of the returned material revealed that the diary and the collage were the least used. There are several possible explanations. The majority of the participants experienced pain in their hands and fingers while writing due to their medical condition. The collage required them to use scissors, which could also be problematic. Many reported that the diary was irrelevant since they had already written short texts in the notebook provided with the camera. They said that the collage was unnecessary since they had already taken pictures with the camera. They were not expected to use all the material in the probe; the reason for the redundancy in material was to afford them with optional means of communication.

The collage depicted in Figure 9 was made by a woman in her mid-forties. She considered the collage to be a very stimulating and rewarding way to express herself, which is apparent when looking at it. In a vivid and colourful way she covered several important aspects of her everyday life. Her strategy of mixing humour and seriousness seems to be helpful when trying to cope with a difficult situation. The way she chooses a funny picture and combines it with a serious and sometimes negative text seems to provide an opportunity to defuse potential feelings of resignation or hopelessness. In her choice of images and the texts she also describes her situation in terms of 'living' rather than 'enduring'.

The second example depicted in Figure 10 is different in style as well as content. It is more structured and organised and lists important events or activities. The simplicity of the drawings should not be thought of as something negative or less valuable. Instead, it should be stressed that although the person who drew this 'storyboard' was not used to drawing, he or she actually did it, and found it useful and inspiring. Hence, it is not the quality of the final picture which is important, rather the quality of the action of drawing and referring to it.

By combining images and cut-outs with their own texts, the participants succeeded in telling their stories. It seemed to be easier for them to write shorter texts in combination with cut-out images or simple sketches than to write in the diary. Perhaps the images worked as an inspiration to write the texts, or they abbreviated what had to be written down. The collages can later be redrawn, adding new features and removing old ones, in a continuous loop.

All of the participants who returned the probes had used the camera. This was a bit of a surprise, since the single-use camera provided was rather difficult to handle, with small parts and mechanisms. Despite the problems and, in many cases, pain experienced in handling the camera, the mere use of it I take as a proof of its 'useworthiness' (Eftring 1999).

All but one of the participants reported that the camera was fun to use and gave important feedback by making them think in another way; and this without even having seen the photographs they had taken. This means that it was not really the photographs as such that were so important, but rather the action of taking them. The opportunity to share important things in their lives was appreciated and meaningful and the feeling of having something meaningful to say was



Figure 9. Collage 1.

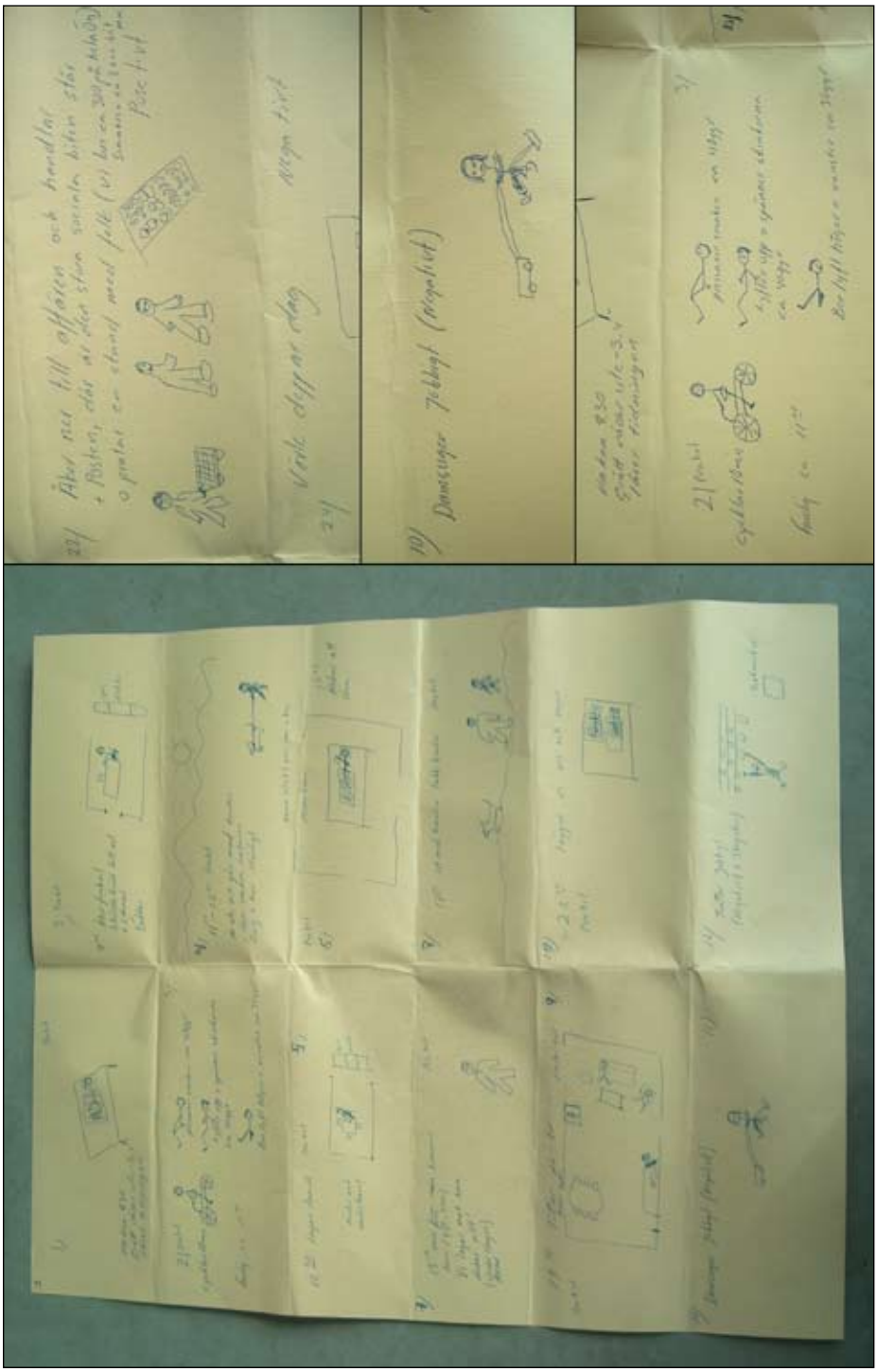


Figure 10. Collage 2.

stimulating and thought provoking. The simple fact that someone was interested in what they had to say and was actually listening proved significant. In the context of visual literacy, I think it is important to stress not only having the ability to 'read' images, but also having the skill to 'write' and share them.

A quick look at some patient-provided images reveals some common features when compared with clinical images of rheumatoid arthritis (Figure 11). They are personal, not objective. This is no real surprise, but it never was a prerequisite in the study. The purpose of these personal visualisations seems to be non-intentional, or non-instrumental. The real function of the collages and photographs appears to promote the actual activity of producing them, including reflection and interpretation. In contrast to the (ready-made) clinical images these patient-provided images are an encouraging activity and enable participation in the encoding of information, experiences, and emotions, often through the use of episodic narratives.

Patient-provided images	**Clinical images**
Personal	'Objective'
Non-intentional	Intentional
Encoding	Decoding
Narrative	Descriptive
Giving (telling)	Receiving (being told)
Performative	Analytical
Active	Passive



Figure 11. Clinical versus personal images of arthritis

3.1.2 Artist group: Getting a diagnosis

There were nine participants in the artist workshop (five males and four females) with backgrounds from visual arts, engineering, creative production, film making, and other related fields. The session was held at the Malmö School of Arts and Communication (K3), Sweden and lasted for two hours.

These people were engaged due to their specific knowledge and skills. One reason for this was their ability to produce concepts and prototypes which could be used as examples later in the project. A second reason was to test the feasibility of the following hypothesis: If they could not produce visualisations it would be less likely to assume lay people would be able to. It was also expected that their output would differ in content and form from that of the group of lay people.



Figure 12. Collaborative prototyping.

A collective brainstorming session was conducted to introduce the topic of the workshop and to define the area of interest. This included making a list of associations concerning medical images, demands on the involved individual in a medical situation such as previous knowledge, ethics, emotions and matters of format, usability, intention, appearance, et cetera.

Using the map of the associations as a springboard, the participants were told to turn the apparent aspects into their opposites, literally and conceptually. This was facilitated by making the familiar strange or by using a range of analogies and metaphors to spark creativity and formulate ideas. It was important for them to

keep their minds open for divergent ideas and spontaneous associations. All ideas were encouraged no matter how strange or far out they might seem.

The participants, who acted as patients, were then told they were hypothetically diagnosed with one of three serious illnesses: multiple sclerosis, myocardial infarction (commonly known as heart attack), and breast cancer. The diagnoses were selected following a number of criteria: they were serious or life threatening, afflicting ordinary life to a great extent; they were not unusual for individuals in the participants' age group; there was abundant information about the diagnosis from a range of sources (internet, friends, medical system, et cetera); and the participants would be familiar with them. A diagnosis was assigned to each participant according to epidemiological probability and presumed individual reaction. Some information was given concerning symptoms and impairments, and possible treatments and prognosis.

The severity of the illnesses was stressed and they were told to return for a second consultation a week later. This imagined week would let them experience a state of limbo until their next consultation with their general practitioner. The participants were told to answer the following question individually: 'What do I want to know about my condition and how do I want it to be presented?' They were then separated into groups of three according to diagnosis. They were asked to create a concept or prototype to visualise the ideas and questions they had in regard to their particular diagnoses.

Simple material was handed out for inspiration and information, material presumed to be available to any person diagnosed with the conditions including: patient-related information about the diagnoses (ranging from basic to advanced), demographics and statistics, diagnostic and alternative images (A4 print outs), paper, glue, scissors, pens, tape, et cetera.

The participants hypothetically diagnosed with multiple sclerosis came up with the idea of creating a game board for their future life – a kind of existential game. It was intended to be used as a tool for exploring a multitude of possibilities and paths in the future (Figure 13). The key issue of the game was hence social and emotional, not medical. This game relates to the day-to-day life of the individual, not just the medical/clinical aspects. It is possible to play ahead of time – to experience the future by trial and error without risking anything. As such, it is a

visual and interactive tool, displaying present and past choices and enabling back-tracking by tracing the steps made, showing their influence on the present (game) situation. It also allows several players to interact with each other, combining their individual game boards, facilitating learning and mutual support. From a patient's perspective, this could be a useworthy approach to a visual/empowering tool. If we compare this to a clinical magnetic resonance (MR) image, they not only look different and depict different aspects of the illness, there is also the inherent feature of interaction and choice in the game board version which is absent in the ready-made MR image. The game is open-ended rather than final. It is a negotiation, not a verdict. Paraphrasing Latour, this is not a matter of following a context, rather of following the simultaneous production of a 'text' and a 'context' (Latour 1991).

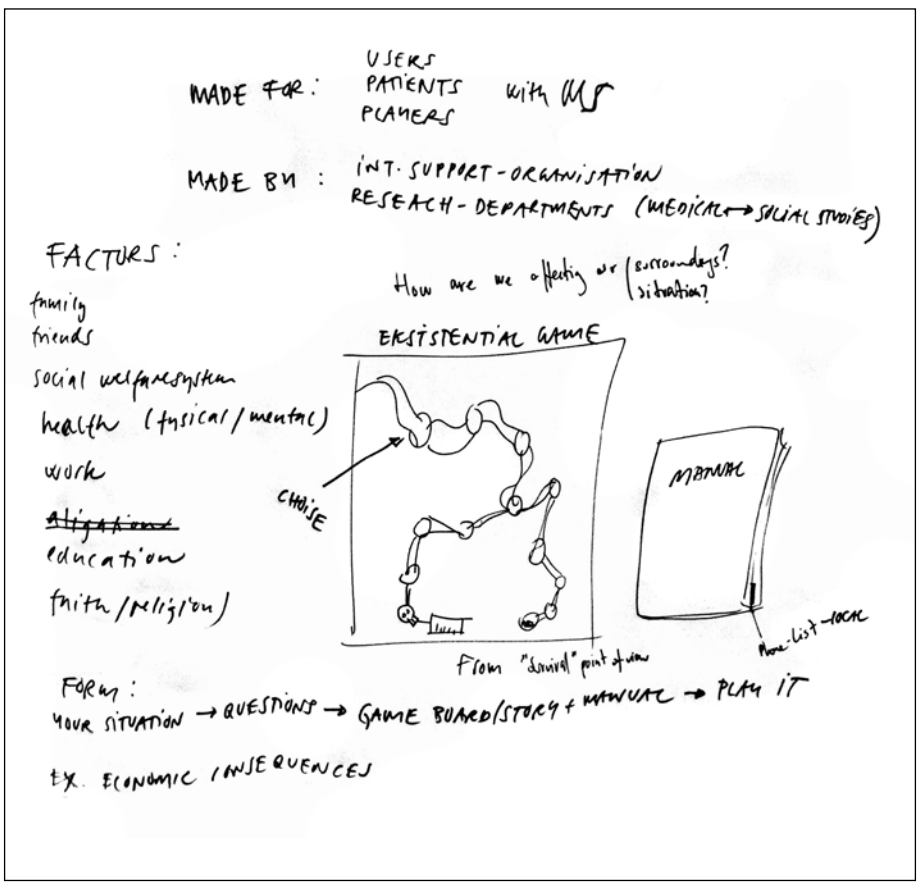


Figure 13. 'Possible futures' concept.

The concept of the solution proposed by the group hypothetically diagnosed with myocardial infarction was based on the notion of enlightenment and the idea of the whole/healing human (a word-play in Swedish). The basis for this is the ability to lift yourself up by pulling your own hair, which is taken from the stories of Baron Münchhausen[2] (Figure 14). First, ten crucial questions must be answered in a straightforward way since everything is uncertain after the first short consultation. It needed to be easy to quickly gain an understanding of what is going on. The format chosen by the group was a web site where the patient could get basic information about certain questions. This was based on the notion that doctors always describe the life and health of the patient as discreet points (x-rays, blood tests, medication et cetera) between which the patient, both conceptually and emotionally, draws the contour of himself. It is a self-generating concept including matters closest to the heart such as family, work, holidays and how everyday life will be. More detailed information could be searched for at later stages. Questions of how to reverse the process by changes in lifestyle were also discussed (e.g. stop smoking and start exercising). In addition to the information provided by the doctor, stories from other patients would be needed to add personal or even poetic accounts of how life was treating persons with this specific diagnosis (patient-to-patient). It should also be possible to get a second medical opinion.



Figure 14. The whole/healing human concept.

2 The English expression would be to pull yourself up by your bootstraps.

Fundamental to this concept is that it is always the patient's responsibility to do the job of healing, not the doctor's. The doctor is to indicate the problem and solution, whereas the patient is the active partner, healing himself. This is to be understood as an emancipatory and pro-active approach.

The most important issue for the participants role-playing the breast cancer diagnosis was how to cope with the week until the next consultation. During this period there will be much worry and anxiety as well as confusion and possible denial. The concept of distraction or escape was chosen to be the way to solve the problematic situation until the next meeting with the doctor. A paper toy, known to all the participants from childhood, was produced and named Move Focus (Figure 15). The toy works like a randomised answering device. You say a number and the player flips the sides of the toy that many times. Then you choose one of four questions visible on the inner side (two sets of four questions, each visible depending on the number of flips, one for odd numbers and one for even). Underneath, there are answers to the chosen questions.

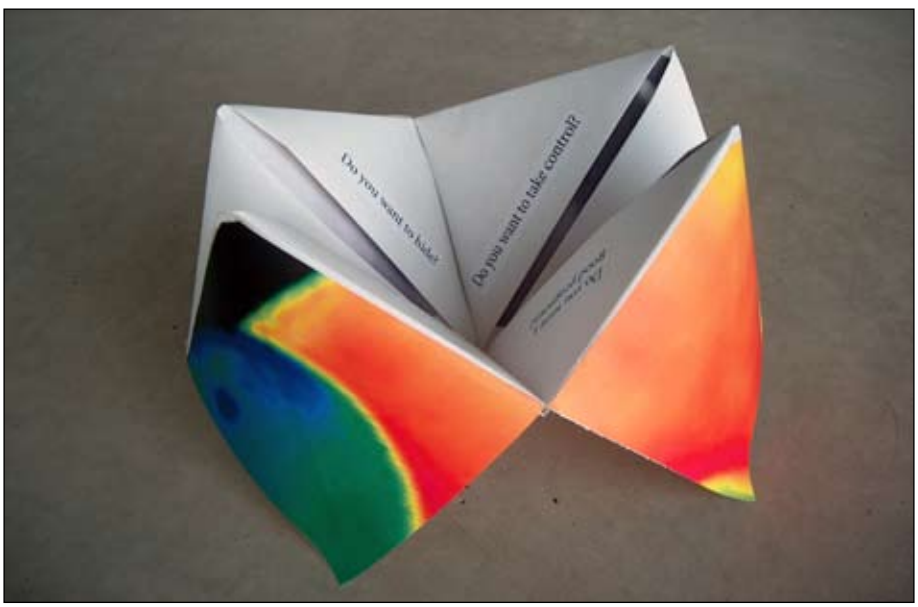


Figure 15. Move Focus.

The themes of the three different artist groups can be condensed to: exploration (multiple sclerosis), emancipation (heart attack), and escapism (breast cancer). These aspects of visualising health should not be seen as unpractical, rather as complementary. One reason why the responses focus on different aspects is that they describe different points in time. Another reason is, naturally, that the participants in the three groups have different roles and interests.

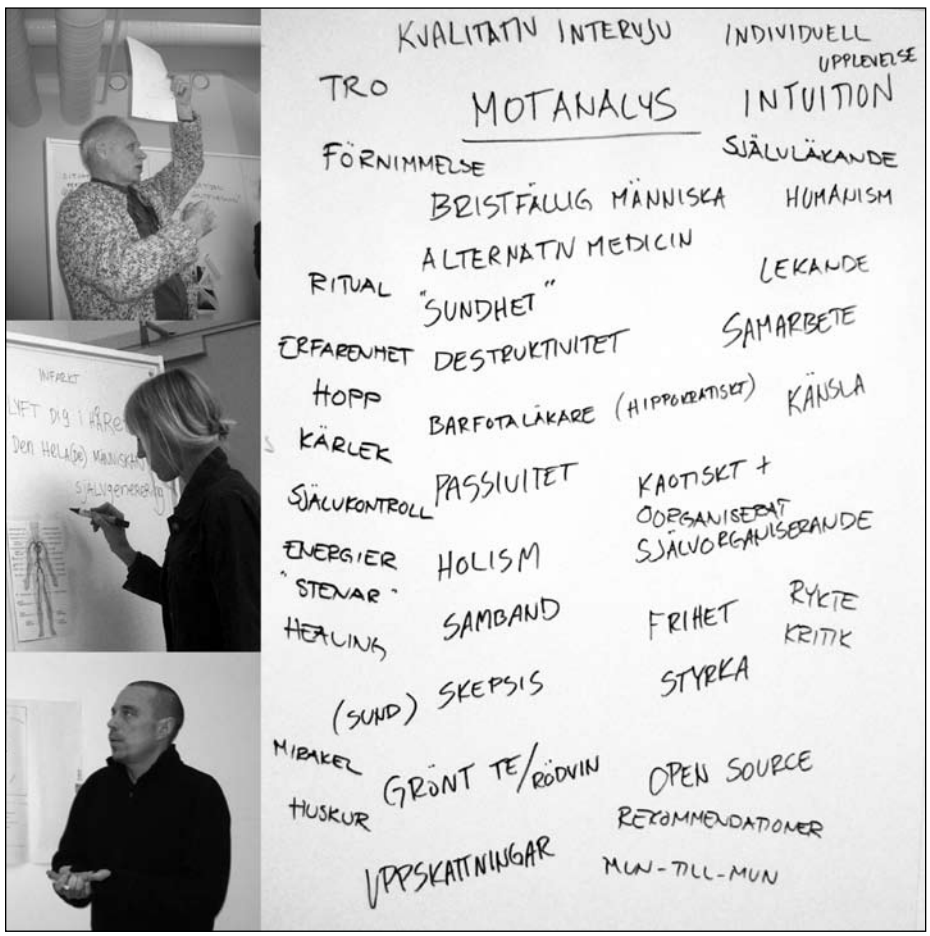


Figure 16. Workshop discussions.

3.2 Case 2: Pregnancy and early maternity

The main objective of the pregnancy case study was to investigate the impact and use of pervasive technology to support the needs of pregnant women and their partners, as well as maternity care professionals during the course of a woman's pregnancy. A digital device called the Memory Stone was developed intended to support the women and their families in different health-related and social contexts. Of interest for this thesis is how the Memory Stone can be used as an artefact for self expression. By using this device the pregnant woman – and her spouse – become the main carriers of information and as such are supported in collecting all information of personal interest or usefulness, whether at home, in contact with healthcare professionals or with family and friends. This device, and the entire concept, is applicable in a multitude of other areas both personal as well as in a medical/rehabilitation context. It can be used wherever there is an interest in keeping personal diaries, handling medical information in novels ways, and interacting with information technology at home and in healthcare.

3.2.1 Participatory creation and reflection

The pregnancy case study included eight workshops, an ethnographic survey, and development of a series of prototypes. The empirical base was relatively small involving ten pregnant women in two separate sets[3], four fathers-to-be (participating second-hand) and approximately a dozen healthcare providers of different professions. The pregnant women were recruited by being approached in the midwife's waiting room, through pregnancy chat rooms on the internet, and by invitation from their respective midwives. The emphasis from the start was on designing in collaboration with the intended end-users. Insights into the requirements and needs of end-users were gained in mainly two ways: field observations and multidisciplinary workshops. Findings from these activities were used to realise use scenarios and application prototypes which then iteratively were tested in additional workshops.

3 The first set of pregnant women gave birth and thus a second set of participants was recruited.

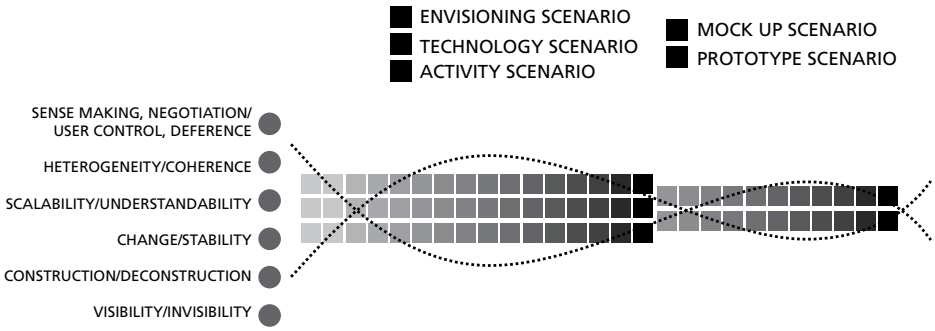


Figure 17. Two strands of scenario development.[4]

One of the project's strategies for successful design and development of palpable systems was becoming familiar with the current work practices that emerging technologies could support in the future. Everyday activities and work routines were observed and analysed. This included taking part in medical examinations, joining pregnant women for doctor and midwife appointments, making rounds with nurses on the prenatal ward, and similar activities. A number of field studies were hence conducted to develop a better common understanding of pregnancy and early maternity as a problem domain. The insights gained through these research projects were used as input in the successive research activities. Two researchers and one of the participating medical doctors conducted the field studies independently at a half dozen sites for a total of 17 days. Notes and video recordings from the field work were collected and evaluated at a joint workshop.

In the first phase of the project three categories of scenarios were addressed: activity scenarios, envisioning scenarios and technology scenarios. These scenarios were selected in a design process starting with the field work observations and then submitted to a further selection process in collaboration with various project stakeholders (Figure 17).

4 In this process it is possible to recognise two main strands, each of them accounting for two different contributions to the development of scenarios (dotted lines). One is grounded on field studies and participatory design. The other is inspired by the tradition of industrial design, borrowing from that field methods and techniques for triggering creative processes. These scenarios converged in early design ideas and solutions and were developed through mock-up and prototype scenarios.



Figure 18. Low-fidelity mock-up.

In the second phase of the project, mock-up scenarios and prototype scenarios were developed. These describe (at various levels of abstraction) the functional requirements of the system under design, indicating what capabilities must be provided. They also represent a means to reflect in the context of 'doing design'. They are focused on representing in an explicit form the function the system will serve in a user's life, the roles it will cover in their activities, and basically aim to provide a global sense of how the artefacts will interact with current work practices. The use scenarios in the pregnancy study can roughly be categorised in two partially overlapping sets: one focusing on technological and interaction issues and the other describing user experience and the activities of the pregnant woman. The aim was to generate and extract discrete elements which could be implemented and tested throughout the design process.

In the workshops, researchers and end-users discussed ideas, and experimented with new technologies or test prototypes. Here doctors, midwives, and pregnant women provided us with feedback and new insights. For a description of the various workshops, see paper III. A simple mock-up ('cultural probe') was used to gather information about and inspiration from the participating women and their daily life (Figure 18).

3.2.2 The Memory Stone

The Memory Stone is a one-button device which provides storage of different data types by connecting it to external devices (Figure 19). Data can be exchanged or displayed on compatible units. Basically, it is a small handheld device consisting of an embedded computer, a flash memory and a Bluetooth radio. It is the size of an ordinary pager, organically shaped, has an extremely simplified interface (one button and a buzzer), and supports storage and use of different data types (e.g. text, pictures, biomedical data, video).

The development of the Memory Stone was based on the ethnographic field work, the various scenarios, and a range of intermediate prototypes. Some of these prototypes focused on user interaction, others were developed in order to better understand media storage and information handling. A third category was used to collect examples of the type of data the pregnant women wanted to store and share.

The development cycle started with low-fidelity mock-ups simulating functionality as a means of demonstrating the concept. The different prototypes were partly developed in parallel and were evaluated separately. The results were used as input for the final functional device. Some of the prototypes were implemented as software on a mobile phone platform in order to test interaction, user feedback, usage of external screens and other device-independent factors.



Figure 19. The *Memory Stone*.

Since many participants stressed the need for keeping track of important dates, general information concerning various phases of the pregnancy, and tools for planning ahead, a calendar function was implemented on a PDA version of the Memory Stone. Since the focus of this prototype was to spark discussion and provide proof-of-concept, the current strategy of choosing an existing hardware platform was seen as most beneficial. One group used a calendar service running on a PDA; another used a notebook and a low-fidelity mock-up. The services implemented on the PDA were:

– A diet monitoring service. This service supports the pregnant woman in monitoring her intake of various substances such as food, alcohol or tobacco, perhaps according to some pre-set limits or purely as a motivator for a healthier pregnancy. This service is used as a proof of concept on entering data into the Memory Stone.

– A breathing exercise support service. This service is intended to facilitate birth preparation training programme, but could easily be used for other purposes. Since this prototype hardware does not have a vibrator itself, it searches the environment for a device with vibrator functionality (e.g. some newer phones). Once discovered, the device can transfer a small service enabling the phone to vibrate at predetermined intervals. This service is a proof of concept on connecting to and communicating with external devices in this context.

– A media service. This is for managing and viewing various types of media. Currently it is only able to view videos and pictures already on the PDA. The media service could store pictures and videos from ultrasound scans, for instance, as well as private pictures and video clips.

– A calendar service. This service resembles a regular calendar with all its uses. In addition, events and data from the other services are associated with a date, enabling the pregnant woman to access them according to date rather than type through the calendar. For example, on one date there may be a diet entry regarding something she ate, along with a media entry with a picture of her tummy. Another date may store a reminder for an ultrasound scan appointment along with the video recorded at that session.

3.2.3 Storing and knowing

One of the first findings from the field studies was that midwives spend a large amount of time administrating data about the pregnant women and the consultations that take place during pregnancies. Discussions with the midwives show that much of this administration and co-ordination could be optimised, eliminating redundant information across the different IT systems used. Another observation was the abundance of technologies in the work environment, both high and low tech. There was an apparent imbalance between the amount of technology available to the midwife and the technologies used by the pregnant woman. This imbalance had obvious reasons, but was identified as a possible area of design and improvement. At present, the pregnant women keeps a pregnancy file ('vandrejournal'), a paper folder containing all medical information related to the pregnancy (Figure 20). This increasingly thicker folder is brought to each consultation and updated by the midwife or general practitioner. It has a dual function: the main collection of health data and the main means of communication between groups of healthcare professionals. Currently, there is no way for a midwife to access the medical record of a patient kept by a doctor. The information systems are separated and in most cases not even compatible.

Many sources of information (and misinformation) are at hand for the participating women. This was reported as being confusing and leading to a situation where one does not know what to believe in and which source of information to trust. Internet, relatives and friends, articles in newspapers and magazines, TV programmes are some examples of information sources at hand for the pregnant woman. The women in the focus group interview stated that it was important for them to feel safe during the pregnancy.

> It makes us feel safe to know that someone is looking after us – telling us what to do when. It would make us feel unsafe if we had fewer visits to the midwife – the midwife makes us feel safe. Opposing information is confusing (pregnant woman, focus group).

Providing correct and limited amounts of information was not enough – the women also had to understand and remember it. This was stressed several times by all of the participants. The idea was to use the Memory Stone as tool to engage them to actively take part in changing or updating the information in a way

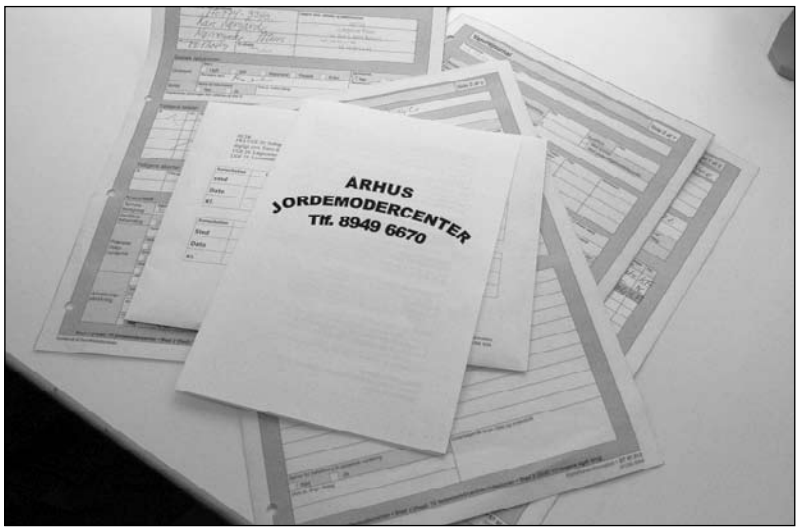


Figure 20. The pregnancy journal ('vandrejournal').

that is not currently supported technologically. This increased the sense of safety for the pregnant women since it gave them an opportunity to co-operate in the data handling as well as to re-experience the consultation on a later occasion by browsing through the facts and comments stored on the device.

Since the pregnant woman's body is subject to a tremendous change, the women were eager to know what to expect during the coming months, not only physically but mentally. Most importantly, they wanted to be able to document the physical change especially regarding the belly: pictures showing the belly week-by-week, belly measurements, an activity calendar of when the baby is active (allowing for comparison with the activity of the baby, once born), sound recordings of the sounds from the belly, and so on.

> Definitely a multimedia part for different pictures, not only for the ultrasound scans but also pictures of my growing belly, of mom, dad, siblings, the baby's room, et cetera (pregnant woman, diary).

Most of the pregnant women in the study welcomed suggestions for exercise and diet – what to eat and what to avoid. The women thought it would be useful to have advice about how to take care of their body. They suggested training programmes on how to strengthen and soothe the body, exercises to get into shape, advice on

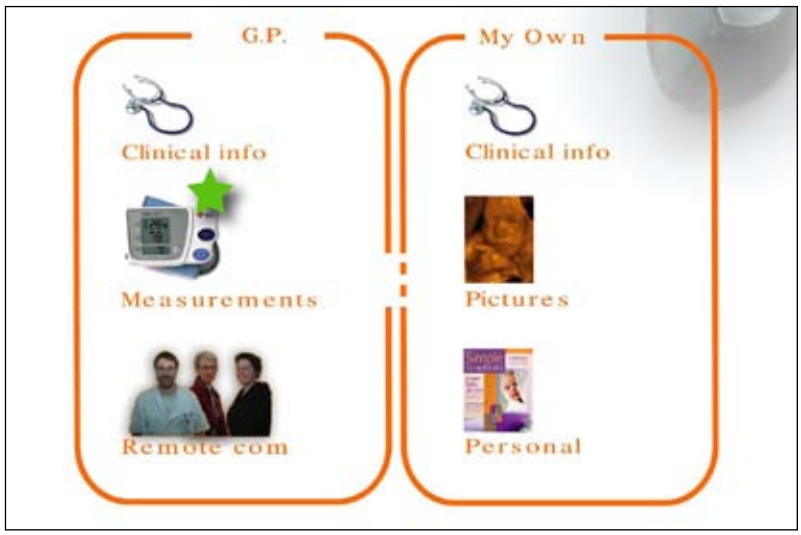


Figure 21. Conceptual computer interface.

what sports to do and to avoid during pregnancy. Physical birth preparation was also mentioned as a part of the lifestyle for a pregnant woman.

Late in the pregnancy, all the women grew more interested in several aspects related to the birth, such as preparations, anaesthesia, and different ways of giving birth. They also wanted recommendations on how to manage the initial period after discharge from the hospital – how to transport the child home, equipment you might need at home, over-the-counter drugs that might be needed, advice on the breast feeding, how to help the baby get rid of stomach gas, et cetera. The women also wanted to prepare the entire family for the new arrival – and specifically, if there were other children, how to avoid jealousy and how older children normally react to their parents. They wanted more information on vaccination programmes and in some cases, on post-natal depression.

It became obvious that the pregnant women were interested in having much more than clinical facts available on the device. They wanted to keep more personal and informal records similar to a scrapbook of the pregnancy and the first years, perhaps something for the child to have later in life. There was a great interest in creating a list of 'first times': the first time the pregnancy test came out positive, the first time you told someone about the pregnancy, the first time you went to the physician and midwife, the first time you felt the baby or the first time the baby kicked, had hiccups or the first time the father felt the baby.

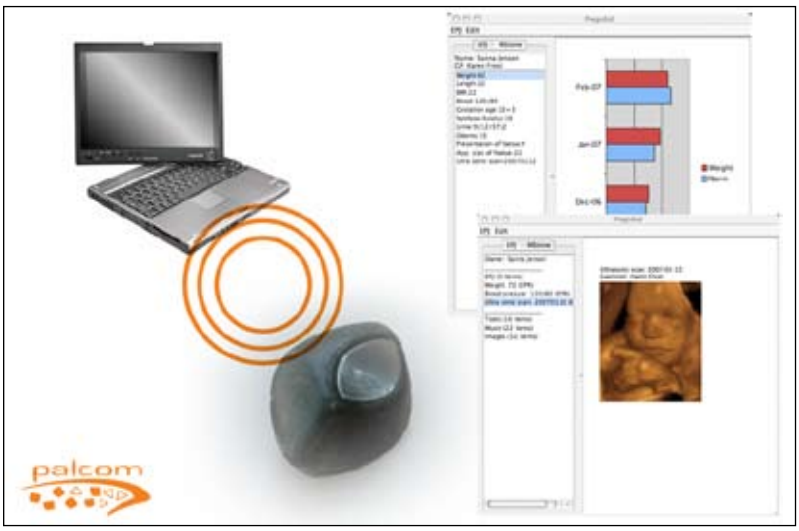


Figure 22. Information handling.

There was a general fear among the pregnant women of 'messing up' the clinical information on the Memory Stone, partly because not everyone felt competent with computers, partly because of the novelty of the device itself. This was interesting from an experiential perspective. Although all participants knew that the information downloaded to the Memory Stone was a duplicate of a selection of data and only intended to be used by the pregnant woman herself, both the professionals and the women were worried it could be lost or degraded. Hence, they all needed reassurance that the healthcare records and the data stored on the device were two connected but separate systems. Storing personal and clinical information on a portable device poses several questions about data security and integrity. In case of theft or misplacement of the device, the information should be safeguarded to a reasonable extent. Providing password protection and encryption were aspects of security discussed in the study.

Also, when displaying data on an external device during a consultation, for example on the PC of the midwife, or in a public space on a laptop, the participants stressed the importance of selective access (Figures 21 and 22). Some information, such as very intimate health data, could be made visible to healthcare personnel, but inaccessible for family and friends. On the other hand, some information could be public to family and friends, but irrelevant or even hidden from personnel.

3.3 Methods and practicalities

In design research there is a constant negotiation of tendencies of generalisation and specification. Often, relatively small samples (few individuals) are studied and on the basis of the collected experiences, some general conclusion may be drawn (including the proper caveats). Using Windelband's Kantian terminology, this is a trade-off between the objective nomothetic knowledge, and the knowledge of the contingent and subjective idiographic knowledge (Lamiell 2003, 89; Windelband 1894). This is especially apparent when using the experiences and knowledge of few or even single informants in design research.

Several different techniques and approaches often are applied together in case studies to collect input from the participants. The information gained is also used as a basis for development of for example scenarios, prototypes, and software which are fed back into the iterative design/research loop. This feedback is another way of minimising effects of misunderstanding and conflicting interpretations.

In the following sections I will comment on some of the techniques and methods used in the case studies and make some reflections on practicalities and problematic issues.



Figure 23. Workshop provotyping.

3.3.1 Methods in the cases

In **fieldwork**, participant observation with users was carried out by ethnographers, interaction designers, travelling architects, developers, and other members of the research team. An interdisciplinary review of ethnographic data, selection and analysis of significant pieces of data was conducted. **User workshops** were held for developing and evaluating a joint understanding of work practice, scenarios, prototypes, individual experiences, and so forth. **Fieldstorms** was used as a kind of brainstorming technique grounded in analysis of ethnographic data and experience (Büscher et al. 2003). Ideas are documented as sketches, video prototypes, animations, and mock-ups. **Wizard of Oz** experiments, a method for testing non-functional prototypes, were used in several workshops (Kelley 1983). In these experiments, mock-ups and non-functional prototypes are given to users to utilise in as realistic a way as possible. Wizards (researchers) then simulate functionality and behaviours of the technology. One idea behind using semi-functional prototypes in user workshops was to apply provocation through concrete experience in order to create new practices on the basis of current ones, something Mogensen calls *provotyping* (Mogensen 1992).

> On the one hand, provotyping resembles prototyping with respect to the need for concrete experience by working with concrete 'types'. On the other hand, the intention is not to 'guess' a possible solution ('proto'), but, as in activity theory, to *provo*ke current practice. … Provotyping can serve as a bridge between analysis and design. It uses the results of analysis by taking as point of departure a general knowledge about the organization in question. And it facilitates the construction of first 'guesses' in a prototyping process by providing ideas as to what should be changed and what should remain (Mogensen 1992, 49).

The concept of **Future Laboratories** was used as a means of speeding up socio-technical change (Büscher et al. 2004). Participants use functional prototypes to accomplish work as realistically as possible, in as realistic as possible settings. By actively crafting such partial 'artful integrations', future practice is developed in interaction with future infrastructures, environments, applications, devices and architectures; all can be evaluated and developed in the light of all others. Collecting information in private settings was done using a **cultural probe**-like technique in which personal creativity was essential. This concept was originally developed by

Gaver and colleagues as a way of tapping into the life of people by engaging them to reflect and interact with the material provided (Gaver et al. 1999). It has been debated whether this is a bona fide method or not, as well as its applicability in different contexts (Boehner et al. 2007; Crabtree et al. 2003; Gaver et al. 2004). Digital probes, implemented on mobile phones, for example, have been used as a similar means to collect users' experiences (Isomursu et al. 2003).

One can argue that using several different methods, and comparing the outcome is a way of triangulating data and strengthening the validity as well as the overall credibility. In the case studies, many of the methods were indeed practically different, but not paradigmatically. Researchers representing different scientific paradigms should be involved in order to achieve stronger triangulation of the results, as was done in the field studies of the second case.

Another technique used in the cases was **scenarios** and **use cases**. A scenario is an 'informal narrative description' (Carrol 2000, 41). This kind of storytelling draws on the knowledge of everyday life and is expressed in the individual's own words. Letting first persons tell their stories can be a good starting point for setting up requirements in the initial phase of a project. Naturally, a set of scenarios cannot capture all requirements and the full scope of an activity, nor the details of it. Rather, it should be seen as a personal account and as such, offer one perspective among many others. Gathering a number of these personal stories and iterating over time, this process provides a concrete tool for assessing the early or more advanced solutions. Scenarios themselves are design objects, artefacts that evolve along the design process being created, refined, dismissed and also sometimes deleted and as such, represent the basis by which the next design cycle should start. In the visualisation case, the scenario was hypothetical and introduced to the participant as an a priori condition. In the pregnancy case, the scenarios were constructed from information extracted from existing conditions. It would be helpful to keep in mind that these scenarios are artificial.

> Like all personal narratives, these stories are, to varying degrees, fragile constructions … that might shatter at any moment. (Jago 2006)

Use cases also take the perspective of the individual, but are more goal-oriented than use scenarios. Generally, a use case describes the 'normal course' taken through an activity (the course presumed to be the most common among the participants)



Figure 24. Future Workshop.

(Preece et al. 2002, 226). Taking the step from use scenarios (individual user stories) to use cases, several things happen. First of all, the actual words of the first person are lost. They have become spokespersons for a larger group of people. Secondly, itemising activities tends to simplify the original complexity of the activity. A third consequence is that only things that are possible (or easy) to add to a list are included. In effect, the story loses both the content which lies between the lines and the 'flavour' of individual experience and practice. Although the focus is on the activities and experiences of the first person, the overall aim of the scenarios and cases is to define requirements for implementation. It is in this step the initiative is taken over by the designer/researcher.

3.3.2 Practicalities

These things and others not mentioned here, indicate that there appears to be a voluntary pragmatic naivety in relation to the individuals engaged in research projects. Certainly they are acknowledged as individuals, and this is actually one of the reasons for engaging them in research initially, but in the end there is a need to make more or less crude generalisations from their input. I call this pragmatic since it is difficult, or even impossible to study a larger group of individuals as thoroughly as a few using the techniques mentioned above. It is a naive attitude since it is well-known that reality is more complex than can be captured by the more

or less crude techniques and methods of design research. Disbelief and distrust are in a sense bracketed, since the process would be impractical or even impossible otherwise. In other words, we do what is practically possible although we know that there is much to be wished for. It might be useful to shed some light on the flipside of this pragmatic approach. In the (natural) sciences, for example, these things would not matter since people (and their peculiarities) are not considered to be part of the research process. In participatory design and other sciences involving people as subjects, it definitely matters who conducts the experiments, where the research takes place, and under what circumstances.

First of all, there are several practicalities which seldom are mentioned in research papers, reports, or conferences, but are well-known to all engaged in practicing design research (Pedersen 2007). These are things which in effect influence the outcome of the studies in a way that must not be ignored. This is not only a matter of prototypes failing and thus infringing on the effectiveness of a workshop, but the mere fact that something goes wrong affects the quality of the participants' responses. A dead battery, lost network connectivity or screens that are too small will produce different results than if everything runs smoothly during a prototype test, even if the battery is exchanged, the network re-connected and so on. One simple explanation for this is that the level of attention of the participants is different; they have become distracted or disinterested. Another explanation is that the object of research is actually different.

Secondly, people cannot always be counted on to strive for what is 'good' or optimal. They are irrational, have physical or cognitive limitations that affect their ability, they may lack inspiration that particular day, or even be lazy. This in itself is nothing new. MacIntyre points out that in the social sciences, there is a counter-example for each prediction made in accordance with a social theory (MacIntyre 1985). These counter-examples derive from to the unpredictable behaviour of human beings. So if one is going to try to establish a practice based on actual human behaviour and abilities, these factors should not only be taken into account – they must be considered essential. Passion, superstition, fatigue and distraction should have the same impact on methodology as rationality, empathy, knowledge and creativity.

One (potential) problem or ethical issue arises when developing technology is co-operation with prospective users who are in a situation of change. This is especially

true when it comes to transitory states such as pregnancy. As mentioned earlier, the first group of women actually disqualified themselves from the study by simply giving birth. This resulted in them actually never getting a chance to really use the Memory Stone they had helped to develop. Also in rehabilitation, the time factor is often the most crucial one in determining if engineering efforts will be meaningful or not (Jönsson et al. 2006, 135).

3.3.3 Roles and relations

The researchers have a (natural) professional role in the research context, but the first persons do not. On the one hand, first persons are representatives of a group. As such they perform according to a certain 'programme' within the research project, fulfilling a need of the researchers. On the other hand, they are individuals with vastly different needs, wishes and incentives.

Participation is mostly voluntary, and the disinterested mostly do not bother to engage themselves in this kind of activity. There are a number of reasons one may want to participate but all participation involves a certain degree of risk of shifting the balance of existence in one's life. It can be experienced as threatening to deliberate over your own views of the world or of yourself, and to change habits and behaviours. On the other hand, taking a risk often means that there is something to be gained. Risk taking is a question of deliberation, preferences and odds. Foucault argues (in line with Nietzsche and the Greek-Roman tradition of 'parresia', speaking freely) that a valuable practice must include risks (Foucault 1983; Bleakley 2000). Without risk there is no gain. The approach is to challenge the unelected, weak, unethical and the double standards, to denounce the established truth. Risk-taking and boldness can be a protection against the potential narcissism a navel-gazing autobiographical practice can lead to. Considering that participation includes some form of risk-taking, it is clear that certain personalities are attracted to volunteer. This can in turn lead to a selection bias, which influences the outcome of the research made.

Personal relationships develop between researchers and informants, especially during long-term projects. Researchers are in many ways dependent on the participation of volunteers, who get little or no compensation for their efforts and time. This tends to compel (although willingly) researchers to be enthusiastic and persuasive

when interacting with informants. Reciprocally, the answers provided by the first persons may be tailored to keep the researcher happy and content. This personal relation is an important factor in the process of engaging participants. Especially when using techniques such as workshops and fieldwork observations over an extended period, the relationship between the participating individuals evolves and to some extent becomes personal. This affects the informants' compliance and the way they act in the various research activities. They want to 'be good', perform according to the presumed expectations of the researchers and contribute to the greater good and 'science' in general.

It is obvious that coming from outside design research and being asked to contribute is a difficult task. At the same time, there often is a desire to keep the participants protected and in a way innocent in order to get to the untainted 'reality' of the participants' experiences. It is in the interest of the researcher not to influence the participants in such ways that the outcome is compromised (biased). There are many things which influence the participants and their opportunity to perform. This includes the design research context as such, for example, the participants' unusual situation, the physical environment, and the unfamiliar methods used. It also includes the pre-understanding of the participants and their assumption of the researchers' expectations. Finally, the language, media and technology chosen by the researcher affect the content and responses delivered by the participants, as expressed in McLuhan's slogan 'the media is the message' (McLuhan 2003). A general issue is if the informants are capable of being unaffected by these factors.

> As a reviewer for my 2000 *Qualitative Inquiry* submission pointed out, "[Elizabeth's] narrative seems to me to be riddled with clichés and canonical ways of talking about family dysfunction that testify to her lack of a voice of her own, though I can't really say for sure."
>
> So I am left wondering who is really speaking in Elizabeth's story? …If Elizabeth doesn't possess the narrative authority I attributed to her, how stable is her story, her family, her self? (Jago 2006, 416)

One conflict of interest became apparent when collecting the cultural probe/diary after workshops. Several of the women had torn pages out of the diary to keep intimate records from the prying eyes of the researchers. This illustrates the paradoxical situation of a design for personal change. From a designer's point of

view, this only proved the success of the initial concept. The involvement of the participants had reached the intended level of intimacy and had engaged them to such a degree that they rebelled. In other words, the concept was appropriated.

From a researcher's point of view, this rebellion had two effects. Some (possibly) vital information was withheld from the research team. Through an open discussion in a meeting, the nature of this information was revealed and could be used for further analysis. The second effect was that the arguments used by the women clarified important aspects of the concept. Safeguarding intimate information, enabling data stratification, empowerment, and usability issues concerning visibility and control were just a few of the reasons for tearing pages from the diary.

3.3.4 Incentives and investments

Projects have a 'before' and an 'after'. Before the project is initiated, there is often a long period of planning, drawing up specifications, applying for funding, organising co-operation, and other activities which in one way or another define the work later in the project. To some extent, this constitutes a hidden agenda which the participating informants know little or nothing about. A question is the extent to which this agenda affects the actual research activities. Also, when the time is up the researchers move on to other projects and the first persons are often left with little or no means to proceed on their own.

There is a considerable investment on behalf of the research team. It is not customary to talk about this, but certainly it has consequences for how the work progresses. Strict time schedules, budget issues, gaining personal academic qualifications, competition, et cetera. On the other side, the lay participants also invest in this exchange. Time, money, personal integrity, and ideas are just a few of the things they bring to the table. In other words, they want it to be worthwhile, mean something in a larger picture. This is, of course, known to the researchers who hence want to give something back. Research is in a sense a matter of continuously feeding the stakeholders, be it the funding institutions, project partners, workshop participants, academic journals, or yourself.

All these, and many more aspects of doing research in practice can impinge on what is considered 'a result' and how the chain of research activities proceeds. In

the best of worlds (projects) this is not a problem, but it is always a critical issue in research to balance the practicalities with the scientific research activities. Walking this tightrope in day-to-day work, it is easy to lose focus and drown in problems emerging from technical breakdowns, administrative overload, and uninspired or hungry workshop participants.

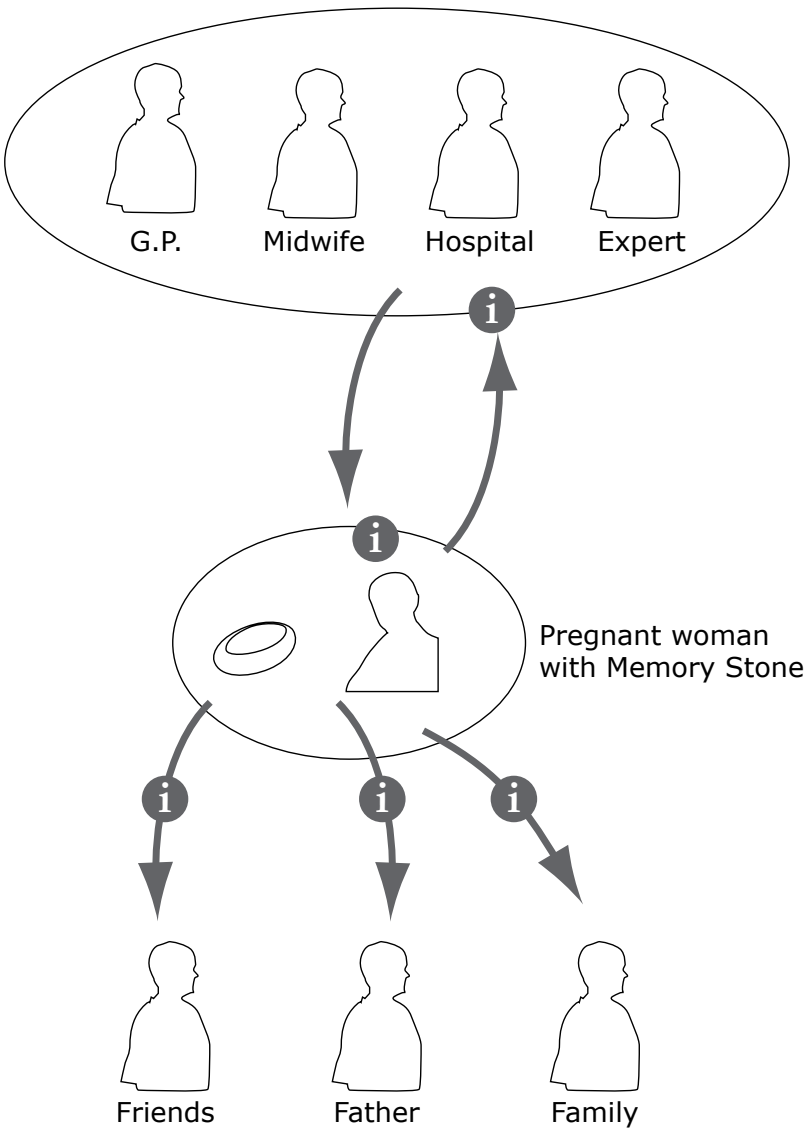
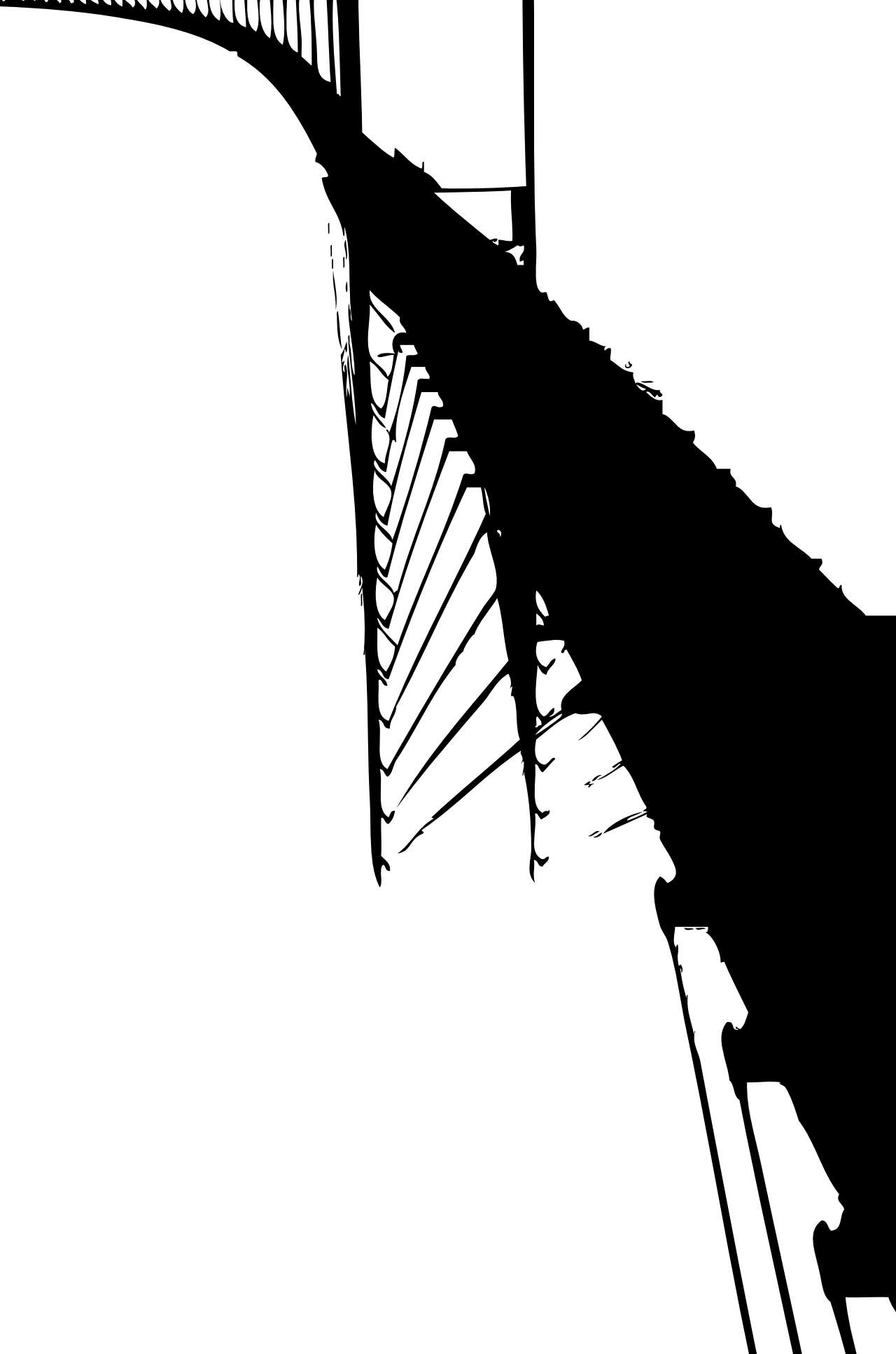


Figure 25. Primary stakeholders (case 2).



4. A bridge

We now leave the first part of the thesis which focused on what I have done empirically. In some respect we leave the past and look into the future. In the second part, I will try to bring together the three aims of the thesis. In the spirit of design, this part should be considered both as a result of the work performed and as a proposal. I have made a selection of three topics I think capture what I want to say. The first, 'Technologies of the self', discusses technology's role for the practice of autobiographies. The second, 'A science of the self', describes how it is possible to use autobiographies as means and materials in a research process. The third, 'Autobiographies', introduces various models of autobiographies that may aid and inspire design researchers. The last chapter, 'Coda', presents some reflections on the thesis as a whole.

5. Technologies of the self

In this chapter I address the meaning and impact of (information) technology as well as the possibilities these 'technologies of the self' provide for self re-creation. Clinical images and the quality of the information they contain are some of the issues discussed in 5.2. In section 5.3, the focus is on digital technologies used for storing and handling experiences and memories as data.

5.1 Meaning of technology

> The Greek for 'to bring forth or to produce' is *ticto*. The word *techne*, technique, belongs to the verb's root tec. To the Greeks *techne* means neither art nor handicraft but rather, to make appear, within what is present, as this or that way. The Greeks conceive of *techne*, producing, in terms of letting appear (Heidegger, 1971).

Originating from the words 'techne' and 'logos', technology is related to the knowledge of making and production. Since the times of Aristotle, four elements have been discerned which constitute technology (Rammert 2004). The first element is the stuff or material out of which a techno-fact is made. The second element is the form or shape that is given to it. The third element is the end or use for which it is determined. The fourth element is the efficient action carried out by the tool-using man. In what broadly can be defined as modern times, the understanding of technology has shifted towards the practical, utilitarian, and mechanical arts (Wilson 2001). Technology has at the same time become a hybrid of both science (episteme) and production (poiesis) since development and advances in technology are tightly interlinked with that of the natural sciences. Since the objects of this making (technological artefacts) are produced as a means to an end, it involves specific actions (praxis). As poiesis deals with things, praxis deals with people. This chain from knowledge, skill, materials, production, intention, and use resembles what we nowadays call design, and perhaps most obvious, industrial design.

It can be argued that this change of meaning of the concept follows the increase in the proliferation and impact of technological advances in society. One description of how technology determines cultural change is referred to as 'technological determinism'. This view includes a variety of positions with different strengths and it can be said to work on separate levels, for example micro/macro. The materiality of technology (the notion that technology is the things, machines, and tools which occupy every corner of our world) is consistent with this technological determinism. One consequence of this perspective is that it seems to lead to an inevitability of technology. The stance that technological change, pervasiveness, and application are beyond our control is easily adopted and hence widespread. The leader of the Manhattan Project, Robert Oppenheimer made this attitude clear:

> When I saw how to do it, it was clear to me that one had to at least make the thing. Then the only problem was what would one do about them when one had them. The program in 1949 was a tortured thing that you could well argue did not make a great deal of technical sense. It was therefore possible to argue also that you did not want it even if you had it. The program in 1951 was technically so sweet that you could not argue about that. (Winner 1977, 73).

This kind of understanding of the rationale of technological advancement is clearly more common than is apparent at first sight. Winner calls these unintended consequences of control 'technological drift' (Winner 1977, 88). In twentieth philosophy, there have been many critical voices trying to map the relationships between technology and society, for example Foucault, Heidegger, Adorno, Horkheimer, Habermas, and Ellul. Ellul uses the term 'technique' which is applicable to many areas in society, not only technology: 'Technique is a means of apprehending reality, of acting on the world, which allows us to neglect all individual differences, all subjectivity. Technique alone is rigorously objective' (Ellul 1964, 131). This seemingly independent, unstoppable juggernaut of consequence surfaces in the most unexpected places once you have become introduced to the concept.

Another approach to technology is provided by Dewey, who describes it as the art of experimental thinking (Dewey 1958). This is similar to sketching which is common in design, both as drawings but also more generally as a practice of creating tentative prototypes and mock-ups of various kinds (Budde 1984; Jonson

2002). It is clear that the individual, both as the maker of these technological artefacts but also as the user, is involved in the creation of the meaning of these artefacts (Csikszentmihalyi and Rochberg-Halton 1981). Technology enables the creation of individual and tentative universes, and gives access to different levels of reality. Through the use of (digital) technology we can create a world to fit our needs, wishes, and desires – a meaningful, although virtual, world. This view broadens the perception of technology from being gadgets or tools to being artefacts for creating meaning. It seems almost as if technology is the material of the creative human, constituting a specific hermeneutic (Asplund 2003).

> The hermeneutic relations emerge with the use and they determine the very meaning of a technology by the way how it is really practiced and not how it was originally projected. The evaluative relations connect different technical practices and artefacts with one another and regulate how they get included in the social collection of legitimate technologies and how this techno-structure gains influence. Altogether these relations constitute the particular form of technicisation that is practiced and institutionalized in social life (Rammert 2004).

It is clear that technology is not only a set of physical objects or artefacts. It also fundamentally embodies a culture or set of social relations made up of certain sorts of knowledge, beliefs, desires, and practices (Balsamo 2002, 2). Technology is pervasive, and society cannot be understood without or represented without its technological tools. Poster calls our contemporary digital era 'the second media age', a time when the old hierarchical structures are broken up (Poster 1995). Computers have changed from being a tool for information and communication to becoming a means (medium) for creation, and have been described as the tools of 'Homo Faber', the Renaissance concept of the creative man (Schneiderman 2002). Sobchack talks about technologised (techno) subjects when discussing the technological impact on our lifeworld and our symbolic experience of the self (Sobchack in Jones 2002). This has similarities with the notion of the 'cyborg', cybernetic organism, a term coined by Clyne and Kline in 1960 in a proposal for a new and more flexible human being (Clyne and Kline 1960). Haraway uses this term metaphorically, where the cyborg is 'a hybrid of machine and organism, a creature of social reality as well as a creature of fiction' (Haraway 1991a, 149).

> Information technology evolves in a distinctively different pattern than previous technologies, thus constituting the 'informational mode of development': a flexible, pervasive, integrated and reflexive, rather than additive, evolution. The reflexivity of the technologies, the fact that any product is also raw material because both are information, has permitted the speeding up of the process of innovation (Stalder 1998).

New media and information technology expand our ability to express ourselves, but at the same time they require us to manage the new demands and challenges that arise. This balancing act of negotiating media, content, intention, usability, and even existential issues is the formidable task of the designer as well as the 'user'. In spite of the widespread integration, power, and versatility of technology there is however a danger in blindly believing that you could be emancipated only through mere access to technology and media. Obviously, it is not things that change the world but the way people use them (Enzensberger 2003). Similarly to the fact that access to more information does not automatically lead to greater knowledge, new technology will not necessarily provide novel modes of expression and understanding. Cultural values, personal preferences and skills, social relations, and a range of other factors all contribute to determine the impact of new technology. In order to break habits, conventions, and in some cases rules, one has to have the necessary means and a certain degree of power. Not only power over oneself, but also over other people and technology/artefacts.

Foucault talks about four major types of techniques people use in order to understand themselves:

1. technologies of production, which permit us to produce, transform, or manipulate things;

2. technologies of sign systems, which permit us to use signs, meanings, symbols, or signification;

3. technologies of power, which determine the conduct of individuals and submit them to certain ends or domination, an objectivizing of the subject;

4. technologies of the self, which permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies

> and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality. (Foucault 1988, 16).

These 'technologies of the self' can be used to describe the reflexive practices which bring about a certain mode of existence, or subjectivity, such as being a 'patient'. The aim is to use these technologies of the self to emancipate the individual. To this end, access to and skills to use technologies of production and sign systems are necessary. In other words, it is clear that one must have a vital and ready-at-hand medium for shaping one's own understanding, something Schön means also is vital for design (Schön 1983, 271).

Mediation can lead to an autonomy of the artefacts in that they obtain an existence beyond their intended function. This can be taken so far that the artificial takes precedence and the real disappears into the background. For example, photography can change our perception of the world to such a degree that it leads to a situation of living by proxy – where images are more 'real' than reality itself (Sontag 1977). This phenomenon is well known and does not only apply to photography, as in the case described by Sontag, but to any representation, formal notation, and even the natural language (Molander 1996; Sällström 1991). It may also be possible to say that (technological) artefacts have become a part of ourselves as human beings and as such necessary for our communication with and understanding of ourselves and others.

> Technologies give access to different, multiple, and unknown levels of reality, and by its mere presence, this access alters the encoding of our world. … We are turning into Oliver Sacks' patients; explorers of worlds that are ours alone, worlds that have tastes, colors, and realities unique to each of us. Sacks' patients are, to some extent, prototypes of the cultural being (Dyens 2001).

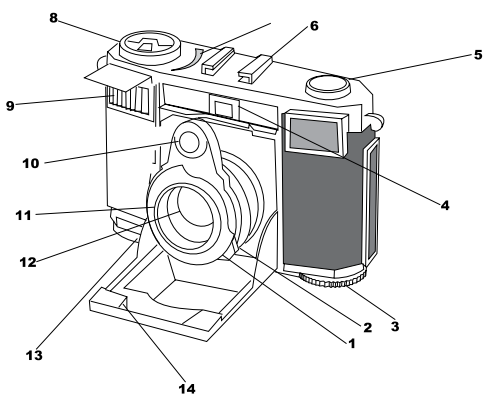
One question to ask in relation to the cases presented in this thesis is how we can talk about memories, experiences and to some extent ourselves as bits of data extracted from images or stored in digital devices. This might seem to be an overly instrumental and almost inhumane idea. To reduce the complexity of human experience and the almost infinite number of associations sparked by a memory cannot be captured by ones and zeros. Or can it?

5.2 The self as image

In this section I argue for the use of personal images in healthcare and rehabilitation as a technology of the self. The intention is to frame the first case study and to put it in a broader perspective. This section will be mainly argumentative rather than descriptive. First, the difference between clinical and personal images is discussed. Then, some examples of subjective visualisations are presented. Finally, I mention some issues concerning introducing these images into a healthcare context.

> Thus from both sides the image is felt to be weak in respect of meaning: there are those who think that the image is an extremely rudimentary system in comparison with language and those who think that signification cannot exhaust the image's ineffable richness (Barthes 2002, 133).

Medical images are increasing in number and are appearing in more places and contexts throughout our society. These images generate a great number of emotions and thoughts: on one hand curiosity, interest and fascination over the technological ability to show what used to be invisible and hidden, on the other feelings of disgust, fear and alienation since they are showing things we may not want to know. Most of us have no experience of relating to clinical images and even less so if they portray the inside of our body. From the design research perspective taken here it may not be relevant to ask if we want clinical images but rather how we can use the material to produce another kind of personal image to answer our own questions as lay persons/patients. In this section I will try to address these issues



5.2.1 Objectivity

Vision has long been associated with knowledge to a greater extent than the other human senses, an attitude which partly is a relic from the Renaissance (Cavell 1979). This has in turn given images (especially 'photographic' images) a very strong position as mediators/brokers of truth and authenticity. This tradition of attributing a form of objectivity to images is also present in medicine (Johannisson 2004, 2). Consider a simple photograph such as a self-portrait. If the image is sharp enough and exposed more or less correctly it is fairly easy for you to identify yourself in the picture. The image needs not be visually faithful when it comes to scale, colour, or perspective. Nor is it necessary for you to have certain skills to understand that it is you in that picture. How can images contain and convey 'truth' or rather, meaning, and how can we make use of such knowledge to develop patient-initiated and patient-oriented images in healthcare and rehabilitation? Barthes writes about the ability the photograph has to (uncritically) convey something that has really happened or existed (Barthes 1981, 80). What he means is that the photograph is not perceived as being the object itself but that testifies that the depicted object has existed. Historically, this has been the hope or even a prerequisite for the use of (photographic) images in medicine (Johannisson 2004, 127).

> When Roland Barthes wrote of the 'photographic paradox' by which the camera appeared to produce 'a message without a code,' he was writing of optical photography. In his account, the truth injunction of photography results from the laws of optics appearing to overpower those of semiotics or discourse, which, until the invention of the camera, were in total control of every message (Fiske 2002, 387).

The objectivity of the photograph as discussed above is no longer relevant, perhaps not even possible. Not only has the view of photography in general changed since after the post-industrial and post-modern era but also the digitisation of image production and consumption has transformed its association with objectivity. There is no longer a direct link between the object and the image as in the optical-chemical process of traditional photography. Transforming the image into bits of data ruptures this historical warranty of authenticity and this shift of the nature of objectivity is also present in modern medicine. Modern medical imaging technologies are much more advanced than conventional photography, some of

them not even depicting objects (organs, limbs) but biophysical processes such as metabolism or circulation of specific substances in the body.[5] The procedure of taking a diagnostic image often involves a formalised and almost ritual behaviour and often requires large apparatuses located in specialised departments. The image is a technical and conceptual construction whose 'meaning' and content is determined by the rational intention of the image (diagnosis), the technical and physical processes of the production (magnetic resonance imaging), and the interpretation (linking knowledge from past diagnoses and their images with the current one) (Burnett 2004, 50-51). There is no image without interpretation; the choice of mediating technology affects how the image appears. Imaging is a hypermediating activity in the sense that the medium and the imaging process will themselves be visible and present in a way that cannot be ignored (Bolter and Grusin 2000). Consequently it is no longer clear that the image is a depiction of the object. On the other hand, arguments like 'this is your femur' are normally used in conversation with the patient. It is not a matter of blindly and naively believing this as a literal truth. Nobody confuses an X-ray of a femur with a real bone, but the relationship to the image is metonymic – the meaning of the image is based on contiguity and association. This metonymic interpretation and use can be an initial starting point for the discussion of creating meaning through non-clinical images of perceived health. In Reinventing Biology Lynda Birke and Ruth Hubbard speculate how alternative perspectives on objectivity can change how we see the relation between the subject and the object in, for example, medicine (Birke and Hubbard 1995, ix). This collection of essays provides several examples of how research which is invasive, fragmenting and reductionistic ignores useful skills and perspectives that do not fit within the established framework. The criticism is not only directed against the object of study but is also a methodological critique.

5.2.2 Studium and punctum

> …the photograph analyzed offers us three messages: a linguistic message, a coded iconic message, and a non-coded iconic message (Barthes 1981, 137).

One way of studying the differences between the diagnostic-clinical and personal images is to use Barthes' two terms 'studium' and 'punctum'. 'Studium' represents

5 For example scintigraphy and functional magnetic resonance imaging.

a world of codes, culture, and conventional context. It is the content (meaning) encoded into the picture which can be detected, interpreted, and understood. In radiology this interpretation (studium) has a very specific purpose – to find anomalies, deviations. The studium of diagnostic images is the science of medicine and biology – stretching from the original intention of the venture based on rational science and practical knowledge, to treatment, and creation of new (medical) knowledge. In this study there is no or very little room left for other interpretations of the images. Nor are other types of images considered necessary, suitable or appropriate for this studium. For obvious reasons, the view of the patient is irrelevant when it comes to diagnosis, but there are more to these images than diagnosis.

'Punctum' is a certain characteristics or detail of an image (in Barthes, the photograph). It is not culturally designed or constructed in the sense of a traditional sign or semantic message. It is rather a quality of the image which attracts attention but may not necessarily be possible to interpret or 'read'. This 'punctum' is volatile in the sense that it varies between different observers. It can also vary over time for a particular viewer. It is not necessarily something that the photographer has seen or intended. The interpretation or rather the impression of a punctum is individual and depends on where and how the image is observed. The concept may account for one aspect of the non-conventional emotional and subjective properties of clinical images.

Using these two concepts one can argue that patient-focused or patient-produced images may have certain qualities that are not necessarily included in conventional clinical images. These patient-focused images can be seen as portraits in which its 'punctum' is the focus of a personal 'studium'. According to Rogoff, it is a question of granting the first persons the right to include their own values and concerns in the images as well as providing the methods and means necessary to do so (Rogoff 2002). It is simultaneously a question of exchange and participation. The emphasis is on interaction and exchange rather than depiction. Being able to produce and perform, to make yourself understood and to develop an understanding of your own is the goal of my approach.

> Depiction is therefore less important than interaction, process, and the interpretive judgments brought to the scene of images. …In this context of relations of interaction, it becomes very difficult to talk about images as if they were objects and therefore outside of the continuum of experiences that link seeing and understanding (Burnett 2004, 54).

5.2.3 Deconstruction – reconstruction

> Organisms are biological embodiments; as natural-technical entities, they are not pre-existing plants, animals, etc., with boundaries already established and awaiting the right kind of instrument to note them correctly. Organisms emerge from a discursive process. Biology is a discourse, not the living world itself (Haraway 1992, 298).

One aspect of medical imaging technology is to focus on increasingly smaller parts. Greater magnification enables the study of processes at the microscopic level and the ability to depict elements or processes that have not previously been accessible to the human eye. This in turn leads to a visual and conceptual fragmentation of the body and its functions, in part because of the scientific rationality which is the basis for modern medicine. The mechanical metaphor is still used, viewing the body as a system of interconnected and interchangeable parts. This metaphor separates the mind from the body and leads to a devaluation of emotional factors for healing (Lupton 1994, 60). The body is divided and codified according to a 'pars pro toto' thinking. Haraway describes a similar phenomenon when she talks about the encoding of the world (Haraway 1991a, 164). Much good has come from the sciences that use this type of rationality. On the other hand, it requires awareness in the understanding of the results coming from this transformation. This might be one of the reasons clinical images are out of reach for the first person. They are detached from the lived experience.

> Visual images are potent mediators of the lived experience of the body. … The making and meaning of the visual body's cultural message is a dynamic process under constant revision (Callen 2002, 603).

The creation of personal visualisations provides an opportunity to (re)construct oneself, at least conceptually. This reconstruction can be arbitrary in the sense that it does not need to be 'true' or static – as long as it is meaningful it fulfils its purpose. It does not even have to be a depiction in the traditional sense. Looking at these visualisations as transformations (re-pictions) they can be a way of reformulating questions and providing a different perspective than that of clinical medicine. Stephen Wilson writes that the art's interest in the impact of technology on identity and perception of self, (something that theoreticians in areas such as critical theory are concerned with) now has reached the biological sciences (Wilson

2002). The material which the human body is, is no longer given but subject to change and transformation. The effect of modern medicine and biotechnology is that the apprehension of the self becomes conceptual rather than natural. There is now a greater freedom to transform oneself physically (and mentally) by surgical and pharmacological means, but a freedom which is also restricted by how others perceive us (Wilson 2002, 156).

5.2.4 Examples

How can this extremely malleable but abstract digital material be used to re-construct oneself? Patrice Cair uses images of cross-sections of her own body to create a virtual environment in which the viewer can move around (Cair 1994). In another, collaborative work, Virtual Explorer you can navigate a miniaturised submarine inside a body:

> The basic plot outline is simple: you are caught in the middle of a compromised immune system, currently under attack, and must seek to determine the invader (antigen), it's type (viral, bacterial, unknown), and then attempt to understand and assist the immune system as it responds to the invader (Dean et al. 1997).

These two examples of an appropriation and reorganisation of the clinical discourse can be seen as educational, instructive and informative. You can explore an environment which in many ways can be seen as real and learn a lot about the body. One can also see it as a 'coping strategy' in cases where the individual's immune system is under attack and where there is a rational and instrumental reason for wanting to know more. A third option is to see this virtual environment as a computer game that takes place in both an exotic and personal environment. In this case, the intention and the approach to the material originally produced for rational, medical purposes are different. In a medical context, this game is subversive in the sense that it is unnecessary, useless, and false. It distorts the entire rationality underlying the images and does not contribute to the (medical) solution of the immunological problem.

…. image also has another, perhaps older, or at least more fundamental meaning, where image means 'offspring, child' (Weimarck 2003, 23; my translation).

Alongside X-rays, photos from diagnostic ultrasound examinations are probably the best known clinical images to the general public. As images of your own body they are the only clinical image which is available to you personally, at least in Sweden[6]. They have a significant emotional quality, something which mostly has been seen as a positive although unintentional side effect, but now has been acknowledged as a possible tool for encouraging improved diet and changing smoking habits during pregnancy (Pretorius 1996). An ultrasound image is a simple but clear example of how images that originally were exclusively clinical can be introduced into a private and emotional sphere as part of the (re)construction of self and self-perception. We can use ultrasound images of foetuses as an example to look at the difference between the medical knowledge and the personal meaning originating from a single image (Enquist 2006).



6 In contrast to Sweden, clinical images in many countries are kept by the individuals themselves and not in the archives of the hospital.

These images are in a way the child's first contributions to the family album, although they function somewhat differently from other kinds of family photographs of weddings, parties and holidays. First of all, they help to animate, or make real, the 'person' that the foetus is to some people. By looking at these images, the parents-to-be project emotions onto the image/foetus and start imagining how the baby will be after birth. These images are also shown to other people, family and friends, and thus the baby is introduced into a social context even before it is born. Secondly, this phenomenon gives the foetus an independent status. Deborah Lupton writes about how the ultrasound images of foetuses have given them a 'cultural' body, which is increasingly separated from the body of the mother (Lupton 1994, 18). This practice of providing images of foetuses strengthens their status as human beings, which has led to a separation between the different interest groups, with abortion opponents ('pro-life') on one side and the more liberal forces ('pro-choice') on the other, both using images to prove their point. This example demonstrates the power of vision and the impact images have in our society. To my knowledge there has been no similar debate as a result of the practice of listening to heartbeats which is conducted regularly during a pregnancy. Next to feeling the foetus kicking, these heartbeats were the strongest experience of 'reality' I had when I became a father for the first time.

5.2.5 Issues

Digital technology allows a creative and dynamic appropriation of the images produced and stored in the hospitals but there are several limitations to an 'open source' approach. Economic, legal and ethical issues provide strong arguments against sharing this material, even on an individual level. There has also been a technological argument claiming among other things the difficulty in a smooth, safe and inexpensive way to duplicate images, although this has largely been eliminated by the digital revolution.

> The computer-mediated milieu renders the body nakedly public. …Will this open-ended trend toward complete exposure give rise to the same sense of vulnerability, shame, and powerlessness that the eighteenth century associated with anatomization? (Stafford 2006)

The traditional relationship between medical doctors and patients is another obstacle against using patient-focused images. The depicted person, often a patient who is examined clinically, must have a mutual agreement, or 'contract', with the physician. It does not need to be, and is actually very rarely explicitly stated but rather is the result of traditions, practices, personality and other factors. Donald Schön has described two types of such a contract: the traditional and the reflective (Schön 1983, 290). The first type is based on an expert-client relationship where the client relies on the expert knowledge, which in turn provides a feeling of security and certainty. In the second type the client takes a more active role in creating the behavioural world to engage, understand, and thus influence and have (some) power over the situation. In the second contract, we can speak of an information process where the client ('first person') in interaction with the physician is trying to create a personal knowledge of himself (and his illness). In this process, the client/first person becomes what could be described as an informed patient. Depending on which contract is agreed upon, different types of 'medical' images are produced.

Ownership and the right to use clinical medical images are often unclear which may cause problems if you later want to take home and distribute your medical images. Although these types of pictures depict events in a person's life that may be of utmost personal importance and concern, they are not readily available to the individual. This situation will remain as long as these images are considered to be tools exclusively for the professional expert.



5.3 The self as data

In this section I will present examples of technological attempts to store human experiences digitally. The intention is to frame the second case study as it was presented earlier and to put it in a semi-historical context. I use the term 'memories' as a crude approximation of the aspects of human experience which can be stored as data.

5.3.1 Bits of memory

It can be argued that a person's memories are an integral part of his or her identity. Memories are constantly adding and removing anchor points along a mental timeline, through which we as human beings construct and reconstruct our lives and our 'selves'. Human memories are not true and static records of events but are constantly being mixed, altered, and partially forgotten. They are, in a sense, open for debate and deliberation. Memories are also vital for being able to have a notion of the past, present and future. Without memories, there is only a 'now'. Since life, as Kirkegaard puts it, must be understood backwards, but is lived forward, your memories tell who you are today and shape your future self (Kirkegaard 1958, 1843/89).

Using various types of artefacts to preserve memories has a long history and modern information technology can be seen as a powerful distributed memory bank of humanity as a species. One question is if we remember more today, or in fact less, due to this monumental increase of information available. Information technology has not only changed the quantity of the information/memories that is possible to store, but also the quality. Contrary to human memories, the digital are well-defined, constant, and universal. Exchanging digital data is a matter of retrieval, duplication, and transmission – not experience. The actual human use of technological memories is not just a matter of shuffling bytes, but more importantly how to select and make sense of them. Developing intuitive and efficient user interfaces for facilitating fruitful and mutually beneficial social and cultural exchange is one challenge, transforming bytes into meaning is another. The way we filtering memories through technology may fundamentally change the way we remember and perceive ourselves and each other. In the end, remembering is, as it perhaps always has been, a matter of re-telling the story of oneself.

5.3.2 Mnemonic technology

Many types of external technological memory aids have been developed. Some are simpler than others and the functionality and focus differ considerably depending on what the user is capable of and what kind of *memory* is intended. Some try to tackle the task of remembering massive amounts of information (the most ambitious aim of storing all experience and knowledge of an entire life), others are used to remember where you put your keys five minutes ago. No matter which approach is chosen, the issue of managing and presenting the data in comprehensible and sensible ways is apparent. One of the pioneers in this field of massive data management was Vannevar Bush. In his essay As we may think from 1945 he describes a series of information tools a scientist could make use of (Bush 1945). His essay is concerned both with the tremendous growth in information production and exchange, and with the increasingly specialised sciences and their division into increasingly narrower fields. This demands efficient means to store, retrieve, and disseminate data. A mass production of information hence necessitates an advanced infrastructure in order to make use of it in intelligible ways. He foresees the problem that even if the machines would work, it would be difficult to make them practical to use.

An implementation of another of Bush's concepts called Cyclops was carried out by Steve Mann. Cyclops is a miniature camera placed on the forehead with which a person instantly and without effort can capture anything interesting or important (Mann 1997). At the Tryckolera day-care activity centre in Lund, Sweden, the staff uses digital cameras to document everyday life and events (Jönsson et al. 2002; Jönsson 2004). The images are then used by the people at the centre to communicate and share experiences and stories. This body of pictures has, in some respect, become a person's 'memory'.

Another of Bush's concepts is an extension of the Voder machine where a microphone is used for converting speech into text. Knowing that ordinary spoken language is not suitable for print, Bush suggests a specific language for this kind of transcription. For an example of this technology, see the iRemember long-term memory prosthesis by MIT Media Lab (Vemuri et al. 2006). By combining these and other concepts in a single device, called a Memex an ultimate tool for collecting, storing, manipulating and disseminating information is created. There have been several attempts to actually create a Memex-like device have been made. Computer

researcher J.C.R. Licklider was one of the pioneers in the field of human-computer interaction. Two of his important articles are Man-Computer Symbiosis (Licklider 1960) and The Computer as a Communication Device (Licklider and Taylor 1968). Among many other things, he proposed a complex of software programs, named Oliver, which would function similar to the Memex. It is an 'on-line interactive vicarious expediter and responder,' a complex of computer programs and data that resides within the network and acts on behalf of its principal, taking care of many minor matters that do not require his personal attention and buffering him from the demanding world (Licklider 1968, 38). This machine can take notes (or refrain from taking notes) on what you do, what you read, what you buy and where you buy it. It will know who your friends are, your mere acquaintances. It will know your value structure, who is prestigious in your eyes, for whom you will do what with what priority, and who can have access to which of your personal files. If we take a look at the social network applications on the internet, and couple them to mobile technology we see that much of this functionality is present today.

Microsoft's research group Media Presence (previously known as Telepresence) has several projects running concerned with these types of questions (MediaPrecense/ Microsoft). In the MyLifeBits project, Gordon Bell and collegues are trying to achieve what Bush envisioned (Bell and Gemmell 2007).

> MyLifeBits is a lifetime store of everything. It is the fulfilment of Vannevar Bush's 1945 Memex vision including full-text search, text & audio annotations, and hyperlinks. There are two parts to MyLifeBits: an experiment in lifetime storage, and a software research effort.
>
> The experiment: Gordon Bell has captured a lifetime's worth of articles, books, cards, CDs, letters, memos, papers, photos, pictures, presentations, home movies, videotaped lectures, and voice recordings and stored them digitally. He is now paperless, and is beginning to capture phone calls, IM transcripts, television, and radio. (Microsoft/ MyLifeBits).

Of course, the military industry has interests in this kind of research, for example the Defence Advanced Research Projects Agency (DARPA) which is the central research and development organisation for the Department of Defence in the USA. DARPA's own massive information research project was called LifeLog, which was one part of their research efforts in cognitive computing (DARPA/Lifelog).

The research is designed to extend the model of a personal digital assistant (PDA) to one that might eventually become a personal digital partner, a program allowing individuals to capture and analyse their own experiences, preferences and goals. In essence it would be an electronic diary to help the individual more accurately recall and use his or her past experiences to be more effective in current or future tasks. Another similar approach is described in Memories for Life, which takes on the challenge of managing information over a human lifetime (Memories for Life).

> It is now possible to store digital versions of life's memories. As Alan Dix playfully noted, it takes 100 kbits/s to get high-quality audio and video. If we imagine someone with a camera strapped to his or her head for 70 years (2.2×10^9 s), that is something of the order of 27.5 terabytes of storage required, or about four hundred and fifty 60 GB iPods. And if Moore's Law continues to hold over those 70 years (admittedly a large assumption!), it would be possible to store a continuous record of a life on a grain of sand (O'Hara et al. 2006, 352).

Obviously, it is not only the management of the raw digital data that is important, but also the design of the data container and user interface. Norman has a vision of a lifetime collection of personal information stored in a toy bear named Teddy (Norman 1992). The design of this personal portable storage device could change over time. As a child it could look like a cosy teddy bear, and later in life it could have an appearance more suitable to adults. This device will know everything about you and at the same time give you access to all the databases of the world. The combination of life-long updates, continuous access, and intimacy between technology and human would transform the data into personally tailored information.

For a normal person, without the resources of a 'defence department' or a 'university computer research lab', the capacity and handling of a mnemonic device has to be downsized and simplified. From a user's point of view, such a device would have to be easy to carry around, familiar, easy to use, relatively inexpensive and be customisable to some extent. One apparent alternative is a mobile phone or a PDA. These are standard mass-produced devices, widely disseminated and used by many on a daily basis. They are also becoming increasingly powerful. This, in turn, facilitates a wider use of multimedia such as photographs, music, and video.

At first glance, this looks promising, but how could such a device be used for the intended purpose, that is, as a practical mnemonic tool?

The most obvious thing to use when setting up a memory scenario on a mobile device would be to use the existing PIM functionality. PIM stands for 'Personal Information Manager', which normally means a to-do list, a calendar and a contact list. These let the user store data and be reminded of something at certain points in time specified by the user. The data types which normally are accepted are text (characters and numbers) and date. In some cases it is possible to store an image within a specific contact, for example a portrait. This is certainly useful, but could be perceived as restrictive and unintelligible by a non-literate person. An image-based system, or one using sound could be more useful and useworthy for other user groups. Another draw-back with the pre-installed PIM is that you have to tell the system to remind you of something and when to do so. You may not be able to predict when you need a reminder, or you maybe want to be surprised by an unsuspected randomly picked recollection of a record. Certainly, there are things to investigate here; a custom system could be a way to dig deeper into the usage of a memory aid. So, let's have a look at some alternatives.

With mobile technology and an almost omnipresent world wide web, storing and retrieving data and media from a central server is made relatively easy and quick. One type of webpage management which is becoming more popular is the mobile blog, 'moblog', which is a blend of the words mobile and weblog (Blood 2000; Glotz et al. 2005). A mobile weblog, or moblog, consists of content posted to the internet from a mobile or portable device, such as a cellular phone or PDA. This could be an inexpensive, easy-to-use alternative for the non-expert user, especially compared to the gargantuan systems presented above. The storage capacity varies depending on the service provider, but in most cases it is enough for everyday use. An entire lifetime data storage of everything is obviously not possible yet, but it is only a matter of disk space (money). On a moblog, images, text, hyperlinks, video and sound recordings can be stored and shared among users, often within a specific community or interest group.

If photographs/images are the primary media to use, there is an inexpensive and simple option: on-line photo albums. A wide range of companies provide services to upload and share photos online. The business idea is that the users will order paper prints of the images stored on the server. This need not be the real benefit

of these services. With an account on one of these sites, it is possible to use it as a password protected photoblog with a number of selected friends. This option is a little different from the moblogging in that it is focused on the photos, often structured in albums with captions or comments.

The potential use of mobile phones or other handheld devices as mnemonic tools is obvious due to the rapid development in consumer electronics. There have been many projects on using handheld devices as external memory aids for persons with memory difficulties (Gyllén 2003; Inglis et al. 2003; Jacobsson and Magnusson 2004; Wade and Troy 2001; Wilson 1984). These represent a random selection among a vast number of attempts and studies aimed at helping people to remember things.

5.3.3 Memory as social interaction

Mobile devices can also be used for social empowerment and communication between members of specific interest groups. Howard Rheingold, who is known for having coined the expression 'virtual community' describes this phenomenon:

> Smart mobs emerge when communication and computing technologies amplify human talents for cooperation. The impacts of smart mob technology already appear to be both beneficial and destructive, used by some of its earliest adopters to support democracy and by others to coordinate terrorist attacks. The technologies that are beginning to make smart mobs possible are mobile communication devices and pervasive computing - inexpensive microprocessors embedded in everyday objects and environments. Already, governments have fallen, youth subcultures have blossomed from Asia to Scandinavia, new industries have been born and older industries have launched furious counterattacks (Rheingold 2002).

It is apparent that social interaction on the internet shape the way we remember and forget. Facebook, Twitter, and MySpace are but a few of the virtual arenas where we interact socially/digitally and share/store our experiences. It is possible to view the status updates one makes on these sites as personal-social narratives constructed over time. In that respect, the web servers of these forums function as a kind of external diaries, where our memories are duplicated and digitised.

Networking of knowledge and information through distributing data and media is also exemplified by the peer-to-peer file sharing technology. This could in fact be an interesting solution of the mnemonic challenge: to network the memory storing and recollecting in an integrated community. This resembles a tribal system of 'digital natives', in which mouth-to-mouth (computer-to-computer) distribution of a memory or narrative (Prensky 2001). These natives not only reformulate the messages in an eternal loop and thereby secure the preservation of a memory, social event, or piece of knowledge, but also define the cultural entity itself – the 'tribe'. In modern times, such a tribe could be a family, a number of friends or an interest group – a community of practice. Recollecting a memory is hence not merely retrieval of exact data, but also a social activity. Accuracy may not be the most valuable aspect of a memory, the degree of 'truth' in a memory could be a result of consensus or agreement within a group. From a personal perspective, the enacted social storytelling is perhaps more important than some information of what actually happened at a specific point in time. In other words – I am what I share.



6. A science of the self

One possibility of a science of the self is discussed in this chapter. The intention is to provide some background for introducing autobiographic practice in design research. First, a subjective position of enquiry is sketched. Then, autoethnography is described as an reflective and analytical method suitable for researching oneself.

6.1 A subjective position

> It was better, once and for all, to make my protestation of singularity into a virtue – to try making what Nietzsche called 'the ego's ancient sovereignty' into a heuristic principle. (Barthes 1981, 8)

In (natural) science, the concept of objectivity is usually used for what can be proven in a logical-positivistic sense. The results should be independent of the observer and knowledge is therefore beyond the individual and personal. This objectivity excludes feelings and other similar distracting elements. In the humanistic sciences the concept of objectivity has in part a different meaning. The individual interpretation of sociological data, for example, is necessary in a way that has no equivalent in, say, physics. Objectivity exists but has a different quality and is coloured by the individual observer. Still, there is a distance between what is observed and the observer. A third option is a kind of 'embodied' objectivity – an objectivity based on the experiences of the embodied self[7]. Merleau-Ponty speaks of this lived body:

> The body is the vehicle of being in the world and having a body is for a living creature, to be involved in a definite environment, to identify oneself with certain projects and be continually committed to them (Merleau-Ponty 2002, 94).

7 To speak of the embodied self is in a way a tautology since, biologically speaking, there is no other (Damasio 1999; Dennett 1991).

This implies that an embodied objectivity is in turn grounded on the conditions of the individual – a subjective position of objectivity – something Haraway calls a 'partial connection' (Haraway 2002, 681). In a research context, one can question whether it is fruitful, clever, or even possible to start from one's own self[8]. A common objection is that this perspective leads to relativism. It is not necessarily so, including the obvious fact that it is (to some extent) possible for people to share experiences, thoughts, views and opinions. This kind of objectivity is not exclusive to the individual but can be part of a social process, a participation. Baudrillard writes about the same phenomenon that media (i.e. communication) by its form and function, not content, creates social relationships (Baudrillard 2003, 280).

A parallel which can be helpful in explaining my approach of a subjective objectivity is Roland Barthes's essay Empire of signs (Barthes 1983). Here he describes his experiences of Japan and a variety of phenomena he encountered when coming to this country for the first time. His position is that of a Western intellectual using all the methods, concepts and pre-understandings that are associated with this practice in order to make sense of his observations. An example of this is when he uses linguistic methods to 'read' Japan as a text. Since Barthes does not understand Japanese he transforms his reading into a kind of experiment. He considers his inability to speak the language as a form of freedom, since the language as a system is broken down and the sensual and the bodily takes over. Signs are emptied of meaning, but this does not lead to nonsense, but to the sensual. It is a utopian Japan Barthes describes – a fiction. The intention of the book is not to be a travel book or an introduction to Japanese society. It is not a 'true' statement but a personal and self-disclosing autobiographical text. It is not primarily about understanding but about intimacy. What he describes is, in other words, not Japan but himself retold through the phenomena he encounters and the way he gives meaning to them. The autobiographical is everywhere where personal meaning is created and expressed. Barthes presents in Camera Lucida an idea of a science of the unique, a 'mathesis singularis', and takes himself and the photos that matter to him as a starting point for the study of any photograph (Barthes 1981, 8). This approach – bridging the general and the specific, the facts and the fiction – is useful for an autobiographic practice in participatory design research.

8 The shift of meaning of the word 'idiot' can be of interest in this context. Originally it comes from the Greek 'idiot' which means 'private person', or 'individual', in opposition to the state, the society. The closely related 'idiaitero' signifies 'the private', but also the 'separate', 'unusual', and 'specific'.

6.2 Autoethnography

Applying a reflective ethnography of the self in participatory design has several advantages. The approach makes it clear that informants are creating meaning, not merely providing information. Applied by researchers themselves, the method also helps to better understand their own impact and influence on the process and the interpretation. The intention of describing autoethnography is to provide a methodological background to autobiographies in design.

> Autoethnography synthesizes both a postmodern ethnography, and a postmodern autobiography.[It] opens up new ways of writing about social life (Reed-Danahay 1997, 2-3).

Autoethnography literally means ethnography of the self, that is a presentation of the self within a culture. Here, the two subjective worlds of the narrator and the listener coincide, which means that the researcher/ethnographer no longer tries to become 'the insider', but rather *is* the insider. This type of qualitative methodology has several names and comes in many forms and flavours such as auto-anthropology, autobiographical ethnography or sociology, and personal/self-narrative research. Denzin and Lincoln position autoethnography in what they call the fifth moment in the history of qualitative research which concerns experimental writing and participatory research (Denzin and Lincoln 1994, 2000).

The first moment was the traditional period (early 1900s), when qualitative researchers aspired to 'objective' accounts of field experiences. The second moment was the modernist phase (post-war years to 1970s), which was concerned with making qualitative research as rigorous as its quantitative counterpart. The third moment (1970-1986) was concerned with the blurring of genres. The fourth moment (mid-1980s) was characterised by crises of representation and legitimisation. The fifth moment concerned experimental writing and participatory research. Additional stages include the sixth (post-experimental) and seventh (future) moments, whereby fictional ethnographies and ethnographic poetry are taken for granted.

There are several different types of autoethnography based on the position of the researcher (O'Byrne 2007, 1382). The researcher can study:

– his or her own culture, which means that the researcher undertakes an ethnographic study of his or her own culture. 'Auto (of own)' in Table 2.

– a culture into which he or she has been adopted and accepted completely. This refers to 'complete-member autoethnography', meaning the researcher has become a member of the culture under study, but originally comes from another culture. 'Auto (adoptive)' in Table 2.

– the culture of the self. In this 'personal autoethnography' personal experiences of the researcher are studied using traditional ethnographic methods. 'Auto (of self)' in Table 2.

– the culture of another as it relates to the self of the researcher In this 'reflexive autoethnography', where the researcher 'capitalizes on personal experiences, reactions, emotions, and thoughts as they relate to his or her own or a foreign culture … and uses these insights into his or her reactions as the basis for understanding the culture under study.' (O'Byrne 2007, 1383). 'Auto (using self)' in Table 2.

Auto-ethnography stands at the intersection of three genres of writing which are increasingly visible: (a) 'native anthropology,' in which people who were formerly the subjects of ethnography become the authors of studies of their own group also known as auto-anthropology; (b) 'ethnic autobiography', personal narratives written by members of ethnic minority groups; (c) 'autobiographical ethnography', in which anthropologists interject personal experience into ethnographic writing (Reed-Danahay 1997). These genres defined by Reed-Danahay matches to some extent that of O'Byrne. One aspect which is common for all the forms of autoethnography mentioned above is the constant shift of focus between the personal and the cultural, the inner and the outer:

> Back and forth autoethnographers gaze: First they look through an ethnographic wide angle lens, focusing outward on social and cultural aspects of their personal experience; then they look inward, exposing a vulnerable self that is moved by and may move through, refract, and resist cultural interpretations. As they zoom backward and forward, inward and outward, distinctions between the personal and cultural become blurred, sometimes beyond distinct recognition. (Ellis 2004, 37-38)

Autoethnography includes a critical and self-reflective analysis, but an analysis which will 'bear the signature and voice of personal interpretations' (Duncan 2004). Another key element is that this critical and self-reflective approach is viewed in relation to others in a given context: 'Autoethnography can be defined as a self-narrative that critiques the situatedness of self with others in social contexts.' (Spry 2001, 710). This relational attitude also suggests that autoethnographic methods follow the constructivist, or perhaps the existentialist, view of identity as they 'recognize the reflections and refractions of multiple selves in contexts that arguably transform the authorial "I" to an existential "we"' (Spry 2001, 711). There is no single and fixed identity but several possible selves, produced by and manifested in actions in various situations and put in relation to other people and their actions.

6.2.1 Two movements

There are two movements in autoethnographic research. One is 'emotional' or 'evocative' represented for example by Ellis and Bochner (Ellis 1991, 1997, 2004; Ellis and Bochner 2000; Bochner and Ellis 2001), Richardson (1994), and Denzin (1989, 1997) among others. The other is what Anderson terms the analytic ethnographic paradigm. He lists five key features which differentiates analytical ethnography from evocative (Anderson 2006):

1. Complete member researcher status
2. Analytic reflexivity
3. Narrative visibility of the researcher's self
4. Dialogue with informants beyond the self
5. Commitment to theoretical analysis

The first feature requires that the researcher is a complete member in the social world under study. The second entails self-conscious introspection guided by a desire to better understand both self and others by examining one's actions and perceptions in reference to those of others and in dialogue with them. The third

states that autoethnography requires that the researcher be visible, active, and reflexively engaged in the text. The need of engaging with others is stressed in the fourth key feature: 'We must not lose sight of the ethnographic imperative that we are seeking to understand and make sense of complex social worlds of which we are only part (but a part nevertheless)' (Atkinson et al. 2003, 57). The commitment to theoretical analysis stresses the data-transcending goal of ethnographic research, which is to gain insight into some broader set of social phenomena than those provided by the data itself (Anderson 2006, 387).

> Whereas those who produce autoethnography are at risk of being overly narcissistic and self-indulgent, there does seem to be a place for research that links the personal with the cultural. (Holt 2003, 19).

Vryan opposes some of these defining features and wants a more inclusive definition of analytical autoethnography than proposed by Anderson. Vryan states that the 'key difference between analytical and non-analytical (or exclusively evocative) forms of autoethnography – and perhaps it should be the only significant difference at this point – is the goal of explicit analysis' (Vryan 2006).

One thing that is important in both traditions is the relational dialogue between the reader and the author. The reader should be emotionally and critically engaged in the text in order to share the text's meaning. This puts some demands on the style and quality of the text itself: 'The researcher and text must make a persuasive argument, tell a good story, be a convincing "I-witness."' (Spry 2001, 713). This demand of making a credible case of one's experiences is also present in autobiographical narratives.

6.2.2 Autoethnography in design

Concerning the applicability of autoethnography in design research, the nuances in the various definitions of autoethnography discussed earlier might be less important than a more pragmatic and practical application of the methodology. In general, Anderson's key features of analytical autoethnography resonate well with the tradition of participatory design and action research as well as with Schön's description of the reflective practice 'knowing-in-action' (Schön 1987) and its relation to the notion of tacit knowing (Polanyi 1967).

Autoethnography has been proposed as a tool in human-computer-interaction education and software development by Cunningham and Jones (2005). They list some key features of incorporating autoethnography in teaching HCI student, for example that the domain of study should be familiar, the focus should be on requirement elicitation, and that the purpose and specification of the narratives should be detailed (Cunningham and Jones 2005, 5-6). They also see benefits of using both ethnographic and autoethnographic techniques. This is not a straightforward and simple task. Personal ethnography and narratives have been used to study hypermedia product development (Duncan 2004), as well as emotional experiences in young and older adults (comparing it to the conventionally used Likert scales) (Alea et al. 2004). Couser proposes the use of autoethnography in a disability context and provides an introduction to some of its precursors, academic as well as non-academic (Couser 2005).

Autoethnography can be a way to cover the middle ground between the first-hand experience of the first-person and the interpretation or understanding of it made by the situated participative design researcher. Crudely speaking, in a situated and participative design research context, evocative (emotional) autoethnography is what the first persons are asked to do (for example writing diaries, describing problematic or emotional situations) whereas analytical autoethnography is what the researcher should do in order to bridge the subjective gap (that is achieve intersubjective understanding of the first person's lifeworld).

Naturally, there seldom is enough time or resources in a design research project for the researchers to perform a thorough autoethnographic study. More pragmatically, there are several reasons for applying some basic concepts from autoethnography and self-narratives in design research:

1. It may prove constructive and creative when normally applied methods do not cover the subject or the scope of interest:

> I needed a method in which the lifeworld and internal decision making of the researcher were considered valid and noteworthy. I needed methods that encouraged systematic reflection and ensured a scholarly account. I needed a means of analyzing evidence that not only organized a record but also enabled discovery. (Duncan 2004).

Alea et al. mention a creative methodological possibility of the social inclusive nature of narratives:

> The narratives also showed that when talking about emotional events, individuals often focus on their own reactions, but also weave other people's reactions into their accounts in order to tell a complete story. Thus, narratives may be useful tools to stimulate new research in areas such as social process that might be ignored in studies in which responses are experimenter-guided (Alea et al. 2003, 249).

2. Make the pre-understanding and impact of the researcher's involvement clear and transparent in the material:

> Autoethnographers argue that self-reflexive critique upon one's positionality as researcher inspires readers to reflect critically upon their own life experience, their constructions of self, and their interactions with others within sociohistorical contexts (Spry 2001, 711).

3. Avoid misunderstandings by engaging personally. By personally engaging ourselves and our search for meaning through the understanding of others we can avoid what Wikan calls 'the consequences of our own misinterpretations' (Wikan 1992, 474), since we would be 'implicating ourselves, actively and emotionally, in the other's world'. The self can be a resource of knowledge, or a reservoir of experience which may help to understand others (Shapiro 2003, 194).

4. Gain insights and empathy with the informants. This personal engagement has the consequence of a more empathic and respectful relationship with the first persons as the researcher acts as an 'acid test' of the appropriateness of the representation of others. The rhetoric question is: How would we like an ethnography of ourselves to be made?

5. Uncover personal biases or preconceptions. By making the behaviours, activities, and contexts explicit in situations which the designer might be a user, personal biases and preconceptions on behalf of the researcher can be uncovered.

6. Autoethnography is a simple and inexpensive way of testing an ethnographic method yourself before applying it to other people. Testing methods is a crucial step before applying them to the first persons, or users. Failure to do so can lead to invalid information.

Adopting (analytical and reflective) autoethnography fully in a design research project can be both difficult, resource demanding, and controversial. In a lighter version, these concepts are proposed as guidelines when planning and performing a design research project involving an experiential subject matter as well as analysing and reporting the findings.

6.2.3 Mixing ethnographic methods

Combining traditional ethnographic and autoethnographic methods in design research can be achieved in a number of ways, but should be done with care and critical reflection. It is not only a question of which specific methods to use, and the nature of the data collected but also what the intended outcome is – in other words, the purpose. O'Byrne stresses the need of a critical analysis of the underlying paradigm of one's research when mixing methods in ethnography:

> When a researcher is analyzing the advantages and disadvantages of combining any two methods, all subsets of the methods as well as all the differences that the varied paradigms impose on the methods as they span the spectrum must first be identified and addressed (O'Byrne 2007, 1389).

He identifies three main ethnographic methods and their related paradigms:

- Classical ethnography belonging to the positivistic paradigm.
- Critical ethnography in the post-positivistic paradigm.
- Postmodern ethnography within the critical theory paradigm.

In Table 2, these three paradigms are presented and related to the various forms of autoethnography.

In participatory design research, it is not always clear which of these perspectives informants have when sharing personal experiences. Are they acting as true 'natives' (original members of the own culture) or as assimilated 'immigrants' (new members from another culture). Are they studying themselves within their culture, or using themselves to filter their understanding of a culture? These questions are important when interpreting information collected through interviews, diaries, and other self-reporting techniques.

	Positivism	**Post-positivism**	**Critical Theory**
Ontology	Naive realism; ultimate reality	Critical realism; probabilistically attainable truth	Historical realism
Epistemology	Dualist; objective; truth	Dualist; critical objective; probable truth	Transactional; subjective
Purpose	Explanation; prediction; control	Explanation; prediction; control	Critique; transform; emancipation
Main advantage	Theory testing	Triangulation to gain a deeper appreciation of culture	Political involvement of minority
Main disadvantage	Resource capacity and capability	Resource capacity and capability	Possible creation of risk; possibility for political resistance
Ethnographic method	Classical ethnography	Critical ethnography	Postmodern ethnography
Commensurability			
Traditional	Yes	Yes	Yes
Auto (of own)	Yes	Yes	Yes
Auto (adoptive)	Yes	Yes	Yes
Auto (of self)	No	No	Yes
Auto (using self)	No	No	Yes

Table 2. Paradigms and methods (Adapted from O'Byrne 2007).

7. Autobiographies

The intention of this chapter is to view self-reports and self-reflective artefacts produced by first persons in participatory design research as autobiographies. First of all, an etymological description of the word 'autobiography' is presented. Then the process of creating autobiographies is described in terms of reflection, meaning and metamorphosis. In the last section, six models of autobiographies are introduced.

> …eventually the culturally shaped cognitive and linguistic processes that guide the self-telling of life narratives achieve the power to structure perceptual experiences, to organize memory, to segment and purpose-build the very 'events' of a life. In the end, we *become* the autobiographical narratives by which we 'tell about' our lives (Bruner 2004, 694).

In this chapter I discuss the potential of an autobiographic process, which means the use of reflective and self-produced narratives and artefacts, in design research. By introducing the notion of 'autobiographies' I argue that participatory design research can be aided by a change of view when it comes to these kinds of artefacts and processes. Conventionally, the participants are seen as informants who provide personal information, insights, and inspiration regarding their situation and practices. The perspective taken in this thesis involves viewing the participants as creative producers of personal meaning, even when acting as informants in a research context. In this process two things happen: the participants express themselves through artefacts (autobiographies); and the meaning expressed is part fact and part fiction. This change of perspective is assumed by me to have several implications for design research methodology, for example when it comes to evaluating the information provided by the participants, and the tools and methods used for collecting personal experiences. An important starting point is the significance of one's own knowledge and experience on the process. Hopefully, this will in the long run provide an opportunity for people to create and use similar autobiographical artefacts and associated practices in design research as well as in rehabilitation and healthcare.

7.1 Etymology

One way to gain a simple overview of how I use the terms 'autobiography' and 'artefact' is to break the words down.

Auto
The Greek 'autos' means 'self'. It can lead to both autonomy and automation. It can be the self among others, and doing something yourself does not mean you do it alone. Autobiography may then be something you do yourself with the help of others.

Bio
'Bios' is the Greek for 'life'. The study (logia) of life is biology. The body as a carrier of life creates permanence to events and processes and is in itself a physical and carnal autobiography, a being-in-the-world.

Graph
The word comes from the Greek 'graphein', to write. The graph is partly a sign with which to write, draw or record. It is also the drawn, an image of a process, and a measure. The graphic has an aesthetic side and a vulgar one. The autobiography is a person's measure and trace.

Art
The Latin 'artem' is art, skill, aptitude. This art is the result of training or education and not a result of a supernatural talent. An artefact (artefactum) is artificial and often made with certain intentions. 'In nature there are no tricks. The latter are always people-created, artificial' (Asplund 2003, 115; my translation). The autobiography is necessarily artificial and artistic.

Fact
The Latin 'facere' means 'to do'. There is no difference between the activity (do) and production (make), the process and the result have the same origin. Facts originate from events (factum) and now stand for things believed to be true in the sense of something that actually happened or existed. On the other hand, fiction is something imagined, something that has not happened. Fiction is, however, also a result of real (creative) events and therefore also facts. The autobiography is a factual fiction and a fictional fact.

7.2 The challenge

I use the concept of the autobiography to describe an artefact or a process which has its origin in an individual whose focus is the self. I do not, in principle, make any real distinction between subject and object, or artefact and activity. There is a wide range of possible intentions with and uses of an autobiography, from the mere act of writing, to creating personal meaning and understanding of events, to leaving something behind with which you can share your experiences and thoughts with posterity. One can also believe that what you share is of interest to a larger audience. The autobiographical work may well have a more general intention and aspiration than the introverted description or confessions of the author. The autobiography can also be of therapeutic use. It can be a tool or a method of self-treatment in which self-awareness, introspection, and reflection are important elements. The autobiographic practice is in many cases intuitive, subjective and irrational. Often effective methods and tools are not readily available to the lay person. They cannot rely on tradition, habit or experience in the same way as professional biographers, such as writers, can. It is also difficult to keep a distance from the subject at hand since it is intimate and self-reflective in nature. This ability is something professionals often have been trained to do. Despite these seemingly poor conditions, one of the objectives of this thesis is to examine the opportunity of creating an autobiographical practice within participatory design research.

The autobiographic process is not necessarily a question of amateurism, with its often negative connotations. The proposed practice does not claim to be professional and cannot be compared to the conditions of a professional practice. Nor is it a matter of using professional practice in a different discourse. Because even if the individual for some reason may make practical use of certain skills and techniques borrowed from their work practice, the autobiographical practice in design research has completely different requirements.

There is a fundamental difference between the artefact produced by the artist-designer-researcher, and the artefact produced by the first person. Within practice-led research, the researcher is directly involved in both the production and the interpretation of the artefact; the artefact represents a first-hand experience. In the case of the artefacts of interest in this thesis, they are mainly created by the first person, but the interpretation is made by the researcher. Here, the artefacts

represent a second-hand experience from the researcher's perspective. This makes a direct application of the arguments and discussions from practice-led and artistic research challenging. On the other hand, it provides a chance to highlight the possibilities of using these kinds of autobiographic artefacts in design research.

The topic of the visualisation study (Case 1, chapter 3.1) concerns personal images, based on emotions, meaning and subjectivity, within the context of rehabilitation and healthcare. It proposes a practice of routinely creating and using images in healthcare, which starts and ends in the specific needs and capabilities of the individual. This includes a specific design strategy and methodology which should be considered as an additional and contributing aspect to the medical-clinical one (Jönsson et al. 2006a, 2006b). By engaging the first persons as participatory and subjective partners in the making of these personal images, they would contribute with their own aspects of the content, meaning and use of the produced artefacts. The images can be integrated in everyday life and focus on positive or desirable aspects of well-being to support and help the individual outside hospitals and medical institutions. To have images as communicative, informative, emancipative and emotional tools enhances the individual's ability to participate actively in the recovery and rehabilitation work as well as in gaining knowledge and empowerment. It is a matter of designing for a higher quality of life (Dibbets 2002; Kristensen 1999).

For several reasons, creating and using tools, artefacts, and practices for personal use in a medical context is a formidable challenge. Although there is a general interest to empower and help the first person, traditionally there is a strong top-down perspective. The clinical context is truly powerful and any attempt to breach this dominance faces great challenges or even resistance. Besides this, there are many other obstacles when it comes to introducing tools and methods for personal expression and understanding in healthcare. First of all, it is a matter of competence. The first person often lacks experience and necessary skills in producing and using expressive artefacts. Not everyone is a designer, although anyone can gain the necessary tools and sufficient knowledge to act as a designer to some extent. Secondly, the first person is the person who has, in some respect, the worst preconditions to act in this matter (being ill, pregnant, or disabled). Being in the middle of a difficult situation is not always the optimal position to act creatively. A third circumstance is that the first person has no natural organisation which can provide daily support and structure. Although there are many organisations for

disabled people, for instance, which have much knowledge and interest in specific areas, these are not involved in supporting the actual activities in daily life. As an individual you are often left to your own devices, using limited resources and personal networks. Lastly, if this is an unknown situation or condition, the first person probably has little or no previous experience of this situation to rely on. When everything is new, it is difficult to be proactive, creative, and still maintain an overview of the situation.

All these issues put up barriers against initiatives like the one proposed here. I still argue that it is both possible and desirable to try to provide means for the first persons to express their daily experiences. The above points also stress that the co-operation and mutual exchange between professional designers, healthcare personnel, and the first person should be organised in a form which emancipates and supports the first person to become the main stakeholder in this process.



7.3 Autobiography as reflective practice

> I have never seen greater monster or miracle in the world than myself: One grows familiar with all strange things by time and custom, but the more I frequent and the better I know myself, the more does my own deformity astonish me, the less I understand myself. (Montaigne 1580, III:XII).

In the autobiographical activity the self functions as both material and context, while the process is a 'reflection-in-action'. It is not possible to separate the material from the performer – they are both part of a symbiosis and one does not exist fully without the other. Molander writes that reflection cannot be understood in the sense of a duality of subject-object since the activity of reflection in that case will be divided into a simultaneous introspection and observation (Molander 1996, 144). Reflection and action are inextricably intertwined. We are not talking about or analysing our work processes, we carry them out.

> We are agents-experient, in Geoffrey Vickers's sense, who are at once the subjects and the objects of action. We are in the problematic situation that we seek to describe and change, and when we act on it, we act on ourselves. We engage in a continuing conversation with the larger societal situation of which we are a part, rather as a designer (Quist, for example) converses with his design situation (Schön 1983, 347).

Phenomenologically, understanding and documentation are based on one's own experience, one's own way of thinking and personal values. It is closely associated with a sort of pragmatism. Molander writes that theoretical knowledge cannot be as tangible and definite as practical knowledge, since in a practice it is obvious when something works (at least in less complex situations). The enabled and skilled person knows how to address and resolve a task in an appropriate manner. Even though there may be a number of different solutions to a problem they may all be right. The most important thing is not necessarily to do what is best, most true or right, but rather being able to make sense in a given situation. To achieve this, it is important to be attentive to how the current situation fits the experiences of past situations and to act accordingly. In this way, attention is linked to knowledge and this seems to be something you can learn as a routine, a practice (Molander 1996, 11).

When a (professional) practitioner approaches a new, seemingly unique problem it is described in terms of the existing repertoire of the practitioner (Schön 1983, 1987). Kuhn calls this 'thinking from exemplars' (Kuhn 1992). In order to effectively benefit from their experience, the knowledge or skills become a natural part of their thinking and activities. When confronted with a new situation, they can use the experience gained in an almost automatic way. The reflection seems to work in the background and is based on accumulated experience, proven practices and a 'feel' for what can be appropriate. When experience, reflection and action are fused together into a whole we can begin to talk about intuition – knowledge in action. The most essential elements of a reflective practice appears to be presence, attentiveness and openness – not necessarily a conscious and explicit reflection. Asplund uses the concept 'curiositas' which represents both curiosity and inquisitiveness, two forces of research (Asplund 2003, 16). Attention is assisted by curiosity and together they facilitate creation of new knowledge. Rogoff talks about the 'curious eye' as a basis for a new kind of study originating from the individual:

> Curiosity implies a certain unsettling; a notion of things outside the realm of the known, of things not yet quite understood or articulated; the pleasures of the forbidden or the hidden or the unthought; the optimism of finding out something one had not known or been able to conceive of before. It is in the spirit of such a 'curious eye' that I want to open up some dimension of this field of activity (Rogoff 2002, 28).

This is a cyclic process moving from discovery, observation, action, reflection, evaluation, reaction and back. The phenomenon and its context is reformulated and changed constantly. Schön writes that in experiments one is attentive to both the problems and hypotheses formulated as well as to the unforeseen effects of one's actions. From this, coherence and comprehension is created.

To create an autobiography is a 'wicked problem', a task that is difficult to define or pinpoint, nor a clear-cut problem which can be solved. It is vague also in terms of finding an appropriate way to approach the task (Rittel 1972; Nelson and Stolterman 2003). These problematic 'problems' are well known from several types of activities, not least in the creative professions. Design and art are two areas which are largely based on these types of questions. A wicked problem can hardly be solved without creativity, freedom and imagination.

> … imagination has broken out of the special expressive space of art, myth, and ritual and has now become a part of the quotidian mental work of ordinary people in many societies. It has entered the logic of ordinary life from which it had largely been successfully sequestered (Appadurai 2002, 175).

Fantasy is an equally important human asset on a personal level as it is in art and science. Its functions and expressions are different, especially when it comes to the fictitious. Science is constantly dependent on a reality and in itself it is an approximation of reality. Fiction is free to create its own frame of reference, narrative and form. Fiction can be absolutely true in a way that science cannot. Fiction is stipulative and definitive and at the same time manipulative and volatile. Looking at autobiographies from a human perspective it is easily understood that the fictional will be included as a part. Imagination is not only a place of refuge but a starting point for action. Thought requires *both* the principle of reason, *and* what is beyond the principle of reason, arkhè and an-archy (Derrida 1983, 3-4).

> Without imagination, nothing in the world could be meaningful. Without imagination, we could never make sense of our experience. Without imagination, we could never reason toward knowledge of reality… It is a shocking fact that none of the theories of meaning and rationality dominant today offer any serious treatment of imagination (Johnson 1987, ix).

In the reflective practice one must uphold the possibility of a radical critique: '…it is almost always right to revolt.' (Molander 1996, 252; my translation). Krippendorff writes in similar spirit that design is inherently revolutionary (Krippendorff 2006, 210). Autobiography has a more or less explicit core of revolution and utopia, or as Asplund writes: 'Everybody performs (thought) experiments and all risk saying something that cannot be said' (Asplund 2003, 91; my translation). However, there is a strong pragmatic side to all practices namely that it is not possible to completely break with past experiences or knowledge, for it is on this foundation self-understanding and self-image are built. There are limits to how far one can be stretched without breaking.

> Unpredictability and teleology therefore coexist as part of our lives; like characters in a fictional narrative we do not know what will happen next, but nonetheless our lives have a certain form which projects itself towards our future (MacIntyre 1985, 201).

Although we cannot explain everything that happens to us, nor fully predict the outcome of our own actions there are some processes which create an ongoing sense of coherence in our lives. Baumeister has suggested four ways people make sense of their lives (Baumeister 1991, 32-47). These 'needs for meaning' are:

– Purpose: to see one's actions oriented toward a purpose, to interpret one's current activities in light of a future or possible states;

– Values: to have an enlivened set of values to guide thoughts and behaviour, to feel that one's actions are good and right and justifiable;

– Efficacy: to experience a sense of control over the events in one's life, to see that one's actions are making a difference; and finally

– Self-worth – to experience one's self as having worth or positive value, to find a basis for determining positive value.

Frankl, having a more unitary approach to meaning, called this 'will-to-meaning' (Frankl 1988). This should not be understood as an abstract 'meaning in life', but the meaning of life right here, right now:

> To look for the general meaning of man's life would be comparable to asking a chess player. 'What is the best move?' there is no such thing as 'the best move' apart from the one that is best within the context of a particular situation of a particular game (Frankl 1985, 67).

Creating autobiographies could be used a reflective practice which satisfies these needs for meaning right here, and right now.

7.4 Identity and metamorphosis

One could argue that autobiographies are transparent and true presentations of the self. In this sense, they are presenting the self as something given, often in retrospect. One example is the confessional autobiography written late in life, as a means to look back and present the narrative of one's course of life. This approach has a variety of problems, one being the risk of a kind of watered-down existentialism, another thing is the obvious fallibility of memory. Some theorists, to some degree or other inspired by Freud, believe that it is not really a question of a description of an authentic subject or self, but rather a longing for an absent one (Kristeva 1991; Lacan 1986; Zizek 1999).

> By identity, as it refers to social actors, I understand the process of construction of meaning on the basis of a cultural attribute, or related set of cultural attributes, that is given priority over other sources of meaning. For a given individual, or for a collective actor, there may be a plurality of identities.' (Castells 2004, 6).

Bleakley, drawing on Derrida, states that this autobiography 'is not primarily about self-confession or self-revelation in a subjective manner, but as a means by which relation to another is articulated' (Bleakley 2000, 21). In terms of technologies of the self (in the spirit of Foucault) this chain of processes creates a way to construct and regulate the subject through self-monitoring in a network of power/knowledge and truth/meaning. The question is no longer how you perceive yourself, but how to present (expose) yourself, not where you are but where you are going, and finally, not who you are but rather who you are becoming. The being is exchanged by becoming, the factual is exchanged by the virtual. Baudrillard called this hyper-realism (Baudrillard 2003). The virtual has a tendency to be multiple, as opposed to the singular nature of a fact. It is misleading to speak of the world as something that exists, or even as a single world. It seems more sensible to imagine a series of different versions of the world which individuals can create and relate to (Chalfen 2004, 230). The degraded hierarchies of contemporary society, the fall of authority and the narrow focus on individuality and independence have created new opportunities and demands for the conception of a 'self'. The emphasis on choice, freedom and reflexivity may be one of the explanations for the increasing number of people who feel a need to expose and remake themselves, if not publicly then at least in private. This trend is reflected in everything from design, literature,

and art to retired politicians trying to improve their posthumous reputation through mediating (remaking) themselves in confessional books, self-exposing intimate interviews, and filmed 'documentaries'.

> People maintain the illusion of inner continuity and consistency. For one thing, people construct and reconstruct their biographies and their histories, explaining to themselves and others in the process how they came to be and who they are. This process appears to be largely unconscious and haphazard in the most part most of the time (Kiefer 1974, 233-24).

To maintain a viable sense of identity in a world of constant flux and change may seem insurmountable. One solution to this predicament is to be pragmatic. James says that truth is something that will lead us successfully through life and that it is created along the way (James 1909). It is not a priori. There is a parallel to Nadine's notion of anticipation (Nadine 2002), and Suchman's notion of plans as situated action (Suchman 1987). You solve the problem you are interested in, you see what you seek. You create your history to suit your own purposes, a history which responds to your idea of the world. At the same time you are constantly affected by the world and the image other people have of you. 'We are never faced with objects or social relations, we are faced with chains which are associations of humans and non-humans' (Latour 1991, 110). Your autobiography is hence a social relation. You can even talk about a collaborative subject/self, an inter-subjectivity (Habermas 1987; Haverty 2001).

> My own word about myself is in principle incapable of being the last word ... for me myself, my own word is an act that I perform and then my performed act is alive only in the unitary and unique event of being (Bakhtin 1995, 142).

Confessional self-accounting, such as an autobiography, is in principe incapable of being consummated, finished. At the same time it is much more than an expression of yourself – it is created as you simultaneously are (re)creating yourself. It exists everywhere, both outside of you (in all marks and impressions you make on the world), and inside of you (in all the memories you have). It is not obvious that one can distinguish between the media and the mediated (that is between the representation and 'I'). The relation between person and environment does

not have to be seen as moving information across a boundary but rather as a coordination of elements within a system (Hutchins 1995, 288).

> The point in the end is not to assign agency either to persons or to things, but to identify the materialization of subjects, objects and the relations between them as an effect, more or less durable and contestable, of ongoing socio-material practices (Suchman 2004).

When distributed to different artefacts, the self appears in a multitude of shapes, characterised not only by its materiality but also by the necessity to relate to the self of others. The experience of a continuous evolution of these overlapping 'selves', many of which are materialised together with others' overlapping selves, cannot be captured by traditional design approaches, nor can ethical aspects and conflicts of the right to express your self through artefacts. This socio-materiality of the distributed self is the topic of paper IV.

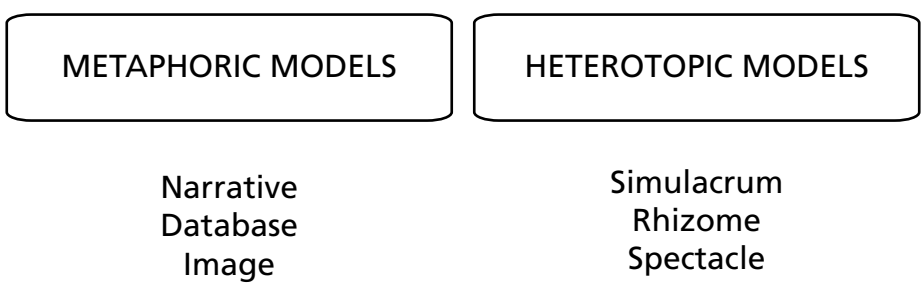
In the light of these lines of thought the autobiography is a question of becoming, not describing. It is a lifelong and continuous process, not a final product. The autobiography is, in other words, a metamorphosis.

7.5 Autobiographic models

In this section I present six models of the autobiography, divided into two categories: metaphors and heterotopias. I argue that the current practice of using autobiographic artefacts within participatory design research is metaphoric (and metonymic). I use Foucault's term 'heterotopia' to describe the autobiography as a place where the self is put aside – a non-place.

> [T]he subject is no longer located in a point in absolute time/space, enjoying a physical, fixed vantage point from which rationally to calculate its options. Instead it is multiplied by databases, dispersed by computer messaging and conferencing, decontextualized and reidentified by TV ads, dissolved and materialized continuously in the electronic transmission of symbols (Poster 1990, 15-16).

In this chapter I propose six conceptual models of the autobiography, divided into two categories: metaphors ('narrative', 'database' and 'image') and heterotopias ('simulacrum', 'rhizome' and 'spectacle'). The division of these models into the two categories is my own and used as a means to clarify their respective similarities and differences. It is not my intention to pit these models against one another, but rather see how they act as complementary perspectives of the autobiography. The point is to view them as places for the self, located outside the body, making up the socio-materiality of a distributed self – or multiple selves. These models are conceptual in the sense that they are not only a matter of language, but also of thought and embodied experience.



7.6 Metaphoric – metonymic models

> In modern Athens, the vehicles of mass transportation are called 'metaphorai'. To go to work or come home, one takes a 'metaphor' a bus or a train (de Certaeu 1984, 115).

Metaphors are means of transportation and transformation[9]. In Aristotle's definition a metaphor is 'the application of an alien name by transference either from genus to species, or from species to genus, or from species to species, or by analogy, that is proportion' (Aristotle 1999, XXI). They are figures of speech describing one thing in terms of something else. As autobiographies, they occupy a relationship to the subject/individual which has the form 'like a', or 'is a'. To read the text in my diary is like taking part of my memories and my life. To look at my childhood photographs is like seeing how I was as a boy. The subject is mediated, likened, and replaced. This replacement is characteristic for metonyms, which are closely related to metaphors. Metonyms primarily have a referential function, that is, they allows us to use one entity to 'stand for' another. They work by association and contiguity – 'the story of my life'. This differs from metaphors which work by similarity – 'my life is (like) a story' (Lakoff and Johnson 1980).

Metaphors are also 'Gedankenexperiments', thought experiments, which establish and refer to a possible world (Asplund 2003, 89). Also, the (design) activities of materialising these realities can be described as creating metaphors (Weimarck 2003). Metaphors are not only indispensable tools for thought, in daily life as well as in design research, but the very processes of human thought are largely metaphorical (Lakoff and Johnson 1980). But if the metaphoric nature is ignored, if it is understood literally, there is a risk of using it as a pseudo-scientific term. Then the metaphor has lost its power and obscures rather than enlightens thought (Asplund 2002, 105).

The three terms I will use to describe metaphoric–metonymic autobiographies are 'the narrative', 'the database' and 'the image'. They are metaphoric in the sense of 'my diary is like a database'. At the same time they are metonymies, 'the X-ray looks good'. Metaphors create the relation between its objects, while metonyms presuppose the relation (Bredin 1984). The reason I chose these three are firstly

9 Etymologically, 'metaphor' comes from the Greek 'metapherein'; meta (over, across), pherein (to carry, bear).

that they represent historically recognized types of autobiographies. Secondly, because they can be seen as comprehensive models for a variety of practices and artefacts. Thirdly, these are common means used in participatory design research for collecting information and inspiration from first persons, as we have seen in the two case studies presented earlier ('the self as image' and 'the self as data'). Finally, these concepts make the transition to a different view of autobiographies clear.

7.6.1 Narrative

> It can be said that each of us constructs and lives a 'narrative', and that this narrative *is* us, our identities (Sacks 1993).

Narratives are essentially about storytelling and the narrative autobiography is known from literature in both its explicitly public forms, often with artistic aspirations, and in introverted and private ones. Often there is an intention to explain oneself – to present 'the true self'. Nietzsche's self-reflective and last work was named 'Ecce Homo: Wie man wird was man ist' (Ecce Homo: How to become what you are) (Nietzsche 1889). In the introduction he makes the purpose of his autobiographical narrative clear: 'Hear me! For I am such and such a person. Above all, do not mistake me for someone else.'

One consequence of the narrative form is that an autobiography can be seen as a message, with a transmitter (narrator) and a receiver (listener). This is analogous to the linear transmission model of communication. As the narrative represents and substitutes first hand experiences it requires consistency, agreements, consensus and a series of conventions in order to get the message through with minimal distortion and noise. The carrier of the message (e.g. a diary) should be virtually transparent, avoiding interference and connotations. But, since the word 'narrative' comes from the Latin 'narrare', to know, it implies that a certain degree of mutual understanding between narrator and listener is necessary. Storytelling is not simply a transmission, but an interpretation. This view is better represented by the transactional model of Barnlund. It is not the book that is read but the content (which in turn provides the meaning of the book), and a book has different meanings in different times and places. In this sense, the narrative is a place for people to meet and to understand each other (although the communication mostly is uni-directional).



What may not be immediately obvious is that the narrative autobiography also occurs in everyday contexts in the form of gossip, daydreams, intimate conversation, wish lists, et cetera. These are rarely written down or in some other way preserved for posterity and thus disappear from the individuals themselves but also from researchers investigating this topic. These stories are often not valued or taken seriously as proper autobiographies. The autobiographical narrative is even less known in the form of medical anamnesis, psychological therapeutic conversations, questionnaires, professional discussions, political and activist writings and a wide range of other stories where the self is expressed and formulated. One can question whether these really are narratives in the strict sense since they often are not conscious, deliberate and intentional, and lack a temporal structure or timeline. These ad hoc 'stories' seem to be unordered, unplanned, and in most cases not intended to be about the self. In a way they are autobiographic meta-narratives.

In design research, the challenge is to extract information (meaning) from these and other kinds of ad hoc narratives.

7.6.2 Database

The accumulation, organisation, and retrieval of information has long been a challenge for mankind. Historically, people who were in need of remembering large amounts of information had to rely on their own memory. For this purpose there has been a assortment of techniques, ranging from rhymes and meter as used in poetry, to special mnemonic strategies. We now have a wide range of technological aids, such as mobile phones and computers, which help us to store information. This leads us to another common metaphor for the autobiography, namely the database. A database can be viewed as a collection of pieces of information, data stored in a systematic way so that overview and efficient access can be achieved. The database is in a way an artificial memory.

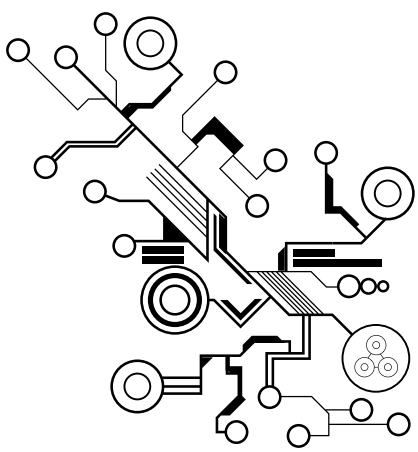
The database basically means a shift from being to saving in terms of accumulation, collection, and systemisation. Data are collected, coded, handled and sorted. Links between nodes can be created, correlations are visualized and interpreted. The database is a fundamental transformation of reality. Meaning is encoded in different media, transferred and processed for a subsequent decoding in order to recover its function as meaning. Manovich speaks of the database as the natural

enemy of the narrative (Manovich 1999). The database refuses to organise the fragments into comprehensible whole, something the narrative does.

How is the perception of the self and its history changed as it is filtered through the artificial memory of technology? Do I recall more, or even less, by saving data? Recollection of memories has been transformed from mnemonics and poetry into keywords and tagging. To remember and to recall are not necessarily the same due to qualitative as well as practical differences.

This reconstructed meaning is not necessarily the same as the meaning once encoded into data. This transformation of memories into data and back can be likened to walking along a Möbius strip (Möbius 1858, 519). Despite the fact that you go straight ahead all the time, you apparently will get back to where you started. But something has happened along the way that is beyond your perception and intention. To remember also has other connotations than the purely factual, based on the information. To remember your own childhood does not necessarily mean that you remember what actually has happened a certain summer. You remember without really recollecting that much. By this I mean that it is possible to have memories without being able to recollect facts. Knowledge as meaning is so much more than just information as data (Winner 2003).

In design research, the challenge is to make sense of heterogeneous collections of data – connecting the dots to get a fuller picture. The question is to determine *how*.



7.6.3 Image

Vision has in the Western culture a special status among the senses (Johannisson 2004). Not only in relation to knowledge, but the eye is also the metaphoric window to the soul. Therefore, images of people, especially self portraits play an important role in the story about ourselves. Photographs as images of the self are interesting in a variety of areas, from ethnography (Pink 2007) to therapy (Landgarten 1981), from neuroscience ('neurophenomenology') (Lloyd 2002) to art (Coplans 1997). These images are common in the private context. Family albums exist almost in every home and photographs from anniversaries and holidays, births and everyday activities in many ways play a role as biographical material and have done so for nearly a hundred and fifty years. Ever since the emergence of hobby photography it has been possible for anyone to participate in this image production – photography as such has become autobiographical. In addition to still images, you can now add movie clips and sound using video cameras and mobile phones (Frohlich 2004).

Photographs function, as already mentioned, as documents of events, the album function as memory banks and evidence, witnesses. Pictures play a performative role which often is social, both in creating and displaying them. Images function as social markers and personal expressions of cultural and personal identity (Chalfen 2004, 214). To create and maintain a photo album is both a pleasure, an investment, and an autobiography. An extreme example of a constant photographic documentation is Steve Mann's experiment 'WearCam' (Mann 1997, 30).

> The WearCam enabled Mann to in effect become a web camera, blurring the line between reality and virtuality, presence and telepresence (Campanella 2002, 269).

Turning this social practice into a research practice often involves turning images into narratives (writing or talking about images), or into databases (collecting, categorising, and comparing). The challenge for using autobiographic images in design research is to see them as something beyond means of information collection (data) and inspiration (creativity) – as means in themselves.



7.7 Heterotopic models

The heterotopia is a refuge where dreams and truths, facts and fictions can be explored and developed simultaneously. A number of principles can be used to describe heterotopias (Foucault 2007, 232-236). The **first** principle states that heterotopias exist in every culture, in every human group. The **second**, that the precise and determined function of a specific heterotopia may vary between different cultures, or over time within one culture, for example the cemetery. The **third**, that the heterotopia juxtaposes several spaces in a single place – on a stage, in a garden, or in a hypertext. The **fourth** principle states that heterotopias are most often linked to slices in time, capturing transitory and fleeting moments such as the emergency room, or to an accumulation of time in museums, archives, and medical journals. The **fifth** states that heterotopias are not freely accessible like a public place. Either it is compulsory (a prison) or it requires specific permission, rites, and gestures of the one trying to enter (the hammam, or sauna). The **sixth** and final trait of the heterotopia is that it has a function in relation to all the space that remains, ranging from the extremes of illusion (virtual reality) to compensation (the allotment garden). If the utopia *par excellence* is the paradise – the ideal non-place, a site with no real place – the heterotopia *par excellence* is the ship – a floating piece of space, a place without a place.

The heterotopic types I propose are 'the simulacrum', 'the rhizome' and 'the spectacle'. The reason I choose these three is that they reflect changes in society at large which have an impact on how people show and express themselves. They are also effective in relation to the metaphoric-metonymic models, not as antipodes but as orthogonal dimensions. Lastly, they are useful to illustrate the incorporation and co-dependency between human actors and non-human actors in the creation and distribution of the self.

> Those who engage in heterotopic communication resort to their 'own devices' both in the sense of personal agendas, strategies, interests, and interpretations, and in the form of the telecommunication tools that help realize them. These personal and technological devices allow individuals with the right educational and technical resources to avoid exposure to disagreement, difference, or other information that does not serve their direct purposes or reflect their particularistic views of the world; yet they also help convey the appearance of openness, availability and cooperation (Lievrouw 1998).

7.7.1 Simulacrum

> The simulacrum is never what hides the truth – it is truth that hides the fact that there is none. The simulacrum is true (Ecclesiastes, in Baudrillard 1998).

In his philosophical thesis Simulacra and Simulation, Baudrillard discusses how we replace reality and meaning with symbols and signs (Baudrillard 1998). What we know about reality is actually a simulation of reality. The 'simulacrum' is made up of the signs of culture and communication media that create the reality we experience: a world saturated with images, audio, advertising in the omnipresent media. Together, they become a hyper-reality, a world that seems more real than the physical one. Through simulacra, control over information is transformed to the control of sensory impressions, interpretations, and knowledge. You can no longer make distinctions between objects and representations, substance and meaning. Asplund wrote that the task of simulacra is to create illusions, not copies. It should be strikingly similar and obviously different at the same time (Asplund 2003, 61).

> The simulacrum is not a degraded copy. It harbors a positive power which denies *the original and the copy, the model and the reproductio*n. At least two divergent series are internalized in the simulacrum – neither can be assigned as the original, neither as the copy (Deleuze 1990, 262).

In contrast to Baudrillard's negative perception of the simulacra, Deleuze sees them as means for empowerment – a way to overthrow accepted ideals and privileged positions by relating to and affirming difference.

> The simulacra also affirm their own difference. Simulacra are those systems in which different relates to different *by means of* difference itself. What is essential is that we find in these systems no *prior identity*, no *internal resemblance*. (Deleuze 2004, 299)

Examples of such simulacra of reality, hyper-realities are massively multiplayer online role playing games (MMORPGs) and virtual worlds[10]. You create an alter

10 For example Ultima Online (http://www.uoherald.com/news/), Everquest (http://everquest.station.sony.com/), Second Life (http://secondlife.com/), Entropia Universe (http://www.entropiauniverse.com/entropiauniverse/).

ego, an avatar, acting as a stand-in during your exploration of these worlds. These digital characters are examples of simulacra of the self – fictitious, hypermediated, and transient. The difference between these alter egos, and the pseudonyms used in different virtual meeting places is that they act as proxies instead of aliases. They exist instead of you, in your place – 'in lieu tenants'.

An apparently similar but fundamentally different form of simulation of the self is the so-called live role-playing games. These are more or less staged scenarios where participants create their own character to act out, a character which replaces your true identity and self. Often these alternative identities have their core in the individuals' nature and physical traits, but not necessarily so. The voluntary nature of the choice of alter ego, involvement in the acting and role-playing, and the game's social nature ensure both intimacy and security. Mutual acceptance of the validity of these alter egos is a prerequisite for the game. This acceptance of deviating behaviour or appearance is often stronger during a game than in everyday life, a situation which ensures a forgiving and understanding place for exploration and experimentation of alternative 'selves'.

If narratives are seen as documents or documentaries of something in the world, simulacra are both world and sign wrapped into one. The challenge for design research is to acknowledge this existence through signs and symbols and not necessarily look for something beyond the simulacrum.

7.7.2 Rhizome

The rhizome is an underground horizontal stem of a plant from which roots shoot off. Carl Jung used it metaphorically in analytical psychology. He wrote:

> Life has always seemed to me like a plant that lives on its rhizome. Its true life is invisible, hidden in the rhizome. The part that appears above the ground lasts only a single summer. Then it withers away – an ephemeral apparition. … What we see is blossom, which passes. The rhizome remains (Jung 1989).



Gilles Deleuze and Félix Gauttari used it conceptually to describe theory and research with multiple non-hierarchical entry and exit points for data representation and interpretation (Deleuze and Gauttari 1987). If the database is about accumulation, classification, grouping and retrieval, the rhizome is about creating connections in something heterogeneous and multiple, to cut cross-sections. The rhizome derives meaning from scattered parts by mapping out and creating assemblages. As a map it is not used for navigating in a real external world, but as a map to travel within (Deleuze and Gauttari 1987). To put it simply one can say that people who use the database model are collectors. They preserve (the memory of) something that existed or happened, and later recreate it. The archetype of the rhizomatic autobiographer is the sampler who creates new meaning by breaking old things up and rearranging the bits, or by assembling originally non-related parts into new wholes. This is similar to the collage techniques of the cubists, used as a method to bring together analysis and subject matter (motif). Knowledge about the motif (its meaning) was in a way intended to be depicted by the rearrangement of illustrative fragments (Sällström 1991, 380). Contemporary artists have worked with similar methods, for example, the Italian group 0100101110101101.org (0100101110101101.org).

> … 'life_sharing' is a relatively complete form of self-exposure. … One could almost describe 'life_sharing' as a kind of online self-portrait. (Baumgärtel 2003)

The social aspects of peer-to-peer networks and mobile technology can in a sense be considered antipodal to the database model. Although these networks can be likened to gigantic distributed memories or databases, they are maintained and generated by an exchange between a number of participants acting in different contexts. Data is stored and shared, but also manipulated and reframed without centralised control or supervision.

> The miniature, as opposed to the monument, is portable and transportable; it empties no room; there is no monumentum on any timeline, but something you carry inside your waistcoat…' (Bäcklund 1999; my translation).

The kind of miniaturisation and fragmentation of the database as, for example, the digital mobile practice entails transforms the metonymic ('pars pro toto')



autobiography into a heterotopic one. Firstly, since the relationship towards the objects is a reflexive wandering around – a 'stumble upon' rather than 'search for'. Secondly, this means a distribution of information, action and initiatives. It is not a question of synchronisation, updating to the latest version, but to update in relation to new version of (the reality of) others. The rhizome, in the form of what is haphazardly called 'new media', is oriented towards action not contemplation, towards the present not the past. The rhizome makes it clear that even the writing of your personal history is always a matter of manipulation – and a social one (Enzensberger 2003, 265).

The true challenge for design research is to understand that it is not only the researchers who cut cross-sections through the lives of the informants, but also the informants who provide provisional and ready-made cross-sections of their own.

7.7.3 Spectacle

> In societies dominated by modern conditions of production, life is presented as an immense accumulation of *spectacles*. Everything that was directly lived has receded into a representation (Debord 2004, vv. 1).

In our media age all are artists in the sense that everyone 'stands on a stage'. To be a star on this stage is to be a spectacular representation of a living human being. Lefébvre used the 'spectacle' as a concept for the present mass consumption – an exhibition. As an autobiography, the spectacle is a mediated self, not a message since there are no actual transmitters and receivers in accordance with conventional communication models. It is a social relation between people that is mediated, not a collection of images. As parts of the spectacle, pictures should not be seen as a form of communication but as a mutual creation of meaning, representation, and interaction (Baudrillard 2003, 286).

The spectacle can be seen as an inverse panopticon, or rather a bi-directional one. The original was a model prison conceived by the English philosopher Jeremy Bentham in which prisoners could be observed at any time without being aware of it (Bentham 1995/1787). This feeling of constant but invisible presence gave a sense of one soul's power over the other. Feminist theorists have used the panopticon as a metaphor for the omnipresent male gaze exerting power over women.

But what happens when the 'prisoner' is the one who transmits images of himself but unaware of who is receiving them? As the digitisation of photography and the prevalence of webcams connected to the internet an increasing number of private photographic images are moved from the living room out into cyberspace. In the future, when other senses can be as vividly triggered one can speak of this phenomenon in terms of 'telepresence', remote presence (Hertz 1996; Minsky 1980). The entire photo album uploaded on servers made available to millions of people, webcams broadcasting your life one image per second, and your home videos making the top-ten list on YouTube. The spectacle is *affirmation* of appearance and affirmation of all human life, namely social life, as mere appearance – not essence (Debord 2004, vv. 10).

As people are getting more and more used to transforming themselves into representations, researchers have to be able understand the difference between presentation and representation. There is naturally also an opportunity to make use of this phenomenon by engaging in people's appropriation of media and technology as representations – or even parts – of their 'selves'.



8. Coda

It is now time for this journey to come to a halt and for us to revisit the formal point of departure – the search for new knowledge. First of all, the aims of the thesis will be recapitulated and related to the material presented in this text. Then, my contribution to the body of knowledge of participatory design research is outlined.

The first aim was to investigate the use of autobiographic artefacts in user-centred participatory design research, that is artefacts for creating and expressing personal meaning and experience. Two case studies were described in papers I-IV and in chapter 3, aiming at providing such autobiographic technologies of the self: personal images in healthcare, and a digital device for personal and clinical information. These were discussed from a general perspective in chapter 5.

The second aim concerned the interaction between two individuals, the researcher and the informant, suggesting using autoethnographic and autobiographic practices. This was addressed in chapters 2, 6 and 7. Interpretation of personal accounts in design research, and the lack of explicit reports of this activity were some of the main issues of paper V. Other inter-personal issues in the cases were discussed in chapter 3.3.

The third aim was to map out concepts, theories, and literature relevant for this autobiographic practice. Chapter 2, 4-7 as well as the literature presented in the reference list and the appended papers constitute an attempt to meet this aim.

The new knowledge I want to contribute with this thesis is positioned on two different levels. On the **specific level** it concerns the interaction and tension between clinical images and images for personal use, and the impact of technological possibilities (during pregnancy) to integrate personal information and clinical data. By introducing the notion of autobiographies, and elaborating on the nature of autobiographic knowledge, artefacts, and practice I have showed that this interaction between/integration of the personal and the clinical is a matter of transformation and metamorphosis rather than of addition and enhancement. This is the case since I argue that autobiographies negotiate orthogonal dimensions, such

as fact–fiction, information–meaning, being–becoming, human–non-human, and so on. When asked to add apples and pears, you have to answer 'fruit salad'.

In respect to rehabilitation engineering and design, I hope that my thesis will contribute to a better understanding of the multifaceted notion of the self which has become increasingly clear in the information era. If 're-habilitation' in the past could be to re-create one's former self, in the professional or personal sphere, it has now become a matter of acknowledging the many 'distributed selves' which are created in the rehabilitation process (paper IV). It is therefore no coincidence that autobiographies can be studied with the eyes of rehabilitation and that for example art therapy can contribute to this re-creation (Landgarten 1981; Lime 2000; NEA 2004). To stress the role of artefacts in this concept of the distributed self does not mean that I grant them equal agency or quality. It is people, not things, who are living, feeling, wishing, and taking initiatives to act. But it is beyond doubt that technological artefacts are playing an increasingly larger role in the making of identity.

Although the ideas and prototypes were interesting to the participants during the case studies, the question of the viability of the concepts and practical implementation and appropriation of them in everyday practice is left to be answered. As we have seen, although participatory design research has the explicit intention to do real things with real people, this reality differs from the one encountered during a case study. Instead of looking at first persons participating in use (design for use before use), or seeing them as designers (design for design after design), designers should be engaged in and committed to their appropriation of personal 'technologies of the self' – their autobiographies.

On a more **general level**, my contribution is constituted by the very selection of background material and literature which is presented in the thesis – specifically in the chapter on methodology, and the entire second half of the thesis. This selection is the result of a necessarily associative and adaptive process – not a linear and methodical one. It has come to existence by meeting both past and current needs. In that respect the selection is both ad hoc and post factum. This process has in many ways shaped me as a researcher and can certainly be characterised as a partial autobiography evolving during my time as a doctoral student. As such, it has merits on its own both for me personally and as an example of how (my) knowledge and experience can be shared.

Reporting this selected sample of literature, theories and methods also has a methodological value since my treatment and use of it functions as the basis of *how* and *why* I have gone about the things I have done. Although not all aspects of the methods, theories, and concepts mentioned in the thesis are used explicitly, for example when dealing with the cases, it does not mean they have had no function. On the contrary, they have become integrated with each other and myself to a degree of (almost) becoming tacit knowing.

The elephant in the dark house – on the reconciliation of contrarieties

> Some Hindus brought an elephant, which they exhibited in a dark shed. As seeing it with the eye was impossible, everyone felt it with the palm of his hand. The hand of one fell on its trunk; he said, 'This animal is like a water pipe'. Another touched its ear, to him, the creature seemed like a fan. Another handled its leg and described the elephant as having the shape of a pillar. Another stroke its back. 'Truly', he said, 'this elephant resembles a throne'. Had each of them held a lighted candle, there would have been no contradiction in their word (Rumi 1930, book III, vv. 1259-1268).

With the help of this ancient poem, retold by Jalal ad-Din Muhammad Rumi among others, I would like to end by arguing that topics like the one of this thesis need to be approached abductively. This includes accounting for and making transparent the researcher's different backgrounds and modes of understanding. The results of the review of design conference articles in paper V can in a broader context serve as an example of the need for this approach. Almost all the contributions had no accounting for how scientists come from primary observation to the results and conclusions leaving the reader without a clue. Abduction – as pattern recognition, tacit knowing, or thinking from exemplars – is important in all phases of design research, but the pattern to be recognised changes according to the perspective chosen and the background information provided; it is a moving target.

Just as different branches of research provide different interpretations of the world, different models of autobiographies provide different descriptions of the 'I' in design.

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Papers

Paper I

Bridging the gap between clinical and as patient-provided images.
Enquist, H.
In *Visual Literacy*. Elkins, J. (ed.), pp. 145-163. Routledge, London, 2007.

Paper II

Narcissus's new mirror. Body images and meaning.
Enquist, H.
Crossings – Electronic Journal of Art and Technology, vol. 5.1, 2007.

Paper III

The Memory Stone – a personal ICT device in healthcare.
Enquist, H., and Tollmar, K.
In *Proceedings from the Fifth NordiCHI Conference*,
(Lund, Sweden, 20-22 October, 2008), pp. 103-112.

Paper IV

A socio-material ecology of the distributed self.
Enquist, H.
Design Philosophy Papers, issue 2, 2008.

Paper V

Intuition in Design & Emotion – Transforming raw data into conclusions,
a meta-analysis of the 2006 Design & Emotion Conference papers.
Enquist, H., and Nordgren, C.
In *Proceedings from the 6th Conference on Design & Emotion 2008*. Desmet, P.M.A., Tzvetanova, S.A., Hekkert, P., Justice, L. (eds.). School of Design, the Hong Kong Polytechnic University, (Hong Kong SAR, 6-9 October 2008).

Contributions

Paper I, II: I am the sole author of these papers.
Paper III: I have participated in all research activities presented in the paper except the field studies. I have developed hardware and software for the prototypes described. I wrote most of the paper and presented it at a conference.
Paper IV: For my contribution to the empirical work, see paper III.
Paper V: Both authors contributed equally to the collection and analysis of the empirical material. I wrote the majority of the text in the paper and presented it at a conference.

Comments

The papers have been re-formatted for the sake of readability. Page layout and figure positioning has been made to resemble the original as much as possible. The original pagination is indicated in-line as {cont. p. #} for papers I, III, and V. Papers II and IV lack original pagination.

Summary

In order to relate the publications included to the thesis, short summaries of their relevant contributions are presented below. The specific results of each study can be found in the appended papers.

Paper I discusses the ability and possible interest of individuals to express themselves subjectively through artefacts in relation to their medical condition. Specific means for this purpose (e.g. cultural probes) are used in the paper and are further discussed in the thesis.

The objective was to investigate the possibility of producing and arguing for the use of artefacts of experienced health. It was a qualitative case study based on self-produced images of experienced health. A group of ten professionals with experience in creative production (such as visual art, design, and film making) and a group of persons suffering long-term illness were recruited. The latter consisted of approximately twenty in-house patients at Spenshult Hospital for Rheumatic Diseases in Sweden. Ten of these used the cultural probe for a period of three to five weeks.

Two workshops were conducted, one for each group, and a cultural probe was handed out to ten of the patients. Results from the professionals' workshop and the patients' cultural probe usage are reported in the paper. A number of concepts, collages, and photographic documentation of experiencing illness/health were produced. Although the two groups had different tasks (getting a diagnosis versus living with a long-term illness) they were each capable of producing meaningful artefacts. The major difference between the professional and the non-professional groups was on the conceptual level, where the former was more abstract and the latter more concrete.

Provided with suitable tools for self-expression, non-professionals are able to express themselves and their experiences of health in, for them, meaningful ways. Introducing the practice of patient-produced images into a rehabilitation process, for example, can be beneficial for both patients and healthcare professionals, enabling alternative forms of communication of subjective experiences.

The area of enquiry in **paper II** concerns how an individual is affected by these kinds of subjective artefacts (in this case images of body and health). There are two main aspects of this proposition: one practical and technological (concerned with the tools and methods to be used) the other epistemological (aimed at disseminating knowledge and understanding of visual communication in a medical context).

The objective was to discuss the impact of technology and medical images on the perception of body and health. In this theoretical paper I propose the use of subjective images in healthcare as a field of design research, and discuss the implications technology has on the ability to see, and consequently know, more about the body. The potential of merging art, rehabilitation engineering and medicine to develop and use images specifically designed to create meaning for the afflicted individual is proposed as a future research topic. The key question is how alternative (i.e. non-clinical) perspectives can result in experiencing well-being, or even improving the health of the individual.

Paper III relates to how the individual can be active in the (co-)creation of autobiographic artefacts, and how they are used in daily life. It also contains a discussion of the interplay between the interests of the healthcare professionals and the individuals (pregnant women in this case).

The objective was to develop and investigate the use of a personal information device in healthcare. A participatory design approach was used including development of functional prototypes. Ten pregnant women divided into two separate groups participated, as well as eight healthcare professionals including midwives, general practitioner, and specialists. The study was conducted in Aarhus, Denmark.

A number of methods and techniques were used to collect information and input from the participants such as workshops (focus groups, concept development, interaction tests), use case scenarios (device interaction, data management, social interaction), ethnographic field studies (work place shadowing, web forum discussions), diaries, and prototype evaluation.

Currently, medical information regarding a pregnancy is stored in several locations and on different media. This was reported as a problem, both for the healthcare personnel and the pregnant women and their spouses. Information was repeated due to a lack of communication between different healthcare providers. The paper files used today were not considered useful by the pregnant women due

to incomprehensible language and lack of personal private notes. Information provided by the healthcare personnel was often disregarded or forgotten by the women. This meant that the healthcare providers needed to repeat instructions. At the same time, the pregnant women found it annoying and felt uneasy and uncertain.

The pregnant women were enabled and empowered through the use of a personal ICT device to be more engaged in the communication of information about their pregnancies. The spouses also reported increased involvement. By mixing medical and personal aspects of their pregnancies, a more comprehensive and personal narrative was achieved. It was reported that new information should be consistent with the present knowledge and expectations. The participants also reported that personal/manual updates along with documentation of the comments on the new information were preferred over automated updates of clinical data.

Paper IV deals with the distributed self which means how self-expressive artefacts can be considered parts of the individual's personal narrative. An attempt was made to capture this phenomenon both theoretically and empirically in order to argue for artefacts as a kind of autobiography.

The objective was to develop a conceptual framework regarding the notion of the distributed self: how artefacts are an intrinsic part of the representation and activities of the individual, and to exemplify how these perspectives can be applied to the pregnancy case. The paper presents a theoretical discussion based on empirical material presented in paper I.

By combining notions taken from actor-network theory and the metaphor of ecology, I argue for a broader view on what is called 'an individual'. The use of artefacts and design objects for self-expression and representation stresses the need for considering a holistic view when engaging in design processes. Although the ecological metaphor can be contested, it has surfaced in many areas indicating its attractiveness and inclusive power. Applying it to describe interrelationships between users and interactive artefacts is fruitful if used cautiously. Combining this metaphor with the notion of alignment of actants from actor-network theory, interdependencies and relationships between artefacts and individuals can be further enhanced in a design research process.

Interpretation is a crucial process when accessing and evaluating subjective accounts of experienced health, which is the theme of **paper V**. The act of interpretation also places demands on mutual empathy, learning, and dependency in the design research process, which is discussed further in the thesis.

The objective was to investigate how interpretations of personal and subjective responses are analysed and reported in experiential design research. As interpretation is one possible aspect which separates design research from design practice, it was considered an important methodological issue to study. The paper is a review of the papers from the Fifth Design and Emotion Conference, held in Gothenburg in 2006. It is a qualitative review based on a series of questions.

In most cases, no separate analysis and/or interpretation chapter was presented. Few papers reported a specific method for analysis and/or interpretation. Generally, the description of the design process, the collection of research material, and the conclusions were intermixed. Often it was unclear how the authors had reached the conclusions presented in the papers. By omitting an explicit account of the interpretation, several methodological issues are raised. From the reader's point of view, interpretation of the collected material and the design process seems to be made intuitively, or based on the tacit knowledge of the researchers. Validity, or rather credibility, of the conclusions presented is thus weakened. It also makes it difficult for the reader to compare papers, find information regarding interpretation, and so on.

Paper I

Bridging the gap between clinical and patient-provided images.

Enquist, H.

In *Visual Literacy*. Elkins, J. (ed.), pp. 145-163. Routledge, London, 2007.

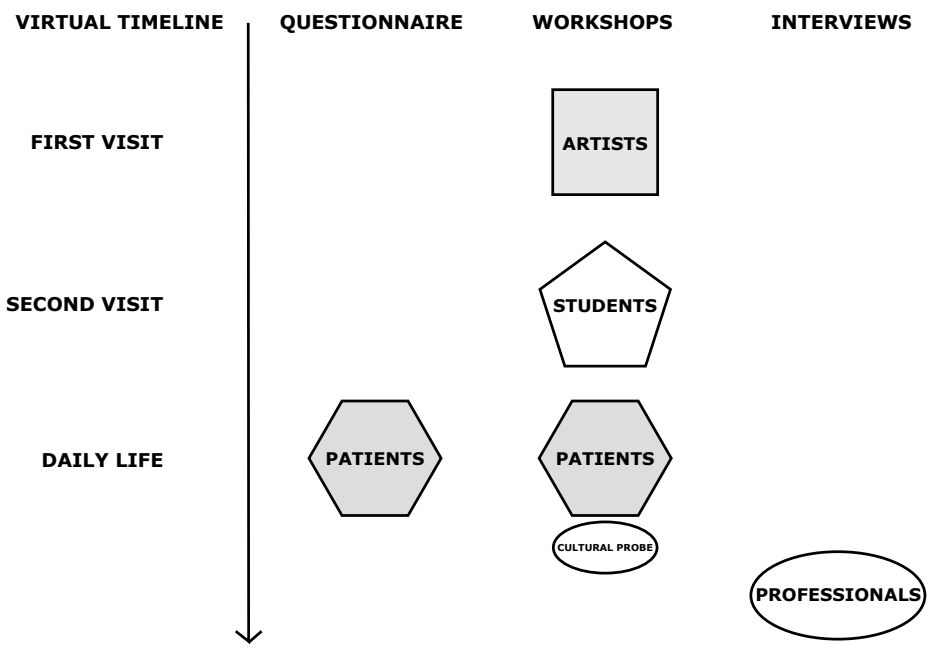
The paper was originally presented at:
The First Conference on Visual Literacy. (Cork, Ireland, 14-15 April, 2005).

For further material from this study, see:
Svenstedt, C.H. (ed.) (2005). Methods 2.0, (ed.)
Studies in Arts and Communication , no. 04. Malmö: Art and Communication, Malmö University. Available at www.certec.lth.se/doc/eatmethods/eatmethod.pdf

Bridging the gap between clinical and patient-provided images

I will be reporting here on how a group of artists and designers and a group of patients approached the task of visualizing the meaning of specific medical diagnoses without recourse to traditional medical imagery.[1] The purpose was to investigate how people relate to images produced in healthcare, and how alternative visual aids might complement printed and verbal communications between doctors and patients. One fundamental concern of this study was to evaluate the influence and effect images have on patients' experience and knowledge of their personal health.

The study examined the use of images at three different points in time: the first week after diagnosis (this was investigated by a group of artists who played the role of patients), the second visit to the doctor's (represented by a group of medical students who played the role of patients), and living with a diagnosis (this subject was given to a group of actual patients).[2] In this paper, I will provide examples from the first and third of these — the artists' and patients' workshops — and focus only on the visual material produced. (The results from the group of medical students are conceptually similar to the traditional clinical images produced in healthcare. As such they do not add anything novel to the visualization of illness.) I have four simple points to make: that in the near future, the exchange of information in healthcare will take a different shape; that visualizations not only are a matter of form and content, but also promote action; that {cont. p. 146} the ability to produce visualizations facilitates thinking, learning, and communication as well as the skill to read new images; and, finally, that there is a wide gap between the clinical images commonly used in healthcare and the images provided by patients — a gap that reflects differences in interests, perspectives, and means. At the end I will consider these four points in light of four questions Marshall McLuhan suggested should be used to understand new media.



The gap

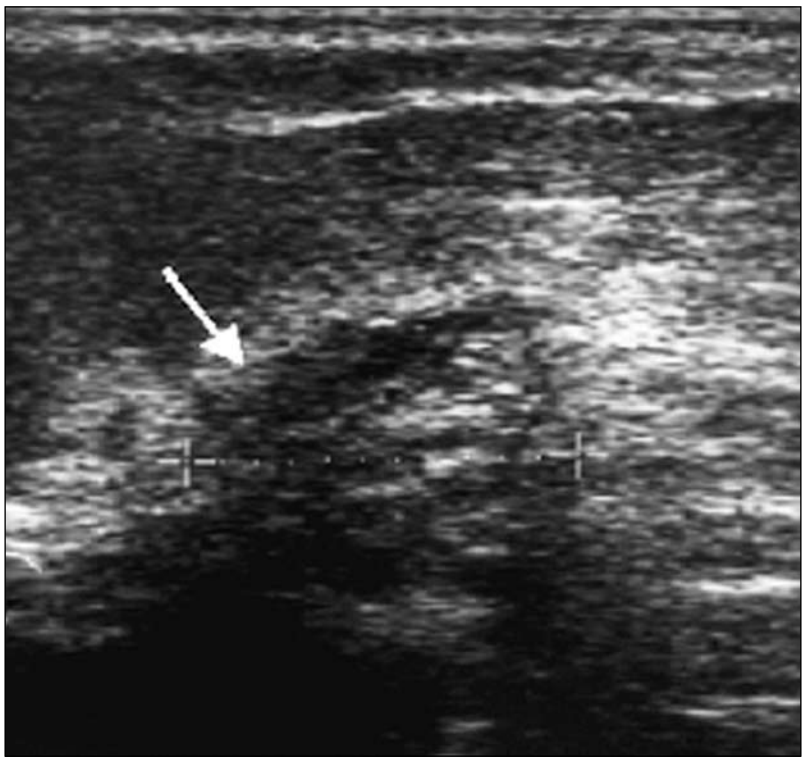
An immense amount of visual material on the human body is stored in the archives of hospitals around the world (at least in developed countries), including photographs, videos, drawings, X-ray films, magnetic resonance (MR) images, slides of pathology samples, sonographic data, and several other types of images. This material is of course invaluable for diagnosis and treatment, but has been rarely used by patients. That inequality is what initially sparked my interest in this subject.[3]

Elsewhere in this book there are bountiful examples of how professionals decode and interpret images within their fields of knowledge, so I will not go into detail as to how, for example, radiologists interpret their images. Instead, I want to consider the question of how visualizations can be used {cont. p. 147} by patients. The most straightforward approach to this, I found, is to let the patients see their own clinical images. Using two typical clinical images, I will try to illustrate that seeing is knowing, but in a different sense than might be expected — a sense in which it is not necessary to understand an image to find it useful or meaningful.



The image above is an X-ray that shows fractures in both femora. The image is easy to understand and useful in explaining what has happened. But if you were the patient, you probably would know what was wrong with your legs without having to look at a picture of them. Having such an image might not be very helpful, because what would have happened is so obvious: you already have information about it. In other words, there is no benefit for a patient to see such an image.

You may not see what the illustration on the next page shows, but with some help you could see something that you might not know anything about — something you might not feel, like the broken bones — unless you had an image of it. This image is not useful for the patient in the sense that it might provide her with medical information, but the very fact that what is unknown or unclear is made more concrete and real has tremendous impact on many individuals. To see is to know more and to know in another way, even if the image is blurry and diffuse. It is not only a question of seeing more or better, but of seeing anything at all. In that specific sense, this image is worth using, while the one of broken bones is not. {cont. p. 148}



This simple example helps to show several differences in the production, information, and meaning of clinical images, depending on whether they are seen by the patient or the doctor. Thus, there seems to be a gap between the doctor's and the patient's perspectives of clinical images, and there are several dimensions to this gap. It could be a matter of information (Is more information necessarily better?), dependency and power (Who sets the agenda? Who is producing images?), competence and skill (What is necessary to know? What can be done?), focus and perspective (What do we look for? How do we interpret images?), or the general "state of things" (the results of tradition, division of labor, and economy). This list is arbitrary, but it helps to illustrate that visiting a doctor is, in many respects, a complicated matter if you are confronted with a clinical image. In regard to images, the relationship between doctor and patient can work in at least two ways: *send and receive*, or *seek and give feedback*. Traditionally, the doctor and the patient have had a send-and-receive relationship. I will argue that the latter state of seeking and giving feedback will necessarily prevail (and already has, in some respects), and that the key question- in creating and using patient-focused images is what the individual wants to be shown.{cont. p. 149}

The artists' group

I will turn now to the visual material created by the different test groups. The session in which artists and designers played the role of patients was held at the Malmö School of Arts and Communication in Sweden, and the problem at hand was to create novel visual representations of health from a patient's perspective given certain diagnoses. Elsewhere, I have documented this workshop in detail; here, I will only give a few examples.[4]

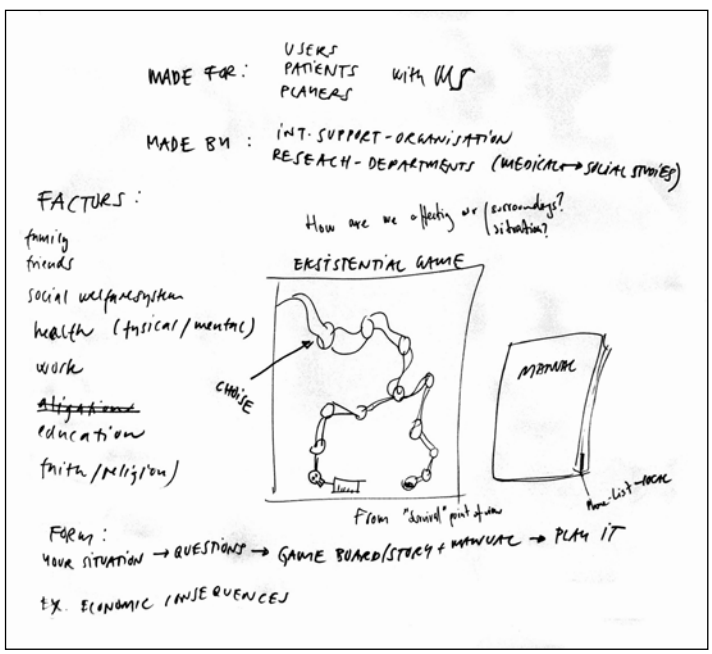
The participants, who had backgrounds in visual arts, design, creative production, filmmaking, and other related fields, acted as patients; they were told that they were being hypothetically diagnosed with one of three serious illnesses: multiple sclerosis; myocardial infarction, commonly known as heart attack; and breast cancer. Some information was given concerning various symptoms and impairments, and possible treatments and prognoses. The gravity of the illnesses was stressed, and the 'patients' were told to return for a second consultation a week later. A full week's interval would have let them experience a state of limbo until the next time they could see the doctor. During this time the patients were each told to answer the following question: 'What do I want to know about my condition and how do I want it to be presented?' Next, the patients were separated into groups of three according to the diagnoses they had been given. They were told to create a concept or prototype to visualize the ideas and questions they had in regard to their given diagnoses. Here, I will comment on the conceptualizations made by two of the groups:



{cont. p. 150} those 'patients' who were told they had multiple sclerosis, and those who were told they had breast cancer. (The heart attack group is not discussed in this paper since the findings from this group are largely consistent with the results from the other groups.)

The multiple sclerosis group came up with the idea of creating a game board for the patient's future life a kind of existential game. The game was intended to be played by patients to provide a tool that would let them explore a multitude of possibilities and paths in their future lives. The key issue of the game was therefore social and emotional, not medical.

First, the player would be asked a number of questions regarding his or her daily life and other important details, such as family, friends, work, special interests, and hobbies. The player would then use the answers to create the game board. By breaking up the horrifying news of multiple sclerosis into small familiar steps, and focusing on specific circumstances, the patients made the week of waiting in limbo for the second visit to the doctor's more manageable. The game was based on these local factors, and its purpose was to enable the players to construct hypothetical future scenarios, depending on their specific mood or their hopes at the moment. With this game strategy, the group wanted to emphasize that there are several possible options

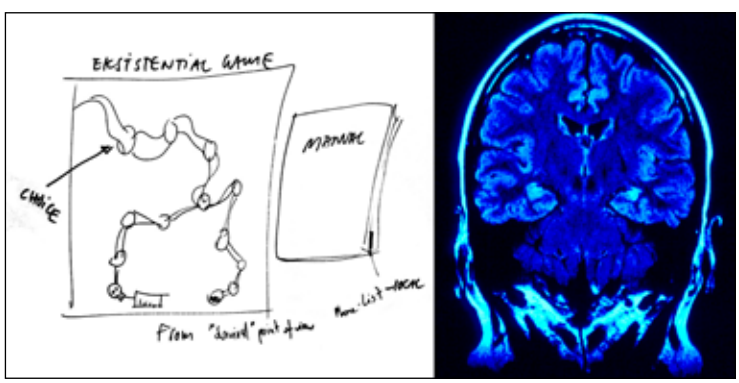


{cont. p. 151} and outcomes. Another reason they gave for choosing a game format was the tendency in modern life toward (often irrational) calculated risks such as smoking, bad eating habits, and poor exercise routines.

The patients were continuously involved in constructing the game by creating the stories to be played; in that, they were guided by a manual they created together. [5] In the process, players were faced with a number of choices for creating different paths on the game board. These paths, finally, led to various endpoints in the game: in the extreme cases, death or total recovery. The players did not give themselves full knowledge of the medi- cal and statistical facts concerning their diagnoses, or did they set out rules in advance that would show them how to continue playing the game. When making a choice at a crossroads in the game, each player would consult the manual and follow the directions it provided. In this respect, the game was an organized structure that could guide the patients through the difficult period in which they had been placed.

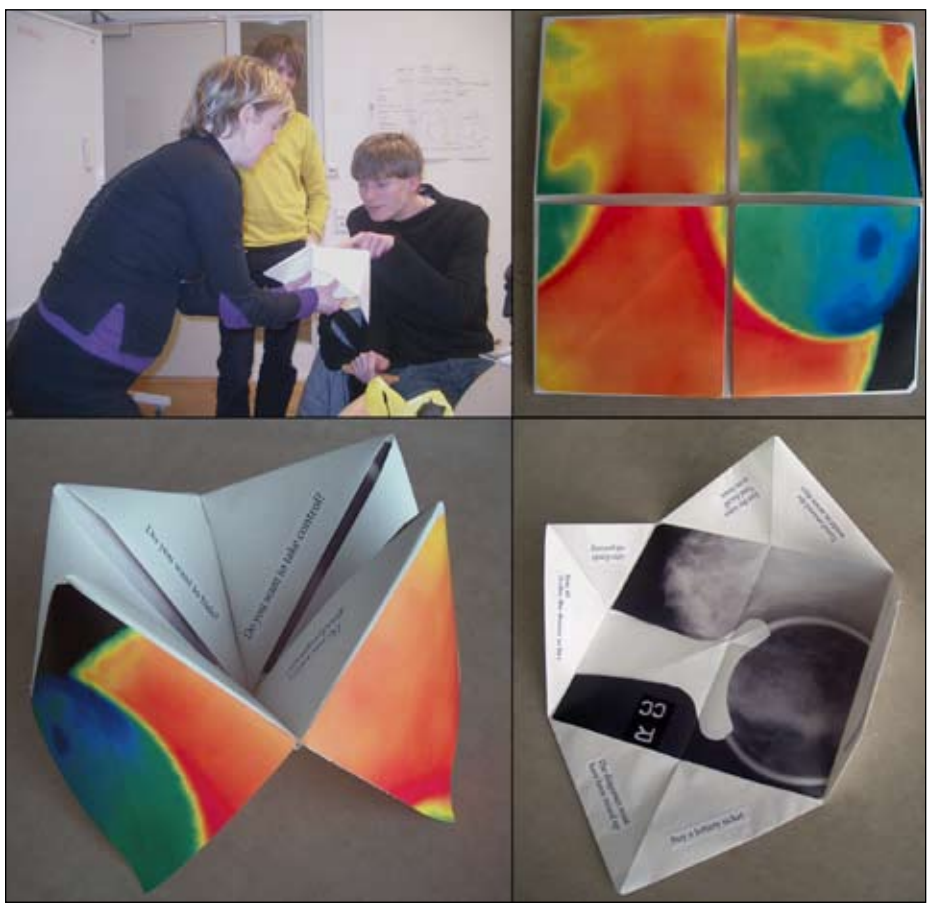
This game also treats the day-to-day life of the individual. It was possible to play ahead of time — to experience the future by trial and error without risking anything. As such, it was a visual and interactive tool, displaying present and previous choices and enabling backtracking — a strategy that revealed the influence of certain choices. It also allowed several players to interact with one another, combining their individual game boards, facilitating learning and mutual support.

If we compare this game to a clinical MR image, the two differ in more than appearance and subject matter. There is also the inherent feature of interaction and choice in the game board version, which is absent in the ready-made MR image. The game is a narrative rather than a simulacrum. It is open-ended rather than final. It is a negotiation, not a verdict.



{cont. p. 152} Paraphrasing Bruno Latour, this is not a matter of following a context, but rather of following the simultaneous production of a 'text' and a 'context.'[6]

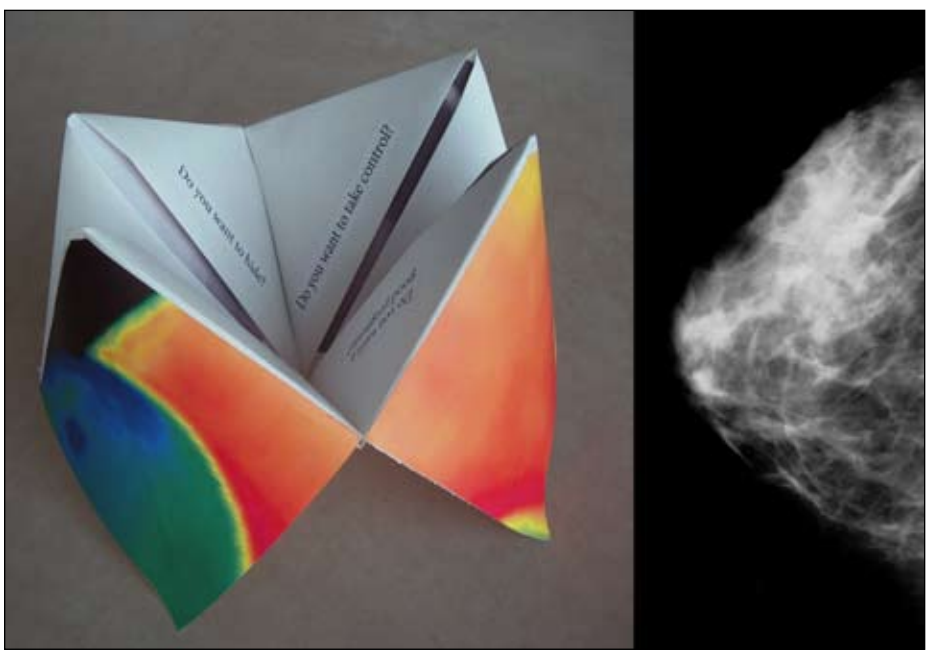
The second group, those who were told they had breast cancer, responded differently. The most important issue for the breast cancer "patients" was how to cope emotionally during the week of waiting for the next consultation. During this period of time there would be a great deal of worry and anxiety, confusion, and possibly denial. The concept of distraction or escape was chosen by this group to be a way of dealing with those emotions. A paper toy, well known to all the participants from their childhoods (in Sweden, it was called a "flea"), was produced and renamed 'move focus.'[7] As every child who has played this game knows, the player picks a number between one and five, and flips the sides of the toy that many times. At that point the child — or in this case, the 'patient' — chooses one of four questions



{cont. p. 153} that are visible on the inner side and inverts the paper to see the appropriate proposals on how to act. These were the questions and answers:

Question	**Answer or Advice**
Do you want to win?	Buy a lottery ticket.
Do you want to deny?	The diagnoses must have been mixed up.
Do you want to act?	Gather all people with good energy.
Do you want a good prognosis?	Buy it! (Bribe the doctor to lie.)
Do you want to take control?	Turn on the autopilot.
Do you want to hide?	You cannot hide from yourself.
Do you want to dream?	Rent the video *Total Recall* seven times.
Do you want to run?	Travel around the world in seven days.

This toy provided a distraction and a more or less irrational response to the difficult diagnosis and the passive situation created by the week's interval between doctor's visits. The hypothesis was that it would help the 'patient' to cope during a limited period of time when action was almost impossible. The visual tool, as we called it, did not deal with the disease or even the diagnosis, but was used to divert their emotional effects. This was similar to the approach of the multiple sclerosis group, which also partly focused on the effects of the disease rather than the medical information.



Patients' group

{cont. p. 154} Another group, composed of actual patients (not people simulating patients, as in the first two groups), received a kit we called a *cultural probe*, consisting of a single-use camera, a diary, a large sheet of paper, a notebook, some blank images of paper, instructions, information about the study, and a short evaluation form. The instructions for the use of the probe were very simple: use the material provided to describe what is important to you and to record whatever affects you and your health in your daily life. The intention was to provide tools to help patients express themselves. We weren't sure what to expect, but the hope was that the cultural probe would result in documentations and images representative of what the patients themselves considered important. (These were outpatients suffering from chronic rheumatoid arthritis.)

Of the eleven probes that were distributed, ten were returned with contents and one was empty. Taking a quick look at the returned material, it was obvious that the diary and the collage were the least used options.[8]

The collage depicted on the next page was made by a woman in her mid-forties (the picture is a detail of a larger sheet). She considered it to



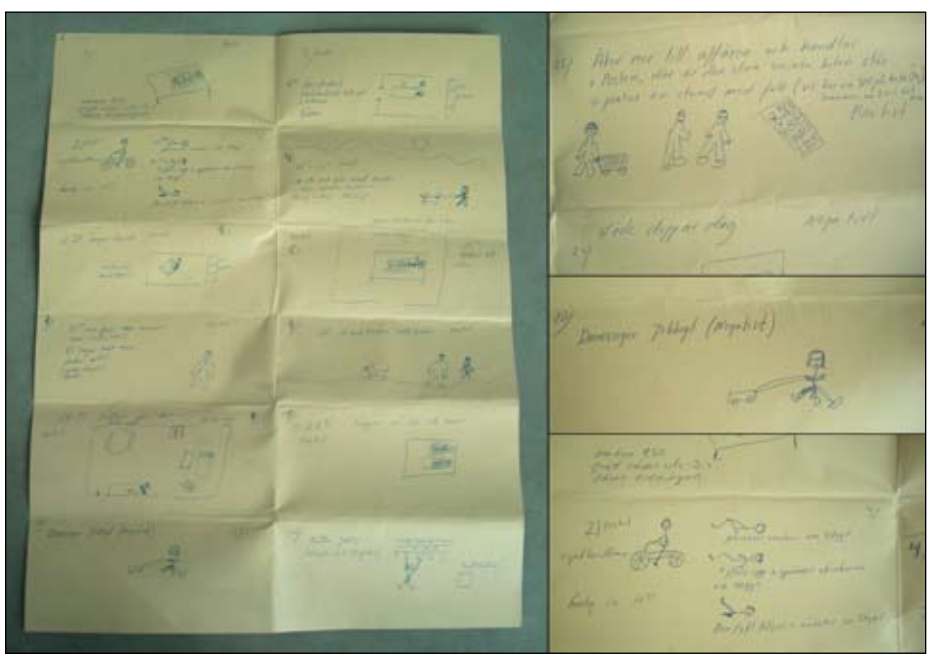
{cont. p. 155} be a very stimulating and rewarding way to express herself. In a vivid and colorful fashion, she covered several important aspects of her everyday life. Her strategy of mixing humor and seriousness seemed to be of help to her in trying to cope with her difficult situation. The way she chose a funny picture and combined it with serious and sometimes negative text seemed to provide an opportunity to defuse a potential feeling of resignation or hopelessness. It's also significant that in her choice of images and the accompanying texts, she also described her situation as 'living' rather than 'surviving'.



{cont. p. 156} The second example, shown below, is different in style as well as content. It is more structured, and lists important events or activities. It should be stressed that the person who drew this 'storyboard' was not used to drawing, but found it useful and inspiring. Hence, it is not the quality of the final pictures that was important, but the quality of the action of drawing, and of describing the drawings.

By combining images and cutouts with their own texts, the patients succeeded in telling their stories. It could be that the images worked as an inspiration for the brief texts that the patients also made, or that the images abbreviated what they had to write. The collages were sometimes redrawn, with the addition of new features and the removal of old ones, as if the collages were moments in a continuous loop.

All of the participants who returned the probe had used the camera we had included. This was a bit of a surprise, because the single-use camera we gave them was rather difficult for the arthritic patients to handle due to its small parts and mechanisms. Because of the problems and, in many cases, the pain that the patients experienced in handling the camera, I take the number of photographs as a sign of their significance.



All but one of the participants reported that the camera was fun to use and helped them think in another way; and this was before they had even seen the photographs they had taken. This means that it was not {cont. p. 157} really the photographs as such that were so important, but rather the act of taking them. The patients appreciated the opportunity to share important things in their lives, and they said they found it thought-provoking to be able to have something meaningful to say through their images. The simple fact that someone was interested in what they had {cont. p. 158} to say proved very significant. In the context of visual literacy, I think this portion of the study shows that it is important to be able to 'read' images, but it is equally important to possess the skill to 'write' and share them.



A look at some of the images made by the patients reveals some con- trasts with clinical images ofrheumatoid arthritis:

Patient-Provided Images		**Clinical Images**
Personal	versus	'Objective'
Nonintentional	versus	Intentional
Encoding	versus	Decoding
Narrative	versus	Descriptive
Giving (telling)	versus	Receiving information (being told)
Performative	versus	Analytical
Active	versus	Passive

Building a bridge

What has been learned during the workshops? Using four questions posed by Marshall McLuhan to describe the essence of new media, I will present one possible interpretation of the outcome of the study; and in doing so, I will also try to clarify the four points I mentioned in the introduction.[9]

1. What does the new medium enhance or intensify?

Is the communication between patient and doctor really working? It is well known that there is a discrepancy between information asked for by the patient and information the doctor considers important. A Swedish case study examining this issue reports that the patients

> Want more information. Most often it is the kind of information the doctor cannot provide. … The patient wants to talk about his or her fears and worries. … The doctor wants to talk about tumour biology, prognoses and possible treatment options, statistical calculations of the outcome, etc. From the patient's point of view, such knowledge sometimes appears both unintelligible and inadequate.[10] {cont. p. 159}



Since a specific visualization acts as a translation of a person's body or a diagnosis, it is by nature arbitrary and depends, among other things, on the intentions of the enunciator (producer). The language used to translate an illness or a diagnosis into an image gets what meaning it has through {cont. p. 160} the uses to which it is put. It is therefore crucial that the patient is involved in the image production, if he or she is going to be able to 'read' the results. To put it simply, it is a matter of learning by doing, and what is gained is not only skill in image production and usage, but also knowledge of the relevant medical and personal information. Paraphrasing Gilles Deleuze and Félix Gauttari, this new situation is rhizomatic, in the sense that it is continuously evolving, subject to redefinition, nonhierarchical,

and decentered.[11] The contexts I have described in this paper are composed of dimensions, not units, and they always take place in a middle region — a nilieu, from which the patient looks out. These contexts are matters of negotiation rather than information or prescription. I feel many doctors would agree with this last statement when it comes to the problematic issue of compliance — the degree to which patients follow prescriptions and act according to rational information.

2. What does it render obsolete or displace?

Patient-provided images also generate empowerment. Because most of the treatment actually is performed outside medical institutions, for example in the patients' own homes, it is appropriate and useful to provide tools requiring individual responsibility and initiative. This is also a matter of the direction of the flow of information and knowledge. Through visual methods, a patient can seek knowledge in a way that does not need interpretation or translation by a medical professional, and requires less knowledge of the specific jargon of medicine. The image can become something concrete to talk about; it can be a starting point for discussion and self-reflection, and it can reshape the dialogue between patient and doctor, removing the dialogue from the traditional hierarchical relationship of a sender and a receiver and turning it into a seek-feedback loop.

3. What does it retrieve that was previously obsolete?

The patient-provided image displaces the focus from the pure clinical 'problem' to the patient's individual abilities. It takes into account the dimension of the 'lived' disease or disability and the knowledge of the individual's everyday life – factors important for well-being that would not always be mentioned in a clinical setting. From a patient's perspective, these images are a question of creating meaning. By constructing meaning, the experience of a medical condition can be altered, and it is even possible to influence the actual healing progress itself. The expression *meaning response* in relation to medical conditions is discussed in Daniel Moerman's Meaning, Medicine and the "Placebo Effect"; he notes that {cont. p. 161}



'meaning can make your immune system work better, and it can make your aspirin work better too.'[12] Images used to create a meaning response could be useful in healthcare, not only as "placebos" but also as emancipatory and participatory tools. {cont. p. 162}



4. What does it produce or become when taken to its limits?

Visual artifacts, including clinical and patient-provided images, are part of the construction of a narrative of health. They function as interacting actors {*actants*, to use Latour's term), and as such they contribute in ways that are complementary to speech and text.[13] In other words, images are an active part of a complex interaction that is at once social, political, and personal. Hence, visual artifacts might prove useful as self-reflective, generative, and proactive tools, as well as provide a common, nonhierarchical ground for dialogue and discussion. That common ground could be called a *writing space*: a shared domain of control and exchange that bridges the gap between clinical and patient-provided images. Visualizations, as loaded artifacts, could function as social objects in various relationships.

Visual studies classes in a medical curriculum would help students and future professionals to understand the potential of visualizations. Such classes could also include the active use of images as carriers of meaning from a patient's perspective — that is, not only as means of extracting medical information (as in the protocols of reading X-rays), but also as ways of creating images that are meaningful for the patient — and that would be especially true of images produced by patients. A strategy based on meaning and participation could then be regarded as an addition to existing practice in the fields of clinical medicine and rehabilitation. Well-designed, patient-focused images stimulate self-reflection and participation: they are epistemological agents, and agents of change and learning.

Endnotes

[1] I would like to thank Rådet for Hälso- och Sjukvårdsforskning (Council for Health and Medical Care Research) and Region Skåne for financial sup- port, Ingemar Petersson and the staff at Spenshult Hospital for Rheumatic Diseases, as well as all the workshop participants and interviewees for their input and creativity.

[2] {cont. p. 163} The interviews were carried out with medical professionals who work daily with images in a health-related context, including a midwife, a radiologist, and a physical therapist.

[3] Henrik Enquist, "Emotional Images in Medicine," in *Proceedings from the 4th International Conference on Design and Emotion, 2004*, Ankara, Turkey, July 12-14, www.certec.lth.se/doc/emotionalimages/emotionalimages.pdf.

[4] Henrik Enquist et al., *Methods 2.0*, ed. Jonas Löwgren, Studies in Arts and Communication #04 (Malmö, Sweden: Art and Communication, Malmö University, 2005), www.certec.lth.se/doc/eatmethods/eatmethods.pdf.

[5] A manual was provided with the game, explaining the rules and possibilities as well as giving specific medical, statistical, and other information such as home page addresses of support groups and personal accounts by other patients with similar diagnoses. The manual of the game would have been designed by international patient organizations and research departments, ranging from medicine to social studies, and it would have been adapted for each individual player based on the answers provided during the game.

[6] Bruno Latour, "Technology Is Society Made Durable," in his *A Sociology of Monsters: Essays on Power, Technology and Domination,* ed. J. Law (New York: Routledge, 1991), 103-31, quotation on 106.

[7] [The game seems to be well known for having no fixed name. A Web site gives names in use in Russia (*gadalotschka*), Norway (*spå*), France (*cocotte en papier*), Austria (*Nebo Peklo*), and the United States (*cootie catcher*). See "About Folded Paper Fortune-Tellers," www.sunderland.ac.uk/~as0bgr/ coot/about.htm.—J. E.]

[8] This could have several possible explanations. For one, the majority of the participants experienced pain in their hands and fingers while writing. The collage required them to use scissors, which also could have been a problem. Many of the patients also reported that the diary was unimportant, because they already had written short texts in the notebook provided with the cam- era. They said that the collage was unnecessary since they already had taken images with the camera. It was expected that they would not use all of the material in the probe, and the reason that there was redundant material was to provide them with optional means of communication.

[9] Marshall McLuhan and Eric McLuhan, *Laws of Media: The New Science* (Toronto: University of Toronto, 1988). (Toronto: University of Toronto, 1988).

[10] Lisbeth Sachs, *Kommunikationen mellan patient och läkare vid svåra beslut* (Stockholm: Socialstyrelsen, 2003), 18, author's translation.

[11] Gilles Deleuze and Felix Gauttari, *A Thousand Plateaus: Capitalism and Schizophrenia* (Minneapolis: University of Minnesota Press, 1987), 3-7.

[12]Daniel Moerman, *Meaning, Medicine and the "Placebo Effect"* (Cambridge: Cambridge University Press, 2002), 20.

[13] Bruno Latour talks about humans and nonhumans involved in a chain of events as actants. The central issue is the relationship between the actors, not their individual existence. Latour, "Technology Is Society Made Durable."

Paper II

Narcissus's new mirror.

Body images and meaning.

Enquist, H.

Crossings – Electronic Journal of Art and Technology, vol. 5.1, 2007.

Narcissus's new mirror. Body images and meaning

Abstract. The wish to see beyond the horizon of the human biological eye is one of the major driving forces in the development of medical imaging technology. This essay discusses the implications technology has on the ability to see, and consequently know, more about the body. Further, the potential of merging art, rehabilitation engineering and medicine to develop and use images specifically designed to create meaning for the afflicted individual is proposed as a future research topic. The key question is how alternative (i.e., non-clinical) perspectives can result in different experiences of well-being, or even improve the health of the individual. There are two main aspects of this future research: one practical and technological, concerned with the tools and methods to be used, the other an epistemological venture, aimed at disseminating knowledge and understanding of visual communication in a medical context.

The technological eye

The human has a tendency to view himself as the measure of all things – homo mensura.* This narcissistic tendency, also present in the history of medical images, has its origin in the fact that people in most cultures throughout history have been fascinated by looking at and depicting themselves and each other. Cave paintings and carvings are in fact examples of the first way of storing symbolic knowledge outside the brain, and the oldest cave paintings are estimated to be as much as 30,000 years old [35]. This kind of image production could have been part of various social rituals, with the images acting as religious, decorative or instrumental artefacts. The seemingly universal human ability to recognize visual representations is a part of the evolution of the unique symbol-learning capability of the human brain. Terrence W. Deacon writes: 'The origin of "humanness" can be defined as that point in our evolution where these tools (stone and symbolic tools) became the principal source of selection on our bodies and brains. It is the diagnostic trait of Homo symbolicus' [9, p. 345]. The usage of symbols, for example

images, thus seems to be unique for the human as a species. Most people can almost automatically recognize a face, a pair of eyes or an entire body in different objects: the shape of a cloud, the arrangement of some random objects or even in an abstract painting. Whether biologically innate or socially imprinted, the fact remains that people tend to see images of themselves everywhere. The evolutionary and social advantages of having this capacity for symbolic communication could be manifold: identifying predators or other enemies, strengthening the ties between members of a group through cultural and religious acts, as well as sharing and preserving knowledge.

'Ours is a visual age,' writes Ernst Gombrich, and vision could even be considered the dominating sense in society today [14]. Images exist almost everywhere to entice, seduce, inform, warn, enlighten, frighten, confuse, entertain and show us. Some images have merged with the collective consciousness to the point of becoming memes in a universal language, while others are exclusively private and anonymous [4, 8]. Only a few images are so intimidating and alienating that we do not know how to interpret or relate to them. From a layman's perspective, medical images are mysterious, and in many cases terrifying, in their enormous potential and fateful powers. At the same time, they have become a fast-growing part of the historical saga about the human being, both in the collective sphere for mankind as a species, but also in the individual and private sphere.

Images are, in other words, artefacts encoded with meaning, a term used here for describing a correspondence between two things, literal or otherwise. This correspondence could be of many different types. In the case of medical imagery, the X-ray plate of a tumour could have the metonymic meaning of (possibly curable) cancer for the doctor, whereas for the patient it could have the symbolic meaning of 'pain' and 'death.' Meaning is a question of creating an understandable relationship between the depicted and the image. How then, has technology changed the meaning of medical images?

Since the revolutionary discoveries of Wilhelm Konrad Röntgen in 1895, the body has been opened, exposed and made accessible to the public in profoundly new ways, of which some are discussed below [32]. Medical imaging technology has since then undergone an amazing development due to the exploitation of newly discovered physical phenomena and technological advancements. X-ray and later innovations, such as magnetic resonance imaging, nuclear imaging and sonography,

contrast in very sophisticated ways with earlier times' more direct relationship with the inside of bodies and function as technological extensions of the human eye. As the Australian artist Stelarc puts it: 'The skin no longer signifies closure' [1]. The quest to depict smaller and increasingly more complex details with higher resolution, faster resampling, more vivid colouring and a greater sense of realism is a direct consequence of the faith in the abilities of the visual.

In general, the (photographic) image has lost some of its historical connotations of truth and authenticity, in part due to the possibility of digital manipulation [27]. In medicine, however, the tradition of images as true reflections of reality is still predominant and in most instances considered untouchable, partly due to the doctors' authoritative power. There is a tacit prohibition against manipulating the images in a way that information is lost or distorted, this to prevent incorrect diagnoses, deaths and legal consequences. These conventions can be both treacherous and useful. If unaware of what the images as such really are, it is easy to be led to believe that they are what they portray – the organ or the disease itself. What is seen is in fact only what the machine is constructed to depict, including malfunctions and embedded weaknesses in the apparatus itself, and the abstract image on the screen has, in many respects, very little in common with the examined biological body. For example, the information presented to radiologists is de facto distorted, partly in the passage through the circuits of the equipment, where tissue and bodily fluids are converted to electronic signals. It is not a visual reality we are seeing, but a more or less arbitrary and conventional reconstruction and representation.

The amount and quality of the information is also restricted by the fundamental limitations of the physical and biological phenomena on which the imaging techniques are based. We can only see what the specific phenomenon is producing. In X-ray, we see a shadow that is dependent on the difference in density between different tissue types. In magnetic resonance imaging, the image produced is the result of radio waves sent out by spinning hydrogen atoms. The radio signals are then processed by powerful computers and reconstructed as visualized data sets. These are more-or-less anatomical image techniques, trying to depict what is there. Another type is the so-called functional imaging. This approach is focused on what is happening in the body, for example temporal distribution of nuclear substances, or metabolism of glucose.

A problem with many of the imaging techniques are the so-called artefacts, unwanted effects in the image, which do not have a physical/biological origin in the patient's body. It is thus not always apparent what is depicted. What you see is not necessarily what you have got.

The body is also seldom depicted as a whole but rather as parts and details. As the image resolution is improved, the depicted parts become smaller, and as a result, the body becomes increasingly more fragmented, and the observed part is even further distanced from the living person. The whole is thus set aside for the benefit of the part, which is equally true for imaging as for treatment. This pars pro toto attitude could be experienced as unnatural and alienating by the patient: 'It is not the heart that is sick, it is me!' This could be important to remember when trying to treat the patient, taking into account the lived situation and not only the medical information.

The interpretation of the presented image also is a form of aberration. Knowledge, expectation, experience and emotion filter the information and affect the result. Interpretation is based on training and education; it is hard to see things that are previously unknown, since you do not know what to look for. At the same time the context in which the observer is placed, professional and/or personal, biases the attitudes towards the image.

Medical images bridge the gap between the seemingly rational mind and the irrational body by providing physical artefacts of what is within. These artefacts can be seen as parts of a distributed body and should be recognised as autonomous manifestations, or actants, using Latour's terminology, rather than passive projections of the inside in the outer world [21]. The machines function as extensions of the biological senses, and the images supplant the body and achieve an autonomous existence independent of the body in space and time, which makes the interior tangible and changeable [25, p.86]. This simulacrum of the body, now in the shape of data, can be processed, manipulated and transformed to any given form and can also be readily stored or transmitted electronically or physically all over the world without affecting the biological body. One example of this is the Visible Human Project, in which the bodies of one man and one woman have been physically sliced (post mortem) and then digitized into sets of digital information.

The aesthetics of the open body

Throughout western history, the body was cut open in order to reveal the wonders of the organism, a procedure demanding volunteers, corpses or, later, sedation and anaesthetics. Often, and regardless of the method used, this has been associated with discomfort, disgust or pain for the persons involved. An example of what an actual public display of the inside can lead to in our so-called modern and enlightened era is the public agitation and uproar in connection with the first public autopsy in England since the 1830s. In November 2002, Günther von Hagens dissected and demonstrated a male corpse in London. This induced strong feelings among the public, media and various officials, and the show was even threatened with legal measures [15]. The emotions stirred surely had several different origins, ethical as well as medical, but underneath all the rhetoric was arguably the often unarticulated and unconscious opinion that autopsy as a method is not sufficiently refined and elegant to be shown in public in our technologically advanced salons. Many questioned the necessity of the procedure for the declared purposes of education and information; some critics referred to modern advanced imaging technology rendering the physical opening obsolete. Is this reaction technological snobbery, or is there a modern fear of the tangible physical aspect of the human body, especially its inside? Has the technological eye, in such a distinct and effective manner, made the organic so artificial and abstract that we cannot stand seeing the real thing? The blood is not as sticky on the screen as on the operation or autopsy table and hence not as repulsive and frightening. The more advanced technology, the less one has to meddle with the abject and repulsive inside of flesh and blood [20]. One artist who has treated this subject is the French performance artist Orlán. In her Carnal Art, she uses her own body as raw material and transforms it with modern cosmetic surgery. She writes about perception:

> I can observe my own body cut open, without suffering!... I see myself all the way down to my entrails; a new mirror stage. 'I can see to the heart of my lover; his splendid design has nothing to do with sickly sentimentalities' – Darling, I love your spleen; I love your liver; I adore your pancreas, and the line of your femur excites me. [28]

What is it that makes the artificial and virtual opening of the body so appealing and captivating? A specific notion of aesthetics and beauty is used as an explanatory model. Beauty was defined by Baumgarten in his work Aesthetica as phenomenal

perfection as perceived by the senses, with aesthetics pertaining to the beautiful [3]. In Kritik der Urteilskraft, Kant separated the two, with beauty as an exclusively sensuous phenomenon and aesthetics as a broader science of the conditions of sense perception [18]. Below, these terms are expanded and used in a more postmodern and conceptual way, not focusing on the sensuous phenomena alone.

The most obvious aspect of the aesthetics of medical imagery is the medical beauty, which to its nature is practical and empathetic. Diagnostics, research, therapy and medical education have direct applications for improving the conditions of the suffering human. There is a fascination for the complexity and apparent sense of purpose of the body and its parts which has been used by some as an argument to prove the existence of a conscious Creator or God.

The sensual beauty of medical imaging is readily apparent. The lack of pain and physical injury in the technologically advanced imaging process spares the senses the strain of a more direct depiction. A technological and artificial opening hence avoids both the direct physical and psychological pain as well as helping to relieve the pain caused by the illness and its symptoms – this is partly the aesthetics of anaesthetics. Sensual beauty also originates in the aesthetic appeal of many medical images. This aesthetics is more obvious concerning images of smaller details, distant from all comparison with slimy organs and physical deviations, since the format in itself protects the observer from a too direct and uncomfortable recognition.

The aesthetics of within is also constituted of a technological beauty. In technology lies an inherent striving for beauty and elegance which is not necessarily associated with an aesthetic design or visual appearance, but rather lies in the technological rationale itself and in the elegance of the achievement [23, 29]. At its best, when the mediating technology itself is transparent, the images produced can elicit strong emotions and inspire intellectual achievements. The fact that the body in many cases does not have to be opened or penetrated, sometimes not even touched, creates an almost magical aura around these images and reflects mental and physical distance as such as an aspect of beauty.

A major driving force behind the development of medical images is the desire to see beyond the horizon of the human biological eye. The ability to see the inner universe and disclose what before was hidden holds a great intellectual beauty. This intellectual aesthetics derives from adding knowledge to a greater whole as a part

of the modern project of progress, development and knowledge and is based on the human's firm belief in her own capacity. The ancient Greek conception of hubris is not considered relevant in modern medicine, but lurks in the future with retroactive accountability for side effects and long term consequences.

Consequently, medical images demand much of us and confront us with new questions, both collectively and individually. We have to learn either to like what we see or correct what we dislike, be it an aesthetical outside or a clinical inside (or even, an aesthetical inside!). These reflections, cast by this new technological mirror, have both cognitive and emotional implications for the individual. They confront us with new challenges in the field of self perception and stress individual and social needs and various intellectual and economical interests as well as stimulating new experiences and evoking emotions, which have cognitive, educational and emancipatory possibilities.

The artistic body in medicine

One difference between the artistic and the medical image is that the former (ideally) is free of restrictions, has many levels of interpretation and is more focused on questions and debate, whereas the latter tries to document a state or condition with the aim of answering and clarifying certain hypotheses. Modern medicine, though, has several intersections with art when it comes to images of the human [11]. Both touch on the origin and substance of human beings and our existential conditions and situation in the world, as well as manifesting ideas and questions and presenting a variety of suggestions on how to answer the problems facing us in life. Primarily, medical images are not considered as works of art, but they might be. Placed in the metaphysics of Plato, in which art objects (and everything else in our physical world) are more or less true imitations of universal forms, medical images are in many respects the truest depictions of the body. As such, they could be held as the best art works of the body, i.e. the least distorted representations of bodily 'form' [30].

In the tradition of art as aesthetic judgement, some medical images could be held as the foremost aesthetic achievements of our times [5]. On the other hand, in more recent times, medical and scientific images could be considered as art

for other reasons: according to Danto, in their function within a context (e.g., presented at an art gallery) [7] or, as Dewey states, simply because it was intended by the image maker/artist that the images should be works of art [10]. By saying this, it is not necessarily so that all images in science and medicine are works of art. Felice Frankel, a well-known photographer working within various fields of science, stresses that her photographs are illustrations of scientific results and not works of art.

The subject matter in medical imagery is also one of the oldest and most exploited throughout what we today call the history of art. The most known example of a person concerned with the study and depiction of the interior of the human body is probably Leonardo da Vinci. He has been regarded as the epitome of a Renaissance man, combining knowledge and practice in what today is known as anatomy, art, science, etc. His illustrations of dissected corpses are well known, and his efforts in illustrating and explaining the anatomy of inner organs are still making a difference in today's practice of medicine. Surgeon and da Vinci specialist Francis Wells reported a surgical procedure breakthrough by studying Leonardo's drawings of a heart valve [6].

Another pioneer in the field of independent and methodical study of the interior structure of the human body was Andreas Vesalius, whose dissections destroyed the foundation of the teaching of Galenism. His major work, De Humani Corporis Fabrica contains over 220 wood-cuts, presumably made by the renowned Venetian artist Jan Stephan van Calcar, pupil of Tiziano Vecelli, Titian [36]. The publication contained the most comprehensive and accurate texts on anatomy to date and began the era of modern medicine.

This tradition of depicting the interior of the human body is now subject to a baffling metamorphosis due to the new methods, angles, dimensions, perspectives and questions that modern medicine and science explore. Medical images are shifting the foundation of the perception of the human body and its beauty in a way only vaguely discernable today and with a striking power envied (and utilized) by many artists. The body and its interior has been the subject of numerous interdisciplinary exhibitions.** Some of these exhibitions were primarily focused on the artistic aspects of the theme, whereas others were more intended for informative and educational purposes. Several contemporary artists are using medical images in their work. A striking example of this is the cooperation

between the photographer Joel-Peter Witkin and the doctor and collector Stanley B. Burns [42]. Using historical medical images from the Burns Archive, Witkin has created astonishing artwork. Stelarc's Stomach Sculpture is an example of how medical technology (in this case gastroscopy) could be used for works of art. His intention was:

> to design a sculpture for a distended stomach. The idea was to insert an art work into the body – to situate the sculpture in an internal space. The body becomes hollow, with no meaningful distinctions between public, private and physiological spaces. The technology invades and functions within the body not as a prosthetic replacement, but as an aesthetic adornment. One no longer looks at art, nor performs as art, but contains art. The hollow body becomes a host, not for a self or a soul, but simply for a sculpture. [33]

There is a tendency in several countries to include visual arts within the curriculum of medical education and also to use artistic perspectives and approaches in some specific healthcare programmes [22, 24, 34, 37, 38, 39, 40]. This could mean that some of the obstacles for using art in the domains of medicine and rehabilitation are getting smaller and that (visual) art could be incorporated constructively, adding values such as subjectivity, experienced health and the creation of meaning for the afflicted individual.

Images of meaning – a future research area

Images of the body, clinical or other, could be seen as reflections cast by a mirror of knowledge and emotions. What then do we look for in this new mirror? In the clinical context, the reflections function as symbols of health in which the medical professionals are searching for the divergent. Medical images are, in this respect, representations and signs of abnormalities and could be interpreted as portents of future suffering and death. As Barthes puts it, 'each photograph contains this imperious sign of my future death' [2, p.97]. These gruesome connotations cast a gloomy shadow over the images, and the constant focus on disease and malignancy promotes and enhances their fateful and judgemental aura. 'Do I really want to see?' actually means 'Do I really want to know?' If I cannot see it, it does not

exist, and then everything is OK. Or is it? The emotional implications medical images have on non-professionals are not extensively studied but are largely underestimated in modern healthcare. Clearly, the distinct separation between the clinical interpretation of medical images and the subjective experiences and emotions related to them do not have to be in conflict with each other. Could it rather be that there are several different and equally important 'truths' which could benefit from each other? The non-professional has limited, if any, medical knowledge and a different perspective when looking at medical images. In place of the professional's skill, the individual brings trust or faith, and the individual's subjective experience and personal emotions substitute for the objective interpretation and expert knowledge of the professional.

What do we mean exactly by the term emotion? According to Harland, an emotion consists of five elements: arousal (instigating stimuli), sensation (physiological correlates), construction (physical systemic coherence), appraisal (cognitive evaluation) and volition (motivational impulse) [16]. An emotion is hence something more or less different from a feeling, sensation, mood or state. This differentiation makes it apparent that emotions are closely related to the concept of meaning. Emotions are thus more than mere responses to external or internal stimuli, since they incorporate reflection and some sort of impulse towards action.

How could these different aspects of emotions be considered useful in healthcare? The proposed topic for future research concerns images, based on emotions, meaning and subjectivity, within the context of rehabilitation engineering and design. It involves a practice of routinely creating and using images in healthcare, which starts and ends in the specific needs and capabilities of the individual. This includes a specific design strategy and methodology which should be considered as an additional and contributing aspect to the medical-clinical [17]. By engaging the patients as participatory and subjective parts in the making of these personal images, they would contribute with their own aspects of the content, meaning and use of the produced artefacts. The images can be integrated in everyday life and focus on positive or desirable aspects of well-being to support and help the individual outside hospitals and medical institutions. To have images as communicative, informative, emancipative and emotional tools enhances the individual's ability to participate actively in the recovery and rehabilitation work as well as gaining in knowledge and empowerment. It is a matter of designing for a higher quality of life [13, 19].

A cross-disciplinary approach could be fruitful and function as a provocative and challenging factor in stretching the limits of the acceptable, possible and desirable in healthcare. In the context of emotions as meaning, art and artistic thinking would contribute to medicine and rehabilitation engineering design by introducing alternative ways of addressing the different elements of well-being. Art could be useful in visualising and diversifying health as experienced, as well as providing tools, methods and attitudes that science and medicine today do not make use of. For a comprehensive collection of intersections of art and technology which could be of interest for this kind of approach, see Stephen Wilson's book Information Arts [41].

From the patient's emotional perspective, the question of creating meaning involves both what is important for the individual and how one can understand and adapt to a diagnosis or impairment. This implies interaction with the context of experience, personal history, memories, dreams, abilities and knowledge. In the end, it is a matter of being closest to yourself and having a personal knowledge of your own health and well-being, one not readily exchangeable with clinical assessments. This can be achieved using simple tools and without any prior experience of the users. A design approach could be to use image boards, single-use cameras, collages and other creative techniques with active participation of the patient/individual [12]. The images could later be included in the medical journal as a kind of patient-provided portfolio as a complement to the clinical images.

The emotional impact of medical and other images on the perception of the self and health as it is experienced should not be underestimated, but rather be used constructively. Art as a field of knowledge has a long history of working with images of the body and would add emotional and personally meaningful aspects to images in healthcare. Through meaning, not only the experience of a medical condition but also the healing process itself could be altered. This effect, meaning response, is described by Daniel Moerman, 'Meaning can make your immune system work better, and it can make your aspirin work better too.' [26, p.20]

Notes

* 'Man is the measure of all things,' attributed to Protagoras from Abdera by Socrates in Plato's Theaetetus [31].

** Such exhibitions include: Under Your Skin: A Voyage Through the Human Body at the Deutsches Museum in 2001; Digitized Bodies – Virtual Spectacles Online Exhibition, presented by the InterAccess Electronic Media Arts Centre in Toronto; Inside the Body: Walk-in Sculptures at the German Hygiene Museum in 1999; Spectacular Bodies at the Hayward Gallery in 2001; Laura Ferguson: The Visible Skeleton at the National Museum of Health and Medicine in Washington, DC in 2004; The Royal Society 2001 Summer Science Exhibition Looking Inside the Body; Gunther von Hagens' Body Worlds; and The New Anatomists, presented by the Wellcome Trust at Two10 Gallery in London in 1999. Stephen Wilson has compiled a comprehensive list of exhibitions dealing with the body and medicine.

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Paper III

The Memory Stone –
a personal ICT device in healthcare.

Enquist, H., and Tollmar, K.

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H.5.2 Information interfaces and presentation (e.g., HCI): User Interfaces: Evaluation/methodology, Prototyping, User-centered design

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Design

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Abstract

New technology enables novel ways of sharing information between healthcare recipients and providers. In this study, however, we found that the medical information for pregnant women in Denmark is located in a number of different places, that midwives and doctors spend a considerable amount of time administrating data, and that consultations are felt to be rather inefficient. This paper describes these problems and some solutions. We explore the idea of providing each woman with a digital artifact, called the Memory Stone. The goal is to supply them with tools to collect and review clinical and personal information concerning their pregnancies. The paper discusses: (1) the user-centered methodology for development of a personal device for healthcare information, (2) the design and evaluation of prototypes, and (3) critical issues concerning the introduction of novel personal ICT in a healthcare setting. The main focus is on the experiences and interests of the individual pregnant woman in the study. Several insights were gained into more general pervasive healthcare issues, including technical and ethical ones as well as safety and security concerns.

1. Introduction

This paper describes the development of a pervasive healthcare device for use by pregnant women called the Memory Stone. The focus is on the individual's point of view and how this kind of device can help the process of creating meaningful learning and adaptation to a new situation, such as a first-time pregnancy. One issue of concern is the current practice of data management and distribution. Another is the emancipatory effects of engaging the pregnant woman and her spouse in the process of handling information about the pregnancy.

According to this concept, the pregnant woman – and her spouse – are the main carriers of information and are supported in collecting all information of personal interest or usefulness, whether at home, in contact with healthcare professionals or with family and friends. The Memory Stone provides storage of different data types (e.g. text, pictures, biomedical data, video) and by connecting it to external devices through assemblies, data can be exchanged or displayed on compatible units (Figure 1).

The information to be stored on this device includes medical information such as instructions, recommendations and test results, as well as personal and intimate entries such as diary notes and photographs. This combined set of data, and the tools for producing, distributing and handling it appropriately, are designed according to the individual's understanding, knowledge and experience. The design process follows and exemplifies a vision of pervasive computing in healthcare and involves cyclic development, inter-disciplinary research, end-user involvement, and knowledge sharing.



Figure 1. Memory Stone Prototypes.

The emphasis from the start was on designing in collaboration with end-users. Insights into the requirements and needs of end-users were gained in mainly two ways: field observations, and multidisciplinary workshops. Everyday practices and work routines were observed and analyzed. This included taking part in medical examinations, joining pregnant women for doctor and midwife appointments, making rounds with nurses at the prenatal ward, and similar activities. One of the project's strategies for successful design and development of palpable systems is becoming familiar with current work routines that emerging technologies could support in the future. In the frequent workshops, researchers and end-users discussed ideas, and experimented with new technologies or test prototypes. Here doctors, midwives, and pregnant women provided us with feedback and new insights.

Firstly, a brief description of the PalCom project is given in order to establish the methodological and technological outset. This includes two key concepts in the PalCom ontology of palpable computing: palpability and assemblies. Secondly, a case study is described with a discussion of current work practices. Then, the development of and user feedback from the implemented Memory Stone concept is outlined. Lastly, there is a discussion concerning {cont. p. 104} the critical issues which emerged through the use of the proposed ICT device in a healthcare setting.

2. The Palcom project

The aim of the PalCom project was to research and develop a new perspective on ambient and pervasive computing called 'palpable computing' [18]. A major focus was the development of and user interaction with design prototypes that fit various application areas. This paper describes one such effort. PalCom is also about software that suits the age of pervasive and ubiquitous computing. The PalCom Open Software Architecture is continuously being enhanced and developed by a large group of collaborating software developers. The toolbox has been released as open source. This paper does not cover the software aspect. Instead, it focuses on the application area of *pregnancy and early maternity*. But first, the PalCom concepts of *palpability* and *assemblies* will be introduced.

2.1 Palpability

In PalCom, palpable computing is essentially about doing pervasive computing right, i.e. designing IT that is intended to be easy to grasp, modify and understand for users [18]. Pervasive computing acknowledges that the user benefits from technologies being small and invisible in use. The philosophy behind PalCom is to put the user in control by providing visibility and control in the system. The user should also be able to inspect breakdowns and errors in the particular device and be offered tools for diagnostics and error correction, a strategy Norman calls 'Design for error' [16]. Palpability, in the PalCom meaning of the word, is thus about software technology being easy to grasp, modify and understand for users. This is important since technology is becoming an increasingly larger part of our everyday life, and the challenge is how to design for a world of palpable technology.

In order to clarify palpability, one main objective of the PalCom project was to develop a conceptual framework for palpable technologies and their use. Visibility and invisibility, construction and de-construction, supporting people in making palpable end-user compositions are some of the most important challenges identified for the PalCom project.

2.2 Assemblies

People combine different technologies, materials, objects and artifacts to accomplish their tasks and activities. One of the most central challenges for PalCom is to design palpable computing devices/systems that can be manipulated and configured to work as resources in changing settings. A key concept in the PalCom toolkit is the PalCom assembly, which is an organized collection of resources composed in such a way as to deliver all or part of a given application functionality. To describe how this works, we will use an example called the 'GeoTagger' [19].

The motivation for this example is that in many situations a picture will be more valuable if it contains information about where it was taken. This is called 'geotagging' and could become a standard feature in next generation digital cameras. Presently, you can do this manually by using a GPS device and a camera. However, with the PalCom architecture this can be done automatically by connecting the GPS and the camera to a combined system – a GeoTagger assembly.

The GeoTagger is a simple assembly consisting of a camera, a GPS device and a storage server. These devices can be connected to a service capable of annotating a picture with a GPS coordinate. Once this combined set of devices and services has been established, a picture taken by the camera will be annotated with the current GPS position and stored on the server.

2.3 Application prototypes

One of the primary goals of the project is to demonstrate ubiquitous technologies with properties clearly available to the senses. This kind of palpable system should support understanding and user control regardless of the level of interaction. In the PalCom project, several application prototypes were developed in different areas such as post-surgery hand rehabilitation, major incidents, pregnancy and early maternity, and community care. These prototypes were developed to inform the design of the PalCom open architecture, and to provide real-life examples of the palpable computing initiative. Our main interest in this study was to investigate the impact and use of pervasive technology to support pregnant women and healthcare professionals. The conceptual framework developed in the PalCom project was used as a vehicle for the design and evaluation of the study and results.

3. The pregnancy case study

This section introduces concepts of general interest for a design of personal information and communication technologies (ICT) in healthcare. The results were used as input when implementing the final prototype, described in section 4. Initial findings have been presented elsewhere [6,25].

3.1 Outset and objectives

During her pregnancy, a woman is in contact with several healthcare professionals in different locations. Many data items are created during the pregnancy; some are valuable and necessary for the professionals, others are mostly of interest for the pregnant woman and her family. Many data items are used both by the pregnant woman and the professionals, but for different purposes. The availability of healthcare professional information is of great importance to women during their pregnancy. In Denmark, this data is currently distributed between many parties, which makes it very difficult for the pregnant woman to assess her situation. In addition, the coordination of information between several parties of the health sector suffers from redundancy that could be rectified by simple technical aids. In this paper we focus on what data the actors in relation to a pregnancy would like to keep, to see and to share. The aim was to create palpable application prototypes (henceforth called the Memory Stone) which could support the women and their families in different health-related and social contexts.

3.2 Scope

The study was conducted from 2004 to 2007, and consisted of eight workshops, an ethnographic survey, and development of a series of prototypes. The empirical base is relatively small involving ten pregnant women (in two separate sets)[1], four fathers-to-be (participating second-hand) and a group of healthcare providers. Despite this, the study provides some insights into a possible future for using personal devices for support and communication during pregnancies. It indicates ideas and issues {cont. p. 105} that will be relevant if a concept such as the Memory Stone is to be developed and implemented on a larger scale.

3.3 Survey-oriented ethnographic work

One aim of the ethnographic fieldwork was to investigate the current work practices of midwives on site. Two researchers and one medical doctor conducted the observations during a total of 17 days at a half dozen different sites. An initial finding is that midwifes spend a large amount of time administrating data about the pregnant women and the consultations that take place during pregnancies. Discussions with the midwives show that much of this administration and coordination could be optimized:

Midwives keep patient records for each pregnant woman with a copy of the invitation letter, a midwife journal and a sheet of sticky labels with the woman's name, civil registry number and doctor's name.

The first section of the midwife's journal contains the same data as the general practitioner collected during the pregnant woman's initial visit. Some of it is also stored in the electronic health journal (EHJ). The data consists of personal health data and the civil/social status.

In the hospital information system (HIS), none of the first consultations with the pregnant women are displayed. Consequently, when visiting the midwife for the first time the pregnant woman does not exist in the system and the midwife has to keep all her consultations notes in her own diary.

The lack of a systematic computer system that can be used during the consultation results in the midwife inventing her own systems, e.g. placing a sticky tag for each pregnant patient she has seen that day on her windowsill.

Another observation was the abundance of technologies in the work environment, both high and low tech. There was an apparent imbalance between the amount of technologies available to the midwife and the technologies used by the pregnant woman. This imbalance had obvious reasons, but was identified as a possible area of design and development.

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1. The first set of pregnant women gave birth and thus a second set of participants were recruited.

3.4 Workshops

The focus of the workshops shifted according to the development of the design and research process as well as the constitution of the group.

In the first workshop, researchers, healthcare professionals (midwives, obstetricians, neonatologists, neonatal nurses, general practitioners) and pregnant women discussed the data collected during the field work. Interesting areas for future development were identified based on the general area of activities and information that is needed for all those involved in the provision of care for the pregnant women and their fetuses.

At the second workshop, healthcare workers discussed how the pregnancy journal ("vandrejournal" in Danish) used in Denmark could be designed to provide better support. Based on the findings in the fieldwork and experiences from other countries, a series of ideas that could be beneficial for pregnancy care in Denmark were presented. The participants were asked four basic questions:

– What kind of information are you searching for on the internet, in books, etc., about pregnancy?

– What makes you feel safe in relation to your pregnancy?

– Are you fond of the "vandrejournal" (pregnancy journal)?

– What could be done to support a good pregnancy?

The answers were then used as input for the development of a prototype of the Memory Stone implemented on a PDA.

In the third workshop, members of the PalCom team joined together with professionals and pregnant women to work out visionary concepts. Through role-play scenarios, the possibility of using new IT-based services for healthcare and personal information to support women during pregnancy was discussed.



Figure 2. Mock-up trials.

A pregnancy focus group interview was conducted at the fourth workshop where six women discussed needs and available support during their pregnancies. This mainly concerned difficulties caused by paper-based journals and information overload. Then we asked the subjects to evaluate a prototype. Six (new) pregnant women were invited to join a pilot test. They were approached in the hospital waiting room and in Internet chat rooms and were invited to participate in the study. Three were given a prototype implemented on a PDA; three others received a low-fi mock-up consisting of a real stone and a notebook (Figure 3, top middle).

Together with healthcare professionals, the fifth workshop focused on various support and tools. It re-iterated some general concepts and demonstrated two semi-functional Memory Stone prototypes that would be tested by a group of pregnant women.

In the following workshop, an in-depth discussion about the use of the Memory Stone prototypes was held with the pregnant women. Issues such as understanding of interaction modalities, information transfer and content were discussed.

The main aim of the seventh workshop was to bring pregnant women and healthcare professionals back together and talk about the services and products that had been discussed during previous workshops. The outcome of the session was then used as input for further development of the prototypes.

The final session was used to sum up reflections and study findings, and to present the updated version of the Memory Stone.

3.5 General issues of current practices

The workshops and fieldwork provided much information about the current work practices as well as the general situation of the pregnant women. The aim of this research was to gather information and identify areas of interest which could be used as input for the design phase of the study. In the following sections, we present some aspects of information management that proved to be the overarching issue of the study.

3.5.1 The pregnancy journal

In current work practices, information about the status of the fetus and the pregnant woman is stored in a number of different places, not only on various media, but in different geographical locations. This scattering of information is partly due to the origin of the data (i.e. information recorded by a midwife is stored on the local computer or paper file). There is, however, no single place where all information is collected. The closest one can get is the personal {cont. p. 106} pregnancy journal ('vandrejournal'), a paper folder kept by the pregnant woman herself. This increasingly thicker folder is brought to each consultation and updated by the midwife or general practitioner. It thus has a dual function: the main collection of health data and the main means of communication between groups of healthcare professionals. Currently, there is no way for a midwife to access the medical record of a patient kept by a doctor. The information systems are separated and in most cases not even compatible.

3.5.2 Coordination

The pregnant women reported a number of problems concerning communication during their pregnancies. They felt that there was a lack of coordination between the different parties of the healthcare sector, sometimes leading to delays of crucial test results and important notes. This was reported to be stressful for both the practitioners and the pregnant women since time, in some circumstances, is a crucial factor. This delay of important information is not common. However, the apparent lack of communication between different healthcare professionals gives rise to concerns for the pregnant women. The *Future Lab* workshop was a major eye-opener with respect to this:

> Now that I have had the chance to hear what the general practitioner asks the pregnant women, I can see we really need some internal data communication (midwife, workshop 3).

It was also reported that questions asked by the midwife often were repeated by the general practitioner. This could undermine the trust between the pregnant woman and the healthcare professionals. In that respect, the simple feat of bringing together the different professions in the same room provided both a common understanding of the situation, as well as an opportunity for change.

3.5.3 Redundancy

At workshops discussing the initial findings from the fieldwork, the healthcare personnel agreed that much time is presently spent on providing information that turned out to have a high degree of redundancy, e.g. explanations of proper diet.

Furthermore, the women found that if an error occurred in the traditional healthcare record, it was difficult to correct since it was stored in many places – if something was corrected at a consultation with the midwife, the pregnant woman had to make sure the same information was corrected in the general physician's records. Thus there was a common interest in finding a better way of coordinating and storing information during a pregnancy.

4. The Memory Stone

To address the issues raised in the workshops, we pursued the idea of providing each woman with a digital artifact called the Memory Stone. It was intended to support pregnant women, their families and their healthcare professionals. It would be the means to store and communicate data between the pregnant woman and the healthcare system by allowing data to be transferred to the device from the electronic patient journal (EPJ) and other personal devices such as laptops or mobile phones.

During the study it became obvious that the pregnant women were interested in having much more than clinical data available on the device: They wanted information on what to expect; they wanted the device to support communication with healthcare personnel; they requested multimedia documentation of the changes in the fetus and the mother; and they very much desired a personal diary for the child to have later in life. Hence, one aim of the development of the device was to investigate the possibilities of introducing this kind of information and interaction in the clinical as well as private environments.

4.1 Prototype evolution

A range of prototypes were developed to investigate different aspects of functionality and interaction (Figure 5) and were used in the workshops to focus on three aspects of palpability:

- A tangible artifact for demonstration, information storage and user feedback
- Functional tests of PalCom software on an embedded system
- User tests (interface/interaction, media management, etc.)

The results from these prototypes have been used in the design and development of the final Memory Stone device.

The first generation prototype was used to exemplify the Memory Stone concept for the participants, mainly demonstrating material and tactile properties.

The second generation prototype was a mock-up intended for information collection and user feedback (physical handling of the device, diary notes, etc.). One group used a calendar service running on a PDA; another group used a notebook and a low-fi mock-up (Figure 3, top middle).

The final functional prototype of the Memory Stone device implements full functionality (data storage, radio communication, and one-button user interface) (Figure 4). Basically, the Memory Stone is a small handheld device consisting of an embedded computer, a flash memory and a Bluetooth radio. It is the size of an

ordinary pager, organically shaped, and has an extremely simplified interface. The Memory Stone makes the pregnant woman the main carrier of information, to be used in relation to her pregnancy and motherhood whether she is at home, with healthcare professionals or with family and friends. In other words, the prototype supports the woman in carrying all the information she chooses to collect. It will support storage and use of different data types (e.g. text, pictures, biomedical data, video).



Figure 3. Prototypes and mock-ups.

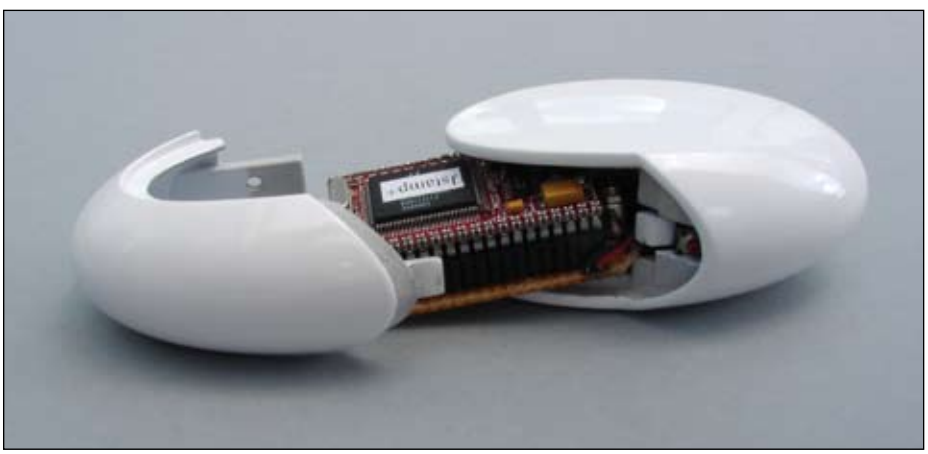


Figure 4. The *Memory Stone*.

{cont. p. 107}

4.2 Reflections

4.2.1 Individuality

One important aspect that was discussed much during the project was the individuality of the pregnant women. When deciding what kind of information she wanted on the Memory Stone device, it was evident that how much and what they wanted to know was very individual. The health personnel also found this to be very important. In their daily work, they see that the pregnant women are very different with respect to curiosity about their condition. Some do not want to know anything, some want to know it all. Some would find it reassuring to have measurements of the fetus' heartbeat, others would benefit from support for physical birth preparation, stop-smoking program, etc. The healthcare personnel saw most of these features as the pregnant women's tools, which was also the idea in designing them.

4.2.2 Physical appearance

At the first workshop with the pregnant women, it was apparent, that the shape and color of the device was important. At the pilot we introduced them to prototypes in the form of an ergonomically shaped stone egg and a PDA. The video of the workshop showed that the real stones were interesting; the women would constantly pick them up, fondle them and almost caress them. The real stones were also spun and rolled across the table, taking advantage of their physical qualities. Hence, the participants all liked to touch the organically shaped stones, not the PDA. The IT-interested women liked to play with and investigate the PDA, but most of them only touched the stones.

> It really makes you want to wear it (pregnant woman about the organically shaped Memory Stone).

It was an ongoing issue as to whether the PalCom service should run on their mobile phone or a dedicated device like the Memory Stone. Some felt it was nice to have something special that embodied the pregnancy, others, mostly fathers felt differently.

> I want it to be on my mobile phone; I have so many devices already (father-to-be, focus group).

With the software architecture that we imagine will drive this in the future, it will be possible to make it run on almost any device, so it will be up to the user to choose whether they want it on the phone or an a dedicated device.

5. Memory Stone interaction

A key concern in the design of the Memory Stone is that it should be easily integrated with other devices and services. Being a palpable system, it should also be easy to connect to a laptop, TV or mobile phone so that the expectant mother can easily share pictures and information with family and healthcare providers.

5.1 The Memory Stone in assemblies

The information on the Memory Stone is always accessed through an assembly (PalCom's primary method of composing a collection of resources into an application) with another device; audio could be streamed from the Memory Stone to a MP3 player, or images from a digital camera could be stored on the Memory Stone. In these simple examples the device could be used in similar ways as a USB memory stick (although wireless). However, what makes the Memory Stone truly unique is that its hardware and software are built on the PalCom architecture which makes it possible to personalize and integrate new services in radically new ways. If we modify the GeoTagger example described above, we can create an assembly between a GPS and the Memory Stone that will tag information that is stored in the Stone with GPS coordinates.

The woman should thus be able to construct and deconstruct assemblies, for example, between her Memory Stone and other devices with medical record systems at the general practitioner's office, and with different types of displays. Similarly, she should be able to construct connections between her Memory Stone and other devices providing services, e.g. biosensors or ultrasound scan machines. The construction/deconstruction is normally of the explicit type – the woman decides

what she wants to make an assembly of and creates it. The goal of the PalCom architecture is that this would be intuitive and that the construction of an assembly could happen anywhere – in all kinds of settings.

Especially in relation to connections to medical record systems and medical equipment, the ability to deconstruct is probably crucial to the success: It is necessary to deconstruct the data structures in the medical records and/or on the stone to get compatible data elements and it will be valuable to be able to deconstruct the medical equipment in order to access the parts of interest and not just the available standard output.



Figure 5. Using *the Memory Stone* in assemblies.

The two assemblies mainly worked on in the pregnancy and maternity case were: (1) a display assembly that renders the content on the Memory Stone on a TV or monitor, and (2) an EPJ (Electronic Patient Journal) assembly that integrates the Memory Stone with the doctors and midwives' EPJ system enabling an exchange of data between the EPJ and Memory Stone (Figure 6).

The idea is that the Memory Stone carries sets of instructions on how to present itself on the displays of various external devices, so called *migrating user interfaces* (MUI) [23]. In Figure 6 (left), an ultrascan image is transferred from an early prototype of the Memory Stone and displayed on a TV running PalCom software. On the right, an example of a Memory Stone MUI running on the PC of a general practitioner is presented.



Figure 6. Migrating UI on the general practitioner's PC.

Let's illustrate these kinds of assemblies through a user scenario. A pregnant woman is visiting the doctor and wants to get an updated health record on her Memory Stone:

– She turns on the Memory Stone and connects it to the doctor's EPJ. {cont. p. 108}

– She chooses the data that she wants and after confirming the data, the records are copied to her Memory Stone.

She then comes home and wants to show her husband the updated health record:

– She turns on the Memory Stone and connects it to the family TV.

– She browses through the data on her Memory Stone and selects the test that she wants to show her husband.

5.2 Interaction tests

To further explore the palpable interaction of the Memory Stone with other devices, we designed and tested two models for the interactions. Common for these models are that the Memory Stone has neither a display nor any other graphical user-interface except a small light-emitting diode and buzzer.

The first model was a Memory Stone with a single physical button as its entire interface. This allows for three types of commands: (1) A long press toggles the

device between on/off (2) A single-click moves a selection pointer forward, (3) A double-click performs an operation (such as display or copy) on the selected object.

However, ease of use and selection among large quantities of data could be in conflict here. Clicking through a large list of items can be very tiresome and slow. We also wanted to test if analog methods are more precise, quicker and thus a more satisfying user experience. Therefore we developed an alternative method where instead of a button we used accelerometer sensors similar to ones used in Nintendo Wii controller. These sensors allow sensing of movements along an x-z axis (i.e. it could sense 'up-down' and 'right-left' movements). Table 1shows the mapping between the two interaction models.

Operation	**One-button UI**	**'Gesture' UI**
On/off	Long press	Shake
Select	Short press	Point left-right
Operate	Double press	Point up-down

Table 1. Functions of the 'one-button' vs. 'gesture' UI.

5.2.1 Participants and tasks

10 subjects between 15-65 years of age, 7 females and 3 males, tested two UI models over three consecutive days. Each participant performed two scripted sets of tasks utilizing each of the UI models explained above (a 2x2 test). The tasks were based on two simple scenarios:

Show a friend some images:

– Turn on and connect the Memory Stone to a display (an assembly).

– Scroll through a list of thumbnails, select and display two specific images.

Interact with the content on the Memory Stone during a consultation:

– Turn on and connect the Memory Stone to a display (an assembly).

– Select appropriate data and display that information on a remote display, or copy that information into the Memory Stone.

The participants were timed in their performance and the error rates were compared. A survey was also used at the end to investigate their attitude towards the two interface methods.

5.2.2 Apparatus

For the purpose of this test, a functional prototype of the Memory Stone based on a Sunspot platform was used in an assembly with a PalCom system running on a standard Mac.

5.2.3 Pre-study

A pre-study with three subjects was carried out. It was used to design the procedure for the test but also suggested a radical change. Instead of 'gesturing' with the device, participants often used 'tilt movements' (i.e. rather than pointing left or right, they tilted it by rotating along the main axis). Hence, we altered our algorithms to also recognize this kind of movement as well.

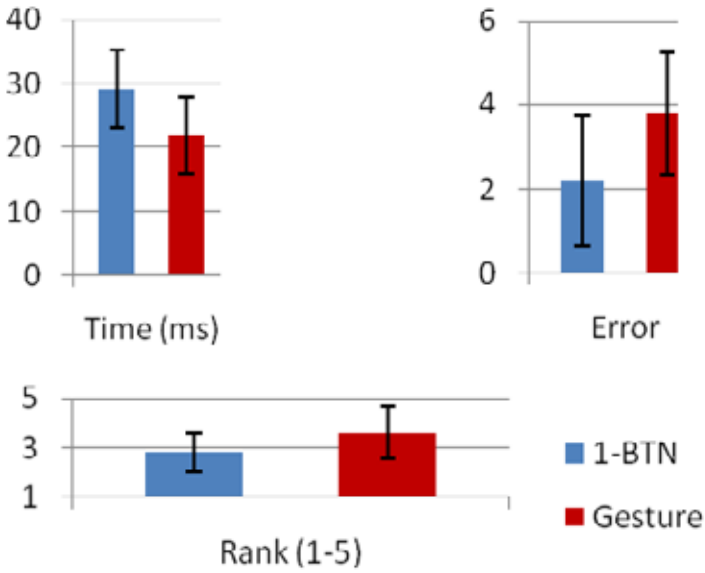


Figure 7. Results from interaction user test.

5.2.4 Results

The test showed that the gesture-based UI was a bit faster, but this is not significantly proved yet. It was also noted that the number of errors was higher using the gesture-based UI. This might be explained by learning effects and that the speed will be even lower after more practice. This might also be attributed towards the round shape of the stone and that the accelerometers were slightly misaligned.

The gesture-based UI was, despite the higher error rates, ranked higher than the one-button UI. One reason might be its novelty. Another explanation is that the more analog gesture-based UI was perceived to be more efficient – even if it generated more errors – by being more direct and more engaging.

5.2.5 Observations

All users found both the one-button and gesture-based UI relatively simple to use. Several of them commented on the simplicity and indicated many other devices that would benefit from this:

> I wish my remote was as simple. I never understood why they need to put 20+ buttons on such device.

The pre-test suggested that we need to use a flexible interpretation of how to interpret a gesture. This was also confirmed in the test where we observed a high diversity between the participants. Some used large pointing movements while other used small and narrow tilting gestures. One also commented that:

> It would be nice to be able to practice so you know how you should gesture.

{cont. p. 109}

6. Discussion

In this section we discuss some of the findings from the case study which could prove to be important when designing personal ICT in pervasive healthcare settings. This includes technical and ethical issues as well as ones regarding safety and security.

6.1 Invasive healthcare design

In this research project, the participating healthcare professionals had dual responsibilities. Their primary focus was on the well-being of the pregnant women, and this was stressed at all times. Secondly, medicine in general has a pragmatic dimension. It is partly based on experience and proven solutions, and is in that respect conservative. By conservative we mean that in medicine there is an inherent skepticism towards introducing novelties that could impinge on the current (working) practice, not that there is reluctance towards innovation and development. This is a consequence of the tradition of the medical profession, summed up by the Hippocratic Oath in the sentence: 'First, do no harm.[2] This conservatism had some implications for the possible design space in the study. There was, for example, a strong emphasis on utility and necessity on behalf of the healthcare professionals. The outset of a design project is to initiate change,

preferably for the better. In essence, this is not in conflict with the conservatism of the medical practice described above. Using a user-centered design philosophy such as Participatory Design could be one way of establishing a process of stable change which not only is acceptable to the healthcare professionals but also sought after and embraced [8,11].

One possible source of conflict in approaching change from this perspective is the sometimes incongruent needs and wishes of the two (three?) communities of practice in this case study [12,26]. The pregnant women and fetus make up the primary focus of the women themselves, the healthcare professionals, as well as the designers. But the nature of this concern might differ, and this difference can lead to contradictions or conflicts. Time, for example, is a crucial factor when conducting design research in general, but even more so when including pregnant women. In our study, the first set of pregnant women 'disqualified' themselves from the study one by one through the simple fact that the no longer were pregnant. This had implications for the longitudinal feedback on the development of the prototypes from these participants.

6.2 Ownership

We have only briefly touched upon the aspect of ownership: Who owns the stone? Should the women buy them? If the municipality owns them, what happens if they are lost or broken? Who owns the stored data? There were also discussions on the concerns of the professionals when it came to ownership of information. It is the responsibility of the professionals to inform and advise the pregnant women, and thus important to be able not only to convey information but also assure that the information given is incorporated into the lifeworld of the pregnant women. The information is, in that respect, handed over, but the responsibility is not. The concern was that if information put on the Memory Stone was altered by the pregnant women, the professionals no longer could assume responsibility for its validity. These questions were considered critical by the participants and should be discussed more thoroughly if the concept is to be developed further.

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2. 'επι δηλησει δε και αδικιηι ειρξειν'. A similar quote has also been attributed to Galen.

6.3 Empowerment

In Denmark and similar countries, a pregnancy is not normally considered to be a medical condition but rather a psychological, social and biophysical one. The pregnant woman is not a patient; she is not ill in the medical sense and hence is not treated. The main concern of the professionals is to monitor the health of the mother and the development of the fetus. This has implications when it comes to the involvement of the mother-to-be and her kin.

From our study we observed several aspects of this involvement. Firstly, the participants expressed a wish for co-creation of media and information selection. Most of the participants were well educated and used to personal responsibility and control from their professional lives. They expressed interest in adding personal annotations such as notes, images, sound recordings and videos along with the medical information stored on the device. Some of them even explored the possibilities of making certain types of data collection at home, such as monitoring their blood sugar levels or blood pressure, and thus contributing to their own and the child's health record. Moreover, the women wanted to prepare for the different examinations and pregnancy stages using the device. These ranged from reminders and timer functionalities to reviewing the purpose of the examination.

Secondly, learning and information compliance were enhanced and supported by engaging the pregnant women and her kin in the information loop. Phenomenologically speaking, the knowledge became grounded in the lifeworld of the participants. Information was updated in dialog with professionals, not automatically synchronized. It was thus commented on and related to the understanding of the individual. They sometimes preferred to have outdated information which was thoroughly explained by a professional than updated information without comments.

Finally, in addition to the personal interaction level, the inclusion of an assistive device permits the user (pregnant woman) to interact with the healthcare information directly. This is currently not supported technologically by the healthcare system, which makes the interaction between care provider and pregnant woman unequal. Using the device the pregnant woman also gains tangible and explicit means to express, clarify, and communicate 'soft' data relevant to the specific context. This type of information is currently exchanged verbally and is mostly not recorded

in any of the present healthcare systems. The device thus functions as a personal counterpart to the electronic patient journal in the interaction and enables construction (and deconstruction) of personal information with the healthcare information.

6.4 Ethical issues

There are several ethical issues to be aware of when designing ICT for personal use in healthcare. These surface in the design process and in actual use. Obviously, ethical concerns shift when moving from the tentative situation of design and research into the lifeworld of the pregnant women and the healthcare personnel.

6.4.1 User-driven design

One (potential) problem or ethical issue is that when developing technology in cooperation with prospective users who are in a situation of change, time is crucial. This is especially true when it comes to passing states such as pregnancy. As mentioned earlier, some of the participating women actually in, some respect, {cont. p. 110} disqualified themselves from the study by simply giving birth. This had the implication that they actually never got a chance to really use the Memory Stone. How does one as a designer/researcher handle this situation? Should the participant be excluded from the study or not? One way of dealing with this is to extend the scope of the study. Originally, the case was concerned with pregnancy and early maternity, thus including those who recently had given birth.

6.4.2 Safety

With the amount of information pregnant women get today, it can be difficult for them to sort out what is relevant and not. The feeling of safety is something the women addressed often in the study. They generally agreed that continuously updated information and personal guidance through the various phases were crucial for making them feel safe during the pregnancy.

> It makes us feel safe to know that someone is looking after us – telling us what to do when. It would make us feel unsafe if we had fewer visits to the midwife… Opposing information is confusing (pregnant woman, focus group).

Providing the information was not enough – the women also had to understand and remember it. This was stressed several times by all of the participants. Women often forgot or misunderstood the information given, no matter how much it was repeated. By letting them use this kind of digital artifact they were engaged in changing or updating the information in a way that is not currently supported technologically. This increased the sense of safety for the pregnant women since it gave them an opportunity to cooperate in the data handling as well as to re-experience the consultation on a later occasion by browsing through the facts and comments stored on the device.

Naturally, there is considerable individual variation of what makes an individual feel safe. Some women have had several miscarriages and needed reassurance that the fetus was developing as it should and even that the heart was beating. Others only needed to know that everything was fine. It is therefore important to be able to use the Memory Stone in such a way that it meets the needs and demands of each user.

Safety can also mean that all information is present in paper form, because they simply do not trust the computer to keep the data. There was a general fear among the pregnant women of messing up the clinical information on the Memory Stone, partly because not everyone felt competent with computers, partly because of the novelty of the device itself. This issue was interesting from an experiential perspective. Although all participants knew that the information downloaded to the Memory Stone was a duplicate of a selection of data and only intended to be used by the pregnant woman herself, both professionals and the pregnant women were worried that information could be lost or degraded. Hence, they all needed reassurance that the healthcare records and the data stored on the device were two connected but separate systems.

6.4.3 Security

Storing personal and clinical information on a portable device poses several questions about data security and integrity. In case of theft or misplacement of the device, the information should be safeguarded to a reasonable extent. Providing password protection and encryption were aspects of security discussed in the study.

Also, when displaying data on an external device (e.g. the PC of the midwife) during a consultation or in a public space (e.g. a laptop), the participants stressed the importance of access. Some information, such as very intimate health data, could be made visible to healthcare personnel, but inaccessible for family and friends. On the other hand, some information could be public to family and friends, but irrelevant or even hidden from personnel.

6.4.4 Integrity of the professional

Initially, multimedia functionality was added to the Memory Stone including 3D scans, pictures of the belly, etc. As the study progressed, the possibility of documenting consultations as video or audio recording was discussed. This feature, introduced by the pregnant women, was believed to be useful since they had a tendency to forget what was said at the consultations. All but one of the professionals found this feature to be potentially useful. The main concern was the risk of abuse of such recordings, such as legal evidence claiming malpractice. However, all agreed that recordings could be useful for specific information that was vital and important for the pregnant woman to understand.

6.5 Success or failure?

One conflict of interests became apparent when collecting the cultural probe/ diary after workshop 4. Several of the women had torn pages out of the diary to keep intimate records from the prying eyes of the researchers. This illustrates the paradoxical situation of a design for personal change. From a designer's point of view, this only proved the success of the initial concept. The involvement of the

participants had reached the intended level of intimacy and had engaged them to such a degree that they rebelled. In other words, the concept was appropriated.

From a researcher's point of view, this rebellion had two effects. Some (possibly) vital information was withheld from the research team. Through an open discussion in a meeting, the nature of this information was revealed and thus could be used for further analysis. The second effect was that the arguments used by the women made important aspects of the concept clear. Safeguarding intimate information, enabling data stratification, empowerment, and usability issues concerning visibility and control are just a few of the reasons for tearing pages from the diary.

6.6 Addressing palpability

Construction – de-construction is a PalCom core challenge. The idea behind the simplified palpable interaction in the Memory Stone is to make the dependency on other PalCom enabled devices– be it a TV, a computer or a mobile phone– explicit for entering and displaying information. This is implemented in the Memory Stone by storing the actual device configurations on a device. The user constructs, through an assembly the Memory Stone with another device, a useful service for a specific task, and later, equally easy, de-constructs this service by closing the connection between the devices.

When pregnant women use the Memory Stone in their daily lives and connect it to numerous other devices, it is important that they can follow the flow of data and can inspect the system if there is error. The visibility – invisibility challenge is also important in another way in the pregnancy scenario, because so much of the data is very personal. Another challenge is change – stability where a PalCom application naturally needs to handle dynamic as well as persistent data. What is more important in this regard is that data needs to move seamlessly from one device to another; here the storage components could facilitate such data migration.

7. Related work

There are several related relevant studies within the scope of this paper – these includes suggestions for design of Pervasive Health {cont. p. 111} Care and Palpable Computing as well as new input for carrying out participatory design in the healthcare environment. Hence, this research takes an equally broad approach with an open-ended exploration and design agenda to develop an understanding of those participants and IT-based design proposals to support them.

The original concept behind this ICT device is called the White Stone. It is based on an interconnected pair of touch-sensitive stones that react upon sensorial interaction by warming up the related peer. The White Stone uses heat and touch to convey a sense of emotional presence between two people [24].The project used traditional material like real stones to design sustainability and lasting relationships into new communication devices.

Pervasive Computing deals with providing computing and communication services all the time and everywhere. Hospitals are natural candidates for this technology, and according to Bludau and Koop [2], more than a 100 clinical trials have been carried out in the past 16 years that utilize mobile technology to make information 'at-hand' in healthcare. Especially electronic diaries that record patient data in-situ have been extensively investigated. Some of those trials also include usage of mobile devices outside of the hospital, such as electronic diaries for keeping track of eating disorders [20]. Much of this work has focused on technical aspects of connecting mobile devices to the existing data used by clinics; research on novel needs and use of pervasive computing in hospitals is somewhat hard to find [2].

As described above, the word 'palpable' denotes that systems are capable of being noticed and mentally apprehended. Where speech, vision and other sensing techniques are able to more passively and continuously monitor the environment [17], tangible interaction is suggested as a more physical and action-oriented approach. Graspable user interfaces [7], tangible interfaces and tangible bits [9] all address how augmenting everyday objects can provide alternative ways of using computers based on the physical world. While these novel interaction techniques could address palpable interaction, the challenge for palpable computing is not only to develop new technology and interaction techniques, but to be able to understand the possibilities generated by these techniques. Palpability is not just

about exploring new interaction paradigm but also about human-technology relations. Therefore, in addition to Heidegger's notion of 'ready-to-hand' that inspired Weiser's formulation of Ubicom, we, and others, have argued for the application of the notions of 'present-at-hand' and 'breakdown' [5].

Our project group has carried out a number of field studies to develop a better common understanding of pregnancy and early maternity as a problem domain. The core of these methods is starting to become widely adopted. In Munoz [15], based on ethnographic studies, a context aware distributed architecture is proposed that takes into account not only the location of staff and patients but also the role of tasks and the artifacts involved. Ethnographic methodologies have also been used to study the daily routines of nurses and to optimize their collaboration patterns [1]. The insights gained by these research projects could positively influence the design and deployment of commercial products. One explanation why this rarely happens could be the cost and time intensive nature of the process [3]. Another could be the unfamiliarity of with the potential of pervasive computing.

Several studies describe the process of going from field studies to prototype design [11,21,22]. Mackay [13] advocates supplementing participatory design with other design methods from different disciplines. Jungk and Müllert [10] describe a three-step method directed at creating new solutions to practical problems–typically among a group of people with similar interests. The method contains a step where problems are 'negated' to translate them into visions. We used elements and techniques from artifacts as triggers [14] and future laboratory [4]; both methods had the developed prototype as their focal point. The first uses artifacts to trigger discussions on a given practice in cooperation with the end users. The second brings the practitioners into the laboratory, where they appropriate prototype technologies by working seriously on a particular, authentic job for a prolonged period.

8. Concluding remarks

We have described the design and development of the Memory Stone, a pervasive healthcare device for pregnant women. This tool could be used to collect and review clinical information as well as personal information concerning women's

pregnancies. We have discussed a user-centered methodology. Through an ethnographic study and a set of workshops we found that the health information is not only stored on various media, but also in different geographical locations. This scattering of information creates problems for the pregnant women. It would be beneficial to provide them with a tool that lets them store and organize this information to become empowered and feel at ease and safe in their situation. A deep analysis through workshops with the healthcare professionals also confirmed this problem; there was consensus that this could be beneficial for all involved partners.

We have also discussed the design and evaluation of prototypes and our suggested concept, the Memory Stone. In spite of the great need for information, there are trade-offs in keeping such a tool simple and easy to use. A more palpable user interface might be one solution and the paper discusses how this could be done. Our main findings are suggestions for easy ways to connect such a device with a multiple range of devices, like phones, PC and TVs.

Finally we raise critical issues about the introduction of personal ICT in healthcare settings. Carrying out user-centered design with this group brought up several ethical issues to be aware of.

In summary we would like to share some additional thoughts on design for personal healthcare technologies:

– Is the integration with healthcare IT systems really necessary? Could a tool that helps our group of users add to and review their own records be sufficient? It is clear that the pregnant women who participated valued their personal information equally high as the clinical information and that ownership of information, data security and personal integrity are major concerns.

– Palpable interaction, such as gesture-based point-and-selection, seems promising in our study. However, the original idea to only use an on-button to interact with the Memory Stone was also easy to use. There might be combinations, though, that would best fit such a large and broad group of users, rather than ultimately striving to find one optimal solution.

9. Acknowledgments

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Paper IV

A socio-material ecology of the distributed self.

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A socio-material ecology of the distributed self

When distributed to different artefacts, the self appears in a multitude of shapes, characterized not only by its materiality but also by the necessity to preserve at least an illusion of a core self. The experience of a continuous evolution of these overlapping 'selves', many of which are materialized together with others' overlapping selves, cannot be captured by traditional design approaches, nor can ethical aspects and conflicts of the right to express yourself through artefacts. This article, with its empirical basis in an interdisciplinary EU funded project, PalCom, is an attempt to test both *ecological* concepts and relationships and *sociological* (actants, actor-network-theory) ones. No meaningful separations are observed between the human ecology and sociology and the artefactual ones. Instead, it is the whole system of people, practices, values, and technologies in a particular situatedness that is meaningful to pinpoint and elaborate.

In this text, the notion of the distributed self will be discussed. By this I mean the way artefacts are included in the study of an individual. There are many things to be considered when thinking of the socio-materiality of this distributed self. Here, two different approaches are tested, separately and intertwined: a sociological and an ecological.

The actor-network-theory (ANT) approach as implemented below rejects the simple notion of the self as being a biologically defined entity. It is a non-linear and non-centralized view, assessing parallel and distributed processes where the individual is in constant negotiation and continuous dialogue with other people, as well as artefacts. Bateson talks about 'the pattern that connects' and suggests a similar holistic approach to knowledge and meaningful relations.[1] The distributed self is considered a snapshot of the relations between the actants (species) in the network (ecology).

Both the sociological and the ecological approach challenge simple design principles that create systems that are isolated, static, and final. People are in continuous

dialogue with each other, as well as with the distributed physical artefacts in interactions that trigger and guide our actions in the world.

As technology and media become more intertwined with our perceptions of the self and the very conditions of life, an alternative approach could be necessary: changing from seeing humans as parts of ecosystems, to viewing the individual together with meaningful artefacts as an ecosystem in itself.

Examples from a case study [2] are provided to highlight issues which are visible when using the ecological/sociological approach.

Metaphors of technology

> Technologies matter anthropologically, among other reasons, insofar as they compromise what Haraway names materialized figurations (1997:11); that is, arrangements of material and discursive practice brought into more and less coherent relations, which in turn shape human experience.[3]

Metaphors are used extensively within design research and design practice. They are frequently used to either describe concepts, or as a creative tool in the design process. A metaphor (from the Greek metaphora – transfer) is '…a set of linguistic processes whereby aspects of one object are 'carried over' or transferred to another object so that the second object is spoken of as if it were the first'.[4] Metaphors as linguistic tools certainly influence the way we think and act.

In design theory, metaphors have been used to describe the activity of design itself, ranging from Herbert Simon's design as problem-solving [5], Rittel and Webber's dilemma approach[6], to Schön's reflective practice.[7] There are also several metaphors used when talking about technological artefacts, for example technology as a tool, text, or system.

Metaphors are powerful for different purposes in different contexts, but they can also be deceptive if used carelessly. This calls for caution and deliberation when choosing one. Using common features of ecosystems, the perception and construction of the distributed self will be described as an ecology made up by the relationships between an individual's body, personal artefacts, and the environment.

Tool metaphor

The tool metaphor is probably the the most widespread one in design and engineering. When using this metaphor in design, the primary focus is on functionality (e.g. efficiency and effectiveness) and usability (as in ergonomics). Norman, who writes extensively on design issues, introduced the term perceived affordance, which deals with the tool aspects of designed artefacts. The term 'affordance' (as a noun) was invented by J.J. Gibson, and originated in his study of (mainly visual) perception and control of action. It denotes the functional value of things and organisms in the environment:

> The affordances of the environment are what it offers the animal, what it provides or furnishes, either for good or ill. The verb to afford is found in the dictionary, but the noun affordance is not. I have made it up. I mean by it something that refers to both the environment and the animal in a way that no existing term does. It implies the complementarity of the animal and the environment ...[8]

The term has been adopted and redefined by Norman and others within the design community in the context of usability. Norman stresses that the word 'affordance' has been misused in so many ways, for example as something which can be designed into an artefact.[9][10] Norman explicitly separates real from perceived affordance in an attempt to clarify the difference between the Gibsonian physical affordances and the perceived functions of designed artefacts in use.[11] The affordance of an artefact is different for different people and situations, as people tend to act in ways that make things and situations meaningful to them based on personal experiences, knowledge and expectations. The affordances that govern the possible interactions within the system are not inherent or static but depend on the functional relationship between an individual or group and the environment. People are in a way defined in their (meaningful) relations to artefacts as well as other people.

It is apparent that the tool metaphor is limited when it comes to encapsulating meaning outside the pure user context. Another metaphor of technology more apt for the description of meaning is the text metaphor.

Text metaphor

The text metaphor of technology is (tautologically?) a linguistic/semiotic one. Critical Theory and a number of postmodern theories propose the 'reading' of phenomena in the world as texts. In his widely cited essay Technology is society made durable, Latour describes how artefacts can carry messages and how they interact in a web of (human and non-human) actors to complete a program, for example returning a hotel key.[12]

In design, there are lively discussions on matters such as the usability, ergonomics, and aesthetics of artefacts, but the link between the self and artefacts in the world is also semiotic – a matter of how people ascribe meaning to everyday things and events as well as strategies for how to act accordingly. Dourish describes this embodied interaction as 'the creation, manipulation, and sharing of meaning through engaged interaction with artefacts.'[13]

The text metaphor complements the tool metaphor since it acknowledges individual interpretation and sense-making in relation to technology. Since this creation of 'meaning' depends on a vast number of factors, this metaphor has its main merits for example when explaining why something is meaningful rather than used as an aid for the design of artefacts.

System metaphor

The system metaphor is a wide concept and includes many different writers and approaches (Nardi and O'Day refer to Ellul, Winner and Postman). There is a common ground in their scepticism towards technology, but where Ellul seems downright pessimistic, Nardi and O´Day find grounds for action and initiative. The system metaphor often takes a bird's-eye perspective on technology. One thing that Nardi and O´Day consider is lacking in this metaphor is locality. Another word for this could be situatedness, as Suchman speaks of.[14] In a design process, it is necessary to be 'where the action is' in order to capture the specifics of a situation.[15]

Ecological metaphor

Ecology ('oekologie') as a term was coined by Ernst Haeckel in 1866 as being the "science of the relations between the organism and the environmental outer world."[16] In biological terms, ecology is the study of the interaction between different species within an environment. Traditionally, ecology is concerned only with living organisms such as animals and plants, and their metabolic processing of organic and non-organic matter in their natural habitat. There are common key features of any ecosystem, e.g.:

– Ecosystems are local, evolving, and self-generative entities.

– Different species in the system occupy separate niches, each with specialized functions within the environment. Keystone species are those that are vital for the existence of an ecosystem.

– Species within this environment are dependent upon each other and exhibit co-evolvement through coordination and competition.

– Ecosystems have some kind of metabolism – a cycling of resources.

Human-made environments can also be considered to be ecosystems, such as a city, an office or a home. Many fields of research and practice, such as philosophy, anthropology, natural philosophy, literature, history, sociology, and aesthetics, have adopted the ecological concept.[17] As a term, 'ecology' has been used by some interdisciplinary scientific genres such as *Engineering Ecology*. Metaphorically it has been used to describe complex environments not relating to biology as such, like *Media Ecology*.

Nardi and O'Day argue that the common metaphors of technology — tool, text, and system — do not quite cover the practice they have encountered 'in the wild'.[18] They introduce the term *information ecology* as an alternative to the above metaphors of technology. An information ecology is a system of people, practices, values, and technologies in a particular local environment. In information ecologies, the spotlight is not on technology, but on human activities that are served by technology. One common feature of such ecosystems is that the creation of meaningful relations within an ecosystem is the result of an ongoing and

dynamic interaction between people, artefacts, and the environment. This has many similarities to actor-network-theory and its view on actants.

Similarly, Krippendorff uses the term 'ecology of artefacts' as a description of how artefacts are related to each other. He claims that in an ecology of artefacts, the meaning of an artefact actually consists of its possible interactions with other artefacts rather than its specific usability.[19] The word 'ecology' is used in a conceptual and metaphorical way, and not in its original biological sense. One parallel could be the common metaphor used in computer interfaces, the desktop metaphor (files, folders, trash bin etc).

ANT - A sociology of associations

Follow the actors themselves, is the slogan of our sociology; indeed, but it is not said how to follow them.[20]

Another, complementary approach to the materiality of relationships is the sociological actor-network-theory (ANT). In his book *Reassembling the Social*, Bruno Latour makes a distinction between what he calls 'the sociology of sociology' and his proposition of a 'sociology of associations'. The former assumes the particularities of what is called social, and attributes it with abilities to describe the world in ways dissimilar from other disciplines, such as biology. The analogue situation in sociology would be to assume a special social 'matter' which could form the units of analysis. This is another reason for Latour´s division and is based on his aversion to the widespread use of the term 'social' as a property in itself; that there is a special matter of which the social is made up. Rather, Latour proposes another interpretation of the word *social* to signify *creating connections*, and wants to investigate what these connections make up, what he calls *assemblages*. This 'sociology of associations' is described by examining five uncertainties of what the world is made up of [21]:

– the nature of groups: there exist many contradictory ways for actors to be given an identity;

– the nature of actions: in each course of action a great variety of agents seem to barge in and displace the original goals;

– the nature of objects: the type of agencies participating in interaction seems to remain wide open;

– the nature of facts: the links of natural sciences with the rest of society seems to be the source of continuous disputes;

– and, finally, about the type of studies done under the label of a science of the social as it is never clear in which precise sense social sciences can be said to be empirical.

By doing this, the need of a 'social glue' that holds the social context together vanishes. The social is no longer a 'thing' but connections between (non-social) phenomena and things. The social is hence no longer an *a priori*, but something the participants make up when dealing with controversies. The sociology of associations is the study of these in-betweens.

According to the original form of ANT, an object is 'an effect of an array of relations, the effect, in short, of a network. … An object is an object so long as everything stays in place. So long as the relations between it and its neighbouring entities hold steady'.[22] This is what Latour calls an 'immutable mobile'.[23] In some respect, there is no difference between human and non-human actors in ANT. Naturally, there are differences, but the overall aim is to re-valuate the importance of including artefacts in the equation.

The point in the end is not to assign agency either to persons or to things, but to identify the materialization of subjects, objects and the relations between them as an effect, more or less durable and contestable, of ongoing socio-material practices.[24]

An actor in ANT is not what performs an action, but rather 'the moving target of a vast array of entities swarming toward it'.[25] In other words, it is never really clear who acts, nor can the actions of an individual actor be isolated from the actions of others. The actor is defined by its relations to the countless actions of others. This system of mutual dependency has many similarities to the ecological view.

The Pregnancy Case

To provide concrete examples of the application of the theoretical approach proposed here, a case study from the PalCom project will be used. PalCom was a European IST (Information Society Technology) project that ran between January 2004 and December 2007. Palpable computing envisions ubiquitous technologies designed to support people in making their actual and potential activities and affordances clearly available to their senses. The research approach was grounded in the participative design tradition, and involved both development of technological systems and use cases.[26]

The case study to be discussed dealt with healthcare services supporting women during pregnancy.[27] The study was performed in Denmark and involved ten pregnant women (in two separate sets) [28] four fathers-to-be (participating second-hand) and a dozen healthcare providers. Input was collected through eight workshops, an ethnographic survey, and development of a series of prototypes. The healthcare personnel and pregnant women participated actively in the study, providing feedback on the prototype development, use situations, and data evaluation.

Background

Currently in Denmark, a pregnant woman is in contact with several different healthcare professionals in different locations over an extended period of time. This includes midwives, general practitioners, and in some cases various specialists. Since the clinical information is presently distributed among many parties, it was difficult for the pregnant woman to assess her situation. One task was thus to support her handling and collection of data. Another concern was the type of information exchanged. From a clinical perspective the focus was on health related topics, such as diet, exercise, medication, drinking and smoking habits. It was shown in the study that personal and clinical information were considered equally important by the pregnant women.

The Memory Stone

In current work practices, information about the status of the foetus and the pregnant woman is stored in a number of different places, not only on various media, but also in different geographical locations. This scattering of information is partly due to the origin of the data (i.e. information recorded by a midwife is stored on the local computer or paper file). There is, however, no single place where all information is collected. The closest one can get is the personal pregnancy journal ("vandrejournal"), a paper folder kept by the pregnant woman herself. This increasingly thicker folder is brought to each consultation and updated by the midwife or general practitioner. It thus has a dual function: the main collection of health data and the main means of communication between groups of healthcare professionals.



Figure 1. The Memory Stone. Concept prototype (left) and functional prototype (right)

One part of the design solution was to provide each woman with a digital artefact, called the Memory Stone, intended as a technological support for storing, recalling, and communicating things of interest, both clinical and personal. This assistive device was to be used both during consultations, and at home or in other private settings. Its physical design was originally intended to mimic a stone in order to give associations of permanence and durability. It had an internal flash memory to hold the data, a Bluetooth radio for wireless communication, and a button for user interaction. Being a part of the larger PalCom technological architecture, it could be integrated with other devices such as a PC or a mobile phone. This extended the simple digital storage functionality of the device to being included in the technological infrastructure of the midwife or physician as well as the home.

Combining ecology and sociology

In this section, a series of examples from the case study will be presented in order to exemplify and integrate some aspects of the socio-material and ecological approach proposed.

Artefacts of the self

> Instead of conceiving the relation between person and environment in terms of moving coded information across a boundary, let us look for processes of entrainment, coordination, and resonance among elements of a system that includes a person and the person's surroundings. When we speak of the individual now, we are explicitly drawing the inside/ outside boundary back into a picture where it need not be prominent. These boundaries can always be drawn in later, but they should not be the most important thing.[29]

To draw the perimeter of the self, one has to have an apprehension of what is on the inside and what is on the outside. Also, agreeing on the fact that people interact, this boundary has to be permeable in the sense that there can be exchange over this border.

One way of drawing this boundary is to see what a group of people have in common. The term *community of practice* (CoP) was introduced by Lave and Wenger to describe groups of people sharing knowledge and practices.[30][31]

An artefact that bridges the gulf between different CoPs functions as a 'boundary object', a term first described by Star.[32]

> (Boundary objects)... are those objects that both inhabit several communities of practice and satisfy the informational requirements of each of them. ... Such objects have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable, a means of translation. The creation and management of boundary objects is a key process in developing and maintaining coherence across intersecting communities.[33]

The different CoPs can organize their interconnections around an artefact, a boundary object, that should be robust enough to transport information between these communities, but at the same time allow for local interpretation. The knowledge embedded in the boundary object cannot be extracted or interpreted locally without prior knowledge within the receiving community.

A boundary object is hence a means for the production of meaning. In Latour's terminology, such an artefact (actor) can be either a mediator or an intermediary. [34] In his vocabulary, an intermediary is 'what transports meaning or force without transformation.' The effects of intermediaries are trivial and predictable. Mediators, on the other hand 'transform, translate, distort, and modify the meaning or the elements they are supposed to carry.' Dealing with mediators, it is not possible to foresee the outcome by studying what is given beforehand. In the distinction between a 'sociology of associations' and what Latour calls a 'sociology of sociology', he states that the latter uses one type of social aggregate, few mediators, and many intermediaries, whereas the former does not have any social aggregate and an infinite number of mediators.

Example: information vs. meaning

The pregnancy journal is a boundary object between different communities of practice within healthcare. Since the clinical information is intended for other practitioners, the content and form of the journal are not supposed to (should not) be transformed during transport. Wenger calls this a 'reificative connection'.[35] In Latour's terminology, the pregnancy journal can be seen as an intermediary in the network.

The pregnancy journal is not intended for the pregnant women. They don't understand the language used in the pregnancy journal (Latin and Greek words, sloppy handwriting, unexplained abbreviations, etc). Thus they are excluded from this exchange. The pregnant woman has the *information*, but since she cannot interpret it, it has no *meaning* to her.

The Memory Stone, on the other hand, is a boundary object between the pregnant woman and the healthcare professionals. Whereas the healthcare professionals asked what the Memory Stone is useful for, the pregnant women described what

it meant to them. For the pregnant women, the Memory Stone was more than a trivial storage device, as in the tool metaphor, and became a part of their identity. It had connotative and semantic meanings due to its shape and material, and there was a sort of attachment between the women and her Memory Stone. Many of the pregnant women reported that they liked to carry the device with them, which is unlikely with the traditional paper-based pregnancy journal.

Since the information stored on the device is (partly) personal, and thus has little or no meaning for the healthcare professionals, it is another form of boundary object, something Latour would call a *mediator*. The meaning of the information stored on the Memory Stone is created through the woman's interpretation in a specific situation.



Figure 2. Handling information.

Niches and species

The environment in the case study included computers, paper journal, telephones, faxes, e-mail, and other media, as well as a wide range of different people and locations. Most of the healthcare personnel used clinical or technological tools to carry out their tasks, such as blood and urine tests, computers, faxes, ultrasound scanners, and others. These were used for gathering clinical data as well as communicating information. The pregnant woman, on the other hand, could not rely on any technological aid in these situations apart from occasional personal devices such as personal digital assistants and mobile phones. These devices were not suitable or adapted for these kinds of tasks and hence were not commonly used. Thus, there was an apparent imbalance of technological support which could be alleviated by introducing the Memory Stone.

Ecologically, the professionals and the pregnant woman (and her spouse, friends, and family) could be said to occupy different niches within this system, having special capabilities and drawing on different resources. The relations between these 'species' could be predatory, competitive, or cooperative. In the predatory sense, it is not necessarily a question of negative conflicts. Rather, a predator species is related to its prey in a feedback loop, thus limiting and negotiating with each other. One example of a competitive relation from the pregnancy case was when different professionals had similar functions within the system. The differences between these categories of species could be a matter of territory, status, or professional focus, and led to confusing and counterproductive situations, according to the participants.

Example: cooperation

In the pregnancy case, there were many different categories of professionals: midwives, general practitioners, specialists, nurses, nutritionists etc. Normally, these healthcare professionals had little or no direct contact with one another, mostly forwarding information via the paper pregnancy journal carried around by the pregnant woman herself, or through an internal database system. Despite this indirect mode of communication they managed to work towards a common goal, i.e. the well being of the foetus and pregnant woman. Hutchins talks about the interplay between these actors as a form of distributed cognition. He describes this phenomenon of collective (cognitive) skills where individual members have limited resources and capabilities, but when combined they function as a unit (like the crew on a ship, as in his example). The distributed collaboration of the professionals in this case can be viewed as an example of a cooperative and symbiotic relation within an ecology where different species are sharing and generating mutually beneficial resources.

The introduction of new species in an ecosystem could also have drastic implications. In the pregnancy case, one of the keystone species when it comes to communicating data was the paper journal carried around by the pregnant woman. This was the only single place where information from all healthcare professionals was collected. The introduction of the digital assistive device not only could oust the paper journal, it would expand this specific niche and compete with other species such as mobile phones and notebooks.

Example: competition

An example of the impact of materiality of information in a relation was the introduction of the digital device to the male spouses. There was a noticeable increase in their interest and participation when the digital artefact was introduced into their lives as expectant fathers. This artefact in some cases proved to be more effective for communicating information than the existing human-to-human relations.

One possible explanation could be that their interests in technology made them more receptive to the content, using the device as a mediator. Another explanation was the transformation of the information from the traditional paper-based written form into a high-tech interactive form where additional types of information can be stored and shared (images, sound clips, video).

Locality

Ecosystems are local to a specific environment. If the perspective changes for example to include a larger area or a different set of species, the ecosystem turns into a different one. Similarly, the use of the healthcare devices and services in the pregnancy case was dependent on the specific location, the people engaged, and the devices used. For example, the Memory Stone was primarily used as a digital memory at the midwife's office, but while lying in the woman's pocket its tactile and semantic properties were the most appreciated (still related to memory, but rather as associations than data). Several of the participating women noted that the device reminded them of an egg, and that this made them think of it as a representation of the foetus. This symbolic association was not only based on the physical design, but also on the meaning of the information stored in it.

Example:

The role of the pregnant woman also changed when moving from one place to another. From being (relatively) less informed than the midwife at her office, the pregnant woman became an expert when explaining things for her spouse at home. Ecologically, she turned from being a dependent species to becoming a keystone

species. The circumstances and environment influenced the meaning and function of the different species (artefacts and people) of the ecosystem.

Multiple selves

It is crucial to avoid seeing the self as something *a priori* in the socio-material approach taken here. Latour, like Goffman, suggests that there are many different possibilities of groupings that are simultaneous and equal. Depending on the context of a study, the notion of a 'self' of any given individual could be seen as a snapshot of all possible selves. This is commonly spoken of as roles; a person has many roles, depending on the context, age, and other factors.[36] One can be a parent, son, and brother at the same time, but one behaves and is defined differently depending on which role is in focus in a given situation. This multitude of identities is one part of the concept of the distributed self, and is a product of time, place, and all the interrelated artefacts in that situation.

Example:

The women in the case study had several roles or identities during the research project: pregnant women (as individuals, and as representatives of the group 'pregnant women'); wives; daughters; research informants; professional workers etc. The pregnancy was also considered by the women as a time of preparing themselves for their new roles as parents and involved a period of change, concerning both their ego identities (the self) and their social identities.[37]



Figure 3. At a consultation and at home.

Change and co-evolution

According to Eriksson, the formation of identity follows certain steps throughout the course of a person's life. One's self is considered to be dynamic over time, constantly subject to negotiations, exchange and flux. Although changing, the self (normally) exhibits a great resilience and seems to be biologically, psychologically, socially and cognitively more or less consistent and coherent over time. One way of expressing this is that past experiences are incorporated into the present self – growth carries history, like the circles in a tree or the spirals of a shell. This homeostasis of the self is a functional balance of personal history over time and has similarities with the evolutionary processes of an ecosystem as a whole, and as such it is a form of epigenesis – a form of becoming or evolution.

Most of the pregnant women in the case study had higher education and professional positions that demanded considerable responsibility. All but one of the participating women in the study were pregnant for the first time, and had little or no prior direct experience of a pregnancy. Due to this situation, they found themselves being to some degree ignorant and powerless, which was even more evident for the spouses who to a lesser degree participated during the consultations.

Example: co-evolution

The progressive learning of these first-timers influenced the focus and depth of the information provided by the professional staff. The collection and arrangement of clinical and personal information changed gradually over time, adding to the accumulated knowledge of the individual women. There seemed to be a co-evolvement between the pregnant woman and the Memory Stone. In that sense, it became an integral part of the re-formation of the self.

From an ecological perspective the participatory development of technology as well as the interaction between researchers, participants, and artefacts can be viewed as a process of co-evolution within the project itself. The close co-operation and interdependency provided instant feedback and regenerative responses, which is one fundamental feature of an ecosystem.

Metabolism

From the ecological perspective, the handling of the Memory Stone device and the data was a form of metabolism in the pregnancy case. The process of storing, retrieving, discarding, and updating information meant cycling of resources. Data were passed from one species to another, each processing and altering it according to his or her specific needs.

Example:

An unexpected effect of changing the materiality of the pregnancy journal was the need of taking care of it. It demanded attention and physical handling in other ways than the paper journal (charging batteries, transmitting data to and from computers etc). There was a transformation of the interaction itself – instead of handling information they were interacting with a digital artefact. So, caring for the Memory Stone became a parallel to (but not a substitute for) caring for the foetus.

Coda

The socio-material approach taken in this text calls for a discussion of what it means to be an individual. By extending the role of artefacts, from being tools to become integral parts of the individual, the aim is to investigate implications for design (research) into the domain of personal expression and meaningful relations. As a parallel to McLuhan's slogan of media as an extension of man, artefacts could be regarded as extensions of the self, or using the terminology of Bolter and Grusin, a hypermediated self. [38]

By putting our physical bodies inside our extended nervous systems, by means of electric media, we set up a dynamic by which all previous technologies that are mere extensions of hands and feet and teeth and bodily heat-controls – all such extensions of our bodies, including cities – will be translated into information systems.[39]

Haraway stresses the general and extensive co-dependency between humans and technology; there exists no opposition between them since they are inescapably intertwined. She writes: "Late twentieth-century machines have made thoroughly ambiguous the difference between natural and artificial, mind and body, self-developing and externally designed, and many other distinctions that used to apply to organisms and machines."[40] Subjectivity and identity must take into account the bodily as well as the technified exterior, as Haraway's companion species, the cyborg, exemplifies.

Technological tools and other artefacts carry social meaning. Social understanding, values, and practices become integral aspects of the tool itself. Most of us probably don't think of a telephone as a machine; instead, we think of it as a way of communicating.[41]

The distinction between the inner self and the outer, between the body and artefacts in the environment is blurred. In some sense, some artefacts could be considered part of an individual, not only as a matter of 'appropriation' where tools are used to fulfil some instrumental purpose, but of symbolic, meaningful incorporation. Goffman describes this symbolic interaction from a dramaturgical perspective taking into account both the roles of the individual and the props and stage.[42]

So where does the self end and the artificial world begin? Are artefacts simply tools or representations or do they have a more profound impact on the perception of self and phenomenologically how we are in the world? When talking about the self as being distributed onto artefacts in the environment, one can argue that the term 'individual' loses its meaning of an indivisible subject and no longer signifies a person but something else. The self is in other words simultaneously embodied (biologically) and embedded (in artefacts).

The boundary of the self is permeable depending on the perspective taken. In this text, the individual is no longer indivisible and isolated from its environment. Instead, the unit of analysis is the system of more or less stable relations between artefacts and people, in this case a single person. What is to be considered a 'self' is thus not bounded by the biological body. As Stelarc puts it, 'The skin no longer signifies closure' [43].

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Paper V

Intuition in Design & Emotion

Transforming raw data into conclusions,
a meta-analysis of the 2006 Design & Emotion Conference papers.

Enquist, H., and Nordgren, C.

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Intuition in Design & Emotion?

Transforming raw data into conclusions, a meta-analysis of the 2006 Design & Emotion conference papers

Abstract

In any research field the transformation of raw data into conclusions is a critical phase, necessitating a systematic approach. The basic question is: How can I as a (design) researcher corroborate my conclusions? This paper is based on a study of the analytical/interpretative portion of papers published in the Proceedings of the 2006 Design & Emotion Conference. We investigate how the authors present the interpretative process in their papers, such as using specific methods for interpretation and analysis. It became obvious that there were few specific methods for interpretation mentioned in the Conference papers studied, though there was a wide range of methodological approaches from theoretical and statistical to purely qualitative. Notably, most papers did not mention any method at all. The issue of interpretation is certainly not new, but in the light of the topic of design for emotions, design (research) *by* emotions or intuition should be discussed.

Conference theme: Methodological issues

Keywords: interpretation, methodology, tacit knowledge

Introduction and aim

One interesting element of the design research process, especially when it comes to the sometimes elusive phenomenon of emotions, is the analysis of the research material. In any research field, the transformation of the empirical material into conclusions is a critical phase, necessitating tools and systematic procedures to ensure validity and reliability of the conclusions. Validity and reliability, in turn, can be argued to be contested measures in qualitative research, but the underlying question still remains: How can I as a design researcher corroborate my conclusions based on the material collected? {cont. p. 2}

> To validate is to question, in particular to continually ask what is being investigated and why, and also ask about the when, where and who of an action (Kvale, 1989, p.81).

There are various analytical methods and models at hand for the design researcher, some taken from other disciplines, others from within the field. The aim of this paper is to investigate and discuss the ways the interpretation of the research material is reported in the articles studied. This includes the formal presentation of the interpretative portions, as well as methodological issues, such as which methods are explicitly used when interpreting the material. There is also the question of the impact of the personal traits of the individual researchers when it comes to interpreting the research outcomes.

> Qualitative research methods are largely subjective in that they rely heavily upon the investigator's skills of observation and interpretation to provide valid information. Therefore, much training and experience is needed to carry out this kind of research (Borg and Gall, 1989, p.379).

In order to achieve our goal, the outset of this study needs to be clarified. This is a descriptive attempt, not an interpretative one. In that sense, this paper resembles a review of the articles studied in order to detect patterns in the interpretation phase. Individual papers are not analyzed, though their form and content constitute the raw material of this study; rather it is the collective impression they give that is examined. Our intention is not to pass judgment on the ways interpretations are made in the individual articles. The goal is to raise general questions regarding the manner in which the interpretation of the (raw) research material is described and presented, and to discuss implications for design research. In this sense, this is an explorative venture.

Material and method

Material

This paper is based on a study of the analytical/interpretative portions of papers published in the Proceedings of the Design & Emotion Conference in Gothenburg 2006 (Design & Emotion 2006). The papers (n=82) were retrieved from the Design and Emotion Society webpage. {cont. p. 3}

Method

The methodological approach chosen was based on a series of questions used for evaluating the content and disposition of the papers regarding making the interpretation of the material explicit:

Is the article 'empirical' or 'non-empirical'? By 'empirical' we mean that it presents original research material. Theoretical discussions or descriptive design cases are classified as non-empirical.

– If empirical: Is any statistical method used for interpreting the research material?

– If empirical: Is any other method explicitly mentioned for interpretation; if so, which?

– If no: Does the article explicitly present an interpretation of the material?

– If yes: How is the interpretation presented?

Some additional questions were asked when reviewing the articles:

– If empirical: Are the words 'reliability' and/or 'validity' mentioned?

– If empirical: Is the position of the researcher(s) stated? By position we mean experience, competence, knowledge, education, cultural background, or any other aspect of the individual which could affect the process of interpretation.

This set of questions was the starting point of the investigation and could be expanded by a more in-depth qualitative study of the integration of the interpretative process in the texts. In each article the above points were investigated.

Results

Some papers reported several aims and methods. Many reported a series of iterative steps leading to a range of different kinds of empirical data. This made it difficult for the reader to understand if a method used for *categorizing* data also affected the *interpretation* of the data. For these reasons, detailed categorization of the papers in this study was considered difficult and unproductive for the purpose of this review. The findings of this study are presented with a range of examples from the papers (n=82). All articles are not specifically commented on, but are included in the investigation.

25 of the 82 articles were considered to be non-empirical (e.g. Wood; Candy, Edmundson; Kong; Anusas). Of the ones considered empirical, 12 used a statistical method of some sort to analyze all or parts of the empirical material (sometimes in addition to other methods) (e.g. Grimsaeth, Baggerud; Stilma; Schifferstein). {cont. p. 4}

In the empirical papers, there were examples of methods and tools for analysis/interpretation such as text coding (Eliot) or qualitative computer software (e.g. Mason, Porter). These were applied to parts of the empirical material in the respective articles. In a few papers (e.g. Fang, Lin), objective measurements were reported. In a handful, methods for analysis were mentioned but not further discussed (e.g. Kim, Zimmerman). Several papers did not mention any method used for interpreting the empirical material (e.g. Ionascu; Tzvetanova, Tang, Justice; Rodríguez Ramírez; Wikström).

Research tools which provided instant information about the experiences of the participants partly freed the researcher from interpreting the material, such as VAS (e.g. Olander, Sperling), Likert scale (e.g. Hårleman, Werner, Billger), User Compass Chart (e.g. Sperling et al.), Sensagram (e.g. Fenech, Borg) and close-ended questionnaires (e.g. Harrington, Lechner, Simonoff), among others.

We have also reflected upon issues which possibly could influence the interpretation process in each study. The first was if the researchers' position was mentioned in the paper, such as personal experience (e.g. Kim, Zimmerman), knowledge (e.g. Mason, Porter), profession (e.g. Skogen; Gonzalez Veron, Evenson), education (e.g. Lilleng, Baggerud), fundings (e.g. Hakatie, Ryynänen; Chhibber et al.; Sperling et al.) or as a biography (e.g. Huang, Deng).

The second issue was if validity and/or reliability was used or discussed. Just a few studies mentioned validity; sometimes the terms were used without declaring the use or definition of the term, e.g. in terms of repeatability or generalizability (e.g. Laurans, Desmet; Lechner, Harrington, Simonoff).

Interpretation of the results

A main concern of this review was to avoid interpretation of the content of the papers studied. This proved to be quite a challenge, since the structure and disposition of most of them demanded detailed reading to clarify the use of methods, theory, and process of interpretation/analysis.

It became obvious that there were few specific methods for interpretation mentioned in the Conference papers studied, though there was a wide range of methodological approaches from theoretical and statistical to purely qualitative. Notably, most papers did not mention any {cont. p. 5} method at all. This makes it almost impossible for an outsider (or insider for that matter) to get a feeling for how similar empirical material is handled in this field. Some use statistical methods to analyze results from Visual Analogue Scales, others discuss them more freely.

So, how come some researchers choose to interpret their data in a structured way using well-known tools, whereas most choose a non-explicit method? Several possibilities can serve as explanations. We want to emphasize that the following list should be regarded as speculative and incomplete suggested explanations based on reading the articles included in this study. We have not contacted any of the authors to ask their reasons for not explicitly describing this process.

– The process of interpreting research material in this community of practice (research in design and emotion) is common knowledge and does not have to be made explicit: Everyone knows how it is done and there is no need to waste time or effort on explaining the obvious.

– There is no tradition in the design research community of including this aspect of the process in conference papers.

– It is a practical matter of number of words. The manuscript length limitations (this year 4000 words, including abstract and references) make it difficult to include elements not considered critical.

– There is a lack of knowledge of how to systematically analyze/interpret raw material or how to describe it in research articles.

– The authors are not aware of the importance, or even existence, of this phase of the research process.

– There is a lack of interest in discussing the process of interpretation.

– The interpretation is made intuitively and cannot be described in text (or it is very difficult and thus omitted).

Again, we want to stress that we have no idea as to the actual reasons for not including a clear presentation of the interpretation of the research material in the articles lacking such. These are just suggestions which can be used as a basis for discussion.

So, how do we counter these explanations, assuming they are true? The first one, that the process of interpretation is shared across the research community and does not have to be explained, is problematic for several reasons. First of all, one can question if this community of practice really is so homogeneous that the outcome of such a qualitative process is transparent and clear to any other member of the community. Looking at the diversity of research approaches and topics among the articles in the Proceedings, along with the backgrounds and {cont. p. 6} professional competencies of the authors, it is obvious that this is a heterogeneous field. Although a more or less shared basis in the training and education of the researchers may exist, one can still argue that it could be expected that the outcome

would vary depending on the individual interpreter. Secondly, isn't the diversity of interpretation one of the strengths of research for design? Sharing the pros and cons of alternative interpretations of the material presented could enrich and vitalize the discussion.

The second explanation, based on a lack of tradition, is a delicate one. Certainly, tradition is of great importance for shaping any branch of research but to answer why and how this tradition has come into existence is difficult. This is not the place to elaborate on design research history and the origin of methodology, nor comment on the format of a particular conference. What is apparent, though, when reading the papers is the many attempts to describe methods and techniques for collecting material, but a lack of similar effort when it comes to evaluation and interpretation. Moreover the reader of the Conference articles has no idea if the author has reflected on the interpretation in the research processes (which is very likely), or not (hopefully unlikely).

The limitations on the number of words for the texts published in proceedings, forces authors to consider what is of greatest interest for the intended audience. If this is the reason why an explicit description of the process of interpretation is omitted, it implies that this is considered less important than an extensive description of the theoretical research background or the design process. Looking at the articles examined, it is obvious that most of the researchers have made this choice, which could be in line with the previous explanation.

The following two possible explanations are not generally considered valid in a research context (lack of knowledge and unawareness). But if this is the reason, it is most certainly in concert with other reasons such as those mentioned in explanations 1, 2, and 7.

A lack of interest in explicitly reporting the interpretation can be a reasonable explanation considering each research project separately, but as a research field, mirrored in the Conference Proceedings, it is arguably more discouraging. There are often lengthy discussions of the design process in the articles, but there is seldom a reflective discussion about the practice of interpretation. So the conclusion could be that it is not considered as important or interesting as {cont. p. 7} the design process. To be fair, the design process is not discussed reflectively on the most part either in the texts, although it is most certainly practised in the research activity itself.

The last explanation is perhaps the most probable one, although the word 'intuition' can be misleading. What we mean by this is that the skills and knowledge accumulated by the researchers during their practice is incorporated to such a degree that in a given situation, appropriate actions and understanding of their effects are almost automated and come naturally without any deeper reflection. In 'The Reflective Practitioner', a widely cited and referenced book in the design community, Donald Schön (1987) describes the practice and abilities of a number of practitioners in various fields. Drawing on Polanyi's notion of tacit knowledge, he claims that over the years, a practitioner develops abilities and strategies which seldom or never are described openly. By reflecting over their ways of dealing with problems within their respective fields, practitioners can improve their own understanding of their practices and thus improve their abilities to handle common as well as unexpected problems they encounter. This reflective practice, hence, is a means of making the tacit explicit. A practitioner, for example an industrial designer, could very well get by without being reflective, and instead rely on gut feeling trial-and-error. We argue that this is not sufficient for a design researcher. In design research, the openness of the 'how' and 'why' is crucial for disseminating processes and results within the scholarly community.

If interpretation and evaluation of research appears 'intuitive' to the reader, in the sense of tacit knowledge, then it is crucial to declare the position and background of the author/researcher since this has direct impact on the interpretation made. It is a matter of transparency and should be made as a courtesy to the readers so they can make up their own minds if the interpretation is within reason. This could be of special interest if there are several authors of an article, especially if their interpretations differ. Sometimes, a conflict of interpretations is more interesting and fruitful than a consensus.

Implications for design research style

Design research, especially in the field of design and emotion – research concerning experiential design such as experiences of pleasure, usability, or emotional responses towards existing products and tentative design proposals – could be said to be based on a hermeneutic tradition. This statement should be taken in its broadest sense, but the common denominator is that this kind of research does not pay homage to the positivistic tradition. There are no (definitive) answers, no correct

methods of investigation, and no truths to be discovered. Design research has more in common with the social sciences, such as ethnography, where the position and {cont. p. 8} experience of the designer plays an important role, both in regard to the research approach and the evaluation (interpretation) of the empirical material produced.

Design research as a field has thus been inspired by the social sciences, and has adapted several methods and research approaches into its own field. One way of establishing design research as an academic field of inquiry is to produce and present relevant and detailed case studies. These are often descriptive in nature, that is to say, the design process, material, methods, and outcomes are presented and discussed. In many cases these different aspects of the research process are presented intermixed in the texts. One thing which is characteristic of design research, and which sets it apart from the social sciences in general, is the attempts to propose future alternatives (or alternative futures) by improving existing ones or proposing novel practices or products. The systematic collection of such successful cases is what makes up science *for* design (Krippendorff, 2006, p. 209).

Doing/making is thus a key feature of research for design. Naturally, this has implications for the interpretation of design research.

– The researcher cannot be objective.

– It is not looking for truths, but propositions.

– The position/experience/knowledge/skill of the researcher/author is important for the process of interpretation.

– The research is conducted in a specific time and place (and culture).

– The designer has some *intentions* (which could be in the form of hypotheses).

– It takes time to create design artefacts used in the research (= less time to interpret?).

Hence, there are many aspects to take into consideration when approaching design research articles.

Conclusions

In this paper we have studied articles published in the Proceeding of the Fifth Design & Emotion Conferences of 2006. Many are descriptive in the sense described above. We have focused on if and how the authors have presented their reflections on the research material presented in each paper. {cont. p. 9}

We have found that the interpretative portion, as an explicit section or separate discussion, is missing in most of the articles. The interpretation is often intertwined with the description of the material and the design process. One explanation is that this is necessary due to the nature of the design research process itself. This approach has several consequences. First it makes it difficult for the reader to evaluate the interpretation of the research. Secondly, it renders a quick overview of large written material almost impossible (as we noticed during our study). Thirdly, it establishes a tradition of devaluating a clear and open discussion on interpretation within this particular research community. For design research to be cumulative, communication and transparency are crucial.

Another consequence of this way of publishing the interpretation of the design research material is that it seems to be partly based on the personal experiences and knowledge of the individual researcher. Combined with a lack of an open and clear reflective presentation of the interpretation of the research outcomes, one risks weakening the credibility of the conclusions. Not presenting alternative and competing interpretations also can imply that the conclusions are present a priori. This may not be the case in any of the articles studied, but as a reader the question is inevitable.

Following this line of reasoning, one might argue for tacit knowledge in design research, in particular in respect to interpretation of the empirical research material. Hence, we want to raise the question of the importance of the personal traits of the individual design researcher when it comes to interpretation. As such, this is not an issue *if* the interpretative process and the conditions for it are made explicit but, if this is missing or unclear, one can wonder what role, if any, intuition plays in research for design and emotion.

We end this discussion with two open-ended (and possibly rhetorical) questions: Can the design research community in general, and qualitative design research in particular benefit from more open and transparent presentations of the interpretation of research presented in conference papers and other design research articles? If so, will this demand a more in-depth declaration of the standpoint, background and knowledge of the researchers?

> Taken seriously, a science for design is inherently self-reflective, within its boundary, while always open to other stakeholders. It is destined to continually reflect on itself, on its strengths, and on its weaknesses. (Krippendorff, 2006, p.271)

Finally, we hope that this paper encourages an open discussion on this topic for the benefit of all. {cont. p. 10}

Note

The selection and grouping of the articles are available on request by contacting the authors.

About the authors

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Camilla Nordgren, with an MBA, is currently a PhD student in the field of traumatic spinal cord injury and societal resources. She has a special interest in methodological questions and the consequences of how empirical data are interpreted.

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