

2013 European Conference

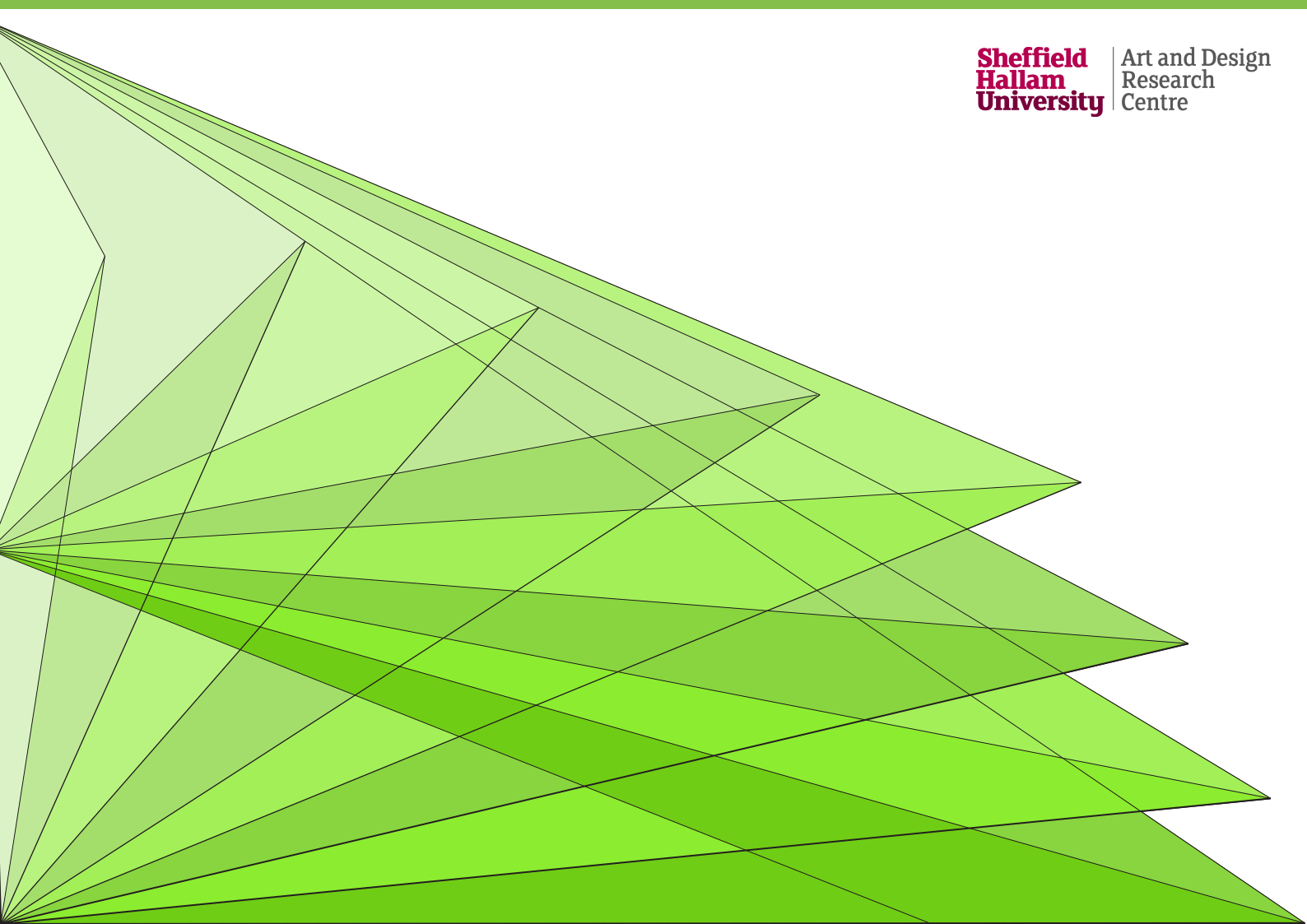
# Design 4 Health

Proceedings of the 2<sup>nd</sup> European  
Conference on Design 4 Health 2013  
Sheffield, 3 - 5 July 2013

Editors: Dr Alaster Yoxall and Kirsty Christer

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# **Proceedings of the Second European Conference on Design 4 Health 2013**

**3 - 5 July 2013, Sheffield, UK  
Sheffield Hallam University**

Volume 1

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## Introduction

Welcome to the proceedings of the 2nd European Conference on Design for Health.

We feel that the conference is unique in its aim to engage a truly multidisciplinary audience, spanning work by health researchers, designers and artists along with professionals involved in industry and regulation.

That broad spectrum of work is reflected in the contents of the proceedings that we hope you find interesting and thought provoking.

We look forward to your contribution for the 3rd European Design for Health conference in 2015.

Dr Alaster Yoxall  
Conference Director  
Lab4Living, Art & Design Research Centre  
Sheffield Hallam University

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Devices for Dignity

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User-centred Healthcare Design

## Review Panel

We gratefully acknowledge the members of our Review Panel, who have generously given their time to review papers submitted to this conference:

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# **Keynote presentation: Cross-disciplinary research: balancing imagination and the extraordinary with factual technical knowledge**

Sonja Bäumel

*Studio Sonja Bäumel / artist, (fashion) designer*

## *Abstract*

*This paper is based on the work discussed during the presentation given at Design4Health2013; it focuses on recent scientific developments, and the translation of such research through artistic experimentation, design methodology and fashion visualisation tools, in a contemporary world's view. The overall aim is to be found in the democratisation of complex and technical scientific facts, through the creation of touchable, tangible and critical artefacts.*

Keywords: facts and fiction, hybrid objects, Human Microbiome, artistic experimentation, public dialogue

## Micro-organisms: Bacteria

All over the world scientists have started to focus on the Microbiome, the multifunctional community of micro-organisms living on the human body. The *Human Microbiome* Project was launched from the US National Institutes of Health in 2008. The project's goal is to identify and characterize the micro-organisms which are found on the human body, together with all their genetic information.

The human body is a hybrid, a walking biotope, where small creatures are in charge. At least from a genetic point of view bacteria are in charge, as the colonizers' genotype contains a hundred times as many genes as the human's genotype. The Microbiome is composed of 3.3 million genes, while the human envelopes only 20-25,000 genes (Baoli *et al*, 2010). We carry up between two or three kilos of bacteria on and in our body, and most of them live in our stomach. So one could pose the question: who feeds whom? The human being, a large host, is not aware of the fact that such an amount of microorganisms live in and on his body. Now we are realizing that a part of the control of the human body ecosystem belongs to the small creatures living on us.

"They were incredibly small, nay so small, in my sight, that I judged that even if 100 of these very wee animals lay stretched out one against another, they could not reach to the length of a grain of coarse Sand" (Van Leeuwenhoek, 1980). In 1683, Antonie van Leeuwenhoek was the first man on earth witnessing the existence of microbial communities. Since that time, more than three hundred years have been passing, during which scientists have been studying bacteria, isolated from their complex environments and relationships. Only in recent years, thanks to the advancements in gene technology, have scientists been widening their focus, starting observing bacterial behaviour in context; this, by directly examining samples taken from the environment, which as mixed cultures, contain a variety of microorganisms. This methodology gave birth to a new field of study: *Metagenomics*. Such novel scientific domain analyses microbial communities on the basis of their genome and promises to provide a new and more complete understanding of diseases and health; this will clearly end up having an immense impact, not only on medicine, but also on society.

## Art/Design Context in Science

Microbial materiality was first probed and experimented by artistic pioneers, providing public access to science research that previously would have been considered out of reach for a cultural investigation. They paved the way for the public to be able to experience and benefit from their findings.

Among the earliest works with living materials on the genetic level is Joe Davis's conceptual *transgenic artwork*<sup>1</sup> (Gessert, 1999) "Microvenus" (1984), challenging our faith in genetics by forming a strand of DNA like the Germanic rune for life.

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<sup>1</sup> In the late 1990s, Eduardo Kac coined the term "transgenic art" to describe living artworks that had been created through genetic engineering.

Twenty years later, the possible incorporation of living organisms in art works had come to be seen in a different context – designers started to incorporate living organisms in their work.

Trans-disciplinary co-operations emerged out of recent developments in the young field of synthetic biology, where one makes use of design principles: molecules, cells and organisms need in fact to be designed in order to create new biological systems with new associated properties. A strong example of such practice could be found in the project “E.chromi”<sup>2</sup> (2009) showing a mutual collaboration between designers Alexandra Daisy Ginsberg and James King, and the *iGEM*<sup>3</sup> team of the Cambridge University. During the development of the project, *BioBricks* were designed and inserted into the bacteria *E. coli*, containing genes of existing organisms that were capable of producing colour.

In the design approach described above and in the following paragraph, the designer is not a scientific communicator, but he/she rather explores, questions and translates scientific achievements, by the means of his/her own language, into artefacts, trying to make scientific information touchable, creating and contributing knowledge and experience, and aiming to bridge the gap between science and the general public.

## Tangible examples, artistic experimentations and public dialogue

“Hidden Connections”, the lecture at the Design4Health Conferences 2013, focused on my on-going research and process of my work in this context.

Since 2008 I have been collaborating with microbiologists, creating objects which mediate between art and science, fashion and science, design and science, between clothes and body and between fiction and facts. The human body and its different visible and invisible skins especially fascinate me. I explore the human skin and its potential.

During my studies at Design Academy Eindhoven in the Netherlands, my creative work revolved around the human body and biology in general. At the beginning, I concentrated on symbiosis and biological adaptation, i.e. mimesis, mimicry and camouflage in animals. Symbiosis, meaning a close partnership between different species, which is beneficial for all partners, provided a strong impetus for my work.

I was obsessed with the thought that some level of adaptation supposedly is also available for human beings. I thought that our clothes – our second skin – ought to be determined rather by personal physical needs, social factors and individual beliefs than by fashion trends. This led to the following questions: Do we expect too little from our clothes? What would a piece of clothing, defined by personal physical needs or, for example, by our body temperature, look like?

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<sup>2</sup> E. chromi won the Grand Prize at the 2009 International Genetically Engineered Machine Competition (iGEM)]

<sup>3</sup> The International Genetically Engineered Machine (iGEM) is a worldwide non-profit oriented synthetic biology competition. It has been organized by the Massachusetts Institute of Technology (MIT) in Boston since 2003.





Figure 1: Crocheted membrane, 2008/09, photo by Wing Lam Kwok

All these considerations led to the development of the *Crocheted Membrane* (fig.1) design. The *Crocheted Membrane* displays a fundamental change in the aesthetics of clothes. Usually the conventional production of clothes is strictly related to certain aspects belonging to the history of fashion design, as for instance, specific shapes: a shirt is defined as a shirt, trousers are defined as trousers, etc. Opposed to this, the *Crocheted Membrane* process had a different starting point, to be found in the specificity of an individual human body and its relative needs, when subjected to an outdoor temperature of 10 degrees Celsius. Completely new functions, aesthetics and shapes emerged. This originated further questions:

“What if our second skin would be able to locally adapt to changing conditions in a flexible and autonomous way? Would the aesthetic diversity of our clothes with individual colors, shapes and structures, be more inspiring and would we be more aware of our surroundings? Is it possible that even social integration would become more dynamic due to the adaptation of the outer layer to its surroundings?”

In 2008 such questions brought me to the Microbiology Department at Wageningen University in the Netherlands. In order to learn more about the lives of bacteria, I had the opportunity to complete a microbiological internship. After having been introduced to the basics of microbiology, I started experimenting with skin bacteria and, at a later stage, to study their interaction with textiles.

During this time I learned how inspiring interdisciplinary co-operation between art and science can be, for all the parties involved. New aesthetics and verbal vocabularies emerged. I noticed that scientists usually focus on their own special microcosm and that designers prefer to adopt a larger view, which puts them in the position of being capable to recognize causal relations more easily.

The following design step was the project titled *Bacteria Mapping* (2009), where I started charting bacteria on my body. I developed a system based on numbers ranging from one to 20 and denoted different parts on my body in order to find out and document how and in which way bacteria belonging to different body-areas varied.

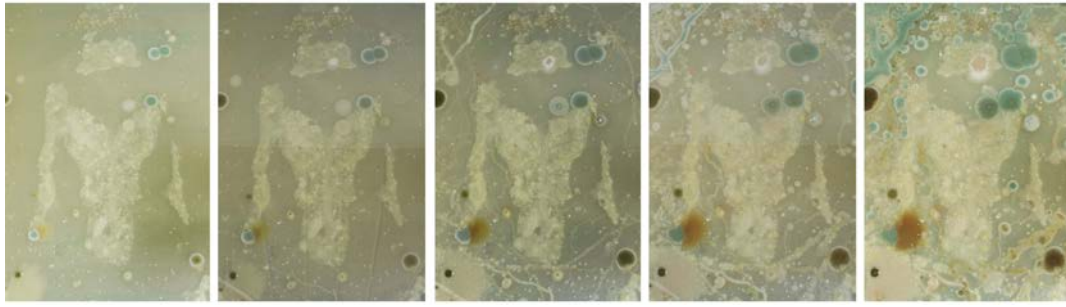


Figure 2: Oversized Petri dish, 2009, dimensions: 110cm x 75cm

This led to a further process step, where I intended to visualize a large part of the invisible bacteria membrane. The *Oversized Petri dish* (fig.2) project proved to be a challenge for me as well as for the scientific team at the Wageningen University, as a Petri dish with such dimensions had never been made before. In the framework of the project, I took pictures of the living and growing part of my body from day 0 until day 44 and documented the changes. Further research revealed interesting results: we only know 2-3% of our skin bacteria.

Through such process I had the direct chance to witness how my invisible skin bacteria, which were part of my body, became autonomous and visible due to the more favorable conditions on an external support: a life-sized Petri dish. To see the shape of a human body outside of the context of its living organism and the general lack of awareness related to the knowledge of bacteria that were composing its invisible beauty made me reflect about the generally accepted "body-image". This suddenly became a new fundamental input which created the basis of my work: to be able to render the invisible, while raising awareness and possibly offering to the larger public food for thought.

Our body does not end with our skin; it rather extends into the room in an invisible way.

I decided to carry out my experiments with the material usually implemented in society as our second skin – textiles. I worked with natural, synthetic and semi-synthetic textiles and with three persons' skin bacteria. I specified certain feeding structures and observed the results. During every experiment I realized that bacterial fingerprints and the tiny micro-organisms grew exactly following the shapes of the fingers. This unless a specific type of wool was used; in this case the bacteria grew around the various small threads. I presented my *Bacteria-textile Experiments* (fig. 3) in the framework of an exhibition, as the act of presenting the process of my work to the public is one of the most important aspects of my work.



Figure 3: Bacteria-textile experiments, 2009

*Visible Membrane I* (fig.4) developed from these experiments and mediates between fashion and science. In this project, I covered an ordinary mannequin with the wool which caused the most reactions in the previously described experiment. The mannequin's body was completely covered in wool except for its belly where a petri dish displayed the skin bacteria's reaction to the wool. The mannequin face focused on its belly to suggest and symbolize the importance for us, humans, of having another closer look to our skin, in order to better study and make use of the already existing invisible infrastructure.

After this stage, I developed the movie *(in)visible*, which shows the four layers of the (in)visible membrane. The first layer consists of our skin bacteria. The second layer is an artificial, living communication layer, which can absorb the information of our individual skin bacteria. Another important aspect, which has to be considered, is the environment. My research led me to the only natural organism, which, as far as I know, is able to flexibly react to environmental influences, namely the slime fungus.

Slime fungi are change artists; they use intelligent strategies of the fauna and flora to move and to reproduce. During the dry period, slime fungi change their structures and colours; they reach a state between life and death. When the rainy season starts, they revive and once again change their shapes and colours. I'm convinced that we could learn something from these natural biologic functions and systems and that artificially created systems like these could be adapted to our individual bodies where layers could then provide us with new opportunities to interact with our environment.

Finally the movie shows plants growing out of human skin and it portrays a human being who is able to breathe under water – a utopian vision and inspiration.



Figure 4: *Visible membrane I*, 2009, photo by Rene van de Hulst

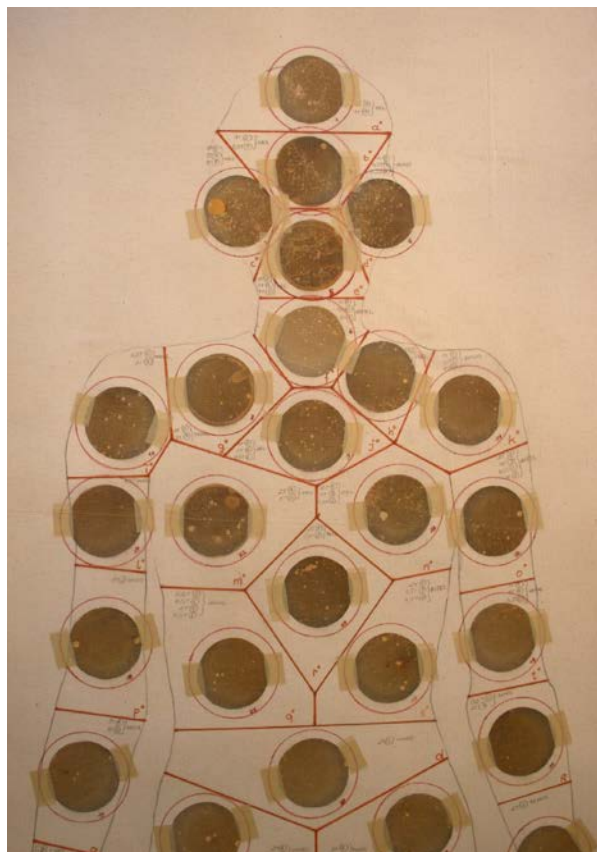


Figure 5: Body Mapping

In 2010 I started working on the project *Cartography of the Human Body* (fig.6) which is a collaborative project developed together with Erich Schopf (University of Veterinary Medicine, Vienna); it is a project which deals with the (in)visible skin bacteria on my body and the bacteria absorbed on a specific day in a specific area of Vienna.

The natural layer of bacteria on my skin was removed and then replaced by an artificial layer of bacteria, representing the bacterial colour range of certain body parts and their immediate surroundings on Nov 11, 2010. To produce such a piece of art on a scale of 1:1 requires high level scientific and technological inputs and can be considered an innovative, courageous challenge. This conceptual journey, including many experiments performed on my body, took us eight months.

The bacteria were collected to let them grow on external media. Thus a certain part of the body grew in all its diversity in terms of colour, independently of the rest of the human body. Additionally, different morphologies, colours and quantities of bacteria were examined on different body areas; they were determined, counted and documented (fig.5). At a later stage, when the body prints were created, such technique allowed us to visualise the bacteria and place them in the related body-areas. The bacteria were bred, partially reanimated and kept alive at -70°C.





Figure 6: *Cartography of the Human Body*, 2010/11, in collaboration with Erich Schopf



Figure 7: Colour palette of an individual and it's surrounding from the 11.11.2010.

Furthermore, the bacteria's interactions with different agars and materials were studied. In the framework of an interaction study, experiments were made to study the bacteria's hierarchies in order to find out in which order the bacteria had to be applied on the human body. After applying the invisible bacterial colour on the body, a body print was made on a textile material, previously impregnated with nutrients. As soon as the bacteria grew visibly, their growth was stopped and the actual state was documented with a body print.



Figure 8: Bacteria Colours

This art-piece aims to help depicting formerly invisible microcosms, while making people aware of them and visualizing and translating scientific information into touchable objects. We created an artistic image of an invisible real moment to create impulses, confront, and trigger reactions.

The reason to do this originates from the conviction we share: that the mental concept, which as individuals we possess about ourselves and about our direct invisible surroundings, is closely linked to a healthy perception of our body.



Figure 9: *Expanded Self*, 2012

*Expanded Self* (fig.9) emerged out of the *Cartography of the Human Body* and has been realised for the documentary film 'Wir sind Planeten', produced by ServusTV-Terra Mater. Supported by the bacteriograph Erich Schopf, I found a unique way of visualising the invisible surface of the human body. I used a gigantic petri dish as canvas and the bacteria living on my own body as colour.

After the application of the invisible bacteria colour on the body, the body was imprinted on agar, the nutritive substance for bacteria filling a huge petri dish (210cmx 80 cm). After few days a living landscape was growing there, consisting of a unique mixture of life forms on my body on a specific day, in a specific Viennese area.

*Expanded Self*, the living and growing picture of a body, was photographed and documented on the seventh day of growth. This imprint of a human body represents a metaphor offering new points of view related to our person, who and what we really are (at least from a physical point of view). The skin border blurs away and proposes novel ways of looking at it. If we merge the genetic material of all our inhabitants it comprises ten times more information than our own DNA. We are only beginning to understand how this astonishing community of different life forms works on and in us and lets us work coevally.



## Conclusion

Design can act as a medium for the public, which stimulates discussion on social and cultural developments in science and technology. In such way science and scientific information can go out of the lab into the outside world. (Fashion) design can visualise scientific processes. Science can contribute by providing methods and data to (Fashion) design. The discourse between art and science should remain as a crucial necessity to question developments in science. The improvement of a step by step collaboration between art and science will allow visions and communication to be merged with technical knowledge and methodologies, to create positive advancements in society; to achieve this I strongly believe that the public needs to be involved in the dialogue. That's what I try and do: to spread my fascination and critical curiosity, while involving the larger public in taking part shaping through current advancements, possible ideas of futures and the resulting society.

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# Keynote presentation: Disruptive, illuminating and generative? Integrating design approaches into healthcare research.

Alastair S Macdonald

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## *Abstract*

*Recent pre-occupations in design practice and research have extended the understanding of design from one comprising activities which were once purely those of the 'professional' (e.g., industrial) designer to the point where design is seen as a 'distributed social accomplishment' and where, e.g., 'stakeholders are co-designers and designers are another kind of stakeholder'. Here, design uses 'participative' or 'co-design' processes where designers' roles shift from a stance of designing 'for' people to designing 'with' people. As such, design tends to be valued for its utilitarianism, i.e. for its potential for reducing suffering, increasing wellbeing, or providing improved scenarios or solutions. In multi-disciplinary research, when designers form part of the team, this utilitarianism may be attractive to other disciplines in helping achieve desired outcomes. Taking a case study approach, the author discusses a series of multi-disciplinary healthcare research projects, where designers were invited for the first time to bring novel approaches and methods to help bear on specific healthcare problems. He questions to what extent design is understood as a disruptive force for change in its own right able to influence, e.g., the dynamics of inter-personal relationships, the way the research itself is designed and conducted in healthcare environments, and how problems are defined and understood. Design can also illuminate data, insights and ideas and, through its rich mix of accessible methods and processes, can create a strong and effective social dynamic between the research teams, stakeholders and clients, allowing everyone to work together in a more fluid and contributory manner, enabling a collective generation of solutions.*

**Keywords:** Design approaches, multidisciplinary research; participatory processes, social-materials, techné-materials

# Introduction

## Legitimacy

When potentially joining a multi-disciplinary healthcare research team there is always that initial question about what exactly will be one's prospective contribution as a 'design' researcher. Given the considerable and demonstrable achievements of medical science, what exactly is design's legitimacy within the healthcare-related research context? When 'design' is first mentioned, it is probably product or equipment design that springs to the mind of the health professional. In the more traditional 'industrial' design paradigm it can be relatively easy to understand, e.g., how 'good design' can improve the design of medical products or equipment. Here, design can bring undeniable achievements, increase user-safety, improve efficiency, and save lives by designing out medical and human error. The points of reference are familiar and achievements recognisable, both in clinical and wellbeing terms: ergonomics and task analysis; product design, engineering and innovative technology; functionality and user-centred utility; and aesthetics. The product, a 'design' designed by a 'designer', forms the focus of negotiation and decision-making and, through a greater or lesser extent of user-engagement, embodies the needs, agendas and decisions of all involved, reflected in its function, features and performance.

The RED papers: Health Co-Creating Services (Cottam & Leadbeater, 2004) brought into sharp focus and to wider attention the continuation of a long-term shift from those forms of design concerned with the material 'object' per se to those more concerned with the immaterial ways things and systems can be organised to create conditions where people are supported and taken care of, and where they can be empowered to take better care of themselves and each other. Debate continues as to what extent Design's potential contribution as a discipline is fully understood in this context: it loses its familiar identity and points of reference, becoming subsumed within more complex, less easily-defined and multi-disciplinary territory.

Amongst healthcare professionals less familiar with this recent area of enquiry, Design might tend to be valued for its utilitarianism, i.e. for its potential for reducing suffering, increasing wellbeing, or providing improved scenarios or solutions. To the clinical leads in multi-disciplinary research, this utilitarianism may be attractive and the motive for engagement to achieving particular (perhaps often pre-conceived) outcomes. Due to its still experimental and exploratory nature, the full potential for the development and application of 'design approaches' within healthcare research is still being uncovered. Inviting Design into a healthcare-related research team might still be more akin to bringing a 'Trojan horse' into the camp, one that unpacks some unexpected approaches and outcomes as a consequence.

## Ownership

The advances and achievements in, e.g., clinical rehabilitation, concerned with the restoration or management of function following stroke, knee or hip replacement, or spinal cord injury are indisputable. An issue arises, however, of disciplines that might be perceived to 'own' certain healthcare problems, i.e. how they approach the problem to advance the field, together with the types of evidence on which further advancements might be based. Many issues within healthcare are complex, i.e. problems that are difficult to resolve, appearing resistant to resolution. Some

disciplines may tend to address potential 'solutions' using a reductionist approach, maintaining healthcare discipline-to-discipline and specialist-to-patient hierarchies: an attempt to resolve just one aspect of a problem may often result in ignoring some - or creating further - problems. Problems can be compounded through the introduction of solutions that may be unworkable or ineffective due to a lack of acknowledgement or a poor understanding of complex interdependencies and relationships due, in turn, to the lack of engagement with - and collective contribution from - all stakeholders involved in delivering and receiving the service.

## Disease or person?

In her 'A view from the front line' (1995), Jencks' description of the *experience* of the cancer service as it then existed inspired the movement named after her, the Maggie's Centres, which acknowledge that it is more than the treatment of the disease itself which needs to be addressed. Her voice laid bare both the reality of her experience of treatment which ignored her as an individual and also of her desire to have some control over what was happening to her: '... sitting in a harshly lit room with her husband ... in a windowless corridor of the hospital contemplating having two to three months to live ... the need to feel in charge (not a helpless passenger in a hospital production line).' Treatment, however unintentional, resulted here as a disease-centric and largely impersonal affair.

## A 'distributed social accomplishment'

Using people's experiences as the basis for co-designing healthcare services now has some significant exemplars, such as in the work of Bate and Robert (2007) and those mentioned by Hampson, Baeck and Langford (2013). Bate and Robert (2007) stated 'This placing of the user of a service or a product at the very heart of the design process has become today's *grande idée* in the design industry professions' although their work does raise questions, addressed later, about where exactly the designer is in this approach.

However, this raises questions both of *how* one mobilises this lay knowledge and also *how* one places the user at the very heart of the design process. Participatory approaches to designing have provided ways of working with people, to exploit previously under-utilised resources of insights and experiences more fully, to illuminate issues in quite different ways, to generate fresh understandings, and to provide a different kind of evidence base with which to work. Participatory design itself is not a new philosophy, arising from the 60s social democracy movement in Scandinavia, but it has been increasingly become part of the design canon. There is now a growing body of literature and case studies of the effectiveness of integrating of 'participative' 'co-design' methods and approaches into multi-disciplinary healthcare research. Other work outside the healthcare context has the potential to be highly applicable within the sector. Simonsen & Roberston (2013) provide a useful compilation of the 'proliferating family of design practices that hosts many design agendas' (Brandt, Binder & Sanders, 2013).

In the multi-disciplinary context, and when involving stakeholders, 'it becomes important to acknowledge the part that end users and other stakeholders play' (Kimbell, 2011) where 'design is a collaborative effort where the design process is spread among diverse participating stakeholders and competences' (Björgvinsson, Ehn & Hillgren, 2012). Kimbell regards the outcomes from this approach to design as a '... distributed social accomplishment', and design 'not just as the work of

design professionals but also of the ... end-users and other stakeholders whose practices constitute design and its objects in different ways.' If participatory forms of designing result in a 'collaborative' achievement and 'distributed social accomplishment', what are the best processes and materials with which to fully engage the principal actors in striving to optimise this approach? Because of the particularly problematic nature of the healthcare sector with its hierarchies, complexities and task-driven accountabilities, how can one best shift the balance to develop a 'greater proportional symmetry' (Strickfaden & Devlieger, 2011) between key players, confronting traditional hierarchies, flattening decision-making and empowering all? How do we 'align the participants around a shared, though problematic or even controversial, object of concern' (Bjögvinsson, Ehn & Hillgren, 2012)?

## The case studies

In the preceding section, the questions arising from the introduction of design approaches into multi-disciplinary healthcare research were raised. These questions are now explored through three case studies, each of which is quite different, from the author's experience of working as the design research lead within multi-disciplinary healthcare research teams. The first describes work within a random controlled trial (RCT), the second a much more recognisable 'design' research and development project, and the third an exploratory and as yet unresolved project. For each, the problem and its context is defined, the achievements in each summarised with references to further publications, and then in the following section, a more generic discussion is provided of the nature and effects of the materials used.

### 1: stroke rehabilitation

The 'envisage' project continued an extended programme of development of visualisations of biomechanical and movement data for use in physical rehabilitation trials, most recently focussing on post-stroke rehabilitation. The issue here was how to improve physical rehabilitation therapy using this method. In 'envisage', the lead discipline's (bioengineering) primary pre-occupations had previously been, and continued to be, how the introduction of visualised data (and the technicalities of motion capture and motion sensor technologies across different trials to provide the data to be visualised) used as an intervention, would affect the quantitative outcome measures normally used in biomechanical trials.

The most significant achievements in this ongoing programme of research were: i) the visualisation of biomechanical and movement data, previously understandable only to trained biomechanists, in an understandable form for both patients and rehabilitation professionals; ii) the trialling of these visualisations within RCTs; iii) the introduction of an over-arching qualitative mixed methods approach (introduced in response to an issue identified by Lewin, Glenton & Oxman (2010) who highlighted the need for mixed methods in trials) as the means to acquire qualitative data in random control trials (RCTs) whereas previously predominantly only quantitative data would have been collected; and iv) the inclusion of stroke survivors and stroke therapists to guide the development of and use of the visualisation tools in the RCTs. Figure 1 shows three of the visualisations tools, used in separate lower-limb, upper-limb and ankle-foot-orthosis (AFO) RCTs.

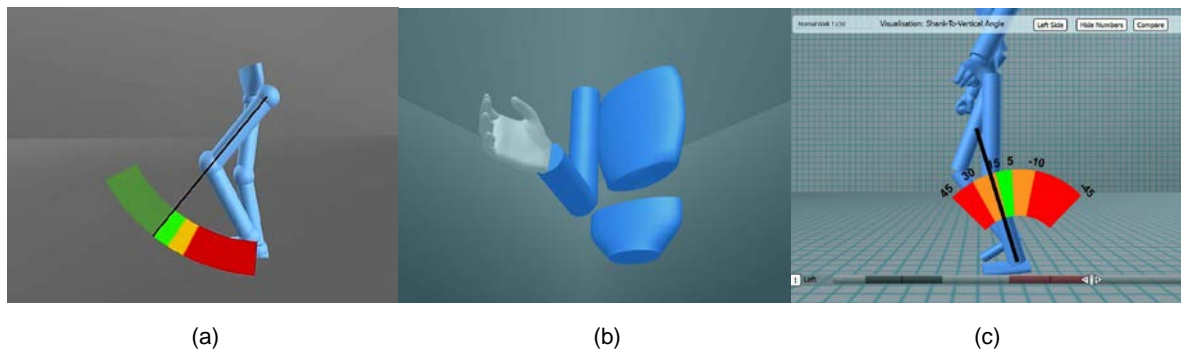


Figure 1. (a) Knee lift exercise visualisation in lower limb rehabilitation following stroke. (b) Reach and grasp visualisation in upper limb rehabilitation following stroke. (c) Shank angle visualisation for Ankle Foot Orthosis tuning after stroke.

The activities introduced by the designers in each of the typical four stages (design, pre-trial, trial and post-trial) of the 'envisage' RCTs helped provide this qualitative data. The participative process helped develop the visualisation tools, i.e. the 'complex interventions', used during the trials themselves. Loudon, Taylor and Macdonald (forthcoming) provide an overview and discussion of the three consecutive projects pursuing this programme of research and of the findings emerging from the recent 'envisage' project which aided understanding, communication and progress (envisage, 2013).

## 2: nutrition monitoring and management

The context for Case Study 2, the 'mappmal' project, is the significant scale of malnutrition in hospitals, particularly amongst older patients. The situation facing the multidisciplinary research team was the combinatory effects of a totally inadequate 'one-size-fits-all' meals service linked with no workable way of monitoring the nutrition intake of individuals, each of whom has their own requirements for calorie, protein and fluid intake. The current meals service is a complex agglomeration of imperfect systems, often conflicting interests out-of-sync with one another, fragmented by a task-driven mentality. Previous interventions, such as protected mealtimes had failed to impact on this problem.

Although the calculation of dietary need (daily calorie, protein and fluid intake) can be calculated on a per-individual basis, one central issue identified was that of monitoring what patients had actually eaten (unknown), as distinct from what was presented to them (known): no satisfactory method or system had yet been developed to do so. After consideration of a number of alternatives, Comber *et al* (2012) reported on the validation of the solution finally adopted by the 'mappmal' team as the most workable to achieve this objective, a 'wipe-away' food-monitoring app which uses a photo of the meal linked to a smart nutritional database on the patient's bedside touch-screen terminal (figure 2) and which enables making a quick visual record of what remains on a patient's plate, found to be within sufficiently accurate tolerances for meaningful recording of a patient's intake of protein and calories. This app and the terminal form part of a larger, more complex system (hospitalfoodie, 2013).



Figure 2. The 'wipe-away' food-monitoring app which uses a photo of the meal linked to a smart nutritional database on the patient's bed-side touch-screen terminal. This was initially built as an android working prototype for testing with the 'food family' and key stakeholders. Illustrations © Peter Baynton Radish Pictures 2011: stills from the animation on [www.hospitalfoodie.com](http://www.hospitalfoodie.com)

Macdonald *et al* (2012) describe the process and means used to co-develop a demonstration prototype for the 'hospitalfoodie' nutrition monitoring and food management system for older hospital patients and Moynihan *et al* (forthcoming) report the findings.

### 3: spinal cord injury

The research in this final case study is at a much earlier and more speculative stage of development than the previous two and, although different in character again, is exploring the idea of introducing design research approaches into another type of rehabilitation context, that following spinal cord injury (SCI). SCI is a life-changing event and a survivor has to learn to manage every single aspect of their daily life anew, particularly functional management: everyday activities - eating, dressing and undressing, grooming, personal hygiene; skin; bladder; sexual issues; management of bowel, chest and joints; prevention of contractures; mobility; accommodation; social issues; schooling; and employment. The relearning of the management of each and all the separate functions by an individual is nothing short of miraculous and a real testament to the skills of all in the clinical and rehabilitation teams. However, the one-year post-discharge stage is particularly problematic when depression and its effects are the most severe for SCI survivors and continues to be a major challenge. The existing 'patient pathway' spreadsheet compiled by the Spinal Unit, used together with a detailed 18-page Goal Planning Checklist booklet to help patients manage their various functions, reveals a highly reductive approach, separating out all the very different aspects of personal (largely functional) management. It is breath-taking in its implications.

The research takes quite a different approach from both the spinal unit's rehabilitation focus, largely on the management of functional issues, and also from that of Campbell (2011, 2012), the initiator of this area of study, in how designers might approach the issue of working with SCI survivors. This author's aspiration is that the work in this case study may help illuminate, through the use of materials to help present new kinds of evidence for both the patients themselves and for the healthcare professionals, not only the complex nature of issues and problems associated with daily living from a survivor's perspective, but also previously unrevealed tacit skills in the SCI survivors themselves.



The use of these kinds of materials has already shown that they can provide the staff in the spinal unit with forms of evidence of and insights into patients' capabilities and issues - from their perspectives (figure 3). The author (Macdonald 2013a, 2013b) provides a description and discussion of this pilot work for which exploratory materials were developed to help open up a new kind of dialogue with patients and rehabilitation staff.



Figure 3. Spinal unit staff discussing SCI survivors' issues and comments from one of the pilot workshop activities. Image: still from a film by Claire Levy © 2012.

## Discussion

Clearly, there are a number of challenges in research of this nature within healthcare. As it is multi-disciplinary it has to confront and reconcile, by various means, the disparate agendas and outlooks of the disciplines and groups individuals involved, with their different terminologies, methodologies and expectations with regards to what constitutes 'acceptable' evidence on which to build a case for an improved healthcare model or intervention. As the sector is traditionally hierarchical, and certain might disciplines appear to 'own' particular problems, when involving a number of stakeholders as key contributing participants, these hierarchies need to be transmuted into a much more level playing field with a greater sense of ownership amongst all involved. Acquiring evidence is one aspect of the challenge but a less familiar challenge, arguably, is the act of shaping – designing - something new and better, using that evidence as a platform. How does one align and bond together all the participants to a common purpose, allowing everyone to work collaboratively in a fluid and contributory manner, and given, e.g., the work of Bate and Robert, where does Design, and the designer, sit in all this?

## Social-materials and techné-materials

Given the 'proliferating family of design practices' (Brandt, Binder & Sanders, 2013), as mentioned earlier, of 'design methods' it might be useful to focus on two broad categories of methods which

have been found useful in this type of work. Björgvinsson, Ehn & Hillgren (2012) discuss the 'infrastructuring' of design activities and the creation of 'socio-material assemblies'.

Apart from the art of setting up the processes and the designing of the appropriate activities and situations conducive to fostering collaboration, the first useful category of materials to define here are those which help change the dynamics between people (both between different disciplines within the research team and between the research team and those external to it, including the more 'lay' participants such as patients, carers, etc.) and also to reduce what Greger and Hatami (2013) refer to as the 'social distance' between the players. There is also the need for 'no one voice, including that of the researcher, claiming final authority' in the "polyphony of voices' (Flyvbjerg, 2001; 139). For convenience these will be discussed here as '*social-materials*'.

The second category of materials to be discussed here are those that can embody and externalise the discourses, agendas and decisions, translating these from theoretical, immaterial ideas and concepts into more tangible and material manifestations, i.e. 'designs'. Strickfaden and Devlinger (2011) use the term *techné* which they define as 'embodied know-how enacted through everyday life'. Flusser's (1999) discussion of *techné* (from the Greek for 'art') is perhaps more useful here, illuminating the art and craft of the designer, the 'agility' or 'ability to turn something to one's advantage', a 'sleight of hand'. Flyvbjerg (2001) elaborates on Aristotle's original discussion of *techné*, providing us with '*techné* is thus craft and art, and as an activity it is concrete, variable, and context-dependent'. This helps us move towards the idea of the particular craft and art of designing, i.e. that art of embodying the immaterial and less tangible into mock-ups, prototypes and designs, whether these are 'products', 'systems' or 'services' familiar territory to 'traditional' design. For convenience here these will be discussed as '*techné-materials*'.

The use of these two broad categories of materials will now be discussed for how these assisted with each of the case studies outlined above. There will be situations, as we will see, where *social-materials* and *techné-materials* will converge.

## Case 1: the visualisation tool as both social and technical mediator

In Case 1, concerned with physical rehabilitation following stroke, although the three groups - clinicians, physiotherapists and patients – could be physically present in the same session, there could be a great 'social distance' (Greger & Hatami, 2013) between them. Their different priorities, terminologies and the traditional hierarchical nature of relationships, tended to define the agenda, determine the decision-making processes, ultimately influencing the model of research, the kind of data collected and evidence emerging on which any resulting therapeutic intervention would be based.

RCTs are regarded as the 'gold standard' for research, and the evidence-base they generate often forms the basis for new treatment plans. However, as Murray *et al* (2010) acknowledge, the complexity the 'multiple confounders' of a situation and approaches to prospective solutions developed by a single discipline may be less successful than those embodying the collective experiences, insights and expertise of all involved, particularly in complex interventions. The rehabilitation session may previously, in research of this type, have been regarded largely as a technical challenge of functional restoration, i.e. how the patient could achieve correct movement, how to collect and measure quantitative movement data and objective understanding of progress,

with interventions designed on this basis. However, the use of the visualisation tools together with qualitative data capture revealed the rehabilitation session to be as much an intensely social as an intensely technical challenge.

In this case, during the design and pre-trial phases of the RCT, the nature - and various iterations of - the prototype visualisation tools proved to be *both* a social-material and a techné-material. The generative process, whereby the therapists, survivors and patients, and clinical leads guided its development, as outlined in Table 1, enabled the complex multi-user agendas of the key stakeholders or actors involved in stroke rehabilitation, i.e. clinicians, therapists and patients, to be embodied in the design of the tools. These proved not only to be a technical mediator in assisting therapists and patients to respectively communicate and understand correct movements and progress but also a social mediator, acknowledging the patient's and therapists' experiences needs, experiences and preferences and reducing the 'social distance' between the players. At a social-level the tools enabled a different quality of discourse to occur between trials patients (or survivors who participated in pre-trial focus groups), therapists and clinical leads. As the qualitative evidence collected demonstrates, this is also an intensely social situation, one of individuals' disrupted lives, the wells of emotions, hopes and aspirations, the frustrated communications, the expressions of achievement and disappointment. The visualisation tools disrupted the normal hierarchies, ensured that everyone was on the same page, flattening traditional top-down agendas and decision-making, allowing illuminating input from the key stakeholders involved in processes of both delivering and benefiting from the rehab process and understanding who needs to know what at each stage.

The findings (Envisage, 2013) resulting from an analysis of the qualitative data bear this out: i) the visualisation of the patient's own motion provided an aid to their understanding of their movement problems and the purpose of their rehabilitation tasks; ii) the visual representation of the movement and the overlay of specific measures relevant to their rehabilitation provided a medium for improved communication between the patient and the therapist; and iii) the combination of quantitative measurement and clear visual representation of the measures provided an objective tool for therapists to monitor progress and communicate it to patients.

## Case study 2: a co-designed technological system

In Case 2, mappmal, the complexity of the dysfunctional context and system which results in frail older individuals being unable to consume adequate nutrition was revealed by engaging all (the multi-disciplinary research team, food family and key stakeholders) through the use of, e.g., i) visual mapping of ethnographic data (normally presented in report or tabular form), 'food journeys', and food preparation processes; and ii) patient mealtime scenarios using visual vignettes derived from ethnographic data (interviews and observations). The use of these materials helped 'illuminate' the complexity of issues in the current context and system in a format which could be shared and discussed amongst all. In this sense, they enabled an improved, or new form of social discourse about the issues. They were also 'disruptive', allowing new kinds of social processes and types of engagement amongst the team, food family and stakeholders, redirecting the focus from the fragmented, reductive, process-driven approach of the catering service and the allied health professions' task-driven pre-occupations, to focus instead on the older patients' individual needs and experiences. These social-materials enabled, in this case, the food family and

key stakeholders to engage with one another, often in novel ways, removed from the normal roles, hierarchies and decision-making processes found within the sector.

The techné-materials allowed the stimulation, simulation and iterative development of ideas and concepts towards prototypes which embodied the accumulated evidence and know-how from the stakeholders during the process. Examples of these included a set of concept boards for the individual core of essential elements identified, through workshops, for an improved service (a stage on from identifying the key issues and problems), such as, e.g., a conducive eating environment, the means to order meals, to monitor nutrition intake, and to provide nutrient dense foods at appropriate times during the day. There would be a further iteration of these into mock-ups and working prototype stages. These techné-materials enabled the stakeholders to understand, and to a certain extent experience in very tangible ways, what might be innovative and workable ways of delivering the meals service. In this sense, these materials were 'generative' and 'illuminating'. The outcome, the 'hospitalfoodie' demonstration prototype of a reconfigured meal service, a co-designed technological system, is a distributed social accomplishment achieved through the use of these two main types of materials.

### Case study 3: new forms of evidence

In this final case study, concerned with exploring difficult issues of SCI rehabilitation with SCI patients, the work is at an early pilot stage. The scarce evidence in the literature that exists about the experiences and difficulties as described by SCI survivors themselves, particularly in the one-year post-discharge phase which has been identified as particularly problematic, was used to provide a tentative alternative model of their pathway, one based on key psychological transitions (the first following SCI injury and their integration, through peer support, into the spinal unit, the second being the post-discharge phase alone back into the community).

However, already the use of social-materials has been both disruptive and illuminating, in the sense of helping the SCI survivors to introduce, to the spinal unit staff, a set of issues around the survivors' agendas and experiences different to those normally discussed in the spinal unit. Exploratory activities used social-materials to help elicit types of data unfamiliar within the unit and which showed the potential for new forms of social discourse. The new types of data emerging from pilot workshop material and the new forms of discourse these can support, have already begun to provide the basis for the discussion of how to improve the rehabilitation pathway, so the alternative pathway model outlined above will be used iteratively as a techné-material to embody the emerging discussions into a more tangible 'product' or approach.

This exploratory work has interested the unit staff in, e.g., further exploring the personalisation of SCI survivors' treatment and access to rehabilitation, how to better socialise, engage and integrate survivors into the wider community, how the process of rehabilitation might be improved and how this is delivered, and how to decrease the dependency on carers and healthcare professionals, i.e. disrupt the established patient-to-healthcare professional relationship. The author (2013a) describes the pilot work exploring these issues and a further grant for collaborative doctoral research has been secured to take this work forward.

## Conclusion

Two main classes of materials have been discussed here: i) those which enable changed interactions, dynamics, discourses and reduced 'social distances' between different individuals and groups (social-materials); and ii) those which enable the progressive embodiment, interaction with, and development of ideas and concepts resulting in new designs (techné-materials). They have been seen to be illuminating, disruptive and generative in the contexts described in the three cases above.

One of the issues arising from the work of Bate and Robert (2007) is the issue of the need for a 'designer' in this area of research. Junginger (2013) has highlighted the need to clearly differentiate between the 'designer' as a professional individual and 'designing' as an activity which can also be engaged in by non-designers. However, although the author accepts, and indeed promotes this approach, the quality of the design of the social-materials and techné-materials themselves to support 'designing' in this sense can also help reveal both the science and the artistry of design, particularly for the latter in the sense provided by Flusser (1999; 18) and Flyvbjerg (2001; 56). As designers, we can help give coherence and eloquent form to these materials to help shape what Simon (1996) referred to as 'preferred futures' allowing us, and others, to re-imagine the design and delivery of healthcare.

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# Moving myself: insights for future patient experience journeys in orthopaedics

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## Abstract

*This paper reports aims, approach and results of an exploratory study into the patient experience in health of joints (ranging from prevention to procedures such as hip replacement). Innovation in treatments increases efficiency, and the time available for specialist-patient communication gets shorter, for example because hospital stays get shorter. Although the treatment improves, this reduces the quality of the patient's experience of it. This study identifies opportunities to improve the patient experience.*

*In a multiple case study approach, various stages of patient journeys were studied. Twenty industrial design master students investigated the patients' life context and experience of joint health through qualitative interviewing, observational research and design prototyping research. Content analysis of the twenty cases revealed four main aspects (themes) of the patients' life experience that affect their experience of their patient journey: experience of time, experience of body, knowledge and behaviour adaptation, and social context. With these themes we contribute knowledge on components of the patient's life that influence the patient journey. This knowledge can serve to design product- service systems that are truly patient-centred while simultaneously contributing to medical efficiency.*

Keywords: industrial design research, patient experience, multiple case study, orthopaedics



# Introduction

This paper reports aims, approach and results of an exploratory study, using a multiple case study approach, into the patient experience in health of joints (ranging from prevention to procedures such as hip replacement). Innovations in orthopaedic treatment mean that the treatment itself is qualitatively improving. This has the side effect of reducing the opportunity for patient-specialist communication, for example because of shortening hospital stays. While that benefits both the patients in that they spend less time away from their normal environment, and the hospitals and practitioners in that they can achieve gains in cost-efficiency, it becomes harder for specialists to inform and accompany patients throughout the journey of their treatment (Jimenez, Romero and Keyson, 2011). Less specialist-patient contact produces new undesirable side effects that need to be addressed. A new perspective on the patient journey in orthopaedics is needed that does not rely solely on specialists' support of patients. This paper identifies aspects of such a perspective.

## Combining concepts from experience design and nursing into a patient-centred perspective for the study

Patients' journeys through encounters with healthcare providers have been widely studied and designed in the healthcare domain in the form of care pathways, as first formulated by Zander & Bower, 1987. The widespread implementation of these care pathways has facilitated the personalisation of healthcare. However, care pathways tend to be oriented on clinical indicators and outcomes, not on the patients' experience. While a qualitative view of patient experience has been recognised as crucial for health outcomes and patient satisfaction in the medical context (e.g. Needham, 2012), the question remains what actually constitutes this patient experience and how it can be influenced. This study applies a design approach, and with it concepts of user experience. These concepts have been widely heralded in design research as unlocking the potential of new technologies and creating truly sustainable and qualitatively good interactions between the stakeholders in the context (Bødker, 2006, Hassenzahl & Tractinsky, 2006). User experience concepts such as iterative design, experience elicitation, experience enactments (Buchenau & Fulton-Suri, 2000) and experience journeys have become successful and mainstream in design. Applying these concepts to patient care pathways could potentially promote quality of care and identify opportunities for sustainable efficiency of healthcare systems.

An earlier study (Melles and Peeters, 2013) portrayed an orthopaedic patient experience journey on the basis of interviews and observations. There are very few documented patient experience journeys in the literature as yet, according to a keyword search on Google Scholar. Figure 1 shows how the patient's perspective is central in a patient experience journey. The figure shows a) the patient-specialist interactions and environment, b) the patient's concerns and experiences, and c) the involvement of other stakeholders who are not part of the immediate interaction.



Figure 1: Excerpt from a patient experience journey demonstrating a patient-centred perspective.

## Approach

The study presented here documents aspects of patient experience journeys in more depth than in the initial overview journey excerpted in Figure 1. The case studies included analyses of patients' experiences and the generation and evaluation of design concepts. The insights into the patient experience journey were grouped into themes that could inform future healthcare design and planning projects.

## Research questions

Taking a truly patient-centred stance means to focus the study on the patient's perspective on their patient journey. Conceivably, when someone becomes a patient, he or she continues to experience him- or herself as a person embedded within a context of life (consisting of social context, life activities, preferences and habits). He or she needs to integrate this experience with the experience of being a patient. Therefore, the research seeks out patients and potential patients (who have not yet formed a partial patient identity) and enquires how the circumstances and concerns of their life affect their experience of the health of their joints and of a patient journey, if they embark on one. The study poses the questions: what aspects of the patients' *life* experience affect their experience of a patient journey to improve or regain the health of their joints? And consequentially, which issues arise for the incorporation of these aspects into their experience as *patients*? In other words, into future patient experience journeys?

## Method

For this study, a multiple case study approach (Runeson & Höst, 2009) was selected. This type of case study approach was specifically developed by Runeson & Höst (2009) for software engineering, to contribute knowledge for design and innovation. Just like the similarly project-oriented discipline of software engineering, the design research described here studies the

situation of change rather than the stable use situation, it is project-oriented rather than oriented on 'normal' practice, and the studied work is the design and iteration work of design professionals, medical professionals and lead users (cf. Runeson & Höst, 2009, p. 132). Aggregating different cases provides a source of data triangulation to improve the precision and depth of the insights.

The study takes an 'improvement' perspective (Runeson & Höst, 2009, p. 135) and seeks to explore the themes that mediate in the patient-specialist interaction. By intervening in relation to these mediating themes, the designers investigate how they facilitate the patient's journey and where the learning opportunities are within the context.

Runeson and Höst (2009) point out, citing Yin (2003), that "case study research benefits from the prior development of theoretical propositions to guide data collection and analysis." The theoretical perspective taken in this study is to focus on the patient experience as a journey of encounters with healthcare providers and health providing situations. It takes a 'discount' socio-technical perspective in that it assumes that people and artefacts interact in mutually influencing ways. However, it prioritises "a pragmatic and result-oriented view (...) rather than a philosophical stand" (Runeson & Höst, p. 133) in order to stay closely grounded in the data (Corbin & Strauss, 2008).

## Data collection

20 industrial design master students each investigated a different context related to joint health through qualitative interviewing, observational research and design prototyping research (eliciting people's responses to various possible interventions), in the context of a master design project. The first two authors carried out an overall content analysis of the twenty cases.

The multiple case data was collected in a planned and consistent manner by documentation analysis. From the twenty master students' reports after the project, the same structural parts were extracted across the projects. The students' work and data collection, and hence the reports, have a required format that facilitates comparison between them. The reports are structured in this way:

- Selection of, and contact with a situation of daily life that is relevant to the topic of health of joints.
- Generation and description of in-depth insights from 1-4 real patients and their encounters with the healthcare system, with an explicit focus on patient experience.
- Description of the current patient experience in terms of experienced interaction qualities.
- Formulation of explicit intended improvements to the current situation, oriented on envisaged experienced interaction qualities
- Generation of multiple and iterative interventions that are each evaluated in terms of observed and elicited experienced interaction qualities in the situation of use.

## Results

The study revealed four main aspects (themes) that affect the development of future patient experience journeys in joint health: experience of time, experience of body, knowledge, behaviour and context.

Apart from the four main themes, a general observation is that many of the student projects, namely eleven projects, focused on preventing an operation. Earlier research (Melles and Peeters, 2013) had identified eight stages of a hip replacement journey: pain-relieving behaviour in everyday life, consulting a general practitioner (gatekeeper), getting diagnosed by an orthopaedic specialist, preparing mentally and physically, being hospitalized, recovering (rapid recovery procedure (Hartog, Mathijssen & Vehmeijer, 2013)), getting rehabilitated, and looking back. The students' work in this study added a ninth stage at the beginning, prevention, and the patient journeys here did not always include an operation phase. A possible explanation for this is that the students chose contexts where they could easily find participants. But it may also be that the students empathized with the wish to be as 'not sick' as possible, and sought to address it by focusing on prevention. Altogether, the students' projects were distributed over an entire conceivable set of patient journeys in orthopaedics, with some gaps (GP consultation, diagnosis) due to difficulties of access (Figure 2). 'Prevention' involved many patient experiences outside of direct contact with a general practitioner or hospital. These were particularly valuable here because they revealed more of participants' life experience, sometimes even as a non-patient.

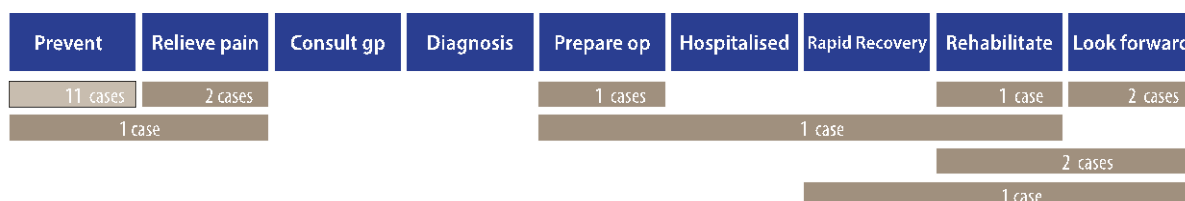


Figure 2: Distribution of student projects over stages of possible patient journeys

Across cases, it can be noted that joint health affects people's lives rather intensely, perhaps warranting future research into a 'life experience journey' that sets the frame of view wider than just the healthcare encounters.

In the remainder of this results section, the results from the multiple case studies are reported in terms of the four themes identified. Each theme represents an aspect of the patient's life experience that affects the way they undergo a patient journey. With life experience is meant, the experiences patients have in relation to how they normally experience themselves in their own life context (rather than patient context). Inferences are drawn on how these aspects could be investigated further and better incorporated into a patient journey to influence its experience positively. The themes occurred across all cases in greater or smaller measure. In the results presentation shown here, examples from specific student projects are used to illustrate the themes. In this paper we consciously avoid presenting the student work as the final research outcome. We would like to draw attention to the implications of each theme for future patient experience journeys. That is why, after an illustration of each theme, we present the implications for future patient experience journeys in a table.

## Theme: Experience of time

Orthopaedic interventions involve long periods of waiting and rehabilitation. Although specialists know and address this, patients still feel unprepared for these long periods. This is for two reasons: firstly, the specialists have limited resources to address it with patients. Secondly, the emotions and physical implications are far from patients' normal life experience (Example: findings from a case covering the stages from preparing an operation to rehabilitation, figure 3)



Figure 3: Illustration from a student project (Lotte Jacobse) on how the experience of time becomes very different and unforeseeable when becoming a patient.

Table 1. Illustration of the theme Experience of time

Aspect (Theme) of life experience	Effect on the patient journey	Resulting issues for future patient experience journeys
<b>Experience of Time</b>	The experience of time is very different for patients than for all those around the patient, whether medical or personal other stakeholders. The patient experiences the journey as very long and unforeseeable in comparison to how they normally live their life.	Detect and support critical points in patients' journey by probing their experience over time. This provides insights that can be used to find opportunities for supporting and improving these experiences throughout the patient journey.

## Theme: Experience of the body

Orthopaedic patients' disconnect from their body experience becomes critical to their overall experience of themselves during non-routine phases such as recovery. Such phases require patients to regain trust in themselves and their body. (Example: findings from a case on swimmers' injuries and rehabilitation, figure 4).



Figure 4. Illustration of patients' disconnect from their body experience. Student: Brigitte Aarts.

Table 2. Illustration of the theme Experience of the body

Aspect (Theme) of life experience	Effect on the patient journey	Resulting issues for future patient experience journeys
<b>Experience of the Body</b>	Even in normal life we cannot easily translate abstract information to body experience. During disruptions of normal body balance, a disconnect between intentions (based on abstract information) and body experience can become even greater. During non-routine phases such as injury, pain or rehabilitation, this requires conscious goal adoption and action.	Investigate ways of providing information and feedback that patients can use to understand and adapt their body, and regain a natural relationship with it. E.g. direct feedback on muscle activity, not just to spur patients on, but also to enable them to integrate the information into their regular body experience.

### Theme: Knowledge and Behaviour adaptation

This theme is illustrated by means of a design intervention rather than an analysis finding. The example in Figure 5 shows how adapting to change becomes a more explicit process when maintaining health of joints than it would be in routine life. The example is of runners who often overexert their joints. Design interventions could help them prevent injury. External informational input supports patients at the very moment of bodily experience, allowing them to internalise the needed adaptation. An auditory running coach provides the needed balance of not too much, not too little adaptation, and of positive and negative motivation (figure 5).



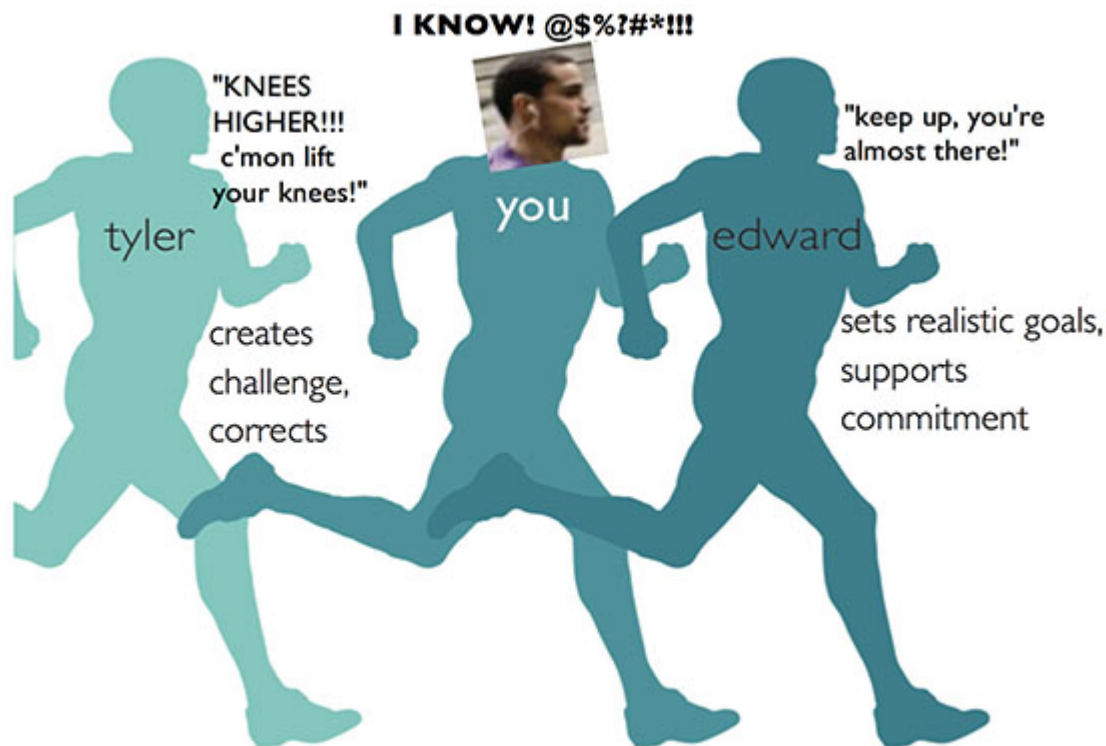


Figure 5: interventions can support the explicit knowledge and behaviour adaptation that is needed to maintain or improve health of joints. Student :Juriën Verweijen)

Table 3. Illustration of the theme Knowledge and Behaviour adaptation

Aspect (Theme) of life experience	Effect on the patient journey	Resulting issues for future patient experience journeys
<b>Knowledge and Behaviour adaptation</b>	Adapting to changes is a process of achieving, losing and re-gaining balance of motivation, commitment and interpretation of body feedback. External informational input is only usable and useful for patients if it fits that process as well as therapy stages and goals.	Investigate what enables patients to monitor and interpret changes and feedback, and how this connects with motivation and commitment to getting better or staying well. Investigate how (and whether) specialists should monitor changes and inform patients.

#### Theme: Social context

The stakeholders in the patient's own social context, although they often appear peripheral to the patient's journey when seen from a medical perspective, are often closely involved in the patient's life and daily life activities as they undergo a patient journey. This affects emotional and practical coping with the patient journey. It also has the potential of helping patients stay themselves and of supporting them emotionally and practically. (Example: findings from a case on hospitalization and rehabilitation, figure 6)



Figure 6: the stakeholders in the patient's own social context are closely involved in the patient's life and daily life activities. Student: Lotte Jacobse. (the spelling in the example is the student's)

Table4. Illustration of the theme Social context

Aspect (Theme) of life experience	Effect on the patient journey	Resulting issues for future patient experience journeys
<b>Social context</b>	The patient's social context plays an important role in the patients' situation of change. A lack of social support can complicate the patient's recovery. Conversely, social support helps patients stay themselves and support them emotionally and practically.	Probe for the patient's social context and how to incorporate it in the medical planning of the patient journey. E.g. create ways for a patient to involve family and friends in coping with the rehabilitation period.

## Discussion

We found that the way patients undergo their patient journey to improve the health of their joints was influenced by four main aspects: experience of time, experience of body, knowledge and behaviour adaptation, and social context. Issues were identified that can be used to design patient experience journeys and inquire further into them. The identified issues were:

- Patients experience the patient journey as a long time with many varied experiences. Experiences should be probed at several points in time during future design and treatment processes;
- People experience an interruption of their natural relationship with their body. Information and feedback should help re-establish and preserve that relationship, and be available intuitively, in connection with direct bodily experience;
- Intervention and rehabilitation demands conscious adaptation of patients. Monitoring and information needs to be designed for both patients and specialists;



- The patient's own social context and level of social support affects their patient journey strongly. This can be a risk or an opportunity.

The findings can be used to create patient experience journeys that incorporate the experience of patients integrally in the way they undergo a patient journey. This could increase the effectiveness of medical treatment. The importance of the patients' social context was something we expected to see, since our experience-oriented perspective suggests it (Bødker, 2006). In the students' iterative cases, we found indications that this could be an opportunity for synergy rather than a challenge of bridging the disparate worlds of patients and specialists. New technologies offer the opportunity of customizing interfaces and information to different stakeholders. For the context of orthopaedic interventions, it can play a crucial role in managing information that it bridges the extremely different needs of patients and specialists. The patients need to be supported over a sustained period of time, whereas the specialists need to monitor the patient's progress through very brief and very summarized encounters.

## Limitations

Only a small part of the cases focused on older patients, who make up a large group of, for example, hip replacement candidates. Further investigation should therefore identify the salience of the four themes identified for different groups of patients. Although all themes were found to apply to all cases, they might be very differently weighted. A fair number of student projects focused on sports injuries and injury prevention. This is an easier to reach target group for the students. The structure of motivation and expectations of older patients should still be investigated in more depth. The diversity of contexts investigated by the students is a further possible threat to the salience of these results. The context of a young swimmer hoping to compete again, for example, is conceivably very different to that of a senior hoping to walk again. However, as mentioned, the themes that were identified and presented here were common to all the cases studied. This indicates that these themes are applicable to health of joints generally, rather than just to specific joint problems or types of people.

## Conclusion

By applying a user experience perspective derived from the field of design to patient journeys that usually would be framed in terms of clinical outcomes, we have shown that patient experiences strongly affect their patient journeys. We have provided a set of issues and questions to address in creating patient experience journeys, and in designing to improve these journeys. This can improve patient satisfaction and possibly, also health outcomes. For example, enabling patients to adapt their behaviour by carefully designing for this experience, could improve the effectiveness of rehabilitation. These four themes can be used as 'drivers' for the development of future patient experience journeys in orthopaedics.

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# How can communication design add value in the context of Alzheimer's disease?

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## *Abstract*

*This paper describes a project that investigated different ways in which communication design can be applied in the context of Alzheimer's disease, which affects millions worldwide. In an iterative process between practice and research, visual outcomes were created specifically to raise awareness and understanding of the disease, and to facilitate better interaction between people with Alzheimer's disease and their family and carers. Using first-hand experience with people with Alzheimer's disease, the study used generative research through observational methods and participatory activities, which were constantly redesigned to fit the practice and the needs of the users. The paper describes this process and the produced outcomes, which are divided in three stages: information visualisations about dementia; reflection and discussion through graphic interpretations of symptoms, thus creating empathy for a deeper understanding of the disease; and support tools to promote interaction between people with Alzheimer's disease and their families and carers, with attention to layout and typographic details.*

*Drawing on design approaches for dementia in other fields such as product, interior design and HCI, this paper discusses the value of communication design for Alzheimer's disease and the considerations to be taken into account when designing in this context. To conclude, this project is a starting point for further investigation in this field, extending the understanding of the disease and providing practical tools to support communication with people with Alzheimer's disease.*

Keywords: communication design, Alzheimer's disease, dementia

# Introduction

Alzheimer's disease (AD) is the most common cause of dementia, a group of symptoms that lead to gradual and progressive weakening of cognitive functions such as memory, communication and reasoning, affecting the ability to perform everyday activities.

The number of people diagnosed with some type of dementia increases dramatically every year, constituting a global priority in public health and care provision (WHO, 2012). There are 35.6 million people diagnosed with dementia worldwide and it is estimated that this number will triple by 2050 (Prince and Jackson, 2009). These numbers do not include families and carers, who are also affected emotionally and economically by their condition (Prince *et al*, 2011).

Design has already proven to be capable of bringing value to dementia care, supporting sense of self in people with dementia, and promoting wellbeing and better relationships with others (Gowans *et al*, 2007; Timlin and Rysenbry, 2010; Zeisel, 2013). However, design contributions to dementia, mainly in communication design, are still scarce. This paper describes a practice-based and practice-led (Candy, 2006) study that explores different ways in which communication design can be applied in the context of AD, using first-hand experience with people diagnosed. It gives a chronological account of the design practice undertaken, explaining the conceptualisation and development behind it. The study was completed as part of an MA in Communication Design at Central Saint Martins, London, and is being developed further as a PhD research theme at the University of Porto, Portugal.

## Reviewed design contributions to dementia

"Design is still an underexplored aspect of the care and support of people with dementia" (Bowman as quoted in Timlin and Rysenbry, 2010, p4). Pullin (2009) argues that this is due to the difficulty for designers to put themselves in the shoes of someone with cognitive impairment, resulting in limited design solutions in this area. Several research works have been produced regarding the built-environment for people with dementia and how it can support independence, comfort and appropriate behaviour (Zeisel, 2013). HCI researchers have studied and developed assistive technologies for people with dementia to cope with memory problems, helping performing daily activities safely, and facilitating care (Lindsay, 2011). Moreover, there exists research on technologies to support therapy and communication (Cohene *et al*, 2005; Gowans *et al*, 2007; Lee and Dey, 2008) and promote personhood (Wallace *et al*, 2013).

Recently some projects were launched to bring design into the world of dementia, such as *Design for Dementia*, a project to enhance the quality of life of residents with dementia in care homes through the redesign of products and environments, developed by the Helen Hamlyn Centre in collaboration with Bupa Care Services (Timlin and Rysenbry, 2010); the project *Alzheimer100*, developed by thinkpublic, that addressed health-related issues regarding AD by involving people dealing with the disease (Tan and Szebeko, 2009); or the *Living Well with Dementia Challenge*, organised by the Design Council and the Department of Health to encourage collaborations between design and healthcare organisations to develop products or services that would improve certain aspects in the lives of people with dementia (Design Council, 2012).

Pullin (2009) suggests that design for disability should embrace more experimentation and playfulness. It should consider the aesthetic values of mainstream design, making artefacts more attractive than the products resulting from the problem-solving approach of medical engineering, to reduce discomfort or shame of those who need it.

People with dementia are often very sensitive to beauty. Therefore it is probable that being surrounded by beauty in everyday objects may increase the value of their living experiences (Orpwood as cited in Pullin, 2009). Aesthetic decisions can support a product's functionality, enabling people's remaining strengths. Contrasting colours can help identify spaces and components of a product, prompting its use. Making spaces, products or interfaces consistent with continuous recognisable elements also promotes better usability (Gowans *et al*, 2007; Timlin and Rysenbry, 2010; Zeisel, 2013). Moreover, complex products can be overwhelming. Therefore, reducing products to their essential function can contribute to an inclusive and improved overall experience, due to its cognitive and cultural accessibility (Cohene *et al*, 2005; Pullin, 2009).

It is important to address diversity, through user-centred design, permitting products to be more customised and adapted to the person's needs and sense of self (Pullin, 2009; Wallace *et al*, 2013). Knowing the background and culture of people with dementia is fundamental to understanding different behaviours and finding creative ways of adapting the product to them. Personalisation is therefore a crucial aspect when designing for people with dementia (Zeisel, 2013), also taking into account the progression of the disease (Timlin and Rysenbry, 2010).

Studies reveal that environmental adaptations and the use of written cues or memory aids are beneficial in everyday lives of people with dementia (Lee and Dey, 2007), helping the patient to perform some activities independently. They also enhance communication between people with dementia and their families or carers by encouraging conversation, contributing to the patient's wellbeing and dignity, and reducing social isolation (Herrmann, 2011). Zeisel (2013) stated the importance of room decoration and recognisable objects to help in room identification, as well as to guide people to find their way around. Cues can be prompted using different senses, making the spaces more familiar and therefore more comfortable (Timlin and Rysenbry, 2010; Zeisel, 2013). Despite of the advantages of providing good stimuli, overstimulation should be avoided. Too many stimuli can be confusing and stressful; to avoid this it is important to make sure that cues are adequate and understandable (Cohene *et al*, 2005; Timlin and Rysenbry, 2010).

Finally, although raising inevitable ethical issues, including people with dementia in research and in the design process is possible and recommended. However, in mid and later stages, the difficulties of communicating and interacting with people with dementia increase, thus relatives and carers can be considered to assist. Nevertheless, it is crucial to involve people with dementia directly, because they can have different and unexpected reactions, even if carers know well their behaviours. To make inclusion possible, communication methods should be flexible and redesigned to adapt to people's capabilities (Cohene *et al*, 2005; Litherland, 2008; Tan and Szebeko, 2009; Lindsay, 2011; Hendriks *et al*, 2013; Wallace *et al*, 2013).

## The project: methodology and design interventions

This project looks at AD through a communication design lens and uses a reflexive approach, bringing in the researcher's personal experience as granddaughter of two people with mid-stage

AD. The incorporation of personal experience and context in research is seen as an opportunity for a deeper insight into the object of study, informing research and its outcomes. Moreover, it allows the research to be more interactive, collaborative and *co-constructed* between the researcher, the participants, in view of their relationship, where in empathy and emotional considerations prevail (Ellis and Bochner, 2000; Finlay and Gough, 2008).

The umbrella research question of '*How can communication design add value to the context of AD*' was explored through a practice-based approach and the constant evaluation and reflection of the outcomes produced (Candy, 2006). This prompted two other research questions, namely '*Can communication design provide a better understanding on AD?*' and '*Can communication design aid people with A?*' This exploratory study used generative research through observational methods and participatory activities (Sanders and Stappers, 2012). Research methods were adapted to the capabilities of people with dementia and involved secondary stakeholders – family members. The risk of overstimulation and harming people with AD was considered by choosing appropriate activities and their duration, avoiding stressing situations.

The project can be divided into three different stages with distinct processes and outcomes that are described below.

## Stage 1: Mapping Dementia

In the first stage, facts and figures about dementia were visually represented. The aim of this exercise was to make visual what is usually written, providing a complementary insight towards the comprehension of what is dementia (Figure 1).

## Stage 2: What if graphic design was affected by AD?

With the aim of getting a deeper understanding of the disease, the researcher brought her personal experience into research. Observations of her grandparents were undertaken and, together with some members of the family, past stories and episodes were recollected from the time since diagnosis. This generated an exercise that attempted to get into the shoes of someone with AD, showing their reality through graphic design interpretation.

Different ways of how memory loss could affect the book structure and narrative were explored with second-hand books (Figure 2).

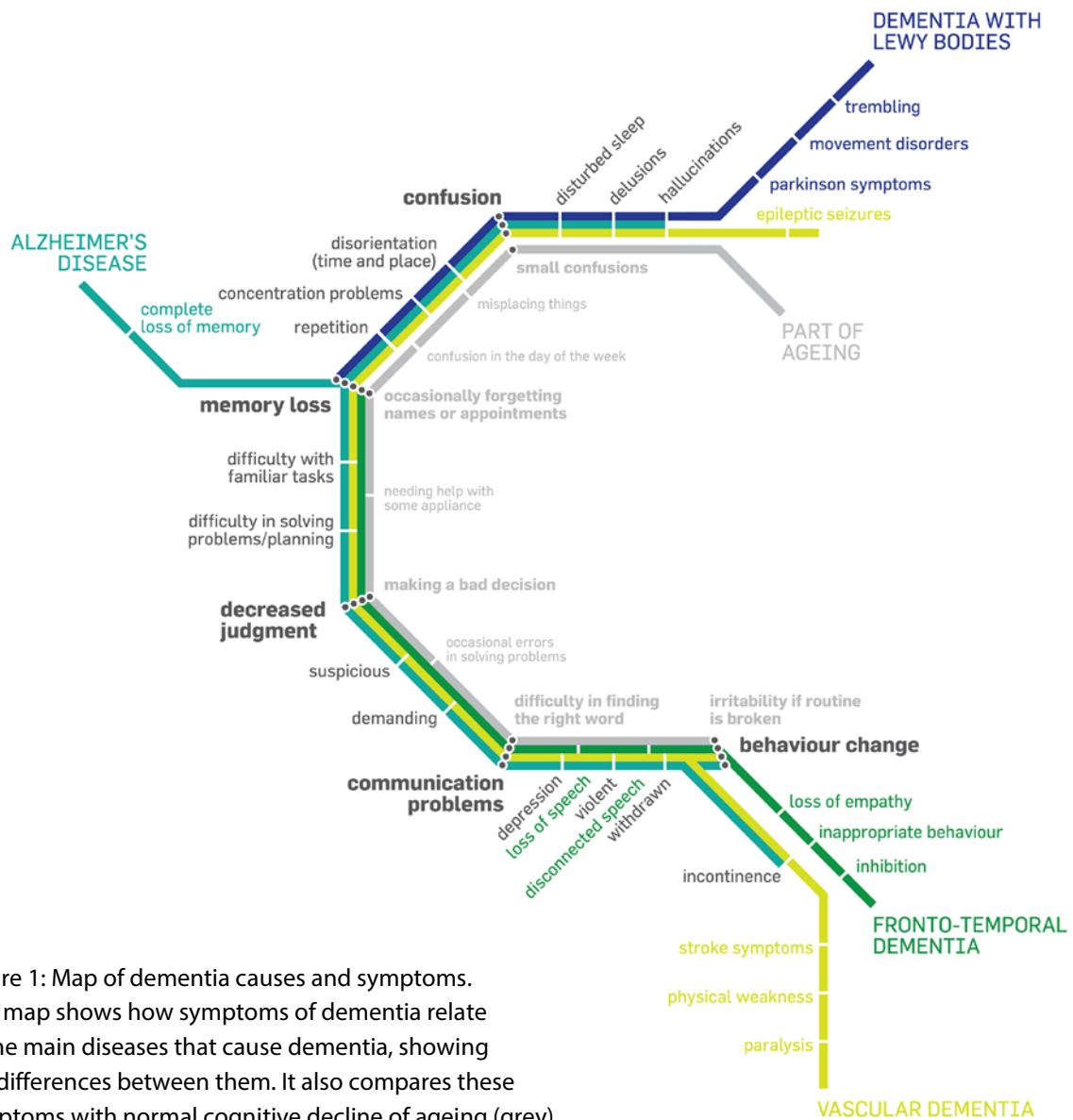


Figure 1: Map of dementia causes and symptoms. This map shows how symptoms of dementia relate to the main diseases that cause dementia, showing the differences between them. It also compares these symptoms with normal cognitive decline of ageing (grey).



Figures 2 (from left to right):

- A Delicate Balance. A play where characters are gradually forgotten throughout the book.
- Digging the Past. Parts of the text are cut on every page, resembling what physically happens in the brain of people with AD.
- Playback. The first pages are repeated throughout the book, alluding to the symptom of repetition, inherent to memory loss.



The second symptom addressed was confusion. People with AD have difficulty remembering objects and where they put them, recognising the people around them, and the places they frequent. As the disease progresses, they also become unaware of time. The book of genesis was redesigned to communicate the progression of this state of confusion through typographic changes (Figure 3).

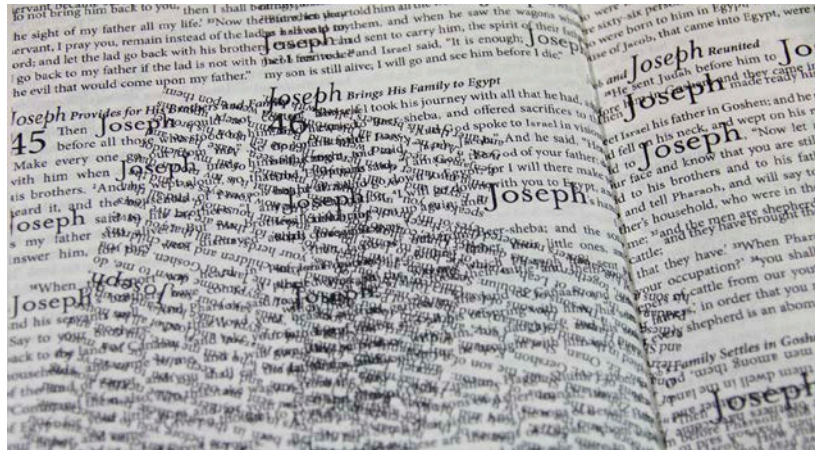


Figure 3: The Book of Genesis according to Vasco Branco (researcher's grandfather). Different typographic variations become increasingly visible throughout the book, referring to four types of confusion: objects, people, places and time, until it becomes unreadable.

The third exercise considered the constant feeling of disorientation experienced by people with AD who are not able to identify the places that used to be part of their daily life. This was interpreted using a map (Figure 4).

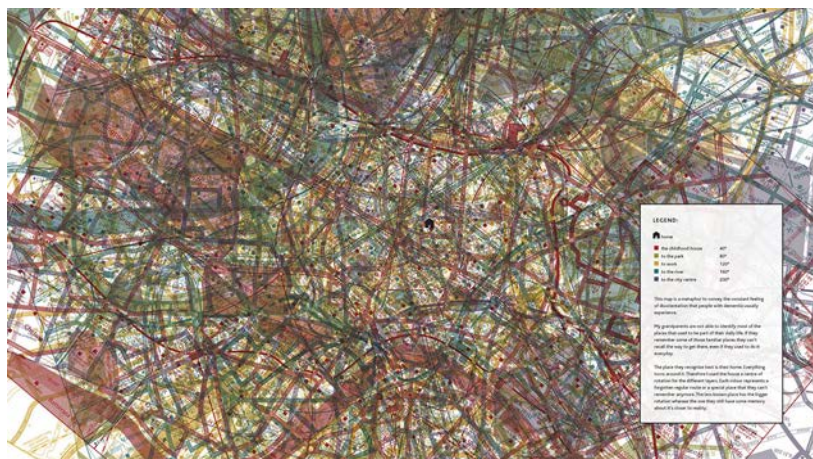


Figure 6: Disorientation map. This map is built with different layers referring to places that were important, but not clearly remembered. Each layer corresponds to a colour and rotates around 'home', the central reference and where people with Alzheimer's always want to go.



### Stage 3: Tools for promoting interaction between people with AD and their relatives

Supported by the previous research, specific difficulties of the researcher's grandparents (Rita and Vasco) in their everyday lives were used as inspiration for possible products aimed to help relatives or carers to interact and stimulate the person with AD.

As a starting point, a set of cards was produced as a game to stimulate the conversation about the relatives. Each card corresponded to a family member, showing their picture and name. Cards could be positioned according to kinship. Colour and patterns were used to help understanding the relationships between people. The game was tested with Rita who, despite the interest shown, was not able to use it (Figure 5).



Figure 7: Testing the first card game.

She demonstrated difficulties in recognising the pictures, patterns and colours, and everything was too small for her to clearly see. The test resulted in a frustrating session, but the family carers found the concept worth developing. Therefore, combined with further secondary research on design for disability and for older people, this user testing yielded valuable considerations that were taken into account in the second iteration.

Considering Rita's visual impairments, the cards were made bigger without colour or patterns. The size and type were chosen support readability (Nini, 2006). A small description about the person on the card was added, as well as a question that would redirect to another person. The pictures were all close-ups with faces clearly visible. Rita engaged with the game, being able to recognise the people in the cards more easily, showing interest in their descriptions. She would get lost with the questions, but would look for the answer in the other cards (Figure 6).



Figure 6: Card Game. Personalised set of visual and written cues to trigger memories in a playful way, allowing different ways and levels of interaction.

The same idea of facilitating communication about the people from the family was adapted to Vasco. He was never keen on cards, so the previous approach could irritate him. He had been very passive, thus very difficult to communicate with. It was observed that he still read a lot, thus reading was reasoned as a medium of communication. Family members were asked to write him letters that were compiled into a book, considering appropriate layout and meaningful typography, highlighting names and words that could possibly trigger some memories. Type size, format of the book and subtle colour indications of who had written were considered in the design (Figure 9).

The caregivers used the book to encourage conversation with Vasco, who showed interest and enjoyment while reading it. He became extremely attached to the book, reading it several times a day, and eventually his wife had to hide it, for Vasco to get different types of stimulus. He also had some spontaneous verbal interactions, asking about the people in the book (Figure 8).

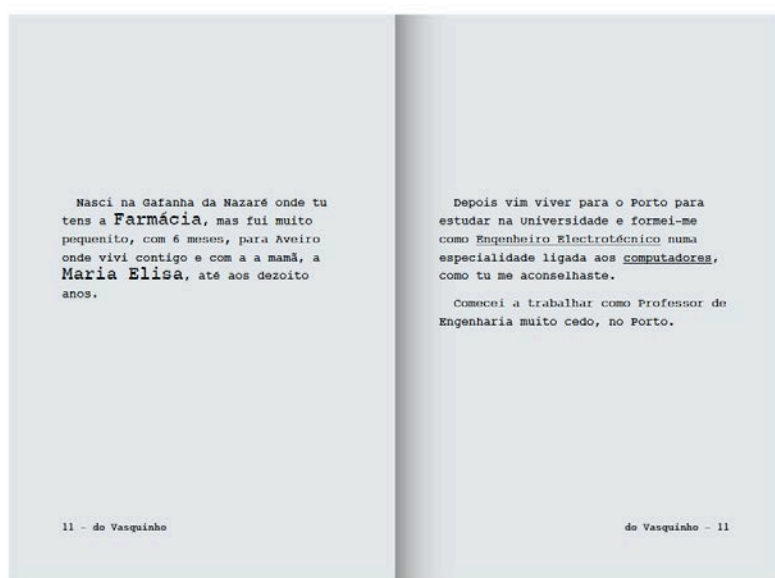


Figure 8: Book spread.



Figure 8: Vasco reading the book. Figure 9: Tablecloth with silhouettes of crockery and cutlery to enable laying the table. User-testing with first iteration of the product.

The third object developed explored the idea of enabling. As a former housewife, Rita was always very keen on helping out at home but, in the last years, her abilities had waned. As procedural memory is affected, simple tasks like laying the table can become quite complex. A simple tablecloth with the silhouettes of the cutlery and crockery was created to guide her on when laying the table.

During the testing, the plates and cutlery were placed in the middle of the table and the drawings on the tablecloth were indicated to Rita. She was able to make the link between the visual indicator and the object and managed to lay the table on her own (Figure 8).

## Discussion

Outcomes from stages 1 and 2 represent different ways of raising awareness and understanding of dementia. The first stage – mapping the facts and figures – is more informative and direct, whereas the second – graphic representations of how dementia symptoms affect people – is more exploratory and suggestive. Both stages were important to inform the third stage of work, critically the second, as it provided a deeper understanding and generated empathy towards the experience of dementia. This helped to overcome previous discomfort and gain confidence in developing ideas aimed directly at people with dementia.

The project adopted a user-centred approach, testing the products and finding conclusions through an iterative process. Regarding the card game, the fact that the first version was not successful led to considerations that were useful, not only for the second version of the game, but also for subsequent objects. Simplicity and reducing things to the essential were the main lessons, as well as the attention to other physical impairments, common in older people. The testing also reinforced the importance of being aware of overstimulation and possible strain to a person with AD. The second iteration took these considerations into account, resulting in a more calm and constructive experience.

Although inspired by and tested with the researcher's grandparents, these outcomes had several iterations of improvements. The second card game prototype was also developed as a template (Figure 12) that can be personalised according to what is more meaningful to a person with AD — not only people, but also places, objects or an image. The card game works with visual and written cues to prompt conversations about meaningful subjects for a person with AD, and allows different ways and levels of social interaction. To design the cards as a customisable template, helps maintain personhood, as proposed by Wallace *et al* (2013) and Zeisel (2013).

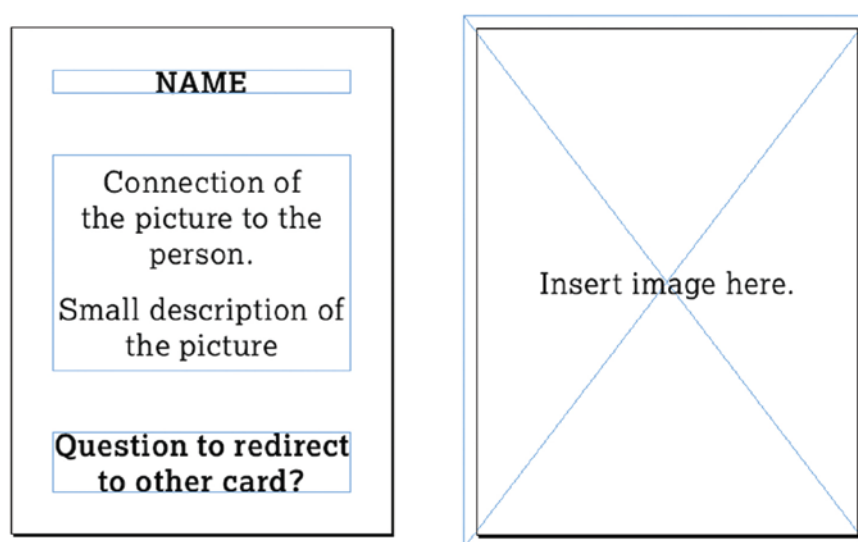


Figure 10: Template for card game.

The family book was the result of adapting the same idea in order to become more usable for Vasco. This exercise is an example of considering the person's behaviour and abilities to find more adequate strategies to interact and communicate, as recommended in dementia care:

It is possible to be involved in meaningful communication with the majority of people with dementia but we must be able to enter into their world ... and realize that there are many ways in which people express themselves and it is our responsibility to learn how to recognize these. (Goldsmith in Allan and Killick, 2008, p165)

Allan and Killick (2008) demonstrate that communication should be a central aspect in dementia care. It reinforces personhood, helps understand the needs of people with dementia, and facilitates care and improves relationships with others. The diagnosis and progression of dementia has a huge impact on families, challenging their functioning and communication. In this project, the participants' families were directly involved, not only in contributing with the content, but also in the design process. This participation was meaningful for them, as it addressed their needs of communicating with their relatives with AD.

Several authors stress the potential of design to enable the remaining capabilities of people with dementia (Zeisel, 2013; Timlin and Rysenbry, 2010; Pullin, 2009). This principle was applied on the tablecloth design. Rita was able to complete the task, which made her feel happy and proud. The tablecloth was then adapted to tablemats, being more flexible to a broader audience (Figure 13).



Figure 11: Laying the Table mats. Final outcome.

These tools were not intended to improve the memory of people with AD, but they were helpful in providing opportunities for interaction and facilitating communication between people with AD and their relatives and caregivers.

The main limitations of this project comprise the lack of medical and specialist expertise involved, the personal approach to methodology and a reduced sample group.

## Conclusions

This project shows that communication design can contribute to the representation of dementia, improving information and raising awareness of dementia (stage 1) as well as providing alternative ways of understanding and generating empathy towards the condition (stage 2). Furthermore, communication design seems to have the potential to act as a mediator between people with dementia and their social circle, through artefacts that provide opportunities for social interaction, support meaningful communication and strengthen remaining abilities (stage 3).

Understanding the experience of living with AD and its daily challenges facilitated the identification of scenarios to design for. The employment of a user-centred approach allowed the artefacts to be inclusive and adequate to the participants. During this process, the importance of tailoring the design to their communication abilities became clear. Creating frameworks that allow personalisation arose as a solution for encompassing the intrinsic diversity in the context of dementia, supporting the recollection of memories through the use of cues.

Families are probably the most resourceful to develop meaningful communication with people with AD, since they share memories and identity. Families can provide the content and communication design can find ways of providing the tools for them to use it.

Having experience in dealing with and caring for people with AD proved to be crucial to this research. Additionally, developing this work aided a continuous learning about AD, improving the researcher's relationship with her grandparents. This project was a good starting point to form and test ideas for further research, involving wider groups of participants, and including the collaboration of dementia care professionals and specialists. Future work (within PhD) will utilise participatory and co-design methods to explore new ways for communication design to enable people with dementia, and their families to develop their own personalised strategies of communication and interaction.

## Acknowledgements

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# Alzheimer – What remains?

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## *Abstract*

*'What Remains?' is a design research project part of G-Motiv, initiated by the CRISP (Creative Industry Scientific Programme) platform. The purpose was to investigate how to stimulate positive behavioural changes in elderly patients affected by Dementia through designing a Product Service System (PSS). The project collaborated with Careyn - a social enterprise dedicated to the health and welfare of older people based in the Netherlands - which provided a valuable research context and made available useful information concerning the Dementia disease and any related therapies.*

*The research behind the project has been conducted from the starting point of observing the daily life of patients living in care homes, with the scope of stimulating codesign activities. Such an approach was not only fundamental for the designers but it also provided caretakers and relatives with new tools to better understand the multiple reasons behind specific behaviours of each patient.*

*As a result, this research approach has led to the design of a PSS that helps caretakers and the elderly's family members to constructively interact with this disease and personalize the type of care offered.*

**Keywords:** Co-Design, User-centered design, Empathic design, Dementia disease

# Introduction

*"Just imagine waking up one day, and trying to speak and finding that somehow words have disappeared mid-sentence – vanished without a trace. You know you are trying to say a sentence, and have a 'gut-feel' as to its meaning as a whole, but important component parts are missing ... If you don't concentrate, you know something stupid will come out. ...*

*... Often you wonder whether it's worth trying to speak, because it always comes out wrong and everyone laughs at you.*

*That's what it's like to have Alzheimer's." (Bryden et al, 2012)*

The severest impact on patients' health, with the most common form of Dementia, is that the sufferer is robbed of the ability to speak, move, remember and even eat. The difficulties in communication and understanding between patients, caregivers and the elderly person's relatives also provoke in the patients a deep state of anxiety and aggression during their everyday life.

Furthermore, they tend to regress together with their memory, for which reason past events very often become their present reality. At that point, completely unplugged from their present and detached from their more recent memories, abilities and families, these people quickly lose the capacity to direct their lives. In most circumstances, their responsibilities fall to their loved ones, care homes and to society at large. For this reason it is necessary to respect the dignity of the sufferers as individuals and, to do so, it becomes fundamental to constantly provide for their needs.

## Creation of CoDesign group and Ethics

This project lasted for one year, within which three months were used to constitute the codesign group, including preliminary observations. In this phase the activities were conducted by involving professional carers in a variable number and with different professional backgrounds. More specifically, especially during the initial phase, the designer worked together with ten carers, including psychologists and art therapists. This number got reduced to four during the direct practise of the codesign activities, which involved also the support of fourteen family members of the patients.

After a preliminary phase the codesign activities were conducted for a period of seven months with four participants in each session. In that period the designer organized a total number of ten workshops, which took place inside the care home.

The precarious health conditions of patients and the limited availability of time of their relatives allowed the designer to work with five dementia patients, but with only one of them it was possible to create a stable and long lasting collaboration, which provided important insight for the project.

Ethical procedures need to be followed while working with people suffering from mental and cognitive impairment, as they are extremely vulnerable subjects. The Social enterprise authorised the study together with care home residents by applying the main restrictions related to the Ethical Committee guidelines. Ethical procedures were followed also while working with caregivers and elderly family members. In these two cases the University ethics procedure was

used (Technical University Delft, 2013). A paper participant information form was given to all the participants without cognitive disabilities and fourteen people gave authorisation to take part to the project.

## CoDesign and Empathic design

To better understand how dementia affects people's lives and consequently to attempt to generate possible solutions, this research proposed an approach where collaboration and co-creation were considered as pillars, necessary for creating the connections between the designer and a small representation of the people who will use the products or services in the future. It is therefore understandable that one difficulty is seeking the correct manner for entering into people's lives, with the aim to create a good synergy and mutual trust. This is one of the reasons why establishing a group to codesign with can be an activity that takes a long time and requires patience and good preparation.

Working with people suffering from a severe stage of dementia required a very unique approach to codesign due to the delicate health conditions and neurological impairment. Furthermore difficult emotions are involved in the relationship between patients and their relatives, all of which might cause painful interactions and difficulties in communication.

As a consequence of the extremely delicate research context it became fundamental to make use of an empathic approach, which might have a better chance of encouraging respect for the different emotions of each patient and stimulate a deeper understanding of tacit needs. As Koskinen stated, "Empathic design starts with a need to understand user experiences in the early phases of the design process" (Koskinen et al, 2003).

Every codesign session was conducted in the morning, since dementia patients usually feel calmer and more active during those hours of the day. Each session involved a group of four participants, specifically a designer, a caregiver and an elderly with one of his or her relatives. In the initial phase, the codesign sessions were very short; during the first two months each session lasted not longer than twenty minute due to the difficulties in concentration and mental fatigue that the dementia condition caused to the sufferers. However, the last five sessions lasted for one and half hours. Any cause of agitation and distress was carefully avoided, because two aspects became fundamental to the sessions: the selection of the space was one of them; therefore a quiet and calm area inside the care home was chosen. The other one - as mentioned earlier - was related to the identification of an appropriate time of the day: the sessions were finally from 10 a.m. until midday, which gave evidence to be of fundamental importance to respect a patient's daily routine.

The dialogue format in relation to this ethics-sensitive context was recorded using audio tracks, pictures (only hands), written transcription of body movements and facial expressions. Feedback suggests these formats allowed the participants to feel more relaxed and concentrate on the activity than when using a video camera.

# The Role of Memories

Marja Dijkwel, manager at Careyn, explained that memories play a very important role in the life of the patients living in a care home. From her observation she experienced that the elderly with Dementia spend most of their time inside their own memories, completely disconnected from everything around them. The sharp contrast between the patient's experienced real world of the care centre and the recalled fragmented memories of the patients generates very often negative emotions that can provoke feelings of anxiety, fear, aggressiveness in the mind of the elderly. Moreover - very important - the communication between caregivers and patients is not only problematized by the impaired communicative skills of the sufferer but also by the lack of available personal information on each patient when they enter the nursing home.

In order to investigate the role of memories in a patient's life, a wide range of dialogue formats were tested. Verbal communication, questionnaires and workshop experiences were used to stimulate a dialogue during codesign activities with caregivers and elderly family members.

Due to the patients' incapability to properly speak or promptly react, this project initially investigated different forms of sensory stimulation to initiate communication with a number of elderly suffering from dementia.

These stimulations were sound, touch and visual inputs. As an example, sound was initially used to test and understand a reaction to the most popular music of the 1940s to 60s. Touch was used to stimulate a reaction by proposing to approach the surface of different fabrics, textiles and materials. Furthermore tests were also run by asking patients to touch the hand of the designer, relative or caregiver whenever they perceived something pleasant.

Compared with other sensory stimulation, visual inputs were finally found to be one of the most effective, because it was seen as capable of opening a new communication channel.

For this reason during the codesign activities with dementia patients, we started to make use of cultural probes such as personal pictures belonging to each patient life-story and, by doing so, we discovered a very important communication tool to drive the research with. As Wallace stated, "The probes mediated the development of a close relationship between design researcher and participants and their empathic use acted to help deepen and sustain this relationship, as well as turning the focus towards design and co-creativity." (Wallace *et al*, 2013).



Figure 1: CoDesign activities

At that same research stage the elderlys' relatives played a very important role in collecting and sharing all the available personal pictures about their loved ones affected from the disease.

The collected autobiographical photos were afterwards shown to each patient with the purpose of testing their reactions. The outcomes were absolutely encouraging and the enthusiasm that we found pushed us to collectively decide to continue with that type of sensory stimulation.

Each patient started in fact to perceive personal and autobiographical pictures as well as photos of everyday objects as important direct translations of their thoughts. For the very first time it was finally possible to establish a communication channel with each patient using a visual communication tool made of personal photos and probes.

In these project experiments, most of the time the patient would start shifting pictures from their belonging groups, to create physical connections between them: behind such actions there are autobiographical memories that - in the mind of the patient - obtain a translation into new images. From the group of patients that collaborated in this project, it became clear that each connection carried a specific meaning and a real – however sometimes hidden - memory. Even if the meaning behind the pictures' combinations was sometimes a complete mystery to the eyes of relatives and carers, the fact that there was a sort of "enigma" to solve triggered them to investigate into the 'hidden memories' of their charges. This autonomous and unconditioned desire for finding the key to solve the "enigma" became itself a very interesting element that was added to the project. In such a way, in fact, carers and relatives codesigned "*What Remains?*", having self generated a solution to a specific issue.

In order to explain the value of the collaboration it is important to present the following stories:

#### A Second pair of shoes:

Rita, affected by a severe stage of AD, was restless because she was looking for a second pair of shoes that she did not have. It was obviously very difficult for the caretakers to understand the reason behind such a strange behaviour. During a few codesign sessions Rita was combining the picture of a pair of shoes and the pictures of her father. After several days and by the help of her sister, we finally understood that her father used to *buy two pair of shoes for all of his children. One pair was supposed to be used during the weekdays and the other one was for Sundays and special events.* Knowing this story the Rita's son bought a nice new pair of shoes and placed them next to

the bed of Rita. From that moment the lady stopped her nervous searching behaviour and became calmer.

## Fear of falling:

*Paul* expressed fear of falling, and saw the carpeted floor as a hole.

Sharing images wasn't a good option, he was quick to become aggressive and our objective was to reduce distress, not increase it. We did succeed in understanding only that the dark floor's colour provoked this fear. He seemed to think he would die if he fell. The interaction with Paul taught to the designer something about the limits of this approach when faced with the sheer complexity of a faltering brain. We didn't succeed in understanding more of his fear of falling and his distress.

However, caregivers paid special attention when choosing a material and colour for the floor of his dwelling. And being the centre of attention of his family – this was a real improvement.

(Cadamuro, Boekbinder *et al*, 2013)

The numerous evidence and stories collected during the research contributed and inspired the design of the prototypes. In this project phase the collaboration with caretakers and elderly family members was very important. Our collaboration was in the form of 30 minute interviews that were done immediately after the end of each session, without the presence of dementia participants.

## Prototype

The first prototype comprises of two stages and two mixed-media tools, which both strictly depend on each other. The first stage involves a computer application whose features are shared between the patient's relatives and the care home. This computer application works as a mind map tool, which the relatives of the patients are asked to use for collecting and uploading pictures that can offer important life information about the patients. Pictures and information are divided in different categories, including family, jobs, holidays, memories, hobbies, pets, religion, favourite food, things they do/do not like to do, and other categories that may be extended by the relatives. The carers are also invited to collect pictures and information centred on objects that the patient frequently mentions or which seem to provoke restlessness during the daytime. All the information uploaded to the computer application is accessible by the relatives as well as the carers, and each patient has his own file.

The *What Remains?* application should initially be used during the intake phase of elderly people in a care home, providing the carers with a good understanding of each new patient. Immediately after intake, the app can be used to consult the personal information of the patient to quickly personalise the type of care. The interface of the application is also designed to continuously facilitate the update of pictures by carers and relatives of the patient, through new and more detailed information and discoveries. As a consequence, the application becomes an important tool to support the work of the carers, who can quickly memorise visual information about the patients

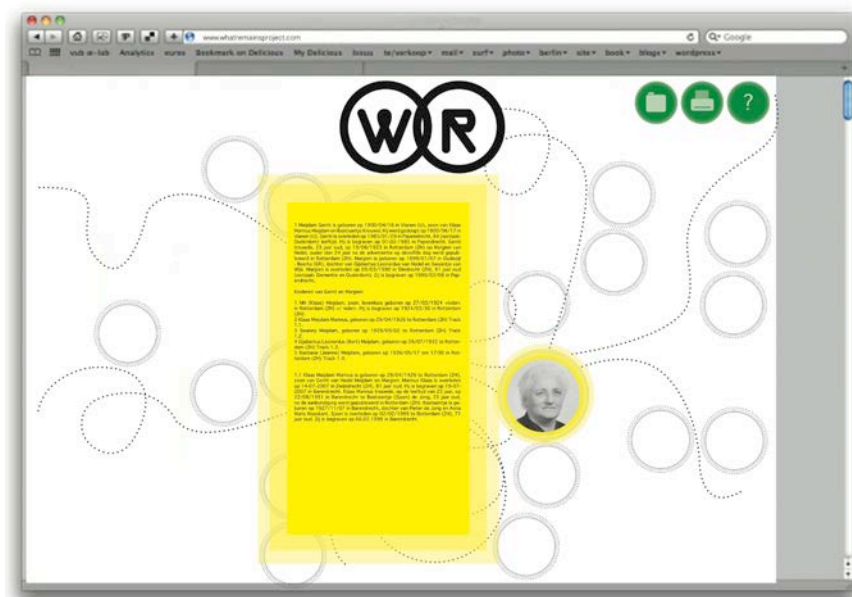


Figure 2: *What Remains?* Computer application

The second phase only starts once the patient's relatives finish uploading the majority of the pictures and information related to the patient's life. The relatives and the carers make a selection of 40 to 50 pictures based on the scenario offered by the application, which allows the pictures to be selected one by one from the categories and printed in a circular shape. The pictures are then cut out and inserted into the game's twenty spheres, which become the triggering elements for the elderly patient, their relatives and carers. The shape and materials for the game's spheres were designed as a result of the multiple co-creation sessions, where abilities and deficits of the patients were tested to create a triggering, playful experience. For example the game pieces increase the visibility of pictures that had been inserted, as the glass spherical shape magnified the pictures' size.







Figure 3 and 4: *What Remains?* Table game elements

## Conclusion

*"What Remains?"* showed good potential in generating meaningful changes to the lives of the patients as well as their carers, who took full part in the design research and tested the prototype. From the side of the professional carers, it was immediately noticed how a deeper understanding of their patients could be beneficial for their work, due to the meaning added by a better understanding of a patient's tacit needs.

Looking at the side of the elderly's relatives, the improvement was surprising, as they started to perceive the importance of their role in the care of the patients. *"What Remains?"* changed – by simplifying – the communication channel between elderly and their relatives becoming a meaningful activity to share within the whole family.

This activity proved to stimulate dementia patients, strengthening at the same time the bond with their loved ones. Of the same importance are also the improvements that patients can help to self-generate by respecting their own dignity and personal attitudes without conflicts and oppositions that led to negative behaviours.

In conclusion - from the designer's perspective - this has been a challenging project, developed within a delicate environment, rich of emotions to cope with. The first meeting with dementia patients and their life conditions provoked on myself strong emotions, especially after some episodes of violent behaviours and restlessness against objects and caretakers. As a designer I didn't know how to approach such these complex behaviours and therefore I spent long times into the care home, acting more like an observer rather than just a designer. This approach helped me to understand the daily life inside the care home and a possible way to approach patients, assisting at the same time caretakers and sufferers to accept my presence as if I was somebody



familiar. The initial lack of confidence slowly became over time a relation of mutual respect and trust, which finally generated a valuable form of collaboration.

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# The SCP model: A three dimensional methodology for understanding, profiling and evaluating mental healthcare architecture

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## *Abstract*

*Purpose: Architecture for community based facilities for acute mentally ill people predominantly borrowed vocabulary and methodologies from neighbouring fields or relied to experimentation in order to accommodate the uneven and varied development of community psychiatry in the Western world. Mostly, the model used was normalization theory, a linear model of understanding, designing and evaluating healthcare facilities, originally developed for learning disabilities. This research supports that the domesticity-versus-institutional concept suffered from a number of limitations, especially since it was not originally constructed for acute mentally ill people.*

*Methodology: To develop a methodology that fits mental healthcare architecture, a three-dimensional, comprehensive theoretical model has been created. The methodology puts together the dialectics behind mental healthcare: the idea of dangerousness that includes the danger of harm and self-harm, the idea of disability as a result of the illness itself or as an effect of institutionalization and the idea of social reintegration as expressed by clients reclaiming their role in decision making.*

*Findings: The three parameters stated above are analogous to the three prevailing models of mental health care -- the jurisdictional, the medical and the psychosocial-- presenting an integrating three-dimensional grid of the various mental healthcare regimes and architecture. Those dimensions/parameters were safety and security, those of competence and of personalization and choice. The model created was named SCP from the acronyms of the parameters. Due to this flexibility, the model can be used for evaluating and defining the therapeutic environment of the facilities when combined with evaluation tools such as checklists, to highlight any limitations regarding the domestic character of those environments.*

**Keywords:** mental health architecture, evaluation, normalization theory, psychiatric facilities

# Introduction

The study of the physical environment of psychiatric facilities is of fundamental importance for the care and the treatment of mentally ill people. It is also of great value for understanding and caring for mental illness, since this is still among the diseases that present low diagnostic accuracy and low medical treatment accuracy factor (Christensen 2009). According to Tucker (2010) space is an essential component for de-institutionalisation and the social re-integration of mentally ill people. Yet, despite the fact that the study of the environment is a central theme for the quality of care of mentally ill people little research has so far involved the actual environment of those facilities. On the contrary, borrowings from other fields, such as normalization theory borrowings from learning disabilities, were imported into the discussion regarding the design and evaluation of mental health facilities. This prevented the development of a purpose-designed methodology.

Throughout history, changes to institutions that dealt with mental illness transformed society's attitude towards the illness and subsequently affected its buildings and treatment regimes (Foucault 1961, Goffman 1961). Each new concept would question and subsequently substitute the previous one. The idea of the protection of society initially that Foucault described eloquently, and the protection of the individual from oneself, which has been described under the term of dangerousness (Liakos, 1990), gave judges the power of incarceration and dealing with mental illness (Cavadino, 1989, Cayla 1992). In the nineteen fifties, though, the discovery of anti-psychotic drugs set the medical model as the predominant model of care and the psychiatric ward of the general hospital became its physical locus (Vavili, 2003). Yet, limitations of drug treatments and lack of long term care policies cast doubt over the medical model, which could not comply with de-institutionalisation approaches. The approach that succeeded the medical model became known as 'care in the community' (Ekdawi *et al*, 1994). Under the community care prism, the hospital was accused of cultivating institutional behaviours and preventing the social reintegration of the mentally ill. Thus, although the medical model opened up an important perspective for the care and treatment of the mentally ill and indeed removed some of the stigma placing mental health back into the premises of socially accepted institutions, such as the general hospital, it gradually presented limitations on dealing effectively with mental illness.

Gradually, once the limitations of the medical model appeared, paramedical services, such as the services of psychologists and social workers, started to be accepted as an essential component of care (Edwards 1975). The inadequacy of the general hospital to deal effectively with the whole spectrum of mental illness, and especially the long term and relapse episodes, created a web of experimental residential facilities located in the community. These, started to host functions previously attributed to the hospitals (Muijen, 1993). However, as de-institutionalisation presented striking variations even within the same country, it would be very difficult to describe it as a model of care (NAHA, WHO and WONCA 2008). Despite the fact that it constituted a global trend, it affected each context in a different way according to the role of the hospital in provision of services: from central to redundant.

## Purpose

The variety of approaches for the treatment and care of the mentally ill, hindered the progression from experimentation to an evolved model of care. This happened to a great extent because this

wide variety of care options was combined with inadequate funding for the architectural research of mental healthcare. To this was added the fact that the building stock tends to adapt far more slowly than organizations (Brand, 1994). There was also insufficient experience of those involved in the planning and architects' inexperience in patients' experience (Norman, 2002). Subsequently, architects could not refer to evidence-based guidelines or adequate briefing documents on the part of the healthcare providers. Anecdotal evidence, assumptions and 'personal' references were the basis of most of the architectural literature on the subject (Chrysikou, 2011). As a result, occasionally even newly built facilities had to be demolished and replaced because of the severity of the problems due to inadequate knowledge and planning (Elderfield, 2002).

The aim of the research was to create a methodology for designing mental healthcare facilities in a form of a flexible model that could follow all the design process, from briefing to evaluation. The research questioned the prevailing thinking for designing for mental health, which was normalisation theory, as a loan that did not sufficiently cover the needs of psychiatric facilities.

Normalisation theory was imported from the field of learning disabilities in the late 1990s to compliment care in the community as a response to the lack of direction, even though normal as a desirable spatial quality appeared earlier in architectural discourse for mental health (Goodman, 1976; Garety, 1988; Weller, 1993). For normalization theory the optimum milieu for care were those that bore references to the equivalent structures of a normal life in the community. Regarding accommodation, for example, the optimum solution was the one closer to that of the home. The metaphor of an environment with domestic references for facilities that provided accommodation was a fundamental part of the paradigm shift. However, a more precise definition was missing (Chrysikou, 2012). Under the strong influence of normalization theory, the term that is most often used in the literature –architectural and healthcare related—referring to the spatial qualities of psychiatric facilities that provide accommodation is that of 'domesticity'. To a certain extent, domesticity expresses the shift towards community-based options and differs from its meaning when applied to family housing. In short, it tends to describe psychiatric environments that offered alternatives to institutional references.

The two frameworks, care in the community and normalization theory, constitute the major theoretical concepts in current use, and especially community care has not yet been seriously questioned in respect of the planning and design of mental health facilities.

## Methodology

The research grouped together past and current thinking on facilities for mentally ill people in order to create an integrated model of approaching design that would incorporate all major axes relevant to the illness. Criticizing normalization theory, one could claim that domestic environments might compromise the true needs of acute mentally ill people and counter the serious implications that mental illness causes to several aspects of life. Instead, these environments might exclude people from therapy. Indeed, during the first decade of the new millennium, as the normalisation theory model was increasingly tested in practice by everyday experience, its inadequacies started to appear. That was more apparent in the UK, where limitations with respect to safety reached the media headlines, after assaults committed by patients who should not have been discharged from secure environments.

The imposition of domesticity in every environment related to the care of mental health might compromise the therapeutic outcome in the name of a so called return to a 'home'. To identify the limits that should be set to domesticity, the research revisited the concept of domesticity as it has been interpreted within psychiatric environments for the acute mentally ill, as opposed to designs that have an institutional origin. This was done in a critical and independent fashion, through evidence based, empirical research.

To develop a methodology that fits mental healthcare architecture, a three-dimensional, comprehensive, theoretical model has been created. The methodology puts together the dialectics behind mental healthcare: the idea of dangerousness that includes the danger of harm and self-harm, the idea of disability as a result of the illness itself or as an effect of institutionalization, and the idea of social reintegration as expressed by clients reclaiming their role in decision making.

Regarding the first parameter of **safety and security**, risks include harm and self-harm, violence and abuse, vulnerability, substance abuse, self-neglect and noise (Royal College of Psychiatrists 1988). In acute wards, the risk of harm towards other patients or staff had been estimated at 1:20 and the risk of self-harm at 1:8 (Sainsbury Centre 1998). Safety and security of psychiatric buildings could be of significant importance, as part of the system component (Dickerman *et al*, 2008).

**Competence-wise**, mental illness has implications for the practical aspects of clients' life, some of them with disabling effects. Competence referred to the clients' ability to retain a degree of independence in terms of sustaining oneself both physically and socially, with capability for independent living being the optimum. With regard to the disabling effect of mental illness, Osmond in 1957 made a grouping of issues regarding perception and Davis *et al* (1979) made an extensive list of deficiencies stemming from that illness.

Also poor resources, could increase boredom or 'incapacitate' clients (The Audit Team, 2005) indicating the interactive aspect of designing for safety and the importance that enhancing clients' competence might have for more benefits than merely increasing their wellbeing (Norman, 2002, Dickerman *et al*, 2008).

**Personalisation and choice**, the third parameter, refers to the degree of freedom that the client can achieve inside a facility. Both were limited in the institutional environments of the past but have gradually increased in recent years. Staffing levels and training, stigma, resources and design could interfere with the clients' interaction with the facility. The personalisation and choice umbrella and its relation to the reduction of stigma covered also issues related to clients' personal life. These included privacy and territoriality as well as clients' socialisation as expressed by the opportunities for interaction with other clients, staff or even people from the community, inside or outside the facilities.

The three parameters formed a theoretical framework that could serve as a grid for research. To test the model (Figure 1) a research questioned the direct transfer of normalization theory to mental health (Chrysikou, 2012). It was empirical, synchronous and comparative. It questioned normalization theory as a linear loan that lacked the complexity to address the needs of mental healthcare: linear, as it shifted mainly between the two poles of institution and home, ignoring many of the dimensions of a patient's life that were not necessarily connected to either of these

poles and loan as it did not address the particularities of the illness itself following its transfer from another field. Data were collected and triangulated from community mental health facilities from two very different European contexts, the UK and France, via architectural auditing of ten buildings, the development of a detailed checklist and 50 staff and 65 client interviews. Yet, it is beyond the scope of this paper to go into detail in the details of the fieldwork.

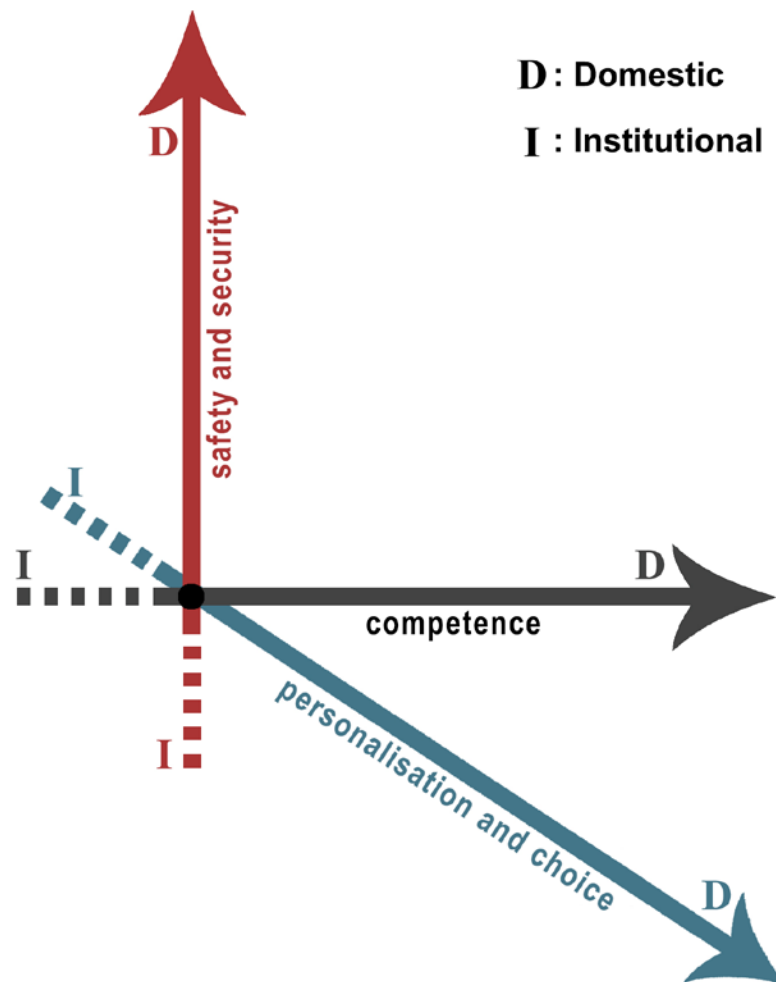


Figure 1: Illustration of the SCP model

## Findings

The ineffectiveness of normalisation theory regarding the needs of mentally ill patients was raised. Instead, the research resulted in a fit for purpose model for viewing the design of mental health care facilities. The model acknowledged the fact that not necessarily everything domestic in the environment is positive for the care and treatment of mentally ill people. Regarding windows, for example, the fieldwork indicated that windows opening without any restrictions (domestic) might have been safe for mentally ill clients once they have stabilised but were not safe enough for people at the acute stage of their illness. Thus, this decision about the design of the windows relates to decisions on the desired level of safety for a particular client group and care model (acute vs stabilised and open vs closed facility). In short, at the planning stage the team can decide

whereabouts in the safety axis (positive-domestic or institutional-negative) to place the red lines. On the competence axis, for instance, there might be a decision to be made for the presence, the type and the use of the kitchen(s). It might be better for patients to be able to use a domestic kitchen with or without a cooker when they have the motivation or willingness and there is enough staff to supervise, instead of eating reheated food from a trolley (Figure 2). On the same example, the planning team might reflect on the option of a domestic kitchen (domestic) against clients even using a full professional kitchen (institutional) under staff supervision to prepare meals for the ward (Figure 3). Also, the presence of a domestic kitchen next to a professional one that is accessible only to staff (Figure 4), might not be a standard homelike feature, yet it might add to the quality of life of the clients and might be in alignment with the care programme compared to an over simplistic option of a domestic kitchen that remained locked because there is no staff to supervise and food came with a trolley from elsewhere.

Regarding personalisation and choice, for example, an Occupational Therapy (OT) room for art therapy might not be found in a typical family home, or might not be necessary in open facilities where clients follow individual therapy programmes elsewhere, yet it might prove important for clients that were ward-bound (sectioned clients) or because there was not enough staff to escort them or even because there was not such a network of activities in the vicinity. Thus, the planning team of the facility can decide where on the personalisation and choice access of the diagram will shift the priorities, i.e., closer to institutional that might allow for some more choice and options of services or to domestic where specific OT rooms would not be included in the facility.



Figure 2: The kitchenette has no cooker or microwave. Food comes with a trolley from elsewhere.



Figure 3: Professional Kitchen, where clients cook on daily basis with staff.

Source: Copyright Evangelia Chrysikou.





Figure 4: The clients' kitchen, connected to a fully equipped professional kitchen accessible only to staff.

Source: Copyright Evangelia Chrysikou.

These three different examples indicated that a 'domestic' choice is not necessarily the best option for all patient groups and this could depend on the stage of the illness, the care programme and the staff resources or even the rest of the network resources in the community. On the other hand there might be institutional elements that do not serve patients best interests, such as the lack of a dining room in the facility or even the presence of a toilet in the middle of a shared bedroom. Again, it is through the use of the SCP model as an evaluation and decision making tool, that priorities can be placed in a more systematic manner and all design elements evaluated and discussed, so that the minimal amount of decision is made through a black box procedure and the more amount of decision is according to the care programme philosophy and closer to user's needs. That way, each individual facility might occupy its unique space on the three dimensional grid according to those priorities that allow evaluation and provide a basis for comparison.

That model was named the SCP model from the acronyms of the main design issues –safety and security, competence, and personalization and choice. The SCP model addressed the relation of the facility to the individual in terms of the ability of the facility to cater for clients' needs, as those are expressed by the jurisdictional, medical and psychosocial models of care the mental health services historically incorporated and which still play a dominant role to the mental health care regime and mental health architecture. These parameters correspond also to a model of needs, with most basic the need of surviving an acute episode (safety and security), then once this is satisfied, the need to reduce the disabling effects of the illness (competence) and finally when all previous is met, the need for psychosocial wellbeing (personalization and choice).

It is not unusual for community mental health facilities, even if they have been praised by the architectural press or awarded, to perform poorly in terms of patients' social re-integration and to develop institutional environments. When evaluated using the SCP methodology, awarded buildings performed badly in the purpose-administered checklist and at the same time received negative comments from staff and clients (Chrysikou, 2008). These buildings had been designed with the best of intentions in mind and from architects who dare to be innovative and invest a lot of thinking in their architectural solutions. Similar was the case of the social housing in the previous century around the world, where architectural innovation and confidence but also lack of knowledge of how space operates lead to buildings that generated a series of social problems (Hanson, 2001). Hanson also states, that the more vulnerable the user group of the buildings, the more severe the consequences can be and thus the stronger the need to develop knowledge-based design tools.

In short, there might be spatial qualities that favour institutional practices that might not be apparent from the use of the SCP model. The model could depict the quality and of the institutional environment as well as the consequences to patients life because of it, but could not go deeply into the reasons and methods that created it. For that purpose, a more elaborate spatial methodology might be more suitable to uncover the social dynamics of space and therefore, the reasons behind the institutional environment generators when all design intentions aimed otherwise. The model, however, could not cover the social relations of people, and the social logic of the psychiatric space, that could play a significant role for the social context of these facilities and their ability to integrate in the community.

Finally, because mental illness was not regarded as life threatening in the same way as coronary heart disease or cancer, and since the Great Recession, the shortage of government funding has taken its toll on the efforts to establish new standards in mental health care and in implementing the new frameworks in European countries. Thus, although there have been changes in the last ten years, they have not been as dramatic as they would otherwise have been or taken the directions they would have done if there was less shortage of funds. In that respect, many of the issues explored by the research, which would shift the focus if had been presented here, are of substantial relevance -- not only for countries like Greece or the Balkan countries, that lagged behind in its psychiatric revolution -- but also to the UK and France.

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# Designing for 'meaningful' patient experience using Xperience-based designing (XbD): A new twist on a familiar approach

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## Abstract

*A major reform program has been instigated within the Danish Health system aimed at establishing Super-hospitals to replace smaller facilities (GE, 2013). This revolutionary change is expected to be achieved by reducing both the number and duration of patient stays in hospitals. Realising this goal requires a heavy reliance on welfare technology solutions currently being developed that promote outpatient self-management and home-care. In the rush to accomplish these admirable goals the patient experience of existing and proposed services and products in most cases, has been largely overlooked. In this paper we present ways to address this gap with a number of new twists on established Experience based Design practices (EbD) that have gained popularity in the UK and other parts of the world (NHS, 2013; Cain, 1998).*

*At the Experience-based Designing Centre (XbDC) we are currently working within the larger Danish the Patient@Home (P@H) research and development project. We base our design perspective on deep phenomenal understanding of patient experience beyond what is said and immediately observed, working only with the meaning level in data. We utilise immersive embodiments (always with an edge); standard observational/conversational techniques (with a technological twist) and hermeneutic meaning analysis methods (The SEEing process - Coxon, 2008) that elevate the deep meaning structures within field data. Based on the understandings so produced, we 'design' a process for sharing insights (experiential knowledge exchange) with various stakeholders (patients, therapists and technology manufacturers) so as to begin designing activities such as co-creation workshops. Applying such methods has resulted in new and useful outcomes in projects investigating patient experiences such as disability and sexuality; home rehabilitation of paralysis patients; long-term patient monitoring; chronic medication supply and use; living with visual impairment – these projects, the application of new methods and their outcomes are described in this paper. The information presented will be immediately helpful to practitioners who value the patient experience as an important aspect of designing-4-health in terms of products, services and systems.*

Keywords: Experience-based Designing, patient experience, hermeneutic phenomenology, meaning-filled design, SEEing process

## Introduction and background

In this paper we will present a number of techniques on which we have been experimenting, within a health research project and engineering teaching program focused on Experience-based Designing, or XbD as we call it. The techniques we have been using while not exactly revolutionary are new twists on old ideas that are giving us some interesting results. The techniques also support our commitment to a deeply empathic, hermeneutic phenomenological approach to understanding the lived experience of patients with whom we work. This approach is by necessity intimately embedded in patients' personal experiences within a defined field, for example, home rehabilitation of stroke patients. Their experience and the value it can bring to the design table have largely been overlooked in the economic and political imperatives driving an increasing focus on technological solutions especially in the health field.

### What this paper is really all about and why this is important

The focus in this paper will be on four key areas: Ways to access a patient perspective; how to help to make sense of it; how to share this understanding with the people most affected by it and how to show how they might proceed towards doing something about it. Underlying all of these 'Hows', is a very big 'WHY'? The entire process is really about giving patients more of a voice in their future determination. The procedures and technologies for treatment for most of the illnesses that fall within the scope of the P@H<sup>4</sup> project, of which we are a part, are all very well established. In this paper we refer to therapies, therapists, systems and procedures (with no disrespect intended) as *technologies* because they are all designed interventions in other people's lives. However, if we propose to simply transpose these technologies into the home realm, they are in many instances likely to fail. The home environment is not as controllable, not as manipulable and only partially as monitorable as the hospital environment. Our preliminary work has shown a high likelihood that many technologies that have already been applied without regard to the sovereignty of the patient's home have and do fail to be applied correctly or at all. This presents significant risk to the patient, the efficacy of therapies, the liability of care providers and, from our perspective, the success of the P@H project in which we are involved.

### How we go about it: the Experience-based Designing (XbD) process

We will present some of the learnings we have gained through applying four key processes or pillars of Experience-based Designing at our Centre in Denmark (XbDC). These pillars reflect a fairly standard design process formula: we firstly explore the field; we secondly find ways to understand or make sense of what we find; thirdly, we attempt to share the findings with appropriate people; and lastly, we begin the process of doing something about the situation. These stages of the

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<sup>4</sup> The Patient@Home (P@H) project is one of the largest research projects (US\$33Mil) ever mounted in Denmark. It is a Danish platform for research and innovation funded by the Danish Council for Strategic Research, The Danish Council for Technology and Innovation and the Growth Forum of Southern Denmark.

design process, expressed as the four pillars of Experience-based Designing can then be labelled, Explore, Understand, Share and Show How. In the following sections we will discuss each of these pillars by describing how we have been applying them in various projects within the Patient@Home project ...but with one crucial caveat, they are all predicated on a foundational understanding of patients' experiences and the explication of the deepest meanings contained within them. In what follows we will describe our experiences in applying this approach, using examples from various projects and we will present these from three main perspectives

- What we are doing that is new or different and how are we doing it
- What results have been achieved by doing it this way
- What we have learned from doing things this way and where do we hope to go from here

**Explore:** Exploring a particular experience and finding a way into it – also, Learning to recognise meaning when you see it.

What are we doing that is new or different and how are we doing it?

In the explore stage we are primarily concerned with looking deeply into a patient's experience or their 'life-world' before we design anything for them. It starts with being clear about what the experience is that we want to understand. For example, do we want to understand the experience of stroke paralysis treatment or rehabilitation? By focusing the inquiry, we set clear parameters for exploring depth in our insights. Next we need to 'find a way in' to the experience. We approach an *experiencer*, someone who knows this experience well so as to gain a preliminary view of their world that will enable us to design an 'embodiment' exercise. In other words, a free-form conversation with a key patient (lead user) so that we can get a snapshot of the main factors (times of day, situations, relationships etc.) which most strongly impact on their experience of the illness. From this discussion, our researcher will, to the best of their abilities, reenact or act out the situations described by this patient for as long as it is reasonably possible to do so. We usually also add some level of difficulty to the scenario (embodiment plan) such as adding physical disabilities or even emotional pressures to the situation.

For example *M*<sup>5</sup> wanted to embody the experience of a physically disabled person and their sexual life (physical affection through to intercourse).

Her embodiment design included living continuously (3 days) in a borrowed wheelchair. She also painted the back of her right (dominant) hand with light glue, setting it into a claw-like position to simulate a disabled hand that could point but not grasp things well. She adopted the voice of someone who could not talk but could make sounds. Having conducted her embodiment *M* wrote up her experience into a descriptive narrative which could later be used as data in analysis - it was after all, *her* experience of the experience of disability.

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<sup>5</sup> *M* a pseudonym for a particular researcher inquiring into disability and sexuality

Using her now embodied experience, *M* was able to more confidently approach further participants during interviews and observations in their home. These are well known ethnographic methods for data gathering but here is the twist. We have been experimenting with the use of various forms of unobtrusive portable recording equipment. (See figure 1)



Figure 1: Recording equipment; Video glasses; Pet-cam; Video-pen

Researchers can wear any of these items and so can participants. Having researchers wear them is not new but when participants wear them, whole new worlds can open up. We get to see a little of what they see but we can also often talk to them about it afterwards. This enables us to get a lot closer to the event horizon within the experience so that we can begin to understand it better. In recorded conversations with patients after they view their own video-recording, much more detail can be uncovered. The researcher's embodiment also adds value during this entire process. They describe feeling immediately more empathic to the patient's situation. They are also emboldened to talk about subjects that they would otherwise either not have thought of or would be too timid to ask. The patient in return appreciates the extra effort the researcher has gone to during the embodiment and responds as if to an equal rather than to someone who is 'observing' them.

During projects requiring extreme delicacy (not in *M*'s project) such as a person's dressing or bathroom routines, we have used the recording glasses and then played back the video to patients on video playback glasses (see Figure 2).

In this way, only the patient can view and to some degree 'relive' the event and discuss it with the



Figure 2: Video playback glasses for

researcher without the researcher intruding on the patient's privacy. It is a sound and useful attempt to 'get at' some of the more sensitive areas of people's lives which, let's face it, are powerfully guarded but vitally important facets of our lives. In interviews and observations we are increasingly using video equipment to

capture intimate and intricate aspects of people's lives for later analysis. This creates difficult material to work with but conversely, very rich material to from which to begin the analysis. Of course none of these methods are applied without prior patient permission.

What are the results achieved by doing it this way?



*"in ordinary experience embodiment frames our approach to the world" (Gallagher, 2005, p.58)*

The embodiment process has proven particularly successful. It opens the researcher's eyes to detail and empowers them to enter the research process with confidence and embodied knowledge about the experience. Participants respond better to a researcher who has gone to extraordinary lengths to understand them prior to arriving for their first conversation. They are much more receptive to the research process of recording and documenting their experience and rapidly begin to see themselves as part of a research project aimed at improving their lives. All parties buy into it. The data gathered is very rich and the approach tends to reduce the amount of cold data that needs to be edited out, both can reduce time spent on analysis and the number of different patient conversations required.

What have we learned from doing things this way and where do we hope to go from here?

The use of 'spy equipment' has been very successful and productive. We would like to explore more of the use of the video play-back glasses to record patient experiences 'offline' i.e. while we are not there. We would like to get closer to the natural unmediated experience without the presence of the researcher and to lessen even mediating effect of the patient being aware of recording themselves (an auto-ethnographic problem). The idea of a patient as researcher discussing their own recording of themselves is a very interesting way to more deeply explore the experiential understandings of an *other*.

**Understanding:** A deep exploration of the meaning structures within an experience – uncovering meaning in an experience

What are we doing that is new or different and how are we doing it?

Our approach to analysing data is strongly based in hermeneutic phenomenology (Van Manen, 1997) and linguistic theory (Pinker, 2008). We begin by translating all video material, photos, sound recordings, field notes into phenomenological descriptions that not only include a transcription of the actual words spoken but also include nonverbal communications (gesture, sounds, facial expressions). They can also include additional comments and remembrances from the researcher either at the time of the interview or afterwards. This increases the depth of meaning contained in textual data, an enrichment process that makes subsequent analysis much more productive (Coxon 2005).

While preparation for analysis is very important, the process of analysis itself is very, very time consuming and researchers generally dislike it. This is why many researchers so often take 'short-cuts' that reduce access to hidden meaning. We want to avoid this thematic analysis of 'what was said', to get more of what was meant. In the second pillar of the XbD process, the Understanding stage, we apply a nine step qualitative data analysis process called *SEEing*. Explaining these nine steps in detail is certainly beyond the scope of this paper however, the most important aspect of the process, the one that differentiates it from most traditional approaches to data analysis, lies in step 4 – this is an inductive process of meaning construction (see figure 3 below).

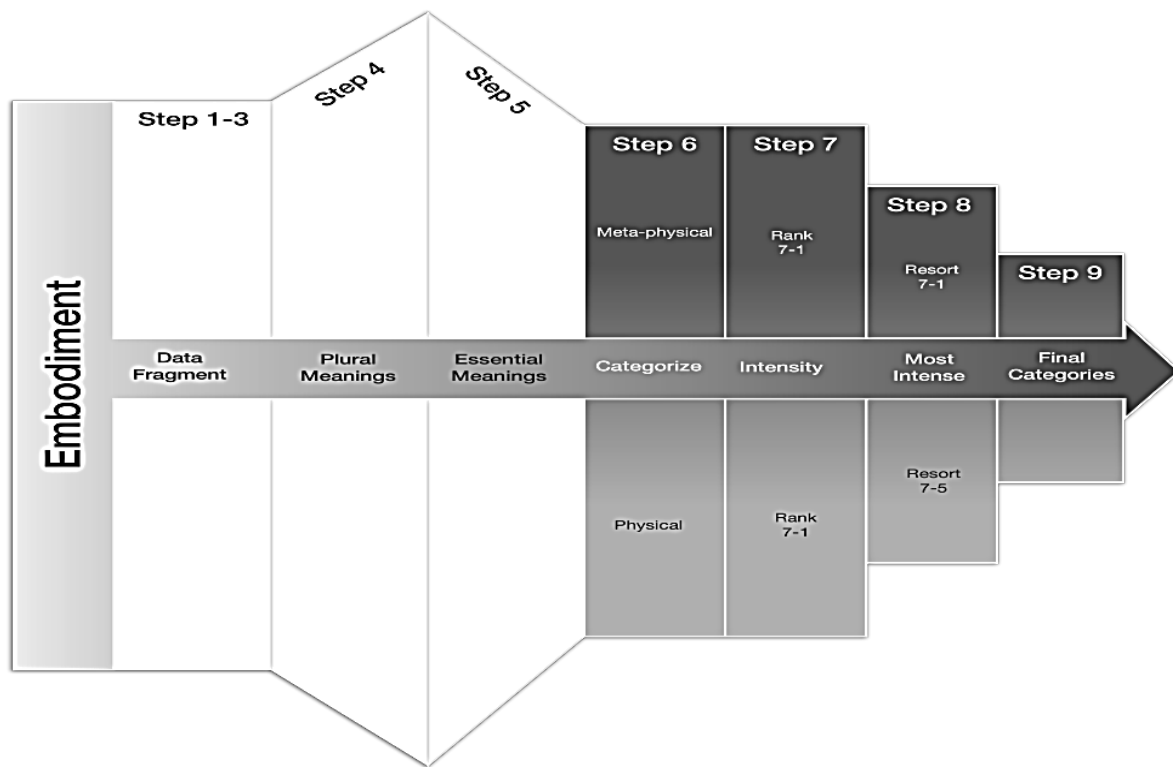


Figure 3: Graphic representation of the *SEEing* process

In step 4 each fragment of text from the data gathering phase is interrogated (interpreted) for its multiple meanings (Ricoeur, 1971, 1978). The subjective process of interpretation is strongly 'primed' by the researcher's previous embodiment and interactions with patients such that they are better able to make *expert* subjective judgments about the meanings contained in the data. This step inductively 'expands' the volume of data and is a time consuming though very valuable process. It produces a much larger and more meaningful universe of data to work with and deepens the researchers understanding of the experience as a whole. Each of the subsequent steps 5-9 are essentially reductive processes designed to distil the quantity of data developed in step 4. These last steps are about filtering the data set into more manageable and meaningful themes so that the meanings contained within the experience can begin to be SEEN.

What are the results achieved by doing it this way?

Researchers who apply themselves diligently to the process are astounded at not only the unexpected depth of their findings but also the empathic change within them in terms of a deepening of their own insight into the experience. The process is demanding and intensive but, with each interaction with a segment of data, the researcher draws closer to deeply understanding the experience they are researching. This is a deep phenomenal transformation that they are then confident in taking back to participants for feedback and validation.

What have we learned from doing things this way and where do we hope to go from here?

The process is very effective and successful with individual researchers however, we would like to explore more ways of working with others in the analysis stage without compromising the integrity of the informed subjectivity process. We have found, for instance, that small teams of researchers working together in the analysis stage can also obtain good results in this interpretive process and all can arrive at a similar point of enlightenment after the analysis. Researchers have also suggested bringing patients into this process while others have indicated a desire to bring in therapists and industry partners. Either or both could be valuable at this very early stage of the process and to continue to foster 'buy-in' to the results.

**Sharing:** Communicating what the researcher now knows, with others - confirming the meaning in an experience

What are we doing that is new or different and how are we doing it?

In principle, sharing is intended to involve patients, therapists and industry partners in a process of sharing backward and forward (and sometimes sideways). It is firstly about involving others in developing the research analysis in such a way as to provide richer understanding of both the patient and therapy perspectives (sharing backwards and sideways). Secondly it is about moving their understanding forward into a doing-something-about-it stage (sharing forwards). Our expertise in this phase of the process is rapidly evolving as we participate in larger and more complex projects.

What are the results achieved by doing it this way?

Toolkits that support the process of sharing between patients and therapists have been well documented and established by Bate, Robert and others (Bate 2007b, Ziebland, 2012). By applying the XbD process of deep meaning analysis, a clearer picture of the 'essences' of the experience can be fed back to patients, using tool-kit items and in the form of stories or narratives which summarise the experience in powerfully succinct ways (Figure 4 (see Bate, 2004)). Bringing these forward enables deeper more personal understandings of the experiences of therapists and/or patients to foreground the co-design stages (Share and Show How) and their mutual conceptualisation (design) space. This also reduces the potential for research impotence where findings are simply filed away after presentation because there is no real buy-in from those who could otherwise activate the results.

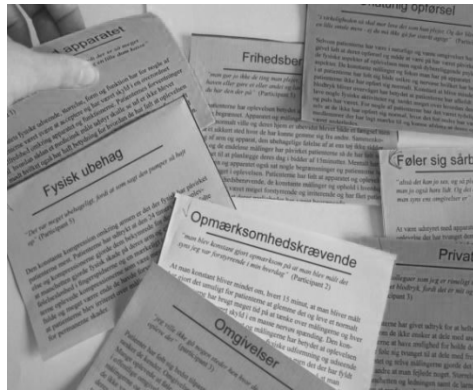


Figure 4: Patient feedback mechanisms – Story cards

What have we learned from doing things this way and where do we hope to go from here?

We all enjoy affirming feedback, however this can also point to a lack of disaffirming feedback as well as non-affirming feedback. The disaffirming is difficult to ask for but the space for participants to contest the result must be made in the face of the researcher's obvious desire to have the results confirmed. Likewise it is almost impossible for participants to identify those elements that are not included (non-affirming) but should have been. The researcher needs to be on the lookout for these and actively probe for them in the feedback sessions.

**Showing How:** Beginning the design cycle with a shared idea of the meaning contained in the experience we are designing for - Putting meaning into designing better experiences

What are we doing that is new or different and how are we doing it?



Figure 5: Experiential presentations in an experience space

This stage is all about taking the insights gained in the preceding stages and making them useful. The difficulty lies in that we have qualitative findings that could easily become lost in a report without leading to useful action. The processes described earlier in Understand and Share, will

produce powerfully meaningful messages. In order for them to be communicated well and for them to guide us towards useful design decisions, we need to turn our findings once more into an experience of understanding for others (Bate, 2007a).

We start by not treating our audience as static and passive receptors of information (Erwin, 2012). This is more than a symbolic act and it sets the stage for a more receptive and experiential message to be both transmitted and perceived. We utilise all the multi-media and interactive technology at our disposal to present research findings in the form of sound, vision and whatever effects are appropriate (see Figure 5). In recent presentations we had the bleep of a cardiac monitor; an animated re-enactment of the moment when a patient collapsed in public with a stroke: an audience moving through the presentation space blindfolded to create feelings of uncertainty that paralysis patients feel. This kind of 'performance' strengthens the communicative qualities and the audience can begin to experientially empathise with the messages presented so that when the call to action arrives there is a greater chance of success.

What are the results achieved by doing it this way?

Erwin (Ibid) describes having patients involved in her presentations in interactive ways i.e. discussing their part in the research and offering their personal perspectives. On the few occasions when patients have been able to attend, they have remarked how moved they were to have re-experienced something they had always known but felt unable to communicate to others. Therapists who have worked in the field for twenty years have been surprised by the insights gained by researchers who have worked with patients for only a relatively short time. Whole audiences were reduced to tears when they experienced the moment when one patients life came crashing down around him after a stroke.

The key reasoning for these elaborate performances is to increase buy in and take out. Why waste all the effort of doing good research and have it die from overdose of PowerPoint. Our intention is focused on communicating a powerful message and following this through with a call to action. This call is more likely to succeed if the audience deeply understands the need.

What have we learned from doing things this way and where do we hope to go from here?

Some very encouraging results have been achieved and we are exploring traditional and non-traditional forms or theater theory and film performance techniques that make for interesting collaborations. The message must be the primary goal and not the technology. This requires a clear focus on the meaning of the experience and how it can be transferred in a manner that is most authentic as well as effective. This kind of knowledge transfer can only be based on the researchers' insight and their long association with the topic.

## Conclusions

Frameworks for Experience Based Co-Design developed within the UK's NHS have proven their worth in terms of bringing health care technologies and patient perspectives together for productive development of solutions that benefit both. XbD can add to this framework in terms of the depth of meaning it brings to the development of solutions so that they are better informed with richer, more meaningful and useful information. Experience-based Designing presents an

opportunity to revisit the design of health technologies and the manner in which they serve patients as well as their loved ones, so as to provide not only more effective health outcomes much more meaningful patient experiences.

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# Adaptive Daily Rhythm Atmospheres for Stroke Patients

## - A patient evaluation

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### *Abstract*

*This paper addresses the evaluation in a lab setting with former stroke patients and their spouses of an in-patient environment that supports patients, family, nursing staff and medical specialists during the recovery process of neurology patients and especial patients recovering from a stroke. We describe the methods that were used to evaluate the Adaptive Daily Rhythm Atmospheres (ADRA) concept (Daemen et al, 2011). ADRA supports the daily rhythm of the patient by generating dedicated multisensory atmospheres for different phases throughout the day (Flinsenberg et al, 2012). Where needed, the atmosphere can adapt to specific interrupts and visits, for example, when a doctor is visiting. The goal of our patient evaluation was to gauge expectations against the different phases of the ADRA concept both qualitatively and quantitatively to determine if the different phases are useful, usable and desirable for the patient. Six former stroke patients and their spouses participated in our test. We invited them in our lab for a user evaluation of one hour. We recruited the participants through the national stroke centre of the Netherlands. Patients experienced every phase of ADRA in our lab. Then we asked them for all the different phases of ADRA, if this phase would have helped them, during their stay in the hospital. They were asked to give a score on a 10 point Likert scale, especially designed for stroke patients (Daemen et al, 2007). Next an interview took place with the patient and their spouse (Goodman et al, 2012; Martin & Hanington 2012). The results show that the patients believe that most of the different phases of the ADRA concept would have helped them while being in the hospital with the waking up phase as most positive (mean 8). The visitors phase scored the lowest with a mean of 5.3. The qualitative evaluation results are used to further improve the design of healing environments in general and the ADRA concept in particular, before starting with a clinical trial in a hospital environment.*

Keywords: Healing environments, Stroke, Patient room, User evaluation



# Introduction

Currently, most hospital patient rooms are highly institutionalized environments that confine patients to an artificial and unfamiliar environment. They provide little opportunity to adapt this environment to individual patient requirements although it is well known that the healing process is affected by various environmental stimuli in the hospital. For example, there is clear evidence for a positive effect of nature on healing. From literature we know that access to (rendered) nature views, including the presence of indoor plants, helps to increase the tolerance for pain and reduce the use of pain medication (Ulrich *et al*, 2004; Grinde & Patil, 2009; Ulrich, 1984). Also, contact with nature has, to a certain extent, a positive effect on short-term recovery from stress and mental fatigue (Ulrich *et al*, 2004; Ulrich, 1984) and moreover, it also accelerates physical recovery from illness (Velarde *et al*, 2007). Not only nature views, but also exposure to daylight is found to be an important factor in the recovery process. Patients exposed to sufficient daylight are less stressed and seem to need less pain medication (Walch *et al*, 2005). Bright (artificial) daylight exposure during day-time and avoidance of too much light exposure during night-time helps patients to sleep better at night (Wakamura & Tokura, 2001) and to feel more energized during the day (Bringslimark *et al*, 2009). In particular, a deep restorative and undisturbed sleep is of high importance for a fast recovery process in patients.

Our research concerns the design and development of patient healing environments and especially for patients recovering from stroke. A stroke event has a large impact on a patient physically and cognitively as well as psychologically (Hafsteinsdóttir & Grypdonck, 1997). To obtain insight into initial needs and requirements of stroke patients and their medical environment (the neurology ward), a contextual research in two neurology departments and rehabilitation centres was conducted. The main objective of this study was to understand neurology patients' experiences of in-patient care environments and best practices in neurology clinical care (Daemen *et al*, 2011). From these findings we were able to generate a substantial number of potential adaptations to the patient environment that could have positive impact on the healing process of the patients and the work environment of the hospital staff. Several application concepts were developed and evaluated with the staff of four hospitals to select the most promising and viable concepts for further development and prototyping. These adaptive healing room concepts have now been prototyped and are installed in our laboratory environment for further evaluation and iterative design and development. One of these concepts that is currently installed is the Adaptive Daily Rhythm Atmosphere (ADRA). The evaluation of this system with patients is presented in this paper. The evaluation with hospital staff is presented in (Daemen *et al*, 2013).

## Adaptive Daily Rhythm Atmospheres

The ADRA systems is derived from findings in the literature on effects on the healing and recovery process and from our user requirements gathering work (Daemen *et al*, 2011). As indicated in the introduction, it is well known that the healing process is affected by various environmental stimuli in the hospital. With the ADRA system we focus on providing artificial nature views and artificial daylight with the goal to enhance the healing process by lowering stress, enhancing sleep, minimizing medication intake and mental fatigue. In addition we focused on user requirements

from the field studies: providing a clear and strict daily structure to support and maintain a healthy sleeping pattern and balancing clinical environment and personal environment.

The ADRA system provides a daily rhythm atmosphere that is in sync with the patient's needs, optimized for the care agenda, and adapts intelligently to deviations of patient and care needs. ADRA supports the daily rhythm of the patient by generating dedicated multisensory atmospheres for different phases throughout the day that consist of manipulating light, audio, and video parameters. Where needed, the atmosphere can adapt to specific interruptions and visits, for example, when a doctor is visiting or a cleaner starts working. It is assumed that by using ADRA the rigid environmental conditions in the healing room will be alleviated and positively affect the healing process of the patients. Since it is clearly established that the day of a patient in a neurology ward in most hospitals consists of eight distinct phases, ADRA implemented these phases in the system. These phases are: 1) Waking up, 2) Breakfast, 3) Clinical care, 4) Lunch, 5) Rest, 6) Visitors, 7) Going to Bed, and 8) Sleep. Each phase has a defined time frame during which it is active. These time-frames are currently based on the actual timing used by one of the participating hospitals, but can be adjusted to the different scheduling requirements of hospitals. For a video showing the different phases, please consult (PhilipsResearch, 2011; Daemen *et al*, 2013).



Figure 1: Waking up phase, Doctor's visit during clinical care phase, Visitors phase and going to bed phase

The ADRA system is a context-aware system based on sensor input about person location, patient activities, and time of day. It consists of a light cove installed behind the patient bed, electrically operated window curtains, and a patient wall in front of the patient containing two RGB light coves, and three multi-media screens. The left multi-media screen is used to show a digital clock, the middle screen is used to show still healing nature images, slide shows and movies, and the right screen is used to show personal photos and drawings (connectivity screen). Furthermore, the ceiling of the room contains an Artificial Skylight (AS). This AS gives the impression of daylight entering the patient room through a skylight in the ceiling. It is an electric ceiling lighting solution

that provides a unique combination of sunny white light and an infinite blue sky view in a window frame structure. Figure 2 gives an illustration of the set-up. For technical details on the context-aware ADRA system and its implementation, we refer to Flinsenberg *et al* (2012).

This ADRA system implementation was evaluated with patients as well as with the hospital staff. In the next section, we describe how the evaluations with patients were conducted and what their assessment was.

## Evaluation of the ADRA systems by patients

The goal of the patient evaluation was to gauge expectations against the different phases of the ADRA concept, both qualitatively and quantitatively, to determine if the different phases are desirable for the patients and useful and usable for the hospital staff. In this report we will focus on the assessment of the patients. User-centered design and evaluation principles are at the heart of our approach toward the development of patient healing rooms. However, for this particular domain of neurology wards in hospitals with patients who are severely ill and incapacitated, the existing methodologies and evaluation instruments fall short. They are just not applicable and we need to develop other means to acquire feedback. Furthermore, a hospital is a clinical setting, in which interventions are only permissible when their clinical impact has been proven. This is clearly not the case for a prototype system that is still in development. Also, the work flow for the medical staff and established clinical procedures and protocols cannot be changed to accommodate a user evaluation. To circumvent these conditions, a hospital room was created in our research laboratory in which we could implement the ADRA system and invite hospital staff, care professionals and former patients to participate in assessment and evaluation sessions. These evaluations were set-up as pilot tests in a laboratory setting to refine the concept and to prepare for a clinical trial. Since, clinical trials are very time consuming and labour intensive, it is important and extremely valuable to pre-test all the concepts in the laboratory to optimize the procedures for the clinical trial and to ensure that all aspects for the trial are valid. Furthermore, an important objective for these patient evaluations is to fine-tune the requirements for the healing room and to achieve a match between the initial requirements and the feedback from the patients.

## Participants

Because we tested the patient room in the hospital laboratory setting and not in a real hospital setting, it was paramount to find a group of participants that could represent the hospitalized stroke patients. In cooperation with the national stroke centre of the Netherlands, a group of stroke patients was recruited to participate in the evaluation of the patient room, according to the therapists, these patients were sufficiently representative for the hospitalized stroke patients and be the best to test the patient room with in a laboratory setting. Six former stroke patients were invited to come to the hospital laboratory. Four of the former patients brought their spouses. The role of the spouses was to support their loved ones during the session and help them with the conversation. Some of the participants had aphasia and had difficulties in communicating. Their spouses helped us with the translation; they were more common with the language former stroke patients used. The average age of the patients was 67.5 years old and the average age of the spouses was 69 years. Two patients were female and four were male. The patients had a stroke between four and 20 years ago (on average 13.5 years). They all still suffered from minor or severe

disabilities that were caused by the stroke, like paralysis, cognition problems, and they all had some form of aphasia.

## Methodology

We invited participants to the hospital lab for a evaluative session of one hour (Martin & Hanington 2012; Goodman *et al*, 2012). Figure 2: Set-up test shows the set-up of the laboratory hospital room that was used for the evaluation. The task of the moderator was to lead the session. Two note takers participated to write down all the feedback the participants gave. Participants, both former stroke patient and the spouse, had to take place next to the patient bed, so they had a similar view as the patient. The moderator was standing on the left side and two note takers took place at the table on the right. At this position they were not blocking the view of the participants.

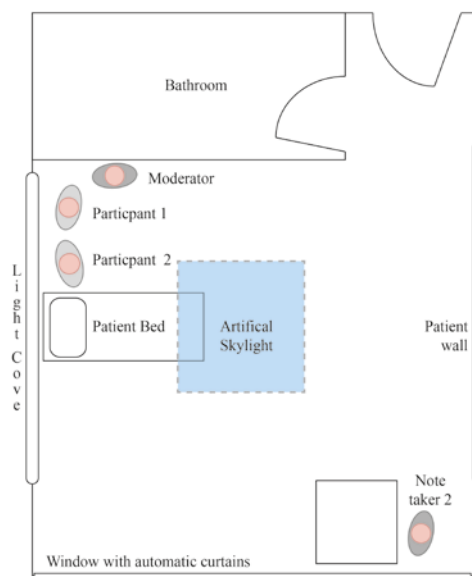


Figure 2: Set-up test

After signing the informed consent, the couple was taken to the laboratory environment where they were introduced to the functionality of the ADRA and where they could also experience how the room adapted to different contextual changes. This introduction was the same for each participant. Then, the participants were seated next to the patient bed so they had a similar viewing angle as an actual patient. A questionnaire was administered in which participants were asked to rate every concept of the ADRA system, i.e., 1) Waking up, 2) Breakfast, 3) Clinical care, 4) Lunch, 5) Rest, 6) Visitors, 7) Going to Bed, and 8) Sleep and provide it with a score. All phases of the ADRA system were presented and rated by the participants. They were asked to give their score together, both former patient and spouse, on a 10 point Likert scale. This Likert scale was especially designed for stroke patients and aimed at reducing discomfort and enabling disabled patients to provide feedback. (Daemen *et al*, 2007)(1: would have helped me very bad and 10: would have helped me very good). After the questionnaire, the session followed up with an interview session with open questions in which feedback was elicited from the patients about the reasoning behind the scoring. During the interview the note taker wrote down all the comments. Afterwards the quantitative results were analyzed by using the average scoring and standard deviation, because of the low number of participants. However, we have to account for noise in the

results as former patients after a traumatic experience are probably very likely to respond positive due to the attention and special feedback of being invited to a research laboratory.

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Figure 3: Likert scale adapted to stroke patients

## Findings

In general, participants appreciated the patient room. They all indicated that this would help them during their stay. As one patient mentioned it, “When I was in the hospital – I didn’t see anything positive – the only focus was on me, to get me better again. This room is positive and will help me to be positive”. Some patients mentioned that the room would help them in the end of their hospitalization, but for the initial days in the hospital this would not be helpful and creating to many stimuli. “A patient is really away the first days – light can be very disturbing in the beginning – you want peace of mind the first days.” Another remark was that when you are in the hospital you don’t have much control over the environment. It would be nice to get more control over the environment. The room could be for example personalized to their needs: patients would like to change the time that they have to go to bed and the theme of the nature views. “The room should be adaptable to my needs: if I want to go to bed later, I should be able to change the time.”

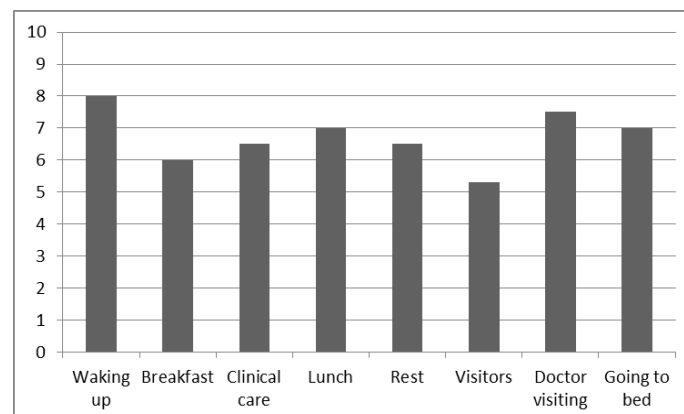


Figure 4 Quantitative results

The **waking up phase** was appreciated the most with an mean score of 8 and a standard deviation of 1,09. Patients indicated that it would be nice to be woken like this. “I like nature- so nice idea to show nature views in the morning – When you are a little bit better – when you like nature this is really fantastic – It gives the feeling that life is still worth fighting for.” They indicated that it is a gentle way of waking up and not as abrupt as it happens now. Many participants indicated that half an hour to wake up is long enough and that the wake up time should be adaptable as well. Some participants indicated that if they are woken they need to go to the toilet, so half an hour

should be shorter. In addition participants indicated that the nature views should be adaptable towards the preferences of the patients.

The **breakfast phase** was appreciated the least with a mean score of 6 and a relatively high standard deviation of 2.09. Two patients scored 8, but also two patients scored very low giving a score of 3 and 4 to this phase. Patients were indicating that we had to pay attention that it would not become too busy because during breakfast it was important to focus solely on eating and not on the environment.

**Clinical care phase** scored a little better than breakfast with a mean score of 6.5 and a standard deviation of 0.8. All participants more or less gave the same score and gave the same feedback. Participants indicated that the light is too bright during clinical care and they would prefer having images on the screens instead of nothing when there was no therapist or doctor in the room. Like on participant mentioned: "The atmosphere is very sterile – It feels like you are on a different planet" and another one "Grey is grey, maybe you can show one picture." In addition they mentioned that therapy was often given in another room, so the need for a boost in the patient room was not that prevalent, but more in the therapy room.

**Lunch phase** scored good with a mean score of 7 and a standard deviation of 1.67. Four patients scored 8, but two patients scored low giving a score of 4 and 6 to this phase. Again patients mentioned that they were easily distracted and during lunch they had to focus on eating their lunch, so not that many items on the patient wall and less bright light were appreciated. Other patients indicated that they would prefer to see more items on the screen especially towards the end of their stay. So again the personalization was an important aspect.

The **rest phase** had a mean score of 6.5 and a standard deviation of 1.87. Four patients scored very positive and only one scored negative, giving a 4. Most participants found the sound relaxing and this atmosphere would be good to fall asleep in. In addition they mentioned that closing one curtain is a nice feature, they could still have a feeling of the outside and in the meantime create a relaxing atmosphere inside the room. Also in the rest phase participants indicated that the room should have more personalization options like turning off the sound or the movie and turning up the sound. The participants who scored negatively indicated that they didn't need pictures or a movie during rest hours.

The **visitor phase** scored the lowest with a mean score of 5.3 and a relatively high standard deviation of 2.65. Two patients scored 8, but also two patients scored very low giving a score of 1 and 4 to this phase. The reasoning for that is that the participants who scored low didn't have good family contact, so for them a visitor phase would not be beneficial and would even have a negative effect by providing this phase and let them think of family not visiting them. In addition these participants mentioned that visitors would look more at the screen than pay attention to them. They indicated that the patient wall should work in the background. In addition they said that visitors can't stay too long, as one patient was indicating: "When I was in the hospital I found too many visitors often too busy. You need to keep track that there are not too many visitors and that they leave in time. This room might have the effect that visitors stay too long." Patients who scored high had a good family contact and therefore would appreciate this atmosphere.

The **doctor visiting** scored second best with a mean score of 7.5 and a standard deviation of .42. Four patients scored 8 or higher, but also two patients gave a lower scoring of 4 and 5 to this phase. "When I was in the hospital I could not remember the names of all these doctors and nurses, this system would have helped me. " Patients also indicated that this would give them more trust in the hospital, because you know who is standing in front of you. In addition they also said it is handy to indicate people's role by an icon because often patients couldn't read the first days of their stay. Patients also mentioned that it would be nice if the information of who entered the room could stay on the patient wall because patients would really like to know what happened during the day and for my spouse who can only visit me during visiting hours this is also interesting.

The **going to bed phase** also scored well with a mean score of 6.8 and a standard deviation of 1.94. Again four patients scoring very positive with scores of 8 and higher and two gave a lower scoring of 4 and 5 to this phase. Patients indicated that personalization here was also a must. "I would like decide myself when I should go to bed – after visitors went home or after my favourite TV show, etc. "and "First I would like to see my own movie and then I should be able to start the system ". In addition patients expressed a need for an extra light that they could use when going to the bathroom during the night. "The night atmosphere is very dark - maybe a night light should be provided" Some patient also expressed that they didn't like the automatic curtains. They prefer a nurse to close the curtains, because when they close the curtains they often have a little chat with the patients. This personal contact with nurses is very much appreciated. In addition participants mentioned that if they can't fall asleep, the movie should not be turned off. Also during the night when they are awake they would like to play the movie again.

## Conclusion and discussion

These results show that overall participants are positive the different ADRA phases that provide a clear daily rhythm structure during the day, but some additional changes should be made. We can conclude that the main finding is that patients expressed the need for a personalization option. The hospital former patient evaluation in the laboratory setting gave us an indication of the likely impact of the Adaptive Healing Environment Patient Room. Furthermore, this laboratory evaluation of the concepts was an important step that enabled to improve the shortcomings of the current concept before starting clinical trials. As mentioned in the introduction, the goal of the evaluation was to evaluate the Adaptable Healing Environment Patient Room with former patients. We have to state that this was only a pilot study because of the low number of participants. With regard to future work we need to test the patient room with patients in a hospital setting. For this clinical trials are required. To prepare for a comprehensive clinical trial, we will first integrate the learnings such as personalization.

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# Design of a Safer Radiotherapy Interface

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## Abstract

*100,000 people undergo radiotherapy in the UK annually (Department of Health, 2007). Potentially fatal errors are estimated to occur in 40 of these 100,000 courses (Donaldson, 2007). Research indicates that there are a range of human factors issues affecting the safe delivery of radiotherapy, including the design of the linac machine interface used to administer the radiotherapy dose (Chan et al, 2010).*

*Immediately prior to the delivery of radiotherapy, two radiographers working together check that the parameters displayed on the linac's Graphical User Interface (GUI) correspond with the patient's paper prescription to ensure that the dose is correct. Research indicates, however, that this type of checking process is error prone (Toft, 2005).*

*This research aims to identify the causes of radiotherapy checking errors. Of particular interest is the role of the GUI design. Semi-structured interviews were conducted with radiotherapy staff and students (n= 15) to understand the checking process, determine likely sources of errors, and identify design features of the current GUI which may impede effective checking.*

*Thematic analysis of the interviews indicated that, in addition to work organisation issues, there were a number of features in the current interface designs which reduced usability. The results suggested that there are three main software packages used in the UK which present similar challenges due to dense presentation of information and limited grouping or highlighting of key information. Furthermore, it was found in this research that the most frequently used interface violates ISO design guidelines for the display of visual information.*

*The findings have been translated into a design specification for a simpler and more intuitive layout. The resulting interface prototype is presented, alongside the results of a usability assessment of the current and redesigned interface. Recommendations for*

*further research involve experimental investigation of the effect of the interface design on user accuracy during verification, to assess the potential impact on patient safety.*

Keywords: interdisciplinary working, patient safety, evidence-based design, GUI

# Introduction

Patient safety is a major concern within healthcare. In the UK iatrogenic harm can result in unnecessary patient harm, death, distress and increased cost to the NHS (Vincent, 2010). The Patient Safety field is multi-disciplinary and seeks to increase the analysis and prevention of errors in healthcare.

In the UK, 52% of cancer patients receive radiotherapy as part of their care (Donaldson, 2007). Accuracy of the radiation beam is vital in order to target and maximise radiation to tumours, whilst minimising damage to surrounding healthy cells (Donaldson).

A patient's radiotherapy treatment is usually made up of a series radiation doses given over consecutive days. The radiation is administered by a linac accelerator machine. The linac accelerator displays on a monitor both in the treatment room, and an adjacent observation room, the treatment parameters, including strength of radiation, area to be radiated and any beam accessories needed to modify the radiation beam.

Radiotherapy is widely known to be one of the safest areas of modern medicine (WHO, 2008:2). However, it has been estimated that incidents occur in 40 out of 100,000 treatment courses per year (Donaldson, 2007). Some 24 of these have been found to result in adverse and potentially fatal clinical outcomes (Donaldson).

A number of checks are built into the radiotherapy planning process to detect errors. The final verification check, whereby two staff check that the dose of radiation about to be delivered is correct, is carried out immediately prior to treatment delivery. The check ensures that the treatment parameters displayed on the linac accelerator interface are the same as those on the patient's paper prescription. As such it is the final opportunity to detect an error and prevent erroneous treatment delivery (Donaldson, 2007). It is a legal requirement that it is conducted by two radiotherapists (Donaldson, 2007). However, despite the checks, errors have passed undetected. An investigation into one such incident found that a patient received 2.5 times her prescribed dose, with the discrepancy between the parameters displayed on screen and the patient's prescription going undetected for 14 daily treatments (Toft, 2005).

A number of suggestions have been put forward to explain failures in radiotherapy checking processes. Towards Safer Radiotherapy (Donaldson, 2007) identified a number of human factors issues believed to contribute to incidents, such as; heavy workload, lack of training, fatigue, stress, poor communication, and the working environment. An audit of practice found that 75% of UK departments had an allocated ten minutes per patient, with a maximum of 15 minutes. Departments treated on average 40 patients per day with some departments treating over 50 patients on an average of 3 linac accelerator machines (Stratford *et al*, 2006). As a result, there is significant time pressure to treat patients quickly.

The checking process is standard and routine with the same four parameters being checked in the same environment, multiple times a day. As with other regularly repeated actions, there is a propensity for the checking task to become second-nature and, as such, conducted without due attention (Toft, 2005). If this process of 'involuntary automaticity' occurs during checking, errors can pass undetected.

Another human factors issue affecting safe radiotherapy delivery is the linac accelerator interface design. There are currently three software programmes used in the UK, the most commonly used of which is MOSAIQ. Chan *et al* (2010) conducted a workflow analysis of the radiotherapy process in one department in Canada and through a heuristic evaluation of the MOSAIQ software demonstrated that it did not adequately align with the Radiographer's workflow or checking process. Usability was considered through use of Zhang's (2003) heuristic evaluation method which combines two predominant heuristic models (Nielson, 1994; Shneiderman, 1998), with a consideration of patient safety. Some 75 usability violations were found in the MOSAIQ software, mostly error, consistency and memory. It was found that all processes in radiotherapy violated some usability heuristics such as consistency, visibility and increased cognitive load (Chan *et al*, 2012). The interface involved in beam delivery (the process during which the final verification is conducted) was found to have five low severity and six medium usability violations. In response to finding that the 'patient set-up' phase of radiotherapy was particularly error prone, Chan *et al* (2010) redesigned components of the interface. Testing of the new design demonstrated a reduced error rate, faster patient set up and increased user satisfaction.

The shortcomings of the current interface as demonstrated by Chan *et al* (2012) highlight the human factors issues within radiotherapy systems, however, the authors only studied improvements to the patient set-up stage. Hence further work is needed on analysis of the effectiveness of the final verification check prior to beam delivery. The study described in this paper considers the design of the interface in respect to the final verification check. It aims to consider whether the linac accelerator interface used during the final verification can be re-designed to improve safety.

## Method

### Participants

Six qualified radiographers were recruited via opportunity sampling from a NHS radiotherapy department. Nine radiotherapy students in their final year of training were recruited from a local university, along with two academic teaching staff who were practising clinically. This group was believed to represent a range of experience and views. Recruitment continued until data saturation was reached, this was the point at which participants provided no new data.

### Ethics

The research protocol was approved by Coventry University ethics board and the local NHS Trust. Informed consent was taken prior to the interview commencing. All participants remained anonymous.

### Procedure

Semi-structured interviews lasting approximately 30-60 minutes were conducted with qualified and student radiographers. Questions explored views on patient safety, how final treatment verification checks are conducted and potential reasons for ineffective verification checks.

## Analysis

The interviews were recorded, transcribed verbatim and the transcripts analysed using thematic analysis. The results of the interviews were then combined with ISO design principles to create a brief for an improved prototype interface.

## Results

Thematic analysis of the interviews revealed a number of reasons as to why verification checks may fail to detect errors. These were clustered into six themes: lack of a standardised protocol, lack of training in patient safety and verification, difficulty maintaining attention, working environment, authority structures and team culture, and interface design. This paper focuses on the findings surrounding interface design.

The majority of the participants used the MOSAIQ software system. However there was experience of three different software packages within the sample. Participants reported that the interface used for verification was not user friendly, as illustrated with the below quote from a student radiographer;

“...when you first look at it, you think, 'oh my god! It's just a bank of numbers.'”

Participants reported that the information was too densely presented, so the key information required for verification cannot be easily or quickly extracted. Participants suggested that the interface would benefit from an improved layout, increased font size, more use of colour and highlighting of key information. The issues highlighted in the interviews are illustrated in figure 1. The verification task requires checking of the energy, monitor units, wedge monitor units and wedge position values, these are highlighted in blue.

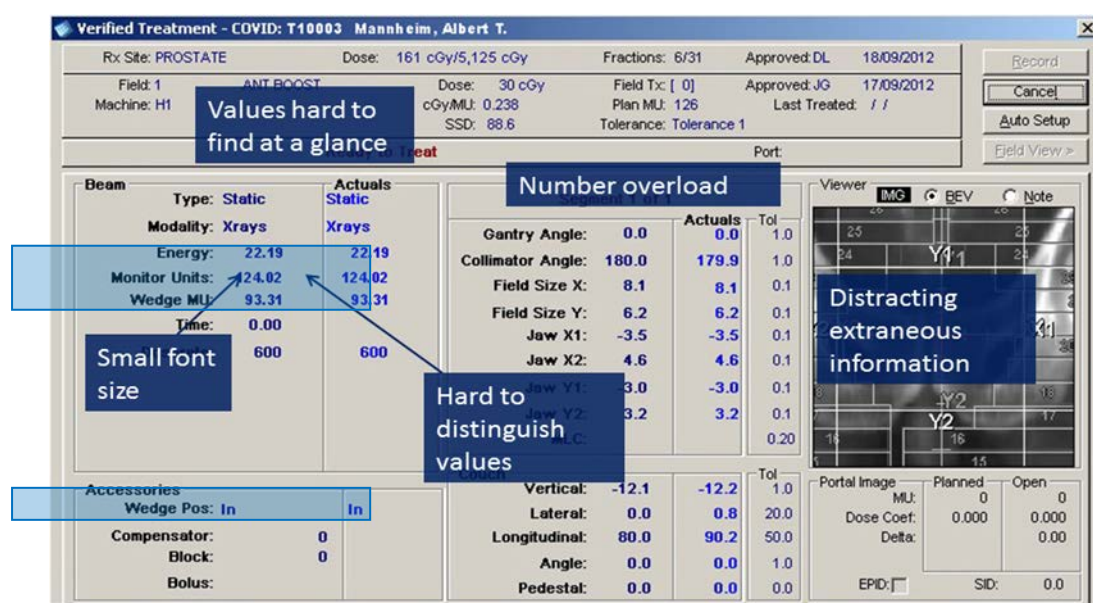


Figure 1: Current interface annotated with findings from interviews

Additionally, participants believed that if the interface required more active input on the part of the user, rather than mere passive checking, this would help to prevent errors.

## Re-design of the interface

As participants reported design issues with the current software, the interface was reviewed against established recommendations for the display of visual information. The ISO 9241 "300" subseries was used for this purpose. This particular standard entitled "Ergonomics of human-system interaction" addresses software and hardware ergonomic aspects of human interaction with computers. Part 12 is of interest here as it details recommendations for the display of static visual information and is intended to be used by interface designers and evaluators. These guidelines were chosen as they are international standards specifically for the display of static information. Furthermore, the standard contains a detailed checklist of recommendations to direct interface evaluation and seven design principles to ensure that the interface supports the user "to perform perceptual tasks effectively, efficiently and with satisfaction". These seven ISO principles of a good static interface are;

1. Clarity: the information content is conveyed quickly and accurately.
2. Discriminability: the displayed information can be distinguished accurately.
3. Conciseness: users are not overloaded with extraneous information.
4. Consistency: a unique design, conformity with user's expectation.
5. Detectability: the user's attention is directed towards information required.
6. Legibility: information is easy to read.
7. Comprehensibility: the meaning is clearly understandable, unambiguous, interpretable, and recognizable.

The interview results suggested that the current interface for the verification check did not meet these principles. Figure 2 illustrates some of the ISO recommendations which the interface violates.

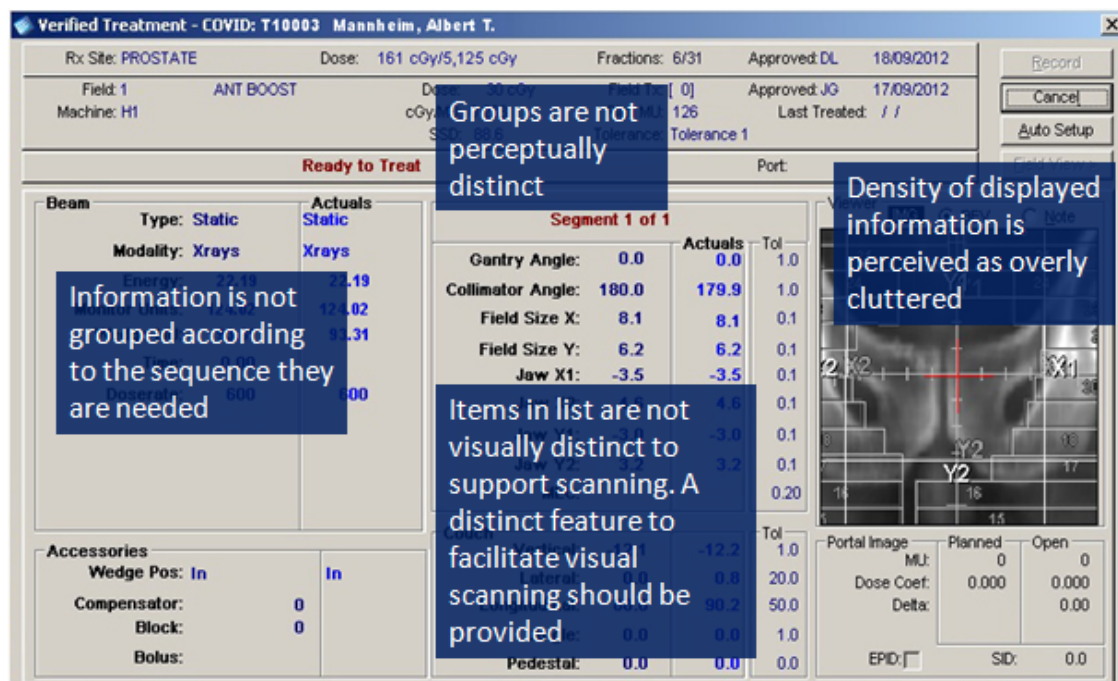


Figure 2: Current interface annotated with violations of ISO design recommendations

The above ISO recommendations and principles were combined with user feedback from the interviews to create a design specification for further development of the verification screen element of the software. This brief, displayed in figure 3, was then passed to a designer.

#### Design Brief for the design of a Safer Interface in radiotherapy

Interviews with users suggest that a re-design of the MOSAIQ interface may improve user accuracy and maintain user attention. The interface is used to conduct the final verification check and as such the vital values are monitor units, beam energy and beam modification. The other information currently on screen is required only occasionally. Patient identification information must be retained.

User feedback suggests that the current design is not user friendly. Users need to be able to look briefly at the interface and retrieve the information that they need. User accuracy needs to be improved when reading out the vital values, these values should be seen at a glance and be visually distinct from one another. The other information should be condensed down to reduce visual clutter. Users also suggested that font size needs to be increased on the vital values. Increased utilisation of colour was also suggested as the current design is monochrome. Yet colour must be used sparingly as it is used elsewhere in the system to indicate other errors (e.g. red to indicate errors and green to symbolise treatment can proceed). Therefore perhaps colour could be used as background shades to distinguish and draw attention to the location of important items, or to make items more distinguishable when in a list.

The interface must also adhere to and achieve the seven ISO principles of a static interface.

Figure 3: Design Brief for prototype interface

Three design proposals were created before the final prototype was decided upon. After each proposal was created it was discussed with a Radiographer, to ensure the presentation of the information required at the point of verification was adequate. The proposal decided upon was deemed to strike the right balance between highlighting only the values needed at the point of verification, whilst still containing other parameters needed to identify patients or occasionally required during treatment.

## Evaluation of resulting prototype interface

The final prototype for the verification screen is shown below.

Verified Treatment - COVID: A60100 Wilkinson, Peter E.																																			
Energy:	31																																		
Monitor Units:	115																																		
Wedge MU:	201																																		
Wedge Position:	OUT																																		
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Figure 4: Resulting interface prototype

The prototype verification screen was believed to meet the ISO recommendations and addresses the design issues raised by participants in the interviews (see figure 5).



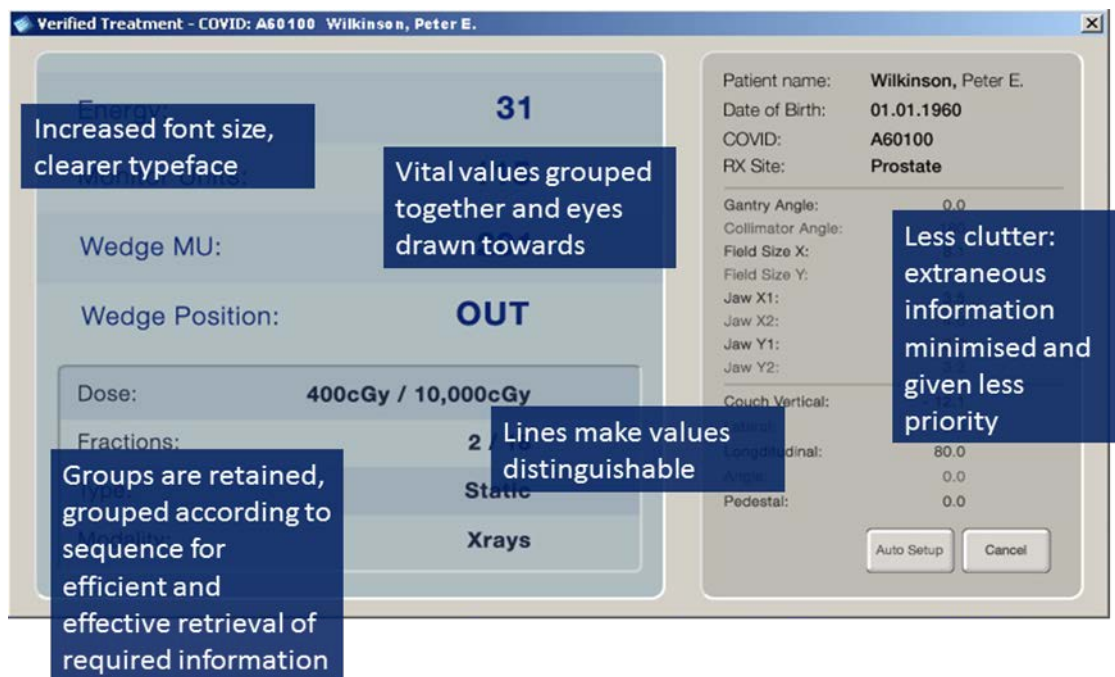


Figure 5: Re-designed interface annotated to show how it has improved upon user feedback and ISO recommendations

In order to evaluate if the new prototype was an improvement in terms of compliance to ISO 9241 principles, a questionnaire was designed to elicit feedback on how successfully both the old and new interface met the seven ISO design principles. Each ISO principle was converted into a statement, with a seven-point likert scale to assess how well users believed the principle had been met.

Participants, recruited from an undergraduate psychology course at Coventry University, who were not trained in radiotherapy, and hence not familiar with the software, were asked to read out the energy, monitor units and wedge position values, to mimic how the interface would be used during the final verification check. Ten participants completed this task using the old interface and ten participants used the new interface, before completing the questionnaire.

The results of the evaluative feedback are shown in figure 6. A higher score indicates the principle has been met to a greater extent. As can be seen, the new interface scored higher on all ISO 9241 design principles. Independent samples t-tests confirmed that this difference was significant for all items except "consistency". The non-significant result for consistency may be because the lay participants did not have experience of other parts of the radiotherapy system and therefore did not have any prior expectations for the interface to conform to.

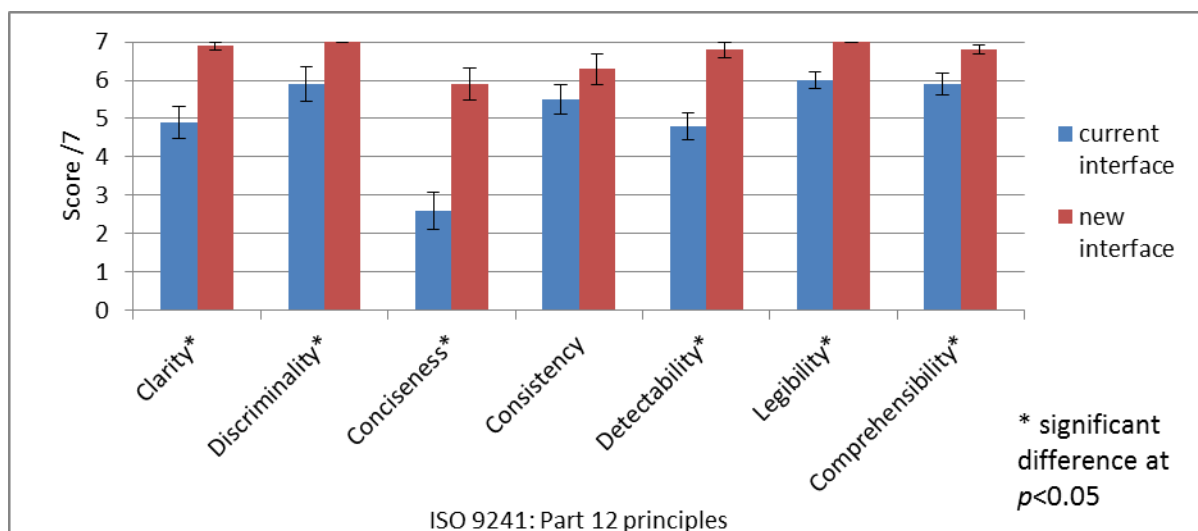


Figure 6: Graph displaying average user ratings

The results suggest that the re-designed interface, based on lay participant feedback, is an improved version of the current MOSAIQ interface. It can therefore be expected to better support users to conduct an effective final verification of a patient's treatment.

## Conclusion

The interview study with radiographers suggested that the design of the interface can contribute to ineffective verification immediately prior to treatment delivery. The three linac accelerator software systems in use in the UK are believed to have similar issues in terms of dense presentation of information, difficulty distinguishing values, a lack of highlighting of key values and lack of colour.

A design brief for the re-design of the static interface used for the final treatment verification was created which combined user identified design issues with ISO recommendations. This prototype interface scored significantly higher on lay user ratings than the current screen used in verification checks, suggesting improved usability of the static screen, and therefore more likely to prevent errors during the final verification check.

Future work will seek to explore whether the re-designed, simpler and clearer interface does improve the accuracy of the final treatment verification, thereby potentially preventing errors and patient harm. Through an experimental design which simulates the repetitiveness of radiotherapy verification, the interface will be comparatively tested to determine whether accuracy of extracting and checking the four key values is improved. Further research will also explore qualified radiographers' views of the new interface design to inform whether potential implementation of the re-design into existing software would be worthwhile to increase patient safety. If results are positive it will be recommended that the design of the interface used for verification is revised in accordance with these results, in order to improve patient safety in radiotherapy.

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