

2011 European Conference
Design 4 Health



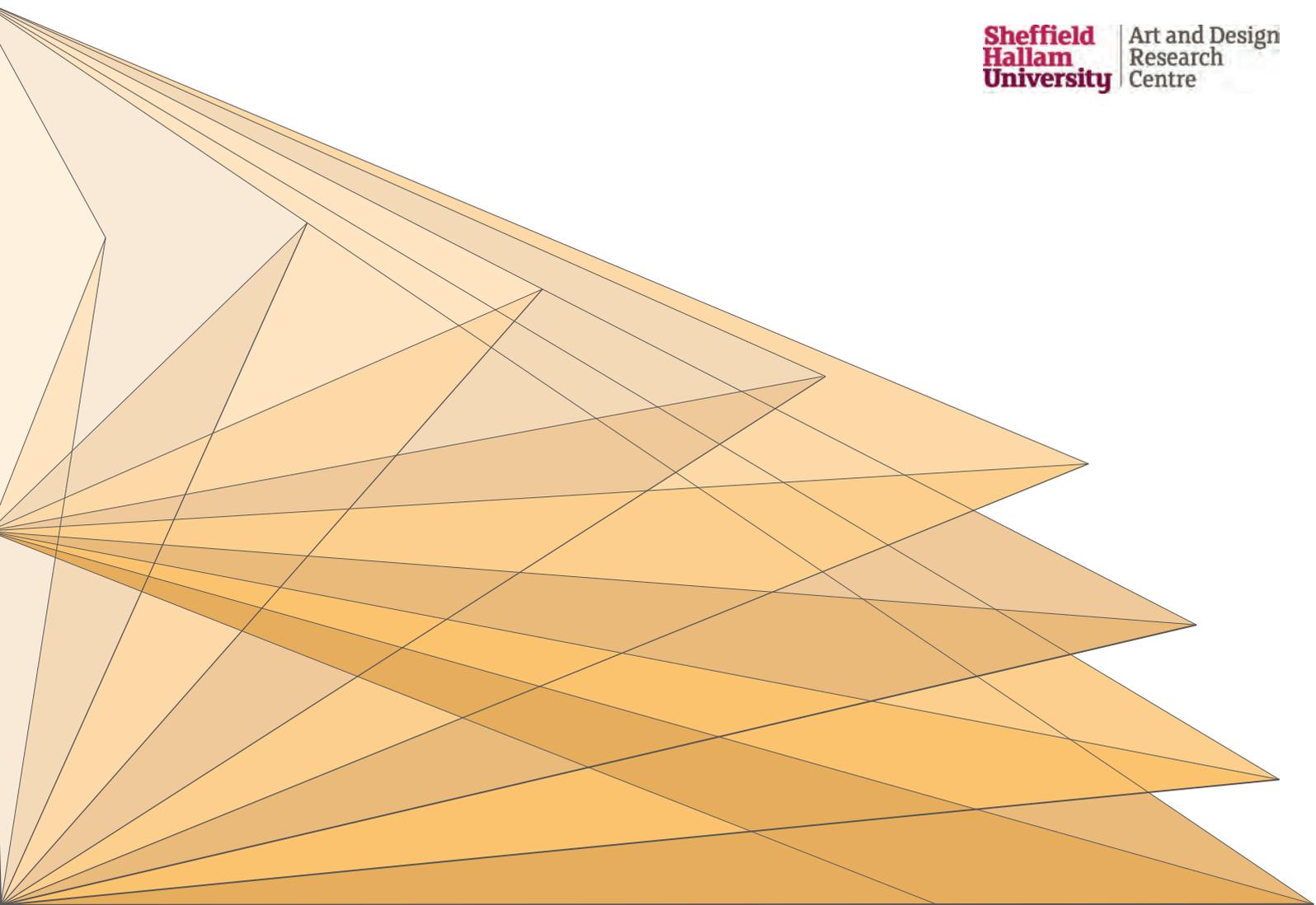
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Introduction

Welcome to the proceedings of the 1st European Conference on Design for Health.

The conference attracted high quality research from all over the world and we are proud to be able to collect it together and make it available to a wider audience.

We hope you find the contents stimulating, rewarding and thought provoking and we encourage readers to contribute to the 2nd conference, to be held in Sheffield in July 2013.

Dr Alaster Yoxall

Conference Director

Lab4Living, Art & Design Research Centre

Sheffield Hallam University

Acknowledgements

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Review Panel

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

Dr Norman Alm, School of Computing, University of Dundee
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Designing Gener-G, the Human Energy Trading Game

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Abstract

Obesity is a serious problem and many government campaigns have highlighted the dangers of sedentary lifestyles (Ekblom-Bak et.al., 2010; Weiler et.al.,2010) and the benefits that regular physical activity can provide (Strong et.al.,2005; Weiler et.al.,2010). Young people require support to increase their physical activity, which should be encouraged early in life (Aarts et al, 1997).

Recently, a way to engage people is through games (Zyda, 2005). This paper highlights the value of making and prototyping in the design development process of 'Gener-G', an electronically augmented board game that encourages people to adopt more physically active behaviour through extrinsic motivation, as a means to gain rewards in the family, an important domain to intervene for promoting physical activity (Sallis et.al., 2006).

Gener-G is played in 2 stages: 1-accumulating energy by exercising during a specific period of time; 2-trading this energy through the board game. The energy generated in stage 1 is used as a currency for playing the board game in stage 2. Therefore, the quality and quantity of exercise in stage 1 influences the game in stage 2. The winner is the one with remaining energy points, and gains family based rewards.

Due to the technology involved in the game, iterative prototypes and simulations were created and tested during the development process, to get prompt feedback and to allow early detection of errors; saving costs and development time.

Even if the tests of Gener-G were conclusive, further development of the game itself is needed but also around the notion of continuous games. This is the intention of the next stage of the research; to explore in a participatory context how to attract and engage young adolescents on a long term basis in playing a game or a series of games to reach the recommended levels of physical activity.

Obesity/Young People/Health

Over a billion people worldwide are overweight and at least 300 million obese (WHO, 2003). The number of obese children in Britain has tripled since the 1980's, to 23% of the population (Lister, 2005). Obese children have a 70% chance of becoming obese adults (NHANES, 2002) and evidence shows obesity negatively impacts young academic performance and long-term prospects in adulthood (Crimmins & Saito, 2001).

Obesity is a serious problem and government campaigns recommended that youths should accumulate at least 60 minutes of moderate to vigorous physical activity on most, if not all, days of the week (NASPE,2004). However, only 32% of adolescents aged 11-15 in England meet these recommendations and it is clear that young people require support to increase these levels (British Heart Foundation, 2009; Maddison et al, 2007).

This is partly due to the fact that physical activity has changed from a natural component of everyday life to something that we now need to choose to do as deliberate 'exercise' (Cavill & Bauman, 2004).

The Wolfenden Gap, reported in 1960s, has established that significant numbers 'flight from sport as soon as individuals left full-time education' (Roberts, 1996). More than 50 years later young people still drop off participation in sports after compulsory school (Green, 2006) starting of a lifelong decline in physical activity. New challenges appeared; society is more divided, young people are more diverse, have a culture of inactivity with 'busy' lifestyles (SMS, Facebook...), and 'exercise habits tend to wear off when entering adolescence' (Aarts et al, 1997). Young people require support to increase their physical activity, which should be encouraged early in life' (Aarts et al, 1997).

Gaming as an approach

Games are fun. This feature has recently been strategically employed to engage people in a range of issues (e.g. Health, Education...) through 'Serious Games' (Zyda, 2005). There has been important growth in the field of serious games for health (Kato, 2012), and Exergames (e.g.Wii Fit, Dance Revolution) is one category aiming to promote physical activity by increasing the energy expenditure when playing video games.

One such example is 'Gamercize' which links 'real exercise' with video games. In order to play games on the X-Box 360, players have to exercise using indoor equipment (stepper and/or bike) which is plugged to an intermediary device linking the exercise machine, the controller pad and the console.

There has been a high focus on obesity through exergaming. However interventions so far haven't been shown to be effective (Elinder, 2005) and more research is needed on how the continuous dimension of game play and exercise can be combined and exploited to promote engagement and exercise on a regular basis.

In this case, it is about combining what young people like, what they would like to do, what they would not like to do – as an incentive to do what they should do, physical activity.

A Physically Active Game: 'GENER-G'

This research aims to find a way to educate and encourage the sustainability of the human body through a healthier lifestyle.

Concept

'Gener-G' is an 'electronically augmented' board game, for 2 to 4 players, designed for the family environment. The game is played in two stages:

1. Exercising over a course of time to accumulate energy stored in 'batteries'
2. Plugging these 'batteries' into a board game as 'energy' for each individual player. Hence the energy cumulated in the battery depends on the quantity of exercise done in stage 1. This can be used as an incentive to accumulate more energy in an attempt to acquire an advantage prior to stage 2. This energy used in stage 2 and regulated through dice can be traded, forfeited, multiplied and accumulated through the chance element of the board game.

The Winner

The winner is the last player in the game with remaining energy and has the opportunity to exchange his/her "family tasks" cards accumulated during stage 2 for the "benefits" cards won by other players. Through discussion and negotiation, the winner is allowed to trade bad cards for good ones hence avoiding household chores such as cleaning the table or watering flowers and enabling to secure enjoyable activities such as control of the TV.

Stage 1

To generate energy and charge up the batteries, set up the Generator (Figure A) as per instructions.

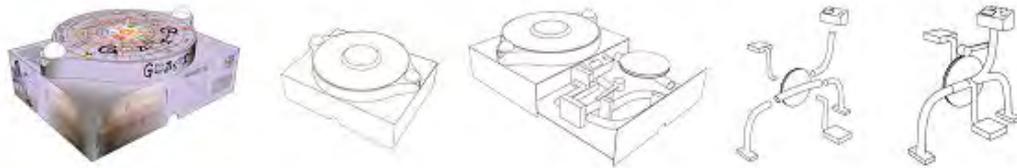


Figure 1 - The Generator included in the box

Stage 2

The energy generated by the players is then applied to the game. The board game element is composed of four concentric rings (Figure B).



Figure2

The outer ring contains more squares than the internal ones but has a greater proportion of 'lucky' and 'benefit' squares.

The game play in the board game is mainly based on elements of chance, risks and strategy to varying degrees. To maintain uncertainty of winning, two devices called 'Musical Boxes' ('Castanets' and 'Barrel Organ') are used through certain squares and allow players to accumulate a small quantity of energy during the game.

Hardware

The game includes the Generator, and all the required equipment is provided and distributed in the four drawers (Figure C). Each contains:

- A 'Castanet Musical Box'
- A 'Barrel Organ Musical Box'
- A set of 4 batteries and 4 tokens
- 2 sets of cards (informative & currency) with a wipe clean marker pen and a set of blank, customisable cards (wipe clean/re-writable).

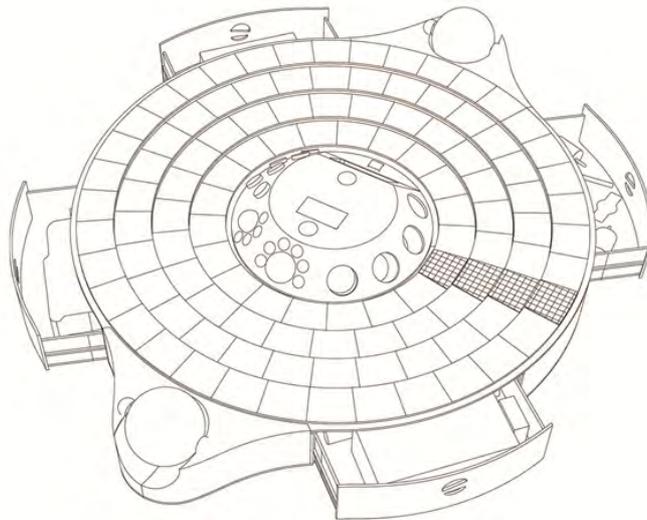


Figure 3

To Start a Game on the Board

The player with maximum energy is player 1 and takes the outer ring. Once the batteries are plugged in the board game, player 1 starts by casting the Normal Dice (see 'Dice'). Players move their tokens in the anticlockwise (Figure D) to the number of spaces indicated by the Dice, and execute the required tasks for the space they land on.



Figure 4

Dice

Each player in turn 'throws' the dice by spinning the clear ball on the game. There are 2 kinds of dice.

- The Normal dice, used to determinate how many squares to move the tokens
- The Jester dice (Figure E) used only when a player lands on the 'Jester square'. Each face has a different meaning ('Freeze', 'Move Forward/Backward', 'Red /Green Jester' & 'Blank').

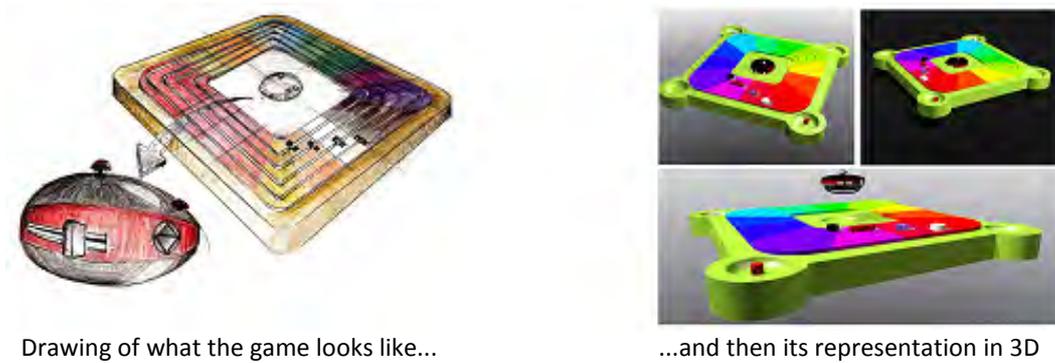


Figure 5

Iterative Design Process

Designing the Board Game

To arrive at the concept described above, there was a complex design development process. Several drawings and 3D modelling were produced to start building the game up (Figure F). The technology in the game was the starting point that guided the design of the game. In order to simplify the transfer of energy, all the electronics was gathered into the middle of the board, dictating that playing squares be laid out around this.



Drawing of what the game looks like...

...and then its representation in 3D

Figure 6

Figure G shows the emergence of different versions of physical prototypes with different levels of resolution. The designer evaluated these prototypes with colleagues and peers for initially feedback prior to presenting it to users (Houde & Hill, 1997).



(A) Visual Mock-Up

(B) Game Play Mock-Up

(C) Concept Prototype

Figure 7

Following a rough determination of the technological requirements, a 'Visual Mock-Up' (A, Figure G) was built to get a sense of the board game proportions, which revealed it to be too big.

'Game Play Mock-Up' (B) (Figure G) was produced in order to test the game play and visual communication of the various elements of stage 2. This simulation model has been tested twice with groups of designers (Figure H). This audience can understand the intention of the trial and hence disregard to the low resolution of the model (e.g. use of matches to simulate real energy). Non-

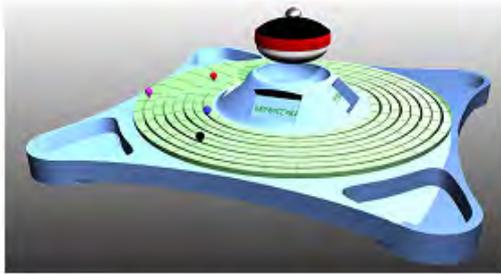


Figure 8

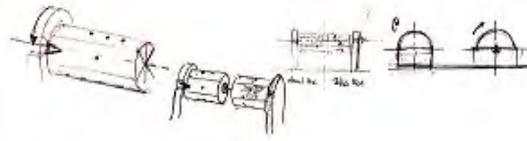
designer groups of participants may not have understood this intention quite so easily. The approach of utilising low resolution models and testing reduces the expense and time and allowed to trial multiple modes, models and layouts economically.

Designing the Hardware

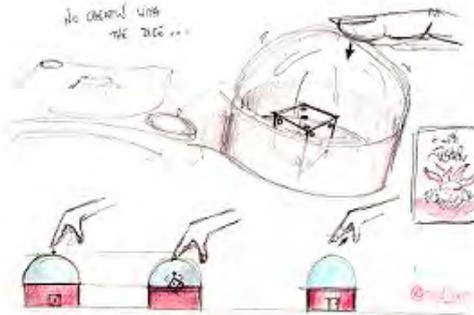
The Jester dice is specific to this game design and their lost can be problematic. Ideas were considered to avoid this problem with a final solution of putting a dice in a clear sphere (Figure 1).



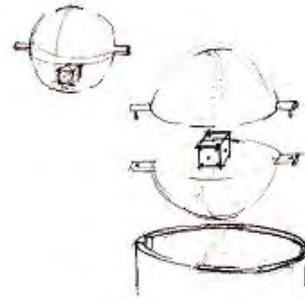
Dice is thrown in the cavity



Spin the rolls



Press the semi-sphere



Spin the sphere

Figure 9

Similar to the Roulette, this has the potential to increase engagement when ‘casting the dice’ as players can see the dice rolling, increasing the suspense of what score the player will get.

Further tests of the components of the game were undertaken and low cost materials (here blue foam) were used to test the ergonomics of the various elements, enabling to explore many shapes of different forms.

Simulation after simulation, the game and its rules developed, with the elements becoming more clearly defined. Based upon the feedback of the prototypes presented previously, an ‘Integration Prototype’ (Houde & Hill, 1997) was built ((C) of Figure G).

Every stages of test were crucial for the development of the game and it is only through a series of prototyping and testing that improvement and coherence in the design can emerge.

Gener-G in Context

Practical test

Once this integration prototype built, another test was conducted over a week in a family environment (Figure J), enabling feedback from a user group for whom the game was originally designed for.



Figure10

Because the prototype was a simulation, physical activity was self-reported by the players in terms of how long players were using the 'Generator'. According to these self-reported levels, a defined amount of energy using one, two, three and four AA batteries (from the least levels of physical activity to the most) was transferred into the right player's battery.

The researcher observed the play of the board game which was followed up by an interview with all the members of the family. The main feedback was that the concept was a good incentive for the players to do physical activity but needed improvements for both stages.

In stage 1, an alternative to the 'Generator' for generating energy would have to be considered. This was an original intention but rejected to avoid cheating (e.g. players can attach their battery onto their dog that will do the job for them). One solution would be that players can charge up the battery when running/jogging, or even throughout their daily tasks (i.e. walking, cleaning house...).

In stage 2, playing the board game was really complex due to the use of physical energy and to the diverse manipulations. There are many switches and buttons that can be confusing and energy can be lost when transferring from one battery to another.

Analytic Evaluation

According to Salen & Zimmerman (2004), players should be able to apply, misapply or subvert the rules to win; this is legitimately cheating.

This last evaluation actually allowed cheating as the levels of physical activity were self-reported but this would be different for a fully working prototype. However the game in stage 2 is based upon the quantity and quality of exercise stage 1 therefore more thoughts has to be made onto how stage 1 can influence stage 2.

Furthermore, fairness in stage 2 also needs reviewing. Even if the whole concept is about rewarding players doing more physical activity, the advantage gained in stage 1 shouldn't be fully certain for stage 2 and other players should be able to get back in the game. If the youngest player in the family generates the least energy in stage 1, winning the game becomes difficult, and he/she will get unmotivated and lose interest very quickly. There should be an element/square in the game that allows players swapping of circle as a way to maintain the uncertainty of winning, crucial element in a game play.

This lack of fairness is also partly due to the fact that the game play is mainly based on luck and players should be able to develop strategies to win. The definition of 'game play' is that a players' actions must change the actions of the other player, making him think of alternative moves, thus allowing players to develop new strategies (Salen & Zimmerman, 2004).

From the tests presented in this paper, Gener-G seems to have a viable working concept however many issues remain in terms of complexity of game play, fairness between all the players and the continuous dimension of gaming has to be more explored; repeated play hasn't been evaluated, partly due to the complex technology associated to it.

Behaviour Change and Genger-G

Theories & Models

Although the effectiveness of theories and models is limited, using concepts drawn from them is helpful when working on behaviour change (NICE, 2007). One theory commonly applied to Physical Activity is the Theory of Planned Behaviour (TPB) (Ajzen, 1991), defining how attitudes can influence behaviour according to an individual's behavioural beliefs, Subjective Norm and Perceived Behavioural Control. The subjective norm refers to the perceived social pressure and models provided by significant others like family and friends to adopt or not adopt behaviour (Ajzen, 1991). Even if intervention based on the TPB is effective in an exercise context (Nahas et.al., 2003; Chatzisarantis & Hagger, 2005), it doesn't account for group level change. Besides, being primarily a model of intention formation, it doesn't ensure that intentions are turned into action (Sutton, 1998).

The TransTheoretical Model (TTM) is a model that uses several theories of psychotherapy (Prochaska & Norcross, 1999) to describe the behavioural processes of change that have been regrouped into five stages to support individuals in the behaviour change process. It offers much potential and has commonly been applied to promote physical activity (Spencer et.al., 2006) however this model has been highly criticised and needs more research (Hutchison et.al.,2008) and evidence to suggest that the application of the model has health-related behaviours changes (Aveyard et.al.,2009), especially when used with adolescents (West, 2005).

Developed from the theory of motivation (Deci & Ryan, 2002), another important theory to consider is the Self Determination Theory (SDT), differentiating intrinsic and extrinsic motivation and suggesting how to move from extrinsic motivation to intrinsic.

Also, promoting physical activity should be based on multi levels interventions in four domains: recreation, transport, occupation (work/school), and household (Sallis et.al., 2006).

Gener-G and the Theories

Gener-G has obvious connections with the theories and models of behaviour change through elements that map onto experience of behavioural processes even if all of this was unknown when creating it.

Related to Sallis et.al. (2006)'s ecological model, Gener-G is a vehicle (game) that fits within a domain (household) using value (family) to engage with a topic (physical activity), which therefore uses the key components for driving behaviour change. The context of home and the value of family are used to engage and bring people together around activity without activity being expressed purpose. Some players may not be motivated to do physical activity to improve their health but to play the game. They get a sense of efficacy from doing the activity to power the game and this is why it may also engage some players to resolve ambivalence they might have to change.

Gener-G is a way to engage players across all the spectrum of stages of change due to the family orientation of the game. People from different motivation stages are brought together and the game has the opportunity to challenge or reinforce them depending on where they are across the process. However Gener-G doesn't provide a staged-match intervention: it is not targeted at a specific individual at a specific stage, and it doesn't support individuals to plan behaviour.

However Gener-G helps developing or reinforcing positive behavioural beliefs through playing the game; it has positive and direct benefits of doing physical activity through the use of rewards. This

extrinsic motivation is a way to initiate or adopt a change in behaviour but other elements need to happen to maintain that change over a long period.

Gener-G therefore uses components of processes of change to enhance or support attitudes and beliefs, and to create a social norm around exercise while increasing physical activity, component of the game.

What's Next?

From the Feedback

As an alternative to be more accurate in the simulations and to avoid complex manipulations in stage2, the game could be developed without real energy, using pedometers instead. This could measure levels of physical activity to be converted into points for stage 2. However it would still be easy to cheat by attaching pedometers onto the dog, making the legitimate cheating 'illegitimate'...

More fundamentally, this board game illustrates one way to play one type of game, in the family environment, but this was all conceived and developed without any knowledge or structure. The added knowledge of behaviour change theories as well as investigating young people might now open up different possibilities and dimensions in game play.

The Research

There is a need to better understand the end-users to find out what is relevant and appropriated so that they will be attracted and engaged by the game over a long term period.

Since the creation of Gener-G, a participatory approach with young adolescents (11-12 years old) has been taken forward to investigate their taste and lifestyle to create a new game design, more appropriate and acceptable. This enabled the researcher to explore more about the game/gaming aspect in the adolescents' lifestyle, where there is the possibility for game(s) to fit, which type, who with... This study has revealed that young adolescents are actually more motivated when playing with their peers rather than their family but it has also shown that orienteering games seem to be an area to investigate further.

As demonstrated in this paper, it is through the making of games that designer/researcher can develop a project further which is the aim of the next case study; combining the understanding gained during the pilot studies with the theories and models of psychology of behaviour change, game concepts are being generated and will be tested in another secondary school.

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Applying Inclusive Design Principles in the Assessment of Healthcare Services

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Abstract

Disadvantaged patients, such as the elderly or disabled, face a range of physical, emotional, and socioeconomic obstacles when dealing with the National Health Service in England. In an effort to address the needs of these patients, principles of inclusive design will be used in the assessment of the delivery of healthcare services.

This investigative study, targeting the experiences of disadvantaged patients accessing acute NHS services, will focus on improving accessibility of services by identifying obstacles and highlighting areas for improvement. This work, along with data regarding patient experiences, will build a strong picture of the needs of these patients. Overall, this research will improve access to services and the overall patient experience.

With the support of patient groups, we are investigating the issues that patients experience when navigating various healthcare services. Conducting interviews with staff will assist in mapping the flow of the patient through the system and identify stages where patients may encounter difficulties.

Semi-structured interviews evaluating patients' expectations within one specific service will help to achieve an understanding of what service characteristics help create a positive experience. To help identify to what extent each patient's capabilities affect the barriers they may face in accessing services, a public opinion survey is conducted with the support of national charitable organizations.

National statistical data, previously collected by the EDC, will be used to understand the prevalence of these issues in the NHS as a whole.

The results of this work will identify obstacles faced by disadvantaged patients accessing NHS services and highlight areas for improvement. This case study will provide a basis for continued improvement of NHS services as a whole.

Keywords: Inclusive design, patient experience, healthcare services

Introduction

The most recent statistic from the World Bank estimates that over 600 million of the world's population can be categorized as disabled, and this number is on the rise (The World Bank, 2004). With the growing demand for the National Health Service (NHS) to be able to support those in the United Kingdom (UK) with disabilities, as well as the needs of the ever growing ageing population, steps must be taken to accommodate the needs of the patients and improve the efficiency of services.

Disadvantaged patients, such as the elderly or disabled, face a range of physical, emotional, and socioeconomic obstacles when dealing with the NHS in England. In an effort to address these needs, principles of Inclusive design can be used in the assessment of the physical accessibility of healthcare services. Inclusive design can be defined as, "the design of mainstream products and/or services that are accessible to, and usable by, as many people as reasonably possible" (British Standards Institute, 2005). While it is apparent that the definition of disability is both relative and lacks some clarity, what is most important is to be able to provide the necessary support to the population as a whole.

There is a distinct need to marry patient perspective with quantitative population data in order to market changes in NHS services. Providing the prevalence of difficulties experienced by the less able community using population data may help to encourage change to help improve the service. With the growing strain on the healthcare system, current studies with site-specific resources are necessary to get a view of what is currently being investigated, and how to re-design the service in order to accelerate improvements in patient experience. For this reason, this study targets the topics of patient experience and improving the accessibility of NHS services.

Objectives

The aim of this study was to develop and use appropriate tools to measure patient experience. The goal was to highlight problem areas that if changed, may improve overall patient experience in acute NHS hospitals.

Improving the patient experience is important to NHS Trusts due to the increasing financial strain on the NHS from the ageing population and the fact that more patients are living longer and with many conditions (Hennessy & Kite, 2005). The focus of this study was on the external factors that affect the patient experience, particularly what the patient encounters in accessing NHS services. The patient journey can be categorized into three sections: a Preparatory Stage, a NHS Service Stage, and a Post-Service Stage. Focusing on the Preparatory Stage can address the patients who are frustrated prior to their appointment. This study paid particular attention to booking appointments, preparation,

transportation, and way finding. If it is possible to improve patient experiences before contact with the NHS, the patient may be in a better state of mind, which may lead to both a more positive experience and increased patient compliance (Donovan & Blake, 1992).

The main objectives of this study involved investigating patient experience, accessibility, and how patient capabilities affect the accessibility of acute NHS services. These are all addressed in the research question driving this study:

What barriers do patients experience in accessing NHS services, and to what extent do their capabilities affect how they negotiate these barriers?

The first objective was investigating the conflicting definitions in literature for patient experience, in order to develop an appropriate understanding for this study. As there are also many methods of measuring patient experience, it is important to develop a way to combine tools to appropriately evaluate it for this study.

The next objective was to address the question of accessibility, as it is imperative to understand the demands on all patients.

The third objective involved using population data to highlight areas most difficult to patients and quantify the magnitude of the problem.

Overall, this investigative study, targeting the experiences of less able patients accessing acute NHS services, will identify obstacles and highlight areas for improvements. The intention of this work was to build a strong picture of the needs of the less able community, and the size of the effect on the current system.

Methods

In order to obtain a holistic view of the patient experience, this study combined investigations both within and outside of an acute hospital, and involved exploring the patient's perspective through qualitative analysis, as well as quantitative data analysis. The methods required to assess the three main objectives of this research are discussed below.

Assessing Patient Experience

This study used satisfaction surveys, online forums, semi-structured interviews, complaint services, and expectation questionnaires to obtain qualitative patient data. Using this information, it was possible to obtain an insight into the patient's opinion of the NHS in general, as well as investigate

operations within an acute hospital. It was important to use many different tools in the investigation of what is patient experience.

Accessibility

With the support of online charitable organizations, it was possible to investigate the cross-boundary issues that patients experience when navigating healthcare services. Online forums were studied to gain an overall impression of the needs of the less able communities, particularly with issues of accessibility.

A public opinion survey was developed for national online distribution using various types of questions, such as multiple choice, rating scale questions, and comment sections. It was a set of detailed questions that helped to analyze each respondent's capabilities relative to their difficulty in accessing NHS services, particularly when booking appointments, preparing, transporting, and way-finding in a hospital. While the original Picker Patient SF36 (Garratt, Ruta, Abdalla, Buckingham, & Russell, 1993) measures severity on a 4-point scale, from none to severe, the public opinion survey follows a similar format to the updated version with a 5-point scale but measures difficulty of task as opposed to severity, disability or pain. The use of a public opinion survey would allow for an understanding of how the capability level of each patient affects his or her difficulty in the access of services and would help to highlight areas in need of improvement.

Interviews conducted with staff assisted in mapping the flow of the patient through the Preparatory Stage, as seen in Results Figure 4, and identifying stages where patients may encounter difficulties. It was necessary to appropriately map out the patient journey in order to gain an understanding of the tasks required of the patient to access NHS services, as well as to later enable the use of an exclusion calculator (University of Cambridge, 2011). The task breakdown was initially completed by the researcher using information gained from background research and staff within the acute hospital. In later analysis, details acquired through the public opinion survey were used to amend this mapping. It could be argued that without input from both the patient and healthcare providers, the task breakdown would not be as accurate.

Population Analysis

Using principles of Inclusive design may aid in re-designing the current system to accommodate the less able population. One method of using inclusive design in analysis is in the integration of general population data. This was made possible with the national statistical data analyzed in the Engineering Design Centre, or EDC (Department of Social Security, 2000).

Quantitative tools such as the exclusion calculator in the Inclusive Design Toolkit (University of Cambridge, 2011), were used to determine the prevalence of issues in accessing NHS services . Figure 1 demonstrates how the exclusion calculator was used.

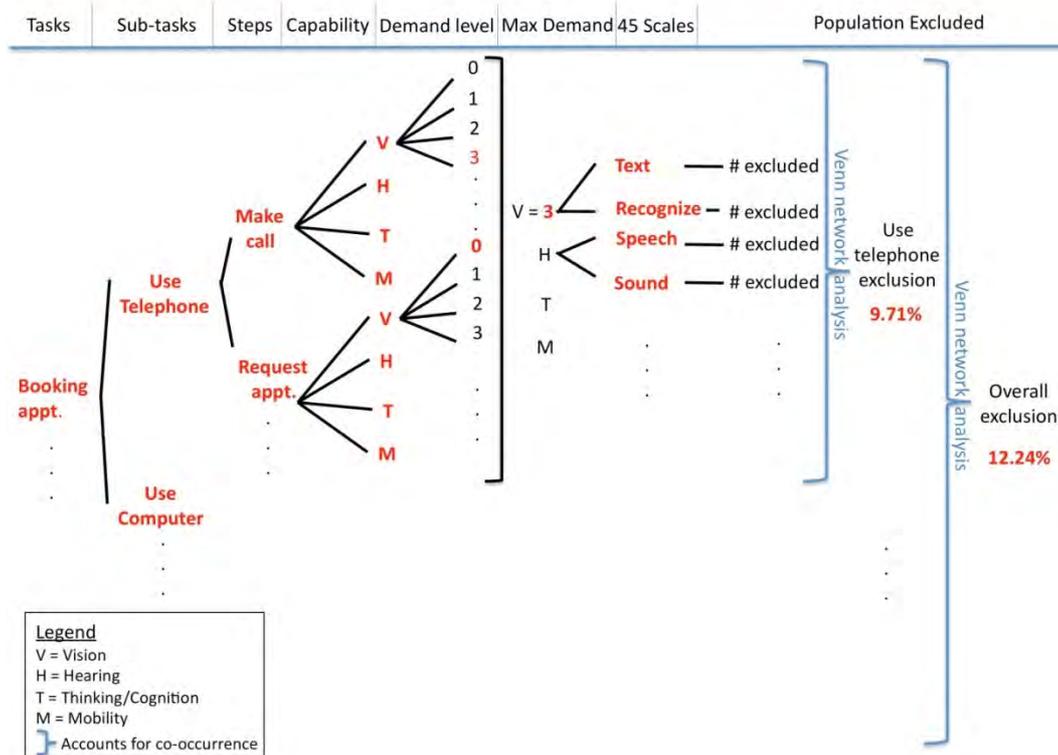


Figure 1 - Exclusion calculator algorithm example

Figure 1 shows the complexity of the exclusion calculator, which involves using the 45-scale database and population data. In order to compensate for co-occurrence of disabilities, methods most similar to Venn circles, as seen in Figure 2, were used to determine what percentage of the population was excluded from a network of tasks. In the patient journey breakdown there are 4 tasks (booking appointment, preparation, transportation, way-finding). Within each task are sub-tasks (ST), each broken down into steps. Each step has various vision, hearing, cognitive, and mobility demands, each on a demand scale from 0-3. The maximum value of these demands over the entire sub-task was taken, and inputted into the 45-scale exclusion calculator. For each demand scale, there is a value for the population excluded, as calculated by Dr. Sam Waller in the EDC. Using a Venn circle analysis of the exclusions calculated for the sub-task, it is possible to determine the total population excluded from that sub-task. Similarly, by doing a Venn network analysis on the combined sub-tasks, it is possible to calculate the overall population excluded from the series of tasks.

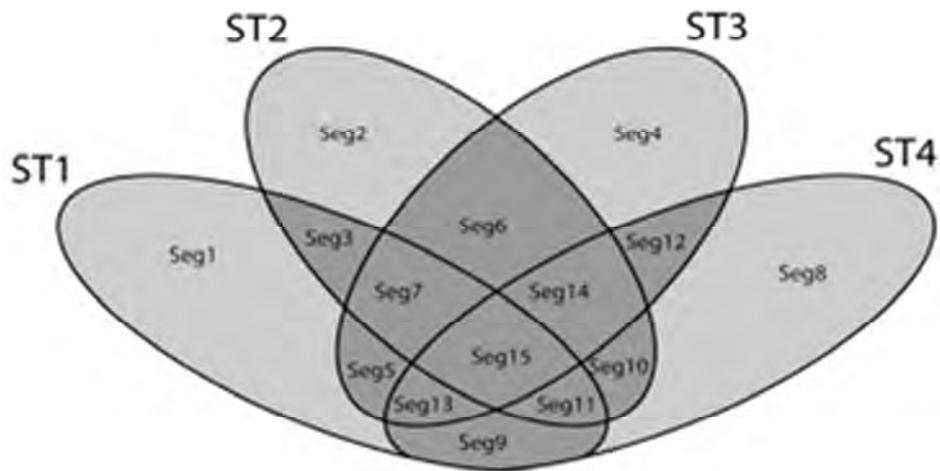


Figure 2 - Venn circle analysis to account for co-occurrence

Each segment represents a sub-task (ST) along the patient journey mapping. Combining the network of four sub-tasks, represented in Figure 2 by booking the appointment on the telephone (ST1), online (ST2), preparation (ST3), and transportation with way finding (ST4), allows for the total exclusion calculation using set theory as in Equation 1.

$$[(ST1 \cup ST2) \cap ST3] \cap ST4 \quad \text{Equation 1}$$

The segments that represent the overall excluded population calculated from Equation 1 above is \in Seg13, 14, and 15 in Figure 2. These calculations were completed on an Excel workbook developed by Dr. Sam Waller in the EDC. Further details regarding this approach will be discussed in a forthcoming paper (Waller, Goodman-Deane, Bradley, Langdon, & Clarkson, tbd).

Results and Discussion

The results address, in order, the three main objectives of the research.

Assessing Patient Experience

There were four studies that involved collecting and analyzing data from patient perspectives. These included patient experience feedback, a satisfaction study, and an expectations study. The public opinion survey also aided in assessing the overall patient experience, however the questions used truly addressed the issue of accessibility, so is discussed in the accessibility section.

In the acute hospital it was important to study satisfaction surveys and patient complaints, their current methods of assessing patient experience, to compare internal results with the more national view of healthcare services. It also gave insight into the current methods used in practice in general today. In speaking with various members of staff at the acute hospital, it was evident that the satisfaction results are very high despite observations of problems with accessibility. It was noted that the two measurements paint a contrary picture given a high rate of reported patient satisfaction, yet also a significant rate of patient complaints. While most complaints addressed quality of care issues, the satisfaction results highlighted the difficulties in accessibility. Better cohesion between the two methods may help to produce a more in-depth picture of their patient needs.

The patient expectation study conducted in a department in the acute hospital involved hospital standardized semi-structured interviews and a paper questionnaire, developed by the researcher. The questionnaire investigated the importance of expectations (a score of 1 being 'not at all important', 5 being 'extremely important') in six categories: choice, information, explanation, test & diagnosis, support, and follow-up. One of the most important issues, with 90% of the participants scoring either a 4 or 5 out of 5, fell within the "Information" section, which is within the Preparatory Stage. By making the patient more comfortable with the details of their appointment, they may be more likely to show up for their appointment on time, well informed, and have an overall positive experience.

Accessibility

Parallel studies were conducted outside of the hospital, such as an assessment of patient experience from online forums and databases. These studies also allowed for a wider view, or more national view, of the patient experience. These experiences also helped to shape the patient journey breakdown, and highlight problem areas.

Using the same charitable organizations, a public opinion survey was administered online and addressed the less able population in the UK. There were 94 participants in the survey, with a 70% completion rate. The participants were most recently either at an outpatient visit (52%), an appointment with their GP (38%), in-patient care (4%), emergency (1%), or other (5%). The age distribution had a positive correlation of $r = 0.66$ between the data set in the public opinion survey and the UK population (Office for National Statistics, 2011). With a confidence level of 95% and the population of those less able in the UK being approximately 14,000,000 (Creative Research Systems, 2011), the confidence interval, or margin of error, for this study is approximately +/-10%. This assumes that the sample is meant to be representative of the less able population.

The most difficult tasks for less able patients are shown below in Figure 3. Those who answered 'Not difficult' are not shown, in order to focus on the tasks that the respondents considered difficult to any degree.

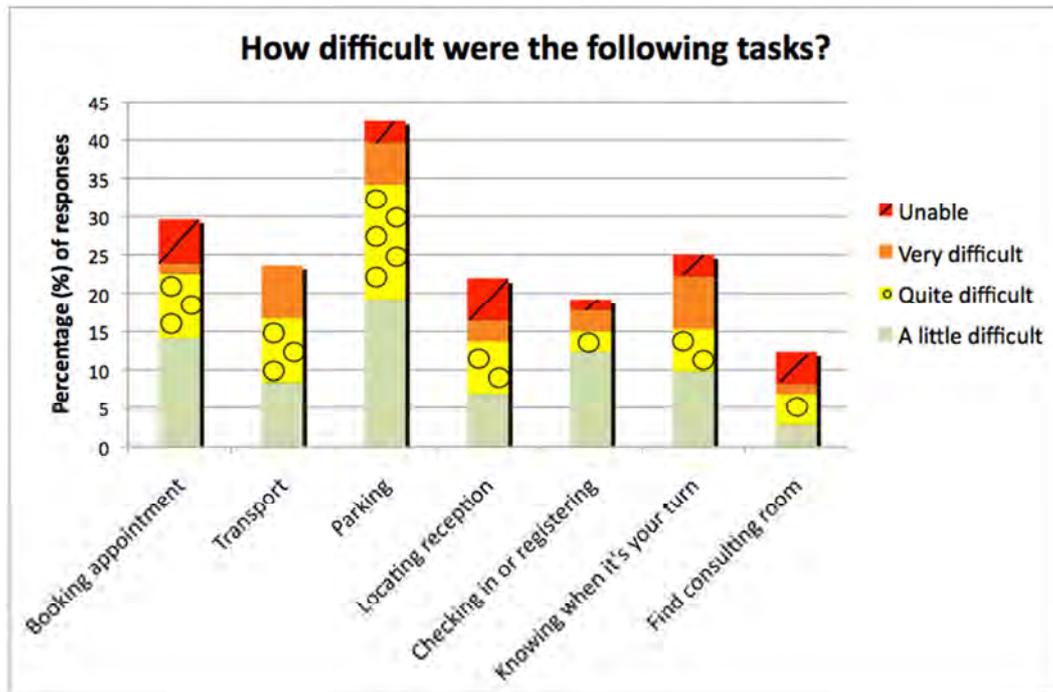


Figure 3 - Public Opinion Survey: Difficult tasks

It was found that 5.5% of participants were unable to locate the appropriate reception or ward on their own. In the acute hospital, this would amount to 60 outpatients in a 12-hour day requiring assistance immediately arriving at the hospital.

While booking an appointment using a telephone is the most common process to book in current acute services, it was found that only 28% of participants booked their appointment this way. No participants who were severely hearing impaired were able to book on the phone. 57.5% of participants said they did not receive any form of reminder about their most recent appointment. Overall, 20.5% had forgotten and therefore missed an appointment at least once.

66.6% of participants mentioned parking in the comments section, which may be the result of poorly marked blue badge (disabled) parking, difficulty in finding the parking area or exit of the parking garage, or even the large distance required to travel from the parking garage to the front door, as mentioned in some of the participant comments.

These survey results are representative of the population who are able to complete questions online. This may mean that these results are underestimating the needs of the less able population, as the responders are on the more able end of this population.

The information obtained from this survey aided in the development of a task breakdown along the patient journey, as shown below in Figure 4.

Exclusion Network

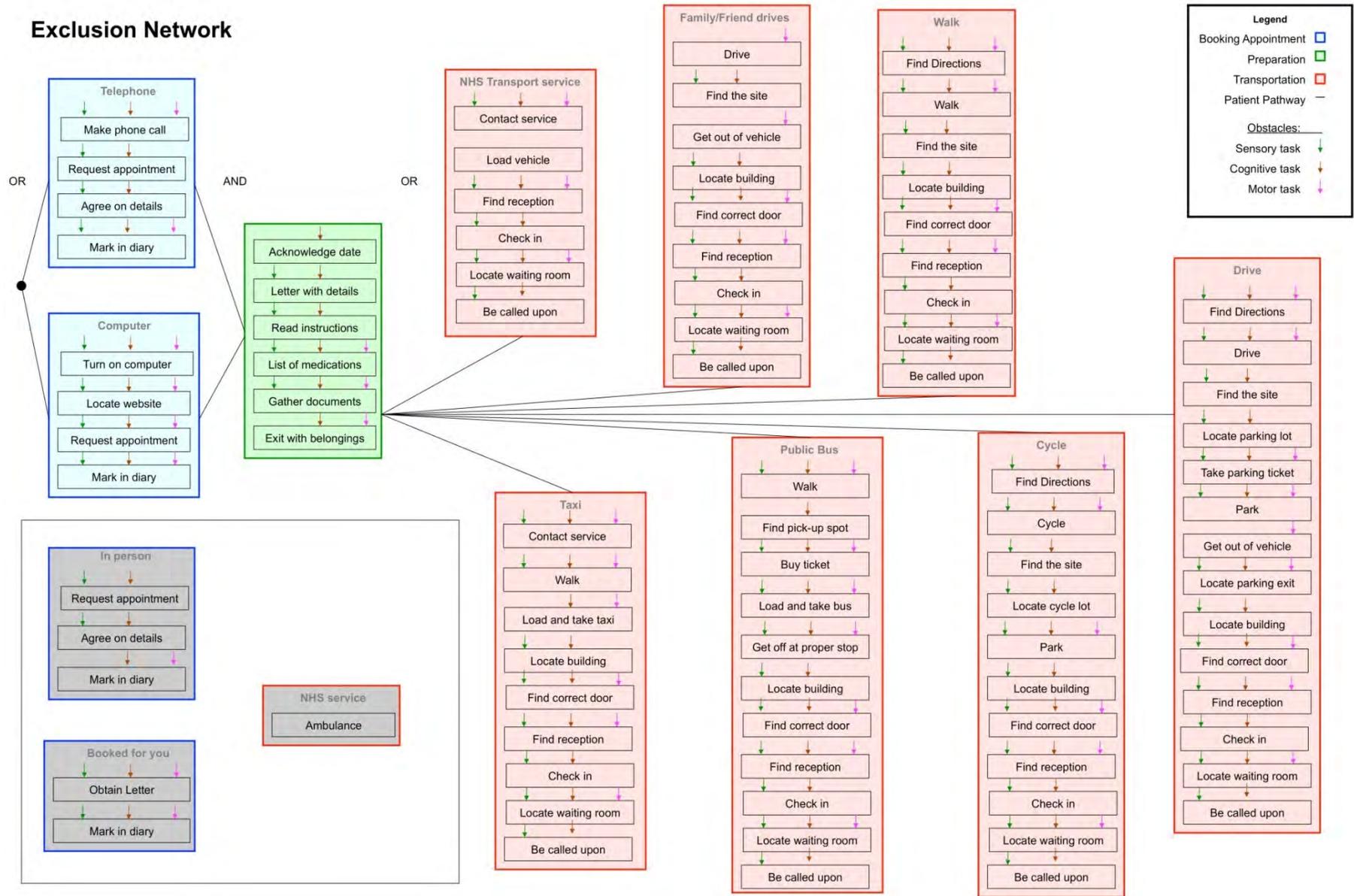


Figure 4 – Preparation Stage Network

This network shows the four sub-tasks that make up the Preparatory stage and were later used to calculate overall population exclusion. Blue represents booking the appointment, by telephone (ST1) or online (ST2), green is preparation (ST3), and red is a combination of transportation and way-finding (ST4).

Population Analysis

Using the Inclusive Design Toolkit exclusion calculator, it was possible to calculate the population excluded from each step along each sub-task. To clarify terminology for example, a task would be “booking appointment”, a sub-task would be booking the appointment by “telephone”, and a step is, for example, “making the phone call”. One assumption is that all patients would have reasonable access to all methods of booking the appointment and transportation. It was also assumed that funds would be available for the bus, taxi, or parking. For the bus and taxi, it is assumed that the patient has access to these within 0.5km from their residence.

The most difficult steps along the journey include making the phone call (9.44%), preparing a list of medications (9.28%), and locating the appropriate reception after being dropped off (4.22%).

The overall exclusion along the Preparatory stage of the patient journey, seen in Figure 4, was calculated to be approximately 12%. There may be considerable limitations to using the toolkit that analyzes a data set collected in 1997. The accuracy of the task demand estimates working in conjunction with the metrics of the original data set may impact the accuracy of this calculated value. For these reasons, and to accommodate for function rounding and floating-point numbers using the software, exclusion will be stated to the nearest percentage. Note that this amount is not a cumulative sum of those excluded from all sub-tasks, as Venn circle analysis accommodated for co-occurrence. This value is most likely the minimum exclusion, as the demand levels for each were chosen to be generous for an able bodied person, let alone one who would experience difficulty with the task. The resulting under-estimation coincides with the fact that 18% of the UK population are disabled, and most likely experience difficulty in accessing healthcare services (Employers Forum on Disability, 2010). The overall exclusion was calculated from the network in Figure 4.

Booking an appointment online was the most difficult method for booking, while cycling to the appointment was the most difficult mode of transportation. The least difficult pathway for the less able population would be as follows: book over the telephone, prepare, and then transport to the location by NHS transport service. If the appointment were at the GP, then having a family member or friend drive would be easiest. If the patient must transport his or her self, this analysis suggests that taking a taxi would be the least demanding method.

A graph showing what capabilities are most affected in accessing NHS services, undertaking ST1 or ST2, and ST3 and ST4 above, as calculated using the Inclusive Design Toolkit, is shown below in Figure 5.

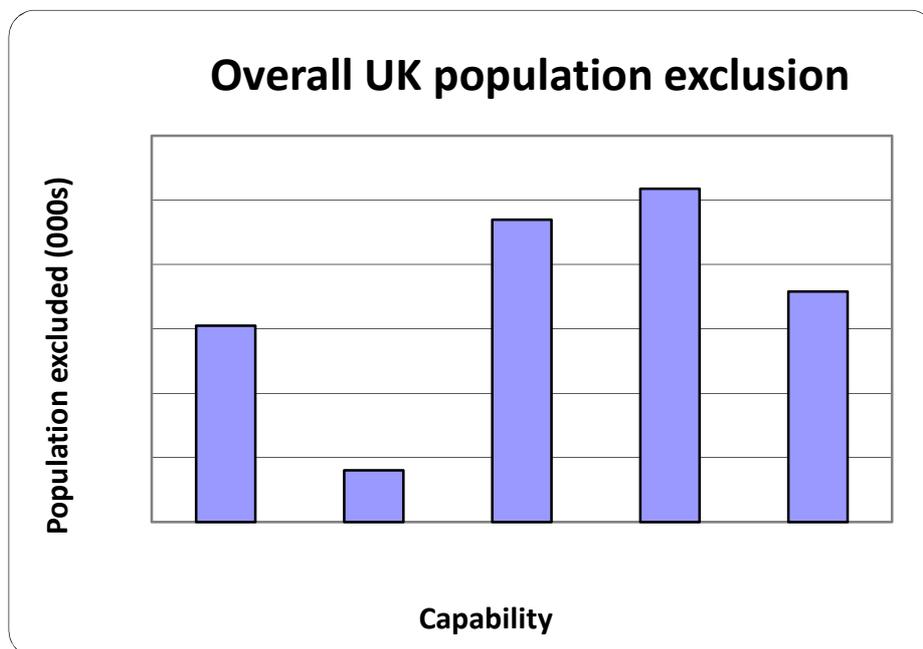


Figure 5 - The UK population over the age of 16 excluded, organized by capability

Those who have the most difficulty accessing NHS services are therefore members of the population who struggle with reach, stretch, and dexterity. This demographic would have difficulty booking appointments using a telephone or computer, opening doors, driving or cycling to the appointment, signing in at reception, and so on.

Conclusion

As the population demographic is continually ageing and the demand for improved care is put on the NHS, it is important to assess the needs of the patients, particularly those who are less able. New users often get frustrated or frightened even, when they have to deal with a complex system such as the NHS (Robinet, Picking, & Grout, 2008).

While most current healthcare studies focus on the service that the patient receives, this study shed light on the need for further investigation into the external factors, such as accessibility, that affect patient experience.

It became evident that collecting as much information as possible about an experience, through not just satisfaction surveys, expectation questionnaires, and feedback, but a combination of all three will enable a

broad view of the meaning of patient experience. Patients in the acute hospital expectation study found information to be one of the most important factors in improving their experience.

In terms of accessibility, public opinion survey results showed that the most difficult tasks for the less able community include parking, booking the appointment, and knowing when it was their turn. Approximately 12% of the UK population was found as excluded from accessing healthcare services. Those who are most affected are with reach, stretch or dexterity issues, amounting to almost 2.6 million people. Therefore, considerations have to be made for the population with these mobility challenges.

Improving the accessibility of services, or efficiency along the Preparatory stage of the patient journey, may ultimately save the NHS from resource and financial burdens, while also improving overall patient experience.

The findings of this study were shared with the partners in the acute hospital, as well as presented to an Outpatient Review Board for consideration. Many recommendations were discussed, such as ways to improve transfer of information between doctors and to the patient, improving booking appointment methods, and providing patient-specific appointment reminders. However, a thorough assessment of the impact of such recommendations would need to be conducted to formally comment on the success of implementation.

Going forward, the methods discussed could be used to investigate problem areas across the entire patient journey, assess changes made in the acute hospital as the result of recommendations from this study, and evaluate the feasibility of incorporating recommendations into other departments and across NHS hospitals.

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Patient 'carry chairs' – risk factors and proposals for their redesign

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I greatly appreciate the contribution made by all those students who have over the years played a part in the development of the carry chair design process detailed in this paper, in particular Tom Opie and Samuel Pearce.

Abstract

Musculoskeletal disorders (MSD) are a major cause of work-related ill-health, sick leave and premature retirement amongst ambulance workers. Over half of all MSD in ambulance personnel stem from the moving and handling of patients, with the use of a 'carry chair' being a primary cause of musculoskeletal injury to the handler. A study was conducted to identify musculoskeletal risk factors associated with carry chair design. Findings from the study ascertained user requirements and design principles for carry chairs, aimed at improving usability, and reducing the risk of injury to ambulance personnel and patients.

Musculoskeletal risk factors associated with the use of the carry chair were identified by means of questionnaire survey, semi-structured interviews, daily records of patient handling tasks, and observations of working practices. These elicited information about the design and usability of carry chairs, working practices and work organisation. Three UK ambulance services participated in the study, their selection being based on the make and model of carry chair in regular use at each service. A series of user requirements and design characteristics were established which led to design concepts.

Approximately 40% of the 64 incidents attended by ambulance personnel involved the use of the carry chair. Principal risk factors included chair instability, the chair height leading to poor posture, patient transfer difficulties, and inadequate patient support/restraint. Three workplace environments were perceived as a major hazard: spiral stairways; and gravel and grass surfaces. The acceptance and implementation of new carry chairs was considered poor, due to major design limitations and a lack of appreciation by manufacturers of daily working practices.

Proposals for the redesign of the carry chair focused on: stair support mechanism; handles; folding mechanism; footrest; seat pan and backrest; wheels; and material selection. Further testing of these design proposals is necessary and involvement of users in this evaluation is considered essential to ensure acceptance and implementation of potential new designs.

Keywords: Carry chair, Ambulance personnel, Patient transfers, Musculoskeletal disorders, Musculoskeletal risk factors, Ergonomics

Introduction

Musculoskeletal disorders (MSD) are the leading cause of work-related ill-health within the ambulance services, accounting for 67% of all reported injuries in the US (Conrad, Reichelt, Lavender, Gacki-Smith, & Hattle, 2008). A survey of accident and incident data collated from six UK ambulance services found that between 30 and 51% of all recorded incidents involved the moving/handling of loads, which resulted in some form of MSD (Boocock, Gray, & Williams, 2002). The incidence of MSD brings with it high social and economic costs, with ambulance workers suffering high rates of absenteeism and permanent disability (Boocock et al., 2002). Furthermore, a disproportionate number retire early due to health-related issues (Conrad et al., 2008; Pattani, Constantinovici, & Williams, 2001; Rodgers, 1998a, 1998b).

Risk factors contributing to MSD amongst ambulance workers include heavy physical work demands (Doormaal, Driessen, Landeweerd, & Drost, 1995), psychological aspects of the job (e.g. dealing with severe and stressful situations) (van der Ploeg & Kleber, 2003; Wiitavaara, Barnekow-Bergkvist, & Brulin, 2007) and work organisation (e.g. time pressure, irregular work hours) (Gamble et al., 1991). Ambulance workers are often required to operate in unpredictable and inhospitable work environments, such as confined spaces and inclement weather. This places a number of constraints on equipment design, as patient handling devices are often required to be lightweight, easy to assemble and portable.

The emergency carry chair is one of the principal handling devices used by ambulance personnel for transporting patients to and from public/domestic dwellings. It is used to transport patients in a sitting position and whilst termed 'carry chair', possess wheels that enable the device to be used in a manner similar to a wheelchair. The requirements for lifting and carrying patients up and down stairways or over uneven surfaces have been reduced in some models by adaptive wheel designs (e.g. caterpillar type tracks) that facilitate partial weight bearing when used in these environments.

An analysis of 1039 incidents identified the use of the carry chair as one of the three main tasks linked to accident/injury causation (Boocock et al., 2002). Despite the high incidence of injury associated with this type of patient handling equipment, the knowledge of risks associated with the use of the carry chair is limited. Consequently, there is a need to provide an objective evaluation of current carry chair handling practices to inform users about the risks, and direct manufacturers to facilitate improvements in design.

The aims of this study were to: 1) determine aspects of current carry chair design features, patient behaviour and working practices impacting on the risk of MSD to ambulance worker and patient; and 2) identify important end-user requirements of carry chair design to propose design features for reducing the risks of injury to handler and patient.

Methods

To determine design features, patient behaviour and working practices impacting on the safe use of carry chairs the study undertook: 1) a questionnaire survey of ambulance personnel; 2) semi-structured interviews with ambulance personnel; 3) observation of patient handling tasks; and 4) documentation of manual handling tasks (field study). Findings from these measures informed end-user design of requirements. The proposals for carry chair redesign involved a review of the design literature and development of concept designs.

Participants and carry chair designs

Three UK ambulance services (A, B and C) participated in the study. Ambulance services were selected to include different makes and models of carry chair, with the range of typical models shown in Figure 1. All three ambulance services covered large geographical areas, both urban and rural. Service C was the largest employer of ambulance personnel with approximately 925 staff compared to approximately 536 and 527 at services A and B, respectively.



Figure 1. The four models of carry chair used by the three ambulance services: Services A (A1 and A2); B; and C

Questionnaires were distributed to each service and contained 27 questions grouped according to: personal details; patient handling; carry chair usability; carry chair design; work environment; training; and incidents/accidents/near misses. A trained ergonomist accompanied ambulance workers when attending incidents to observe working practices. Observational record sheets were used to record the type of incident, patient and condition, handling procedures, work environment, and handling tasks involving a carry chair, following each incident. On some occasions, and with the consent of the patient, video recordings were also made of patient transfers. The semi-structured interviews involved a series of open-ended questions relating

to ambulance vehicles and equipment familiarity, the application, usability, and design of carry chairs, risk perception, risk assessment and control, information transfer/training, and carry chair incidents. These were normally conducted when ambulance workers were on standby at the ambulance station.

Results

A total of 114 questionnaire responses and 111 incident report forms were completed by ambulance personnel directly following an incident involving patient transportation. Twenty four interviews and 64 incidents were attended by observers accompanying ambulance crews.

Carry chair use

Observational data and documented records of incidents attended identified that carry chairs were used in 38% of all incidents of patient transportation. This was a higher percentage than for any other method of patient transfer, such as walking patients (35%) or using stretchers (17%). Seventy percent of patient transfers to the ambulance were from residential properties. The most common handling environments encountered by ambulance workers were: negotiating kerbs (84% of incidents); descending stairs (50% of incidents); and negotiating steep inclines (39% of incidents).

The floor surfaces over which carry chairs were most often moved included carpets (68%) and smooth ground (52%). Transportation over both gravel and grass surfaces occurred during 7% of incidents attended by ambulance workers.

Carry chair usability

When asked to rate the ease of use on a 5 point scale of difficulty (1 = "very difficult" and 5 = "very easy"), three working environments were perceived to present significant hazards for carry chair use: 1) ascending /descending spiral staircases (mean rating = 1.85); 2) pushing on grass surfaces (mean = 1.59); and 3) pushing on gravel surfaces (mean = 1.61).

When asked to comment on features of the carry chair that increase the difficulty of patient transfer during common handling tasks (e.g. bed-to-carry chair, carry chair to stretcher), three common themes emerged: 1) instability of the chair during patient transfer; 2) mismatch in height between the chair and other equipment; and 3) the height of the handles leading to flexed postures.

Carry chair design

When asked to rate the suitability of handles and wheels, 40% of users rated the head-end handles and 35% the foot-end handles as very poor or poor. Approximately 37% of users rated the handles too thin. Wheel sizes and thickness of tread were viewed by many (80%) as being either too small or too narrow.

The usability of the footrest was seen by a majority (60%) as being 'poor' or 'very poor'. The robustness of the chair was not considered to be a problem, as a large percentage of respondents (87%) rated it as being adequate or better than adequate. Ambulance workers commented that patients often feel unstable or unsafe when in the chair, due to lack of arm supports. This also made sitting down and standing up from the chair difficult.

A summary of the key design features of the carry chair which ambulance workers considered poor and influenced the ease of handling are detailed in Table 1.

Design feature	Aspects of chair design considered poor
Wheel size	Small wheel sizes contributed to difficulties of manoeuvring the chairs on certain surfaces, such as gravel, grass and flag-stone paving
Patient restraint straps	Restraining straps were considered poor on some carry chairs and failed to provide lower leg, foot and upper limb restraint
Footrest	Footrest were considered poor on most chairs providing inadequate surface area for the feet to remain supported
Head-end handles	Head-end handles were mostly viewed as inappropriate (too low) and there was a common desire for adjustability
Stability	Poor stability of the chair, particularly with heavy patients, and was often attributed to the lack of upper arm restraint
Compatibility	Compatibility with other equipment, especially during patient transfers and the transporting of other equipment (e.g. gas bottles).

Table 1. Key carry chair design features perceived as poor by ambulance workers

Organisational issues

Training and awareness of risk assessments was considered poor across each ambulance service, with few workers indicating that they were aware of risk assessments for carry chairs. The majority of ambulance personnel regarded training as being adequate when initially introduced to, or following the introduction of a new carry chair design. The importance of user acceptance and 'ownership' was apparent at one ambulance service which had been actively involved in the trialling of a new chair, working with the manufacturers and suppliers to implement modifications. The same chair was disliked by other users from other services who had not been involved in the design and implementation process.

Concept design

Findings from the field survey were used to establish a set of design criteria and core functions of the carry chair. Similar to Conrad et al. (2008), a set of end-user acceptance criteria were established (Table 2).

Acceptance criteria	Requirements
Affordability	Low cost equipment (costs are also associated with training and installation)
Clean-ability	Easy to clean and disinfect
Compactness	Suitable for use in narrow corridors, confined spaces and on tight/curved stairways
Conformability	Comply with appropriate standards and suitable for use with other equipment (e.g. stretchers, gas bottles)
Durability	Low maintenance, high strength requirements (carry at least 180 kg), and withstand exposure to adverse environmental conditions
Functionality	Capable of negotiating common obstacles, e.g. ascending/descending stairs, slopes and inclines, uneven and rough terrain, door sills, foldable or collapsible
Operability	Quick, easy and intuitive to assemble and disassemble, operated by a minimum of two persons, handles sizes and positions appropriate for required tasks, safe to use and minimises risk of injury to patient and care-giver
Portability	Lightweight and suitable for carrying
Stability	Stable during patient transfers and when transporting over different terrains (e.g. slopes and inclines, ascending/descending stairs). Suitable patient restraints
Storability	Easily stowed and accessible on the ambulance

Table 2. Proposed end-user acceptance criteria for carry chair design

Based on these user requirements, a series of concept design features were proposed and tested within a laboratory environment (not reported here). Seven aspects of design were considered important: 1) stair support mechanism; 2) head-end and foot-end handles; 3) folding mechanism; 4) footrest; 5) seat pan and backrest; 6) wheels; and 7) material selection. An illustration of a proposed concept design (Mobilizer) is depicted in Figure 2 and aspects of this design are discussed below.



Figure 2. Carry chair concept design

Stair support mechanism

A key design concept of the carry chair that shapes many parameters of design is the method for ascending/descending stairs. This is a primary function of the chair and has significant influence on the risk of injury to patient and operator. In line with some current designs, a track or 'skid' system for partially supporting the weight of the patient and chair on the stairs during ascent or descent was viewed as the most desirable option and reduces the load on the handlers (Figure 3).



Figure 3. Design proposal for a detachable stair support mechanism

The main requirement was seen as a steady ascent and descent of the stairs with continuous contact between stairs and chair, a braking mechanism for controlling ascent/descent, and good manoeuvrability for negotiating tight turns in the stairway. The proposed stair support mechanism incorporates a rotating track controlled by a braking system and spanned either side by low friction surfaces to assist manoeuvrability. Hinged at the axle of the chair's wheels, the stair support system would be able to pivot about the axle and follow the gradient of the stairs. Additional beneficial features were a damping system to cushion forces during ascent/descent, a detachable arrangement to assist with storage and reduce weight when not being used on stairs, and a carrying handle to assist during transportation.

Handles (head and foot-end)

The handles provide the interface between handler and equipment and therefore, are an important part of the design. Handle design features considered important were: appropriate height and orientation;

adjustability; adaptation of a neutral wrist posture; and positioned to provide equal distribution of load between handlers. Consideration was also given to Pheasant and Haslegrave's (2006) recommendations for optimum handle design, i.e. cylindrical handles provide the most comfortable grip and should be between 30 and 50 mm in diameter; forces should be exerted perpendicular to the axis of a cylindrical handle; and a handle grip length of 100 mm to 120 mm allows optimum force exertion.

The proposed head-end handle is triangular in shape and has an orientation so the handle can be held vertical when pushing along flat surfaces. The upper triangular shape provides suitable orientation and power grip for supporting the weight of the patient and chair during ascent and descent of stairs. A centrally located, quick release handle permits easy adjustment of the handle height.



Figure 4. Design proposals for head-end and foot-end handles

Critical to the design of the foot-end handles is reducing the amount of trunk flexion required by the operator when supporting the chair. The handles are hinged on the front axle and a spring mounted pivot allows some movement when large forces are applied (Figure 4). The handles are a minimum of 300 mm long which allows for a more upright trunk posture. The option of adjustable length handles has been provided, although this adds to the complexity of the task and requires further testing.

Folding mechanism

The folding mechanism is depicted in Figure 5. The main pivot is a critical feature of the folding design as it allows the main frame to be constructed of a single support bar reducing the overall weight of the chair.

When assembled, the leading edge of the seat pan clips into a rubberised jaw, for quick and easy assembly. The folding design allows the chair to be reduced to half its size.



Figure 5. The proposed folding mechanism of the carry chair concept design

Footrest

A patient footrest was a feature perceived by ambulance personnel to offer benefits to both patient and handler. Thus, a folding footrest with raised metal and slip resistant surface has been incorporated into the prototype design (Figure 2).

Seat pan and backrest

A well supported seat position reduces the potential for patient movement and, increases the patient's feeling of stability and comfort. A seating material that incorporated a two-way stretch inside a contoured frame has been shown to promote a person mediated neutral sitting position (Stumpf, Chadwick, & Dowell, 2003). Not only would this design promote a comfortable seated posture, but would reduce materials used in the construction of the chair, thereby reducing its weight and allowing easier folding and cleaning.

Wheels

The design of wheels and ease of use in a variety of environments were of concern to those interviewed. Two wheeled designed chairs require the head-end operator to exert a horizontal force while simultaneously pushing down on the handles to raise the front end of the chair. Due to the height of the head-end handles on many current carry chairs, applying these forces when pushing the chair can often lead to a stooped posture. Therefore, a four wheel design was considered desirable in order to reduce the musculoskeletal stresses on the operator. The proposed design incorporates a set of large diameter rear wheels of lightweight, rigid construction, while the front wheels are smaller and mounted on castors to aid manoeuvrability. Their simple design reduces costs and maintenance requirements.

Material selection

The materials for inclusion in the chair design must be strong (i.e. carry loads of at least 180 kg), lightweight and resistant to corrosion. Cost will ultimately have a significant bearing on the final selection of material. Using Ashby's (2010) material selection charts for strength, density, fracture toughness and cost, aluminium alloys currently offer the best material characteristics for a large majority of the chair.

Discussion

Physical, psychological, work organisational and environmental demands are known to have a dramatic impact on the musculoskeletal health and disability of ambulance personnel (Doormaal et al., 1995; Gamble et al., 1991; Wiitavaara et al., 2007), leading to higher rates of sickness absence and premature retirement than in many other professions (Pattani et al., 2001; Rodgers, 1998a, 1998b). Reducing the physical demands of the task through improved design can offer one solution for reducing the likelihood of injury in this group of workers. As a high dependency piece of equipment, design improvements to the emergency carry chair have the potential to offer significant benefits for the safety and health of the operator and patient.

The carry chair characteristics were modelled to combine user experiences, observational techniques and laboratory testing (not reported here), to determine at the outset the dimensional and functional requirements important to a successful design. From these evaluations, end-user acceptance criteria were established, that targeted and directed design. Using focus groups to facilitate design criteria, Conrad et al. (2008) establish five important user requirements for different patient handling scenarios. The current study classified user requirements into 10 design criteria, which reflects the specificity of the end design, i.e. the study focussed on the one patient handling device as opposed to a range of handling scenarios reported by Conrad et al. (2008). Optimally satisfying each user requirement seems unrealistic and some compromise, or priority placed on specific design features will be required.

Conclusions

Based on user requirements, concept developments for the next generation of carry chair are presented. However, considerable work is still required to develop and test the proposed design features before a final product can be realised. As was evident from the field survey, acceptance and implementation of new equipment within the ambulance service is often poor, due to inherent design limitations and lack of user input in the design process. The current study has adopted objective measures to identify user requirements which will serve to increase manufacturers' awareness of primary functional requirements and the limitations of current designs. Involvement of users in the design process is considered critical if acceptance and 'ownership' of the product is to be established.

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KEYNOTE PRESENTATION

Towards Evidence-Based Design for Patient Safety

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KEYNOTE PRESENTATION

Abstract

As modern healthcare services have evolved, so has their complexity, but insufficient attention has been given to how effectively separate elements and process are integrated into a coherent system. In recent years, concern has grown over the incidence of adverse events and the extent to which these can compromise patient safety.

Products and equipment are required to perform in the context of a complex system rather than as stand-alone items. Their primary purpose is to support increasingly complex processes delivered by teams of clinicians and nursing staff and, as their numbers proliferate, they can interact in problematic ways. To mitigate against this, and in an era of evidence-based healthcare, a similarly robust approach to design is clearly advisable, but achieving that requires confronting several challenges. In the UK, a series of initiatives has sought to address this issue through a better understanding of the role of design in healthcare.

This paper outlines the 2004 Design for Patient Safety study commissioned by the UK Department of Health (DoH) and Design Council, along with a series of case study design initiatives building on that study. In particular, it focuses on the developing methodology and multi-disciplinary teams that emerged in response to the challenge of developing an evidence-based approach, and discusses how such an approach – inevitably demanding in time and resources – can be reconciled with lead times and cost levels that meet the needs of industry and NHS budgets.

The challenge of doing so while ensuring acceptance by the multiple stakeholders involved in selection, purchasing and use of healthcare equipment is also addressed, and suggestions are made as to how evidence-based design for patient safety might be further developed as a robust, effective and cost-efficient solution to significant issues facing modern healthcare services

Background: the Patient Safety Context

Ensuring patient safety is becoming one of the most important challenges facing healthcare today. The NHS is a highly pressured, complex organisation in which the potential for error is ever present. In the UK it has been estimated that adverse incidents occur in 10% of NHS hospital admissions at an annual cost to the taxpayer of approximately £2 billion (DoH, 2001), while studies in the United States, Australia and Britain indicate the extent of this problem, with 4-16% of patients admitted to acute hospitals being harmed in some way by medical interventions (Leape et al. 1991) (Vincente, 2004) (Wilson et al., 2004).

In 2000, the findings of an expert group on learning from medical accidents in the NHS, chaired by the Chief Medical Officer, were published as *An Organisation with a Memory* (DoH, 2000). The proposed strategy was

based around a new national system for reporting, analysing and learning from adverse events involving NHS patients. All of the report's recommendations were accepted by the Government and plans to implement this agenda were announced in *Building a Safer NHS for Patients (DoH, 2000)*, which recommended that early targeted action should be undertaken to identify opportunities for improved patient safety through the more effective use of design.

The National Patient Safety Agency (NPSA) was established in 2001 to take forward this new strategy which, importantly, recognised the key role design can play in delivering safer healthcare products, services, processes and environments. In response, the DoH and the Design Council commissioned *A scoping study to identify how the effective use of design could help reduce medical accidents* (Buckle et al., 2003a). The study was undertaken in 2003 by research teams at the Universities of Surrey, Cambridge and the Royal College of Art and published in 2004.

The research included widespread consultation with deliverers and practitioners of healthcare, experts from industries where safety is a prime concern, representatives from the pharmaceutical and medical devices industries, patient support groups and designers.

The research methodology

A multi-disciplinary team of ergonomists, engineers and designers was assembled from the three institutions involved, led by Professors Peter Buckle of the Robens Centre for Health Ergonomics at the University of Surrey; John Clarkson of the Engineering Design Centre at the University of Cambridge; and Roger Coleman of the (then) Helen Hamlyn Research Centre (HHRC).

Drawing on its wide expertise and experience, the research team was able to combine a range of formal research methods with creative and design-based techniques. This allowed it to arrive at robust conclusions and deliver implementable recommendations within the short time available.

Objectives Methods	Objectives								
	1 Mapping the problem	2 Investigating special cases	3 Identifying problems	4 Identifying best practice	5 Facilitating change	6 Solving the problems	7 Making recommendations	8 Communicating findings	9 Achieving action
1 Systematic lit review, journals	✓	✓	✓	✓		✓	✓		
2 Lit review, reports and "grey" literature	✓	✓	✓	✓		✓			
3 Information exchange with international experts	✓		✓						
4 Prior experience of res. team	✓		✓	✓	✓	✓	✓		✓
5 Workshop: other safety critical sectors				✓	✓	✓	✓		
6 Input from senior health service and agency personnel	✓			✓					✓
7 Interviews with healthcare practitioners	✓	✓	✓	✓					✓
8 Focus groups with healthcare practitioners	✓	✓	✓	✓					✓
9 Workshop with primary/secondary healthcare deliverers	✓	✓	✓	✓	✓	✓	✓		✓
10 Workshop with supply chain stakeholders	✓		✓	✓	✓	✓	✓		✓
11 Workshop with patient support group	✓		✓		✓	✓	✓		✓
12 Workshop designers					✓	✓	✓		✓
13 Systematic consensus / priority setting by res. team					✓	✓	✓		✓
14 Iterative review of report with Dept of Health and								✓	

Figure 1. Research methods plotted against study criteria (design-led methods in red)

The main conclusions of the study were that:

- The NHS is seriously out of step with modern thinking and practice with regard to design. A consequence of this has been a significant incidence of avoidable risk and error.
- There is little evidence of design understanding or practice within the NHS equivalent to those which are commonplace in other safety-critical industries and leading commercial organisations.
- There was cause to question not simply the design of medical devices, products, packaging and information, but the way the NHS as a whole uses design in an effective way and its understanding of what design thinking can bring to an organisation.
- There are no quick fixes. On the contrary, it is of the utmost importance that single design initiatives are seen in the context of the 'big picture' of the healthcare system as a whole and the way it impacts on patient safety and risk management.

- Such ‘big picture’ understanding is not present and the highest priority must be attached to remedying this without delay.

The scoping study was to be conducted on a limited budget in just six months, which presented the researchers with a considerable challenge. Its focus was therefore restricted to the use and flows of medication and associated information within the NHS. Medication is central to modern healthcare and so provided an effective, cross-sectoral viewpoint of the system at all levels, allowing for an effective exploration of the core research question: *how can the better use of design make healthcare safer?*

Mapping flows of medication and information around the system

To better understand how medication and information move around the highly complex system which is the modern NHS, the team first set about mapping sub-flows at all levels, from manufacturer through to patient, to establish a preliminary overview of the system as a whole, seen through the lens of the manufacture, delivery, prescription and administration of medication in the treatment of patients.

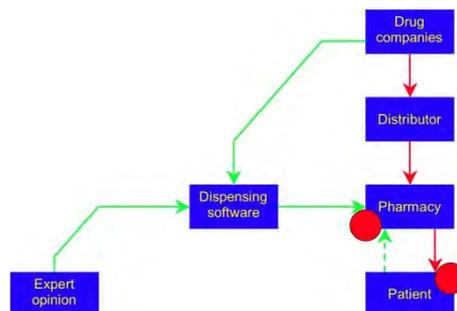


Figure 2. Self-prescribed drugs administered at home

For example: at the simplest level self-prescribed drugs administered at home, we see a direct supply chain linking manufacturer, distributor, pharmacy and patient, with indirect links bringing in expert opinion and dispensing software.

When we move to a higher level, e.g. GP-prescribed drugs administered by a carer, we see significantly increased complexity in the sub-system and in the hospital we encounter the additional complexity of the ward environment and associated drugs round.

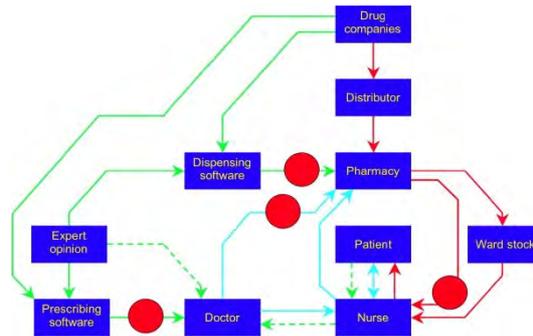


Figure 3. Doctor-prescribed drugs administered in hospital

Building the bigger picture

Literature reviews, expert interviews, input from senior health service, agency and industry personnel and other methods were used to explore all these sub-system views and create a cross-sectoral map giving an overview of the movement of medication and information across the whole NHS.



Figure 4.

The next step was to test that mapping through a series of conversations and workshops with representatives at all levels from across the NHS, where delegates were asked to add and correct detail relevant to their particular field and area of expertise (figures 4, 5 & 6.)

Verifying our initial mapping

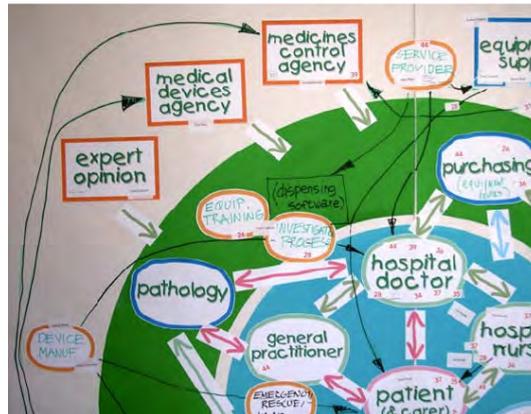


Figure 5.

The outcome of this exercise was an in-depth and accurate model of the system (Figure 7) within which key problem issues, error hotspots, and potential causes and impacts of error were located. Critical flows and interactions of information and products were also identified to better understand how they impact on the system as a whole, and unpack them into sub-systems within interlinked medication prescription, production, supply, storage and administration chains.

A patient-centric model

Up to this point the team had, in effect, explored the system from the outside in: from manufacturing supply and delivery through storing, prescribing and dispensing, and on to the administering of medication to the patient.



Figure 6.

Placing the patient at the centre of this model focused the research on how levels of complexity within the system interact to create the potential for error and risky behaviour, and so compromise patient safety.

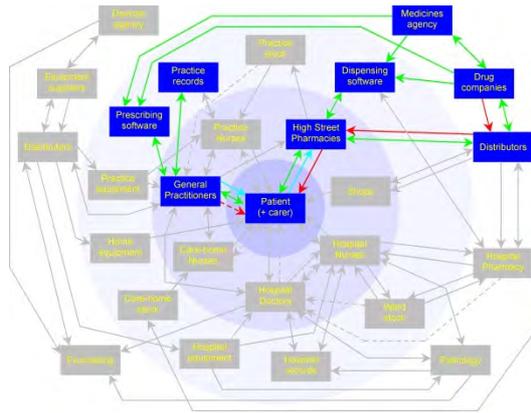


Figure 7. A sub-system within the larger system

The next step was to explore the system from the patient outwards in order to better understand how this complex system impacts upon the individual patient. This was done through interviews with patients and patient representatives, and by tracing the main routes or pathways by which patients make their individual journeys through the system – from initial presentation through to discharge – be that to their own home, to another part of the system, into the charge of another institution, or of family and friends.

Exploring critical points on patient journeys

Through creative workshops using design methods of data capture, visualisation and brainstorming –

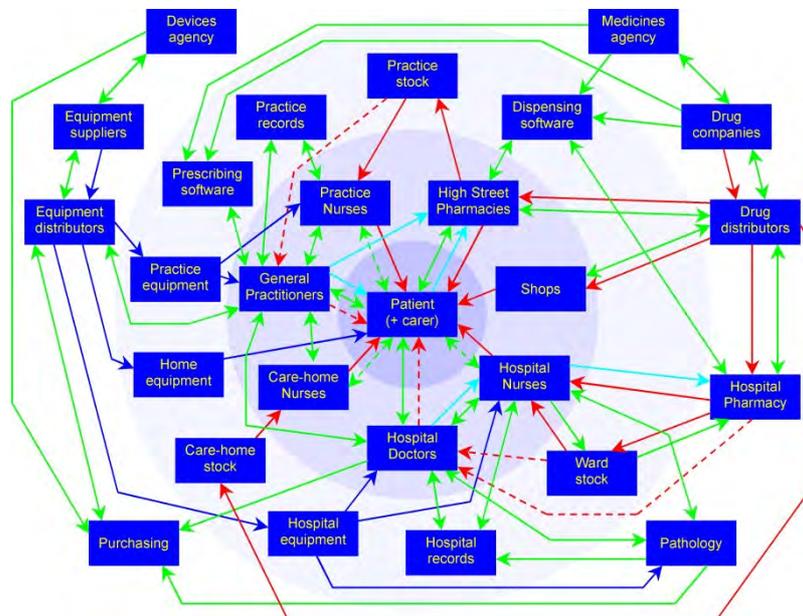


Figure 8. The system-level model.

where we teamed up healthcare professionals with patients and designers – we first shared and tested our understandings of potential risks and sources of error and then used those insights as triggers for the co-design of possible solutions. These centred on key points on a combination of patient journeys through the

NHS – for example: at the roadside, in the ambulance, at A&E, on admission, in the ward, the theatre and recovery ward, and also in the home, the pharmacy and health centre.

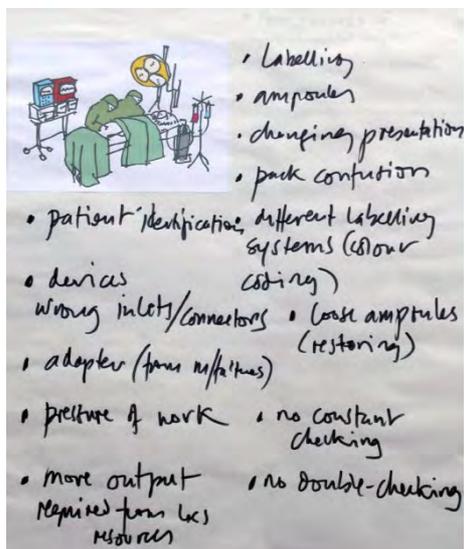


Figure 9. Working material from co-design workshop.

By bringing together well-recognised formal methods – such as literature reviews, consultations and interviews with international experts, senior health service personnel and healthcare practitioners from all levels within the system – with more open-ended, interactive methods from the design and human factors professions, the research team sought to corroborate its findings within the limited time frame and budget available.

Linking academic & design methods

The final phase of the programme focused on seeking convergence and triangulation within a wealth of data from multiple sources and condensing this into a set of robust conclusions and corresponding recommendations. The result was a holistic, design-led, systems-based and user-centred approach to patient safety, a six-step plan of action, and a set of eight initial projects as examples of the work the team believed was needed to get to grips with the problem of medical errors in the NHS. The recommendations were framed in consultation with the DoH and Design Council, leading to two major publications, along with a number of papers and conference presentations, and a programme of design projects initiated by the NPSA in collaboration with the then Helen Hamlyn Research Centre.

A design-led approach to Patient Safety

The keystone of the recommendations was an approach to patient safety placing design – along with associated engineering, manufacturing, packaging, information, data gathering, interface and related factors

– at the heart of a set of interrelated processes and responsibilities. Importantly, it also set the designing of individual products of any sort – be they pieces of equipment, packaging, information, environments or working practices and processes – alongside that of designing the system as a whole. Since any new item or process that is introduced into a system modifies that system and so brings with it potential risks as well as benefits.

The duality of this relationship between any system and its component parts is well-understood in engineering and human factors, and many larger-scale and high-risk modern industries, such as mining, transportation, nuclear and aerospace. That appears not to be the case in the NHS and other health care systems, and the team was strongly of the opinion that the NHS should adopt a similarly systems-aware approach to patient safety.

The 10 components of this approach are:

- Build the knowledge base: e.g. understand NHS contexts; organisational components; specific tasks; user needs; information management; develop best practice.
- Define the requirements: e.g. purchasing and usability criteria/guidance; involving stakeholders; building synergy between NHS agencies.
- Design the product(s): e.g. utilising innovative design, systems engineering and ergonomics.
- Design the medical system: e.g. utilising systems engineering and ergonomics to consider the complete problem.
- Deliver the medical system: e.g. implementation, process of introduction and management of change.
- Evaluate the medical system: e.g. monitoring, auditing, verification, validation.
- Manage risk: prevention, hazard and risk identification, e.g. development of standards, safe practices and policies, European Directives.
- Promote design for patient safety: e.g. across the NHS; to industry.
- Engage advisory panel: e.g. through stakeholders in industry, design and procurement.
- Provide safe medical care: the end result.

- At the heart of this approach is the fundamental relationship between design and healthcare processes, and the recognition that a better understanding of healthcare processes leads to more effective design requirements, and hence to better design and better and safer healthcare processes.

Publications

The immediate outcome of the Design for Patient Safety programme was two publications. One for dissemination across the NHS and the UK design community (Figure 10) and a more formal research document detailing the full research findings along with a comprehensive set of indices. The first – with forwards by the Chief Medical Office, Sir Liam Donaldson, and David Kester, CEO of the Design Council – was published by the DoH and the Design Council (Buckle et al., 2003b) the second by the Engineering Department of the University of Cambridge (Buckle et al., 2003a). At the time of the study, Designer Colum Lowe was Head of Design & Human Factors at the NPSA, and a key member of the commissioning group from the DoH and the Design Council. He was very much in favour of an accessible publication, alongside a more formal report, as was the Design Council, and although the research team felt that it was perhaps overly popular in tone, it went on to become a benchmark for accessible publications on the subject of design for patient safety.



Figure 10. The 'Blood Bag' version of the report..

Unfortunately, around the time of publication the Labour Government, was very averse to negative publicity and the Minister for Health, John Reid, delayed publication for some months, despite pressure from the

CMO's office. As a result, the DoH never fully responded to the reports' recommendations and it was only with difficulty that a follow-on programme of work was initiated.

From Theory to Practice: evidence-based design

However, the challenge thrown down by the DPS study was taken up with great energy by Colum Lowe, who went on to champion Design for Patient Safety in the UK in collaboration with the Design Council and the HHRC.

The result was a series of design-led projects (the case studies) seeking to put the findings of the study into practice by building on the methodology and engaging with stakeholders in healthcare and industry. From the outset, the intention was to have a direct impact on NHS thinking by making patient safety a primary goal, measure and focus for design practice. In short, by developing a methodology for evidence-based design.

Case Study One: Making Medication Safer

Medication Packaging and information 2005-6

Thea Swayne and Jonathan West with Prof. Roger Coleman at the HHRC, Colum Lowe and Prof. David Cousins at the NPSA and Grant Courtney, Strategic Development Manager, Global Pack Management, GlaxoSmithKline (GSK).

Two complementary projects explored issues of safety and medication packaging. One, starting from the patient, worked back along the administration, distribution and prescribing chain, resulting in an NPSA guidance publication on the graphic design of medication packaging. The other started from the manufacturer and worked down through the distribution and supply chain to investigate preventable errors and establish good design practice in pack commissioning. It resulted in an in-house tool for GSK global pack management group.

The research questions:

How can an understanding of failure points in manufacture, distribution, prescription and administration contribute to the design of better medication packaging? and... How can good information design make medication safer in the home, in the pharmacy and on the ward?



Figure 11. Pharmacy stock

Background

Prescription medicine is the most frequent treatment provided for patients by the NHS. General practitioners in England issue more than 660 million prescriptions every year; an estimated 200 million prescriptions are issued in hospitals (DoH, 2004) and the average community pharmacy dispenses between 5,000-10,000 prescriptions every month (DoH, 2004). Not surprisingly, errors occur.



Figure 12. Medication stored in patient's airing cupboard.

There is much anecdotal evidence of patients failing to comply with prescription instructions, and this is particularly true of older patients in the domestic environment, of whom as many as 50% do not take their medicine as intended (Royal College of Physicians, 2000), while a third of medication errors can be attributed to confusion arising from packaging and labelling (Berman, 2004).

As healthcare is delivered in many different environments and patients' capabilities vary greatly across an ageing population, design solutions have to address these factors, and clearly improvements to the design of medicine packaging could reduce this figure whilst also enhancing medication compliance. A similar picture is seen in the United States, where it is estimated that only 1-2% of serious errors are reported (DoH, 2004).



Figure 13. Ward stock

Prior to these projects and other work by the NPSA and the National Institute for Clinical Excellence, guidance and standards on prescribing, dispensing and administration of medicines were fragmented and divided between a range of professional and NHS regulatory bodies.

Methodology

A central plank of the research methodology was to trace the complex 'journey of the pack' from manufacture and distribution to storage and eventual dispensing, and on from pharmacy and hospital stock to the ward or the patients' home, where it is again stored before self-administration or administration by nurse / carer.

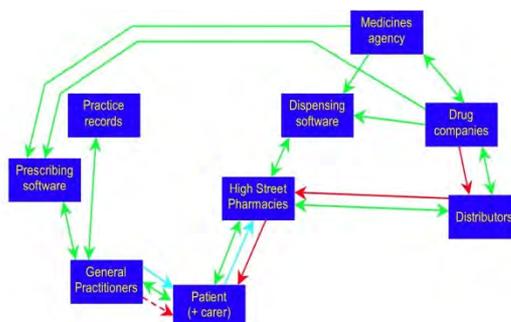


Figure 14. Journey of the pack.

An important sub-strand of this was the 'journey of the tablet', which focused on the medication itself, and its immediate packaging. Both journeys were important in teasing out the multiple performance demands on what at first sight appears a very simple piece of packaging.

The research

The projects began with an analysis of individual patient errors and compliance systems drawn from the NPSA and other sources. Key problems and issues, such as easy identification, dosage compliance and information degradation were identified and investigated, then fed into the observational phase, where the 'journey of the pack' was monitored in detail, through visits to manufacturers, hospitals, pharmacies and patients' homes, coupled with observational research with interviews and focus groups with key users and the shadowing of GSK's global pack development manager.



Figure 15. Ward drugs round

This focus on the pack, the tablet within it, and the information attached to and travelling with them both, delivered real insights into how better pack and information design could offer complementary benefits at all stages on the journey from manufacturer to patient.

An important consideration that was validated by this approach was the multi-faceted nature of the design challenge, and the potentially conflicting needs and priorities of the many stakeholders involved, all with specific interests and ideas about what should be done. In response, a 'stakeholder panel' was established, consisting of informed and influential representatives of as many of those interests as possible.

This proved a powerful – if demanding – way of supporting and informing the two postgraduate designers. It also introduced them to a research-driven approach to design, based on established facts and observational evidence – skills that were to prove a valuable addition to their more conventional design training – and was an important step towards the evidence-based design that the original study had identified as essential to patient safety.

This gathering of evidence was to prove a rich source of inspiration for design innovation while rooting it in real-life problems and concerns faced by all those dealing with medication and packaging at the many stages of its many possible journeys through a modern healthcare system.

While the formal output of both projects was to be industry guidance, this was intentionally supported by exemplar design proposals and solutions conforming to the guidance, in order to demonstrate how complex issues – such as the ways information can become degraded and separated from medication between manufacturer and patient – can be tackled by design solutions that would be welcomed and accepted by both industry and clinicians **and** deliver real safety gains at realistic costs.



Figure16: Exemplar pack designs addressing picking errors in pharmacy and ward & degradation of information. Guidance for busy designers, purchasers and others with an interest in package legibility and comprehensibility was produced as a concise, well-illustrated booklet, allowing them to quickly and simply understand how and why good design can contribute to patient safety through the clear labelling of medicines.

Published by the NPSA in 2006, *Information Design for Patient Safety: a guide to the graphic design of medication packaging* (Swayne, 2007), was well-accepted by industry and became the model for a series of guidance and best practice documents on design for patient safety published by the NPSA.

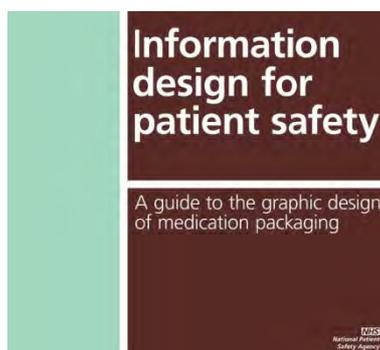


Figure 17. First NPSA 'Design for Patient Safety' publication

User involvement

A wide range of stakeholders contributed to these two research projects – including patients, pharmaceutical industry personnel, NHS agencies, nurses and pharmacists. Observational research was undertaken in key end-use environments, such as wards, pharmacies and patients’ homes.

The outcome was a design rationale presented in two ways: one directed at packaging designers and the other at packaging commissioners. Both were built around illustrations of key design problems and good practice solutions to them seeking to ensure, among other things, that vital information stays with medication until the actual moment when it is taken by the patient. Importantly, both sought to meet requirements from often conflicting elements of the supply chain, and offer real benefits to manufacturers, clinicians, carers and patients alike, while avoiding cost increases that would ultimately impact on the NHS.



Figure 18. Best practice blister pack design ensures essential information remains with the tablet until taken.

Impact – 2005-2007

An early demonstration of the potential impact these two projects were to have on industry came when both researchers were invited to critique a new, GSK Europe-wide pack design, at the design stage, before it went ahead. Their recommendations for improving contrast, giving prominence to the dosage and establishing a clear hierarchy of information, were all adopted by GSK

A further demonstration of the acceptance enjoyed by this work came when the graphic design publication went to a second edition in 2007, reflecting the experience of Prof Cousins and his team in using it as a tool for discussing medication safety issues with industry

A major reason for its success and acceptance by the NPSA and industry was the fact that it understood industry needs for brand presence and differentiation and offered a framework for achieving that whilst delivering clarity and consistency for use in the pharmacy, on the ward and in the home.

As a result, the NPSA adopted the overall approach, research process and format of the publication on graphic design for the roll-out of a *design for patient safety* series on medication and related issues.

The success of this strategy was endorsed in 2008, when the NPSA won a Design Management Europe Award for *Best Management of Design in a Public or Non-profit Organisation*.

Injectable Medicines and Infusion devices 2008-10

Sally Halls & Prof. Roger Coleman, HHRC, in collaboration with Prof. David Cousins and Colum Lowe, NPSA.

Two inter-related projects extended the work of the HHRC and the NPSA series into the difficult area of injectable medicines and infusion devices (Figures 19 & 20,) where there are specific issues relating to usage on the ward and in the home. For example: between January 2005 and June 2007, the NPSA received 59,000 reports of patient safety incidents involving medicines. Of which, injectable medicines accounted for 25 per cent of all incidents, and 58 per cent of the most serious: those that resulted in death or serious harm to the patient (Patient Safety Observatory, 2007).



Figure 19.

The first, published in 2008 (Halls, 2008), explored the design of labelling and packaging of injectable medicine products, including small ampoules, vials, pre-filled syringes and large infusion bags improve patient safety.



Figure 20.

A second, published in 2010 (Halls, 2010), explored how more effective design of infusion devices could deliver systems and products that are intuitive, simple to understand, simple to use and mistake-proofed.

Case Study Two: Making Emergency Care Safer

Two complementary projects running in parallel etc.

Resus:station: 2007... a redesign of the resuscitation trolley

The NPSA had identified, through the National Reporting and Learning System and the Patient Safety Observatory, resuscitation and associated equipment as a strong candidate for a DPS initiative (Patient Safety Observatory, 2005).

The research question:

How can the design of the resuscitation trolley support an improved resuscitation process and enhance risk management, through better team-working under stress, more effective data capture and more thorough checking and maintenance of equipment?

Research team

The first, and central challenge was to bring together all the skills and resources that only an interinstitutional team could deliver. This was made possible through high-level support and involvement from four institutions. Members included: from Imperial / St Mary's, Prof. Sir Ara Darzi, Prof. Charles Vincent, Rajesh Aggarwal, James Kinross and Andrea Smith; from RCA / HHRC Prof. Roger Coleman, Jonathan West and Sally Halls, and from the NPSA, Colum Lowe.

This helped to create an atmosphere of collaborative working and a sense of breaking new ground that facilitated team building across disciplines. Crucially, it also committed all four institutions to the project and gave access to substantial resources, making it possible to deliver a successful programme and so begin to build a track record for the team on limited funding.

Methodology

It also made it possible to develop a dynamic methodology uniting formal data gathering and creative techniques within a clinical setting. In effect a collective research and design process where medical researchers, clinicians and designers work together, investigating problems from different backgrounds and viewpoints, and sharing skills and experience to arrive at a common understanding leading to innovative design solutions.

Rather than simply improving a standalone piece of industrial equipment, the research team evaluated the entire process from actual use, to storage and restocking. Time spent on the hospital ward and observing real and simulated scenarios gave the designers an understanding of human factors involved while clinical input ensured that process improvements met clinical demands.



Figure 21. Resuscitation training / observation

Research methods included:

- Literature reviews
- Interviews with key personnel
- Expert consultation
- Analysis of videos of simulated arrests
- Training in resuscitation
- Process analysis

For example, process / equipment mapping was undertaken to better understand how resuscitation

takes place – what equipment is required when and by whom – in simulated events, and theoretical / training scenarios.

- Observation on wards

For example, this revealed that trolleys can be inaccessible, untidy and contaminated and essential items can be hard to find or missing.



Figure 22. Resuscitation trolley on a ward.

- Data gathering and analysis:

For example, an audit of trolley checking records revealed poor compliance with protocols:

- Medical, surgical & paediatric wards checked on 72.2%, 68.8% and 65.9% of days
- Checked twice 3.3% of days on medical and 4.4% on surgical wards.
- During December, the paediatric ward had two cardiac arrest calls, but the equipment on the trolley was only checked on 11 days (35.5%).
- In December the surgical ward trolley was not checked on 9 consecutive days. It also had 2 arrests.

- Failure mode effect analysis (FMEA)

This team-based, systematic technique was used to identify process and product problems undertaken to further support ward observations and analysis of data. Key issues identified through this process included:

- time taken to initiate resuscitation
- poor teamwork
- inadequate process

- missing equipment
- Modified FMEA (mFMEA)

A design-aware version of the formal FMEA process developed by the research team to home in on 'design triggers' pointing to potential improvements and innovations.

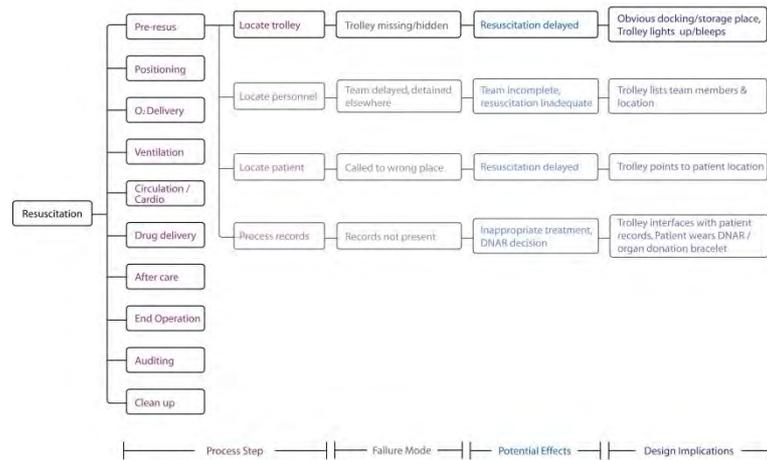


Figure 23. Section of an mFMEA diagramme.

The mFMEA is centred on breaking down the resuscitation process, step-by-step, in order to isolate potential design solutions to identified failure modes, and also to arrive at a set of user-aware requirements addressing clinical and nursing staff needs.

- Co-design

Design ideas were then generated through workshops with nursing staff and clinicians and fed into final design solutions. Significant design input went into the presentation of stimulus material and data, and the workshops were structured in ways to encourage creativity and lateral thinking, in a similar way to the design workshops in the original DPS study.

- Rapid prototyping and iterative testing

At this stage, design concepts are mocked up at full-scale, tested/assessed with clinicians and nursing staff, and iteratively developed towards viable solutions. In this case a training ward and SimMan.

- Final design proposals

Individual, process step-related design solutions are brought together within an overall concept in the form of 2D and 3D visualisations and eventually full working drawings. Although the designers take the lead in this stage, the full team is involved in the process, critically, to ensure that the final design meets all clinical and nursing requirements.

- Industry involvement

As the probable form of the final design emerged a set of industry capability requirements was established and used to identify a small group of potential manufacturers. Each of these was carefully approached, under confidentiality agreements, and a contract was eventually agreed with UK manufacturer, Bristol Maid.

- Prototyping, testing and clinical trials

Under the contract, Bristol Maid produced an initial, testable prototype embodying design solutions and delivering potential process improvements in resuscitation. This was then tested and modified in simulated events under carefully controlled conditions.

The research team successfully bid for and won grant funding of £201,000 from the Wellcome Trust for comparative clinical trials at on the ward at St Mary's Hospital, Paddington, and Bristol Maid supplied a number of pre-production units for these trials, which began in January 2008.



Figure 24. Testable prototype of the 'resus:station'.

Outcome

The physical characteristics of this prototype support improved team working. It allows better and faster access to vital equipment during use by splitting into three units supporting each of the core elements of resuscitation.

The design also logs the team's actions during each resuscitation attempt and affords an instant display of its readiness for use by using radio frequency identification (RFID) tagging to detect the removal and replacement of each item. Trials are concluding with an expectation that the final data will confirm the result is a better supported and hence significantly improved resuscitation process.



Figure 25. User trials with 2nd generation prototype .

Impact

resus:station won two Medical Futures 2007 awards including overall winner in Anaesthesia and Critical Care Innovation

Future Ambulances 2007...

This project looked at the design of the emergency ambulance from a systems perspective. It ran in parallel with the development of the **resus:station**, bringing in as collaborators, alongside the NPSA and HHRC, the Department of Vehicle Design at the RCA, the Healthcare Ergonomics and Patient Safety Unit at the University of Loughborough (HEPSU) and the Ambulance Service Association (ASA),



Figure 26. London Ambulance Service vehicle.

The Principal Investigators on the project were: Prof. Roger Coleman, HHRC, and Dr. Sue Hignett, Director, HEPSU, along with Co-investigator Prof. Dale Harrow, Head of Vehicle Design at the RCA, Joan Russell and Colum Lowe of the NPSA, Hilary Pillin of the ASA, and Peter Bradley, CEO, London Ambulance Service and NHS National Ambulance Adviser who chaired an Advisory Board set up for the project.

The research question:

How can the safety of patients and ambulance staff be improved through better design of vehicles and equipment?

Background

When this work was initiated there was a lack of consistency in the equipment, consumables and interior layout of emergency vehicles, which impacted on the safety of systems of work and the efficiency of clinical care. At the time, NHS ambulance trusts produced their own vehicle specifications, resulting in over 40 variants and individual trusts having more than one specification.

Prior research into ambulance design had considered individual issues rather than the design of ambulance service vehicles as a whole, and there was no guidance specifically related to the clinical or workforce issues investigated by the research team. There was, however, a strong desire for standardisation in the design of vehicles and equipment to deliver national consistency, reduce risk, improve the working environment, ensure better, patient-centred care, and increase value for money through more effective procurement.

Methodology

Again, formal data-gathering techniques were combined with creative and design-led methods, on the model of the original DPS study, to achieve rapid and soundly-based proposals for a sequential approach to design improvement, standardisation and innovation to meet the evolving needs of NHS emergency ambulance trusts.

Research methods included

- A review of international literature from multiple sources, including Mediline 1960-2005, EMBASE, CINAHL and Ergonomics Abstracts
- A review of incident data from the UK NRLS database and the US Manufacturer and User facility Device Experience (MAUDE) database
- The initial research findings were fed into four design-led workshops with operational strategic and stakeholders, including: key decision-makers, manufacturers, organisational and front line staff, and patients and patient representatives (Figure 27.)



Figure 27.

Design challenges

The composite findings from desk research and workshops were condensed into design challenges and related performance requirements. The design nine resulting challenges were identified as:

- Ensure safe and effective access and egress
- Improve working space and layout
- Effectively secure people and equipment in transit
- Ensure effective communication
- Address security, violence and aggression
- Facilitate effective hygiene and infection control
- Maximise equipment usability and compatibility
- Improve vehicle engineering
- Humanise the patient experience



Figure 28.

Validation

The design challenges were then taken in poster form to AMBEX 2006 – the pre-hospital and emergency care trade show – where they were validated through running workshops and questionnaires involving a significant number of AMBEX delegates (Figures 28-30.)



Figure 29.

Research outputs

The research resulted in two publications, echoing the original DPS study. The first *Design for Patient Safety: future ambulances* (Coleman et al., 2007a) was presented as a set of recommendations to NHS ambulance services and trusts, in the form of performance requirements and detailed design suggestions addressing the 9 design challenges, along with proposals for a standardised fleet. The intention was to support standardisation and improvement of vehicle design; ensure equipment reliability and compatibility; and subsequently meet the evolving demands on NHS ambulance services.

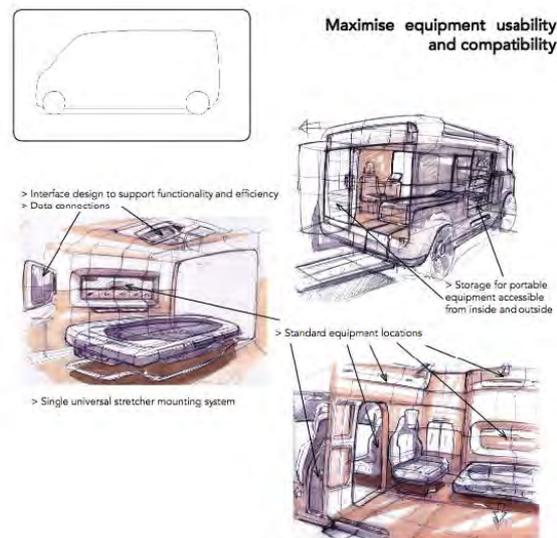


Figure 30.

The nine design challenges identified through the research programme provide an evidence-based approach for standardised safety criteria. These were expanded into a series of performance requirements, divided into primary and secondary considerations, to inform the current and future design of vehicles and equipment.

The framework for these recommendations was set out as a three-stage 'design direction' or route map to facilitate change planning and implementation over a 10-year period based on phases of standardisation and modularisation leading to innovation.

NHS Ambulance Adviser Peter Bradley (2005) said in his introduction: “Concentrating on design for safer emergency care, for patients and staff, this publication seeks to resolve some of the design challenges facing NHS ambulance trusts both now and in the future, and builds on my 2008 report to the Department of Health on Taking Healthcare to the Patient.

Stakeholders from across emergency care were involved at every stage of the work, and this publication draws on their knowledge and experience to give us, for the first time, an evidence base for better and safer design.”

This publication was supported by a second, *Designing future ambulance transport for patient safety: research undertaken* (Coleman et al., 2007b) (Figure 31) setting out the full research process and findings in detail.

The research outputs and recommendations were well received by the NHS ambulance trusts and formed the basis for an exemplar redesign of the standard emergency ambulance completed in 2011.



Figure 31.

Case Study Three: Design Out Medical Error 2008...

This project brought together: a clinical and service quality team from Imperial College / St Mary's Hospital, a design, ergonomics and manufacturing process team from the HHRC, and a small team from Imperial College Business School, with continuing input from the NPSA.



Figure 32: Patient awaiting elective surgery.

The Research Question

Research was focused on ward-based care at St Mary's hospital, with the driving research question: *How can we improve clinical outcomes through safer care on the ward before and after elective surgery?*

The problem

The original DPS study set out a patient-centred model for this, which DOME also adopted by focusing on the patient's immediate environment: the bedspace. The context of elective surgery was chosen as a way of limiting the complexity of treatments and procedures relative to other wards such as A&E.

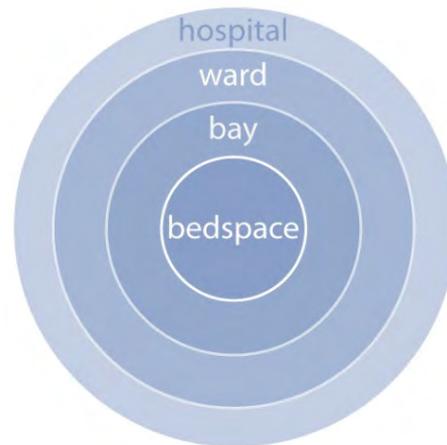


Figure 33. A patient-centric model.

The design of the surgical ward has remained unchanged over many years, despite the increasing complexity of surgical management and recent advances in patient care, and much of current hospital equipment is based on 20th century understanding of healthcare with little consideration given to systems-level issues (Vincent, Moorthy, Sarker, Chang & Darzi, 2004). This design slippage relative to process demands compromises patient safety, the efficiency of delivery of care and the satisfaction of patients and staff.

In the UK complication rates for some of the major operations are 20-25% with an acceptable mortality of 5-10%. However, at least 30-50% of major complications occurring in patients undergoing general surgical procedures are thought to be avoidable (Vincent, 2001) and many adverse events are, on closer examination, found to be due to problems in ward management the administration of drugs and intravenous fluids (Neale, Woloshynowych & Vincent, 2001).

A Patient-Centred Research Process

The key to improving patient safety is to understand how all aspects of care impact on patients. Research therefore focused on three critical issues – transfer of information; the design of the ward treatment space and associated equipment or ‘patient cubicle’ and on ward activities and associated staffing demands – and how those factors influence key clinical issues such as medication error and infection control to impact on patient safety.



Figure 34. Data Triangulation rationale.

The underlying issue being the effectiveness and safety of healthcare processes, which in turn involves multiple direct and indirect factors including not only products and equipment, but the team of medical and healthcare professionals and other staff supporting them, among others It was therefore important to map patient pathways from admission to discharge and understand routine processes along those pathways, in particular around the bedspace. Then, risky process elements were identified and correlated with incident data.

Initial Observation & Process Analysis

This took place over **70** hours across **5** general surgery wards. In all **60** activities and **10** healthcare processes were identified and studied, and some **60** patients and staff were interviewed using questionnaires.

This data was used as the basis for a hazard scoring exercise using a risk analysis method common in other industries, and the five most hazardous of common activities in and around the bedspace were identified as:

- Hand hygiene
- Infection control
- Vital signs monitoring
- Staff handover and
- Medication delivery

Using process mapping, task analysis, in-depth interviews with staff and more detailed ward observations, the five activities were then explored in detail.

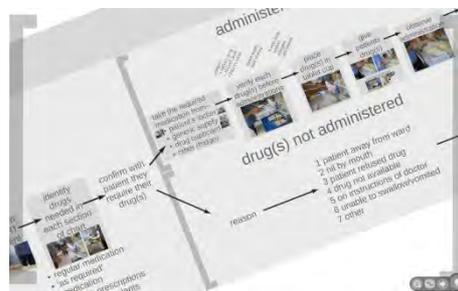


Figure 36. Drug administration process map.

Learning from other industries

In parallel with the hospital-based research, the team visited analogous high-risk industries to observe how they contain risk, understand how lessons from such industries could be applied in clinical settings and incorporated in the design process.

Key safety criteria were identified that could be applied to risk-containment within healthcare. These were then incorporated into the evaluative and design stages of the project. Full FMEAs were also carried out on all five activities to home in on critical points and issues where design intervention might be effective or could support risk-aware process improvements. And a *framework for analysing risk and safety in clinical medicine* (Vincent, Taylor-Adams & Stanhope, 1998) was used to investigate the causes of errors which informed subsequent work.

Co-design with staff and clinicians

The next step was to condense all the research findings into informative stimulus material that could be used as the focus for a series of co-design workshops with staff and clinicians, very much as in the resuscitation trolley project. Again, mFMEAs, coupled with brainstorming and other lateral thinking exercises were to prove an important way of presenting research findings and helping focus in on key moments and risky activities where design innovations could facilitate safer healthcare processes.



Figure 37. Early-stage prototype on ward-based trials.

A suite of design interventions

The outcome was a suite of interlocking design proposals and interventions addressing the 5 hazardous activities by supporting integrated care process improvements. All have had extensive user involvement throughout their development and have gained approval of frontline staff (West et al., 2011) (West, Davey, Matthews & Anderson, 2001). The suite of interventions includes:

- A care station to streamline workflow around the patient;
- A hand hygiene symbol and bedspace signage to aid compliance;
- A flexible, dual-use handover and staff room to better support care staff;
- A new vital signs trolley with integrated data collection and respiratory-rate monitor;
- And a patient-specific medication management system to engage patients with their drugs regime.

All the designs are easy to clean and the aesthetic is one of cleanliness and efficiency with a soft touch. All the designs were prototyped, initially at the RCA, and later refined in collaboration with manufacturing partners through iterative testing and evaluation.



Figure 38. Near-final prototype in simulated ward environment.

Evidence-based healthcare and Process Improvement

In an era where treatments, procedures, medications and, to a limited extent, purchasing are weighed on the basis of robust evidence as to their effectiveness and value-for-money, there is a clear case for demanding a similar robustness in the design of products and equipment used in healthcare.

Better healthcare processes are central to delivering safer healthcare. Products, equipment and environments that support those better processes are equally essential, and are key to safe intervention in a highly complex system.

This requires employing design to incrementally improve the many interconnected processes that make up the uniquely intricate UK NHS. In turn, it requires the involvement of multiple stakeholders in a collaborative process capable of delivering results that are acceptable to both front line staff and senior management, while meeting clinical and ergonomic requirements.

Building a methodology

The DPS study established two important sets of criteria. First, a group of staged and interlinked objectives, with the overarching goal of providing safe(r) medical care; and second, a methodology that combined formal and creative investigative techniques as a stimulus for design.

The first two projects undertaken addressed issues related to medication packaging. Building directly on the DPS study, they set the stage for a series of industry guidance publications tackling the problem of making medication safer at every step of the chain from manufacture to administration – see case study one.

With regard to the DPS objectives, the two packaging and information design projects clearly tackled the first two, being about building a knowledge base and using that to define product requirements in the form of well-accepted guidance. As work progressed there were also good indications that these projects were beginning to influence the design of products, and hence the design of a safer medical system: objectives two to four.

The in-house tool for GSK could also be said to impact more directly on the system itself, if only in a partial way, but both projects provided a framework for risk-assessment and made a real contribution to the NPSA's campaign to promote design for patient safety – objectives seven and eight. In addition, in order to underpin the validity of the work and ensure NHS and industry uptake, these initial projects set an important precedent by establishing expert panels to guide and advise the designers and help them navigate the challenging maze of stakeholder interests surrounding their projects.

Although not functioning at the level envisaged by the original study, these panels very effectively demonstrated the importance of DPS objective nine as an essential component of a successful programme. This was strengthened by clinical expertise coming from the NPSA team and, for the two projects dealing with injectable medicines and infusion devices, a relationship with clinical staff at St Mary's Hospital Paddington.

The expert panel / steering group also acted as a bridge between meeting the DPS objectives and fleshing out the original set of investigative techniques into a full-scale design-research methodology with user studies at its heart. It also acted as a bridge between more formal research techniques, user-studies familiar to the ergonomics community and more informal methods emanating from the design community. These included direct observation and related immersive techniques, feeding into design exemplars and prototypes that can be iteratively evaluated and refined.

objectives	projects	GSK packaging design	NPSA information design	NPSA injectable medicines	NPSA infusion devices
1	build knowledge base				
2	define the requirements				
3	design the products				
4	design the medical system				
5	deliver the medical system				
6	evaluate the medical system				
7	manage risk				
8	promote design for patient safety				
9	engage advisory panel				
10	provide safe(r) medical care				

Figure 39. Meeting the DPS objectives.

Interinstitutional collaboration

In 2004, prompted by the ongoing DPS study, the HHRC and the Dept. of Surgical Oncology & Technology, under the direction of Prof. Ara Darzi began a series of design collaborations. After initial work on surgical instruments, in 2007 this collaboration moved on to focus on ward-based equipment with an innovative re-design of the resuscitation or 'crash' trolley.

The crash trolley project was one of two, the other being a redesign of the emergency ambulance – see case study two. Both were initially intended to run over a 12-month period, but each subsequently developed into a full-scale R&D programme and together they advanced the group's thinking on evidence-based design.

In the case of the crash trolley (and projects on injectable medicines and infusion devices), this gave direct access to clinical and ward staff and research facilities at St Mary's Hospital. This allowed the designers to understand how medicines and associated devices are used on wards and develop co-design techniques for directly involving healthcare professionals in R&D processes.

Team working

The two projects were built around multidisciplinary teams, making it possible to tackle complex problems centred on healthcare processes, and in particular emergency care. Initially this presented significant challenges, in particular in finding ways in which designers, research scientists, clinicians and end-users could work together productively and arrive at a better understanding of each others' skills, talents and expertise. But with time, this promoted a growing respect within the teams and awareness of the power of combining formal and creative methods.

The teams developed their own collaborative methods, giving the process an added dynamic, and delivering design solutions that were arrived at and owned by the whole team. This collective ethos gradually emerged from the two projects to create highly productive teams, where distinctions between disciplines became subsumed into a larger problem-solving collaborative process. It also extended the set of research methods significantly, so adding to the robustness of the process.

The initial set of projects (case study one) had been jointly funded by the NPSA and the Helen Hamlyn Trust, while for the emergency care projects additional contributions came from the HHRC, HEPSU the University of West England and Imperial College / St Mary's in the form of personnel, facilities and associated overheads. This made it possible to validate the approach and build the credibility essential to securing funding from the Wellcome Trust and the Engineering and Physical Sciences Research Council (EPSRC) to continue to develop the work on ambulance design and take the resuscitation trolley through to clinical trials.

projects	DPS study	GSK packaging design	NPSA information design	NPSA injectable medicines	NPSA infusion devices	NPSA ambulance design	NPSA resuscitation trolley
1 literature reviews							
2 expert consultation							
3 interviews							
4 questionnaires							
5 workshops / focus groups user forums							
6 large-scale workshops							
7 co-design workshops							
8 observation							

9	day-in-the-life / shadowing immersion						
10	exemplars / prototypes						
11	user evaluation						
12	expert panel / steering group						
13	clinical expertise						
14	multi-disciplinary team						
15	FMEA / mFMEA						
16	process analysis						
17	simulation / user testing						
18	trial(s) informal / formal						

Figure 40. Extending the research methodology.

Designing Out Medical Error

With a track record of successful and influential work in place, it became possible to strengthen the teams at both senior and postgraduate level and plan a major design-led research programme to demonstrate how safer medical care – the overarching goal set by the DPS study – can be delivered on a broader scale.

Substantial funding of £1.27 million from the EPSRC enabled the addition of high-level expertise in healthcare and safety ergonomics, manufacturing design, surgery and clinical care to supplement the core skills of the team in design-led research, patient safety and healthcare service quality. It also made it possible to bring in an expert partner in business and industry processes.

This allowed a more holistic approach to ward-based care and the broader patient journey, and to seeking to build a deeper understanding of the causes of medical error and the conditions in which it can arise. The core research objectives were to better understand the underlying processes and equipment, and how these interact. Then to identify key risk factors and among them those amenable to design intervention.

A study of analogous industries gave the team a valuable overview of the management of risk and safety, and together with other research findings provided a rich knowledge-base for the later phases of the programme. These centred on sifting and prioritising care processes and exploring design opportunities with critical stakeholders. While not greatly expanding the set of methods beyond that, the greater time, resources and team expertise available to DOME significantly enhanced the robustness the whole process and the scale of the resulting design proposals.

A repeatable process

The case studies from 2005 to 2012, can be considered as a set of translational projects, addressing the overall objectives of the 2004 DPS study and fleshing them out with a range of user-centred design-research processes to deliver *a robust, repeatable, evidence-based process*

Collectively and progressively these translational design projects addressed all the original patient safety goals, albeit at a lower level than the step change envisaged for the DoH / NHS itself. Importantly, they demonstrated that it is possible to intervene in the highly complex and to some extent incohesive system of modern healthcare, with a real degree of certainty as to the inherent safety of those interventions. Importantly, by focusing this evidence-based design-research process on supporting better and safer healthcare processes and practices, emphasis is shifted from the individual product or item of equipment to the broader role of design in modern healthcare.

Delivering safer healthcare

The three larger-scale projects all resulted in testable prototypes and designs ready for manufacture. In the case of the two emergency care projects financing this step proved challenging. In the case of the resuscitation trolley, the early involvement of UK manufacturer Bristol Maid facilitated the process, as did the securing of Wellcome Trust funding for ward-based comparative trials at St Mary's Hospital.

This step was pre-imagined for DOME, but still relied on substantial support from Bristol Maid at the prototyping stage, while the ambulance redesign relied on the support of NHS London, the London Ambulance Service and Imperial College Healthcare NHS Trust.

projects methods	GSK packaging design	NPSA information design	NPSA injectable medicines	NPSA infusion devices	NPSA ambulance design	NPSA resuscitation trolley	EPSRC DOME
1 build knowledge base							
2 define the requirements							
3 design the products							
4 design the medical system							
5 deliver the medical system							
6 evaluate the medical system							
7 manage risk							
8 promote design for patient safety							
9 engage advisory panel							
10 provide safe(r) medical care							

Figure 41. A robust process meeting all 10 DPS objectives



Figure 42. The care station and associated equipment

The involvement of multiple stakeholders and institutions facilitates the validation of designs through formal and informal trials. It also ensures a high level of acceptance of the designs by clinicians and front-line staff, which in turn paves the way for evidence-based purchasing to complete a virtuous circle in support of patient safety.



Figure 43. The redesigned ambulance interior.

In the case of the emergency ambulance, extensive evaluation, simulation and iterative testing was carried out with paramedics under the direction of Jonathan Benger, Professor of Emergency Medicine, University of West England. For DOME, early stage prototypes were taken to over 100 front line staff for critical feedback, and 20 hours of simulation footage are currently being reviewed for an extended link analysis.

Following a clinical trial at St. Mary's hospital the 'CareCentre', is now in UK production, demonstrating a direct translational benefit, while other designs are being progressed subject to negotiation and testing.

Where next?

While the evidence-based design processes outlined in this paper demonstrate an effective response to the patient safety challenge, they also highlight critical conflicts between the needs of patients, clinicians and front-line staff, NHS managers and equipment manufacturers. Understanding and balancing these factors will be crucial to longer-term success, in particular those that have a direct influence on purchasing decisions.

Clinicians and front-line staff have a shared interest in delivering the best possible care, while managers and purchasers focus on cost and budgetary control. These two factors are more closely aligned at senior management level where, for example, infection control, clinical excellence and other quality measures, along with staff satisfaction levels can be weighed against direct costs.



Figure 44. CareStation – produced and marketed by Bristol Maid.

Following a clinical trial at St. Mary's hospital the 'CareCentre', is now in UK production, demonstrating a direct translational benefit, while other designs are being progressed subject to negotiation and testing.

Comparative trials over time are perhaps the best way to evaluate performance against such measures. They also involve staff in the process, allowing them to influence the final design and engage with the challenge of process improvement, which smooths the way for future acceptance. This in turn gives manufacturers the confidence to invest in iterative prototyping and product improvement in preproduction stages, saving the consequential costs of later modifications.



Figure 45: Other DOME outcomes – 'Clean your hands' symbol and reminders & redesign of the vital signs trolley.

The drawback is that comparative trials greatly increase time-to-market and lock up investment, while large-scale R&D programmes are costly and time-consuming. One way of dealing with these problems is to shift the emphasis from validating the rationale behind specific designs to validating the design process itself, by taking a subset of designs through comparative trials. Another, which it is hoped this paper begins to address, is to build on the coherence of the DPS programme as a whole.

One way to do that would be to expand the design programme to the scale of a multi-centred initiative, bringing together similar combinations of teaching hospital, engineering and design-research units and specialists in quality control and patient safety. That way it could prove feasible to meet industry goals by taking products speedily to manufacture while reducing the overall cost of clinical trials without undermining confidence in the safety and performance of the final design and associated healthcare process quality gains.

A multi-centred initiative could also benefit from a wider range of expertise and industry partners within the overall grouping, along with associated cost-savings and the ability to tackle a number of design challenges in parallel. Perhaps now is the time for the DoH to seriously consider how best to profit from this proven programme and deliver the potential patient safety gains it offers.

Postscript

Since this paper was first given as a keynote presentation at the Design4Health conference at Sheffield Hallam University in July 2011, further proof of the innovative potential of the methodology outlined above has emerged.

The redesign of the emergency ambulance was named as a finalist in the first Design for the Real World Redux International Design Competition, held in memory of the Austrian-born designer and educator Victor J. Papanek. It was exhibited in Vienna in autumn 2011, will go to New York later in 2012 and won the Transport category of the 2012 UK Design Museum, Design of the Year Awards in April.

The DOME designs were exhibited at the Royal College of Surgeons Hunterian Museum, London in January 2012 and in March at the Management Centre, Bangor University as part of National Science Week.

Roger Coleman and Jonathan West, May 2012

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**Contextual Research for Healing Patient Rooms Design
Patient Experience Flow Studies in Neurology Departments**

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Abstract

When designing for people, designers need to gain insights into the people they are designing for. Research claims that involving end-users helps to get a better insight into what would delight or serve people, resulting in products that better fit their needs and have less chance to fail when they hit the market. (Laurel, 2003)

Our aim is to explore possibilities of enhancing the healing process in single patient hospital rooms by means of a context-related adaptation of the environment. The gained knowledge and understanding is used to develop relevant solutions addressing the needs of both patients and staff. For the Adaptive Healing Rooms project, the focus is specifically on neurology patients (stroke) and the in-patient environments they find themselves in during their recovery process.

In previous projects, we have discovered that it is extremely valuable to visit leading hospitals, to make observations on-site, besides doing desk research on the topic. Exploratory visits allowed us to gather firsthand knowledge on the way care is currently delivered and experienced, by all of the stakeholders, and on the context in which this experience takes place.

We have used a set of research techniques to capture the experience of patients and healthcare providers, transitioning the role of researcher as an observer to a participatory approach with integration of the patient and the caregiver as creators of the research data. We used techniques such as shadowing, observation and multi stakeholder sessions allowing patients and providers to describe their experience and obtain a voice in decision-making.

Based on the issues from the experience flow study and the established healing effects from literature, a large number of concepts to improve the healing process were generated. After an internal evaluation of these concepts a subset of about 10 concepts were proposed to the staff of two hospitals. Based on their input a few concepts were selected for further development. One of these concepts is called the Adaptive Daily Rhythm Atmosphere (ADRA). The ADRA concept is based on the need of neurology patients for a clear daily rhythm and day/night structure. This issue is confirmed in neurology departments and rehab centers (for stroke, brain injury, and brain infection). Patients in other departments (e.g. cardiology, oncology, mental health) are expected to have a similar need, although possibly not as strong.

Keywords: Contextual research, neurology, experience flow studies, ambient healing

Introduction

The Adaptive Healing Rooms project is a joint endeavor between Philips Research, Philips Healthcare, and Philips Design. Our aim is to explore possibilities of enhancing the healing process in single patient hospital rooms by means of a context-related adaptation of the environment. The knowledge and understanding gained is used to develop meaningful and relevant solutions addressing needs of both patients and staff.

Neurology

For the Adaptive Healing Rooms project, the focus is specifically on neurology patients with the emphasis on stroke and the inpatient environments these patients find themselves in during the post event recovery process. Stroke patients suffer from brain trauma after having experienced a stroke and in general have limited skills. Neurology patients typically have a longer stay in the hospital (from several days to three weeks) in comparison with patients that are hospitalized on other wards, such as oncology and cardiology wards. During their stay, neurology patients go through different phases (e.g. ER, stroke unit, general ward) in which the requirements for the environment differ. Developing solutions for this target group is especially complex because patients can suffer from a range of different disabilities (e.g. neglect, limited eyesight). However, by designing for the most demanding target group, compatibility for other target groups in the hospital is hereby facilitated. Once a case has been made for neurology, it is expected that the outcomes can be adapted further to meet the needs of other dedicated ward situations.

But what did we know about these patients, besides theoretical knowledge? What is the experience of these patients and clinical stakeholders? What are their feelings and emotions? What did we know about the environment: the neurology ward? What are the needs and issues of all stakeholders?

Therefore, we decided to carry out contextual research in two neurology departments and rehab centers in order to:

- To understand neurology patients, family and caregivers experiences of in-patient care environments.
- To understand best practices in neurology clinical care for improving outcomes.
- To investigate the aspects of the healing process that can be supported by an adaptive environment.

Contextual Research

In similar projects carried out previously within Philips, we have discovered that it is extremely valuable to carry out contextual research: visit leading hospitals, to make observations on-site, alongside doing desk research and gathering relevant literature on the topic.

Approach

Our goal was to map out the experience of neurology patients to better understand what their daily activities are, and the role the environment plays during the process of being treated for and recovering from a Cardio Vascular Accident (CVA). We have approached this experience from three angles:

- From the activities of the patient and other stakeholders over time.
- From the relationships and interactions between the patient and stakeholders.
- From the environment and the way it is interacted with, and perceived by the patient and other stakeholders.

By looking at the experience from these three angles, it is possible to highlight and understand the links between different aspects of the experience, and achieve a well balanced view of the CVA care process and its most important issues and opportunities.

For this research the main focus was on the neurology department patient rooms and the stroke unit. The neighboring phases, and connected spaces and processes have been described less extensively but offer many insights into the context of the patient experience.

Methodology

The two methods that are most prevalent and most representative of these field studies are Contextual Inquiry and Participant Observation (Beyer, 1998). Participant observation serves almost as a blanket method covering all aspects of contextual research: interviewing, observing, cultural material review, etc. Contextual inquiry is a field research method used in user-centered design. It is also often associated with participatory design methods (Spinuzzi, 2005). Contextual inquiry can be referred to as “apprenticeship compressed in time” (Beyer, 1998), wherein the researchers locate themselves within the participant’s location in an effort to understand the tasks undertaken by the participant.

Within the literature of the experience design community, there are numerous micro-methods documented by various practitioners under the collective banner of “field studies” (Spool, 2007). Many of these methods are all facets of Contextual research and use a combination of techniques (Potts & Bartocci, 2009).

During the exploratory visits we also used a combination of techniques. We always started with a guided tour, followed by the main field research: shadowing stakeholders, doing observations, environmental analysis, and interviewing stakeholders. During all these activities, we simultaneously made an analysis of all the data. We always ended our field study with a multi stakeholder session where we confronted the stakeholders our draft experience flow. In the next paragraphs we will discuss these techniques in detail.

Guided tour



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Every field study started with a guided tour. This is not just an introduction to the different spaces, but also an introduction of the workflow and the experiences of stakeholders in the environments. The guided tour was given by a ward manager or similar, with a broad overview of the department. The tour was preceded by a briefing, a discussion on the trajectory, and a short explanation of the intended objectives to the clinical staff in charge. The entire team participated together in the tour and took notes as you can see in **Error! Reference source not found..**

Shadowing

Shadowing patients and care givers gives the opportunity to learn from activities “as they happen”. The goal of shadowing is to understand the neurology care experience from the perspective of a particular person in a particular role by observing the stakeholders’ activities, movements, interactions with others, interactions with different equipment, and interaction with the environment.

A researcher follows a pre-determined stakeholder while documenting the experience. The researcher tries to stay in the background with the aim to understand the actions and interactions of the participating

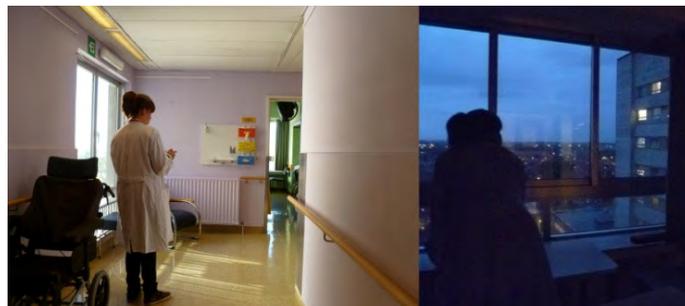
stakeholder. Sometimes a researcher may ask the stakeholder to speak out loud as he or she goes through the experience, in order to explain what is happening. In this way, we gain a better feeling of the stakeholder's mindset and of the process. For example as you can see in Figure 2, we followed nurses during the day and night.



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Observations & environmental quality analysis

We carried out observations in different care environments, and had rapid consultations with different stakeholders that were present in these environments. These informal encounters enrich and verify the findings from the shadowing activity. The objective was to understand the activities in the spaces “as they happen”, including interactions with individuals and equipment. In this way we got an understanding of the main spatial issues and the interaction between the involved stakeholders in the space (see Figure 3).



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Interviews with stakeholders

We conducted semi-structured one-on-one (or paired) interviews with patients and family (see Figure 4**Error! No bookmark name given.**) separately, and with key staff and specialists. The goal of the interviews was to get a better understanding of the experience of the key stakeholders within the selected spaces, and to get insight into the person's mindset, motivations, needs, and emotions. In this ways we also got an

insight into relevant activities and experiences that cannot be observed on site, such as family life at home, and looking for information.



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Analysis

During the visit we documented all the findings in our little war room (see Figure 5) in the hospital where we continuously analyzed the data. At the end of our visit we had a draft experience flow ready to use in the next step: the multi stakeholder session.



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Multi stakeholder session

A multi stakeholder session is an interactive session facilitated by the research team (see Figure 6), with the staff and specialist stakeholders. The objective of the multi stakeholder session is to validate and improve the draft patient experience flow. We want to understand further how the clinical staff and specialists experience their environment, how the space influences their work, and what the needs and issues are within those spaces.



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Outcomes experience flow studies

The patient experience flow has been described using three different ‘tools’ in the different phases of the experience flow studies:

- Patient activity experience flow
- Neurology department interaction mapping
- Patient environmental experience description

Patient activity experience flow

An activity experience flow is a visual representation of a stakeholder’s activities across a process or period of time, and how they link to the patient’s experiences (Figure 7).

The activity experience flow also consists of more information on (the experience of the patient in the context of) a specific theme or key area of interest. These areas of interest have been placed in the flow where they are most applicable, but many run across more than one phase or at many times within the timeline. These key areas of interest are elaborated upon with the observations made during the visit, the quotes from stakeholders on the topic, and visual information (photographs) where applicable.

A stroke patient goes through a number of ‘phases’ in his experience, usually marked by an event or a stay in a particular environment. These different phases have been described through activities of the stakeholders involved. Where applicable, e.g. in the 24 hour cycle of the neurology ward day schedule, these activities have been linked to a time of day.



Figure 6 Visual representation of a phase in the patient activity experience flow

Neurology department interaction mapping

The interaction mapping highlights and describes the interactions between the main stakeholders in the neurology department, such as the patient, the family, and the different caregivers. This provides information about how the relationships between people influence the patient's experience during the recovery process. The focus of this mapping is on the phase during which the patient stays in the neurology department.

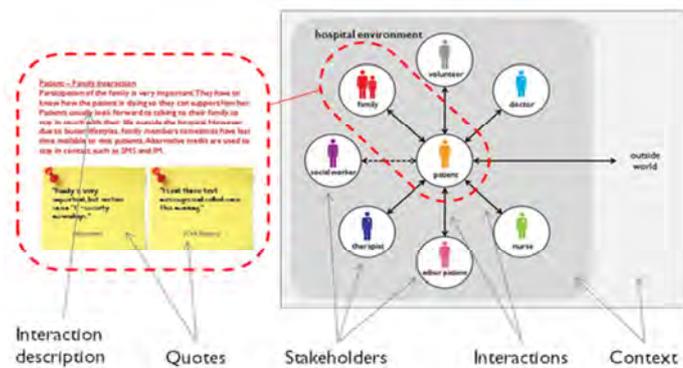


Figure 7 Neurology department interaction mapping

Patient environmental experience description

The patient environmental experience description consists of four analysis parts, namely the environmental experience flow analysis, the environmental stimuli analysis, the staff effectiveness analysis and the spatial analysis of the neurology department.

The environmental experience flow analysis describes the environment that a neurology patient encounters during his stay in the hospital. A stroke patient goes through a number of 'phases' in his experience, usually

marked by an event or a stay in a particular environment. Here we discuss the different environments that a patient goes through independent from the phase he is in.

The environmental stimuli analysis describes stimuli aspects in the neurology ward, such as lighting and sound.

The staff effectiveness analysis describes the difficulties staff encounters during their work caused by the environment, such as inappropriate task lighting in the neurology ward. The spatial analysis describes the architectural properties of the neurology department. For example where the neurology ward is located on the campus, and how the different rooms are distributed in the ward.

Findings

From the patient experience flow study, five main conclusions are derived.

First, stroke patients have sustained permanent or non-permanent brain damage, which affects the way they behave and respond to their environment. The amount and intensity of stimuli that a patient can handle in this environment is very dependent on his or her condition. Too many stimuli could lead to aggression and restlessness. This is especially a problem in the morning, when there is a very high stimulus load due to the clustering of various clinical and auxiliary activities (daily care, therapy, doctor's visit, cleaning, etc.). Too few stimuli could lead to boredom. This is a huge problem in the neurology ward, certainly for patients who are getting better. Currently, the environment of the patient does not change during his or her stay, meaning that the environment that offered too much stimuli in the beginning of the stay could offer too little stimuli at the end of the stay. Over- and under stimulation can e.g. affect the patient's perception of pain. A patient room that adapts the environment of the patient to his or her condition is therefore expected to be very beneficial to the patients.

Secondly, the right balance between a clinical environment and a personal environment needs to be achieved for all stakeholders in the neurology department. Patients and family need personal spaces for privacy, to escape, re-energize, and relax, but it should also give them a clinical feeling whenever a medical action is performed. On the other hand the patient rooms need to facilitate an optimal working environment for the hospital staff. A patient room that adapts the environment to the activities of the present stakeholders is therefore expected to be very beneficial to patients, family, and staff.

Thirdly, a clear structure of the day is important for stroke patients to decrease the risk of disorientation and confusion. Structure is also very important for patients in order to achieve a healthy sleeping pattern, to avoid delirium, to better handle rehabilitation therapy, and to consolidate their memories. However, it is

difficult to stick to a strict day structure for the nursing staff, due to the unpredictable nature of care. Offering a structured daily rhythm in the environment of the patient could therefore be very beneficial to patients.

Fourthly, stroke patients have a large risk of falling and accidents. The main reason for falling accidents is the patient's limited insight in their disease. For example, patients try to get out of bed and don't realize they are not capable of getting out and walk by themselves. The risk of falling can be reduced by reducing clutter and improving lighting conditions.

Fifthly, patients express a need for information. Getting no or insufficient information can cause an insecure and unsettling feeling, while too much information can be frightening. Also information should be given in such a way that patients understand and will remember it. Providing the patient information in a personalized way could therefore be very beneficial to the patient.

Future steps

Experience @ experience labs

Based on the issues from the experience flow study and the established healing effects from literature, a large number of concepts to improve the healing process were generated. After an internal evaluation of these concepts a subset of about ten concepts were proposed to the staff of two hospitals. Based on their input a few concepts were selected for further development. One of these concepts is called the Adaptive Daily Rhythm Atmosphere (ADRA).



Figure 8 ADRA - going to bed atmosphere

ADRA generates a dynamic atmosphere that supports the daily rhythm of the patient. Where needed the atmosphere adapts to specific interrupts and visits, e.g. when doctor or cleaner is visiting. By using ADRA,

the mentioned negative effects of the rigid environmental conditions are alleviated because the system provides a daily rhythm atmosphere in sync with, and optimized for, patient needs and the care agenda and intelligently adapts to deviations thereof.

The ADRA concept is based on the need of neurology patients for a clear daily rhythm and day/night structure (see Figure 8 and Figure 9). This issue is confirmed in neurology departments and rehab centers (for stroke, brain injury, and brain infection). Patients in other departments (e.g. cardiology, oncology, mental health) are expected to have a similar need, although possibly not as strong. (Flinsenbergh, Cuppen, van Loenen, Daemen, & Rajae-Joordens, 2011)



Figure 9 ADRA - waking up atmosphere

We developed these concepts based on our main conclusions, which are currently prototyped in the new Hospital Area of our Eindhoven-based Experience lab. As next steps, we will evaluate the system in a concept patient room lab setting and in an actual hospital environment with as many stakeholders as possible, following the user centered Experience Research processes as described in (Loenen, Van de Sluis, De Ruyter, & Aart, 2010). By allowing stakeholders to see these prototype systems in action and soliciting their opinions, we will be able to refine our adaptive healing room concepts to the point where they can be installed in real hospitals in order to conduct clinical studies with real patients. Philips hopes to start these clinical studies in hospitals at the beginning of 2012.

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Health products; designed with, not for, end users

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Abstract

This paper describes research in progress that aims to explore the role that open design could play in the development of medical products. Including people in the development process of medical products has been shown to have benefits to both producers and users but is not universally applied. There are multiple factors from a producer's point of view as to why a collaborative development process is not used, but similarly there are some medical conditions that preclude a person's involvement in collaborative group work. For example, people who have the chronic condition Cystic Fibrosis are excluded from traditional collaborative design sessions due to susceptibility to certain communicable diseases.

Open design offers the opportunity for people normally excluded in collaborative design processes to not only be included, but also shape the direction of the enquiry. Through the use of social media, and other collaborative internet-enabled tools the dissemination and development of ideas can occur. This goes beyond the fundamental moral and pragmatic arguments for collaborative working, since the knowledge and experience of the people participating is harnessed and available to all. This process therefore bears the hallmarks of a truly emancipatory technique, compatible with the notion of human flourishing and that the concept of a person's 'health' extends beyond a mere absence of illness.

The research is based around a series of practical case studies within an Action Research framework, the first of which is outlined here, where artefacts will be produced using open design; drawing upon established methods using prototypes as research and trialing the combination of physical tools (e.g. 3D printing) and virtual meeting spaces to facilitate the design activity.

Introduction

Early in 2007 an article in the Guardian newspaper appeared- 'Should Apple start manufacturing insulin pumps?' (Bevan, 2007) which expressly links the design practices of Apple with their success, and asks why the same emphasis on design is seemingly absent from the products that people with a chronic condition depend upon. This paper describes a radical approach to this problem by exploring the potential of open design.

In order to include people in the design process, and recognising that collaborative methods of designing are emancipatory and have been used successfully in the past, the aim is to apply these collaborative techniques in circumstances where physical collaboration is not possible. This may be due to a person's condition, or perhaps geographic location. The work will initially begin with people who have cystic fibrosis, using open-source design (open design), since this is a new approach in medical product design, with no set precedent.

Background

People in Medical Product Development

Two imperatives are often cited for including users in design- the moral and the pragmatic (Carroll & Rosson, 2007). Moral, in the sense that those who will be directly affected by the design of a product should have a hand in how that product comes about, and Pragmatic, in the sense that there is a greater chance of the product succeeding if those intended to use the outcome are included. This process can be shown to produce quality work, and can also have an emancipatory effect for those involved (Noble & Robinson, 2000).

There is a documented need to include the users perspectives' in the design process; Shah, et al (2009) note their views are 'particularly important'. However, a number of difficulties are cited in including users during the development process in a traditional medical product company, including: retaining participants, and the costs associated with activities (Shah, et al 2007); and cultural attitudes of the organisation (Kauppinen, et al 2002). Including people in the design process is difficult, taking time and energy from the participants and careful planning to make the work applicable for industrial practice (Pedersen & Buur, 2000). Another issue is the pervasive tendency to view users of medical products as a homogeneous group, rather than recognizing the diverse perspectives of distinct individuals (Shah et al 2009).

On the other hand, certain elite medical product design consultancies certainly do include users via rigorous ethnographic analysis (Wilcox, 2011), and the success derived from this inclusion is apparent- new product ideas, reductions in development costs, improvements in usability, safety & the identification of problems early in the development process (Shah et al 2009). Taking this idea further, (beyond consultation and focus

group participation) collaborative design techniques have been used successfully in projects designing novel medical products (Swann, 2011, Chamberlain & Roddis, 2005).

However, some people may be unable or unwilling to participate in traditional face-to-face collaborative design projects. For example, people with Cystic Fibrosis cannot meet together because of the potential danger of transmitting the *B. cepacia* bacterial infection (Orenstein, 2003). Other groups of people may feel inhibited in face-to-face design activities because of the very personal nature of their medical conditions. Still others may be separated by large physical distances from others who have the same rare condition. Open design offers the potential to broaden the range of people who can be involved in medical product design, and to open up new ways of participating.

Open design enables people to participate in this process on a level playing field; they are empowered to influence the development of these products. All ideas are publically available, in the same way that the company's ideas are available. This approach frees them from the hierarchy that exists with user consultation approaches; this is emancipatory. In so doing, this allows people to flourish by learning new skills and engaging in the process of designing the artefacts that they want and need.

Open Design

Open Design relies upon the sharing of ideas within a community of people engaged in the design process, who meet within a space – usually online, although certain physical spaces (Fab Labs and Hackerspaces) have developed where ideas and designs are generated and then disseminated (via the internet). According to Atkinson (2011) open design is:

“The internet-enabled collaborative creation of artefacts by a dispersed group of otherwise unrelated individuals.”

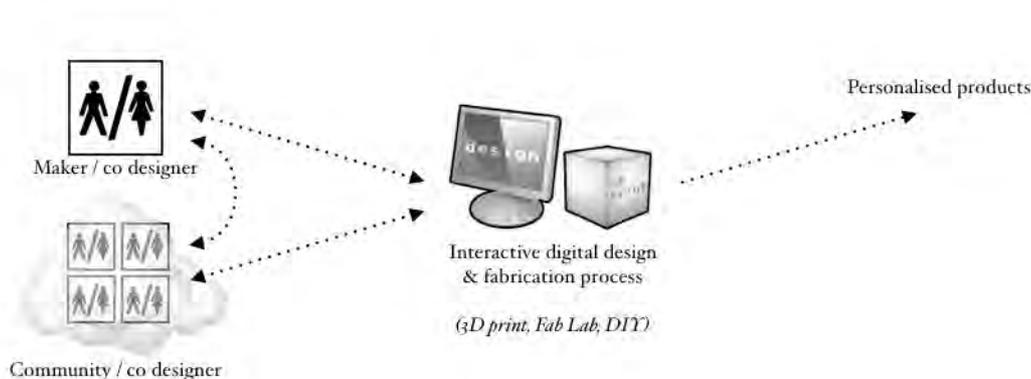


Figure 1 – Open design diagram (adapted from *Orchestral Manoeuvres In Design*, Atkinson, 2011)

The person (here described as a Maker) designs from scratch, or takes another person's design and alters it. The Maker can then either engage in a co-design activity with the wider community or proceed directly to fabrication, using 3D printing in their own workshop, or they may use shared facilities in a community space such as a Fab Lab (Fabrication Laboratory) or Hackerspace. This model allows for a person to either initiate a design, or build from another idea within the community. The community is formed around a core of interested and motivated people, who cultivate activity and sometimes provide direction for the development of some particular ideas (Leadbeater, 2009, Surowiecki, 2004).

Traditionally, the development of products by amateurs has proved difficult, with a high barrier to entry (requiring expensive machinery & software; and/or professional qualifications). However, domestic low cost 3D printing has come a long way in a few years, allowing people to produce detailed, high quality prototypes, and iterate quickly to learn from their failures (as professional designers do). For example, Adrian Bowyer invented the RepRap 3D printer in 2004 (Bowyer, 2004) as a way of creating a low cost 3D printer that could copy itself, and allow people to produce high-resolution parts and objects for themselves. 3D printing is an important enabling technology for open design. It is only recently that there has been an explosion of open-source, inexpensive 3D printers available. The ability to create a digital drawing of an object, and inexpensively print it out lowers the barrier to entry for designing one's own products. As an example, an open-source, consumer 3D printer is approximately 10x cheaper than an industrial version¹. Similarly, the Computer Aided Design (CAD) software required for producing a drawing that can be printed has plummeted, to the extent now that many pieces of software are free to download and use.

Open Design versus Open Innovation

Medical product manufacturers have recognised the need for strategies to involve users in designing future products (Barrett, 2010), with one example being Coloplast's 'Innovation By You' initiative. The company has built a community of renal care patients, who share best practice of using Coloplast devices, support one another and contribute to competitions run by Coloplast for new product ideas. Some members are also invited to a 'VIP' area, where they can work with employees on new products with the work remaining tightly controlled by Coloplast. This example demonstrates that the benefits of a community of users stretch beyond simply product innovation – to product and personal support. However, whilst Coloplast's strategy can be described as 'Open Innovation' as described by Chesborough & Crowther (2006), it does not

¹ The desktop variant of the Objet 24 (http://www.objet.com/3D-Printer/Objet_Desktop_Family/) costs approx £18,000. The MakerBot Replicator currently retails for approx £1800, 10x cheaper than the Objet 24. The new Printr 3D printer retails for approx £320, over 56x cheaper. Of course, the Objet printer has a range of materials that it will print, flexible and optical grade transparent for instance, whilst also being more accurate. However, for many home users, the excellent accuracy offered by the MakerBot and Printr are more than adequate- while the prices reflect just how affordable this technology has become.

constitute 'Open Design' in the sense of Atkinson (2011) because Coloplast retain control over any new product designs and do not share the right to further replicate and modify the designs.

Open design relies upon sharing, which puts the movement at odds with traditional models of idea-ownership (or, intellectual property). As Neelie Kroes (2011) argues, traditionally copyright was intended to recognise and protect artist's work, but too often the same system is used to punish and withhold information. With the development of open source software, there have also been a myriad of different licenses created that allow the dissemination of ideas, ensuring that the original author is credited, and derivatives have no further restrictions placed upon them. 10 years ago, the Creative Commons (CC) license was created, to provide an easy way of licensing work for dissemination online. These licenses are used by some of the largest open design communities operating today.

Even within fields where closed R&D policies are standard practice (indeed, traditionally considered the *only* way to practice) there is a move to share information and designs. The pharmaceutical industry, facing mounting development costs (approximately \$1.3 billion USD *per drug*) and lower revenue from patented products is beginning to explore the potential of open-source approaches (Mehen 2011).

Coordinating and Stimulating Open Design

An important aspect of open design is the community of practitioners, and the space in which they meet; or, the vehicle by which ideas are disseminated. Leadbeater (2009) discusses what spaces are most apt for the sharing of ideas. This involves more than the mechanics of uploading documents and data, the whole process should be one that is as transparent as possible.

The Design consultancy IDEO is a notable example of a business that uses open design- openIDEO² originally recruited a community from Facebook; Tom Hulme (2011) acknowledging that in order to effectively build a community then one must recruit from where people already congregate. Other authors have written about how difficult building a community can be, and from our previous experience trying to create a community from scratch, it is not enough to assume that 'if you build it, they will come'. IDEO leveraged their reputation to attract interested parties from a general community through Facebook, then created a bespoke space where people can upload ideas, and then build on them. User's ideas have creative commons licenses attributed to them, for dissemination and attribution. IDEO's model for open design is very orchestrated, with IDEO posing challenges with sponsors. The stages of the process are timed by IDEO, with individual participants receiving a 'badge' showing their levels of participation in different aspects of the design process.

² <http://www.openideo.com/>

This contrasts with another community of people who design and share with one another. Thingiverse.com is a community that was created by Makerbot, with little orchestration and direction about the artefacts that are designed. Makerbot will occasionally have sponsored efforts where community members are invited to produce certain artefacts for a theme, but the vast majority of direction comes from the individual members. These same members propose, design and produce their own creations, or derivatives of other people's work.

Both of these examples deal with the complexity of transparently facilitating the dissemination of ideas, but both are organised in different ways. openIDEO uses an orchestral model, being centralized & defined; and Thingiverse.com having more of a creative bazaar approach (Nambisan & Sawhney, 2010).

The role of an industrial designer is changing, and just as Industrial designers are no longer concerned simply with the form, function and production of artefacts but also the services they fit into (Valtonen, 2007), in open design the designer's role is more that of conductor (Atkinson, 2011), bringing together a group of people to and orchestrating the creation of a beautiful piece. Similarly, a designer within open design becomes a designer of toolkits and environments, allowing others to design for themselves, or collaborate with others (Press, 2011, De Mul, 2011).

Methods

The aim of our research is to understand how open design might be integrated into the development of medical projects. Since there is no precedent for using open design for medical product development, there is no opportunity to study prior art. Our research therefore uses case studies to test the hypotheses related to open design. This research is based on practice, and as such, case studies are a natural way to test these theories, since they can be shown to mirror the design process (Breslin, et al 2008). Action research is the fundamental methodology guiding our activity. Archer (1995) states that Action Research is sometimes the best way to test certain complex propositions. Action Research is a valid way of conducting a design case study, since it is seen as a sufficiently rigorous methodology for creating knowledge in fields traditionally favouring positivist methodologies (Checkland & Holwell, 2007, Avison et al, 1999)- medical product design being a good example. In order to make the implementation of Action Research sound, the record keeping must be comprehensive, and also transparent. All preconceptions and bias must be recorded, and carefully to weighed against the findings.

An issue with using Action Research is the specificity of the findings, due to the specific nature of the testing (Bødker et al, 2007), but as Archer (1995) and Checkland & Holwell (1998), point out, this specificity is not necessarily a barrier to the creation of new knowledge; indeed with no prior art to examine, the artefacts

created by this open design method will embody knowledge created through the group's work- recorded as part of the Action Research process.

As it is an important condition for good Action Research that assumptions be listed beforehand, these can be summarised here:

It is assumed that open design will allow for a more inclusive, participatory, design process that will have benefits for a range of stakeholders in the production of medical products. Manufacturers stand to benefit from the designs produced by those with lived experiences as a source of research and development, and the users of those medical products stand to benefit from products that better fit their lives.

It is not the view of this research that open design will replace the traditional model of medical product design in its entirety, but that a hybrid model combining open and closed development is most likely. This is a view shared with Leadbeater (2009), who describes such a system.

Case study 1

In order to test the assumptions above, we are seeking to build a community of people with whom to design medical products. Drawing on recommendations in the open design literature, a suitable social network space has been created online.. To give the case study a clear identity, and to make references to the space less cumbersome in correspondence, the case study has been branded as *AIR*. The name is intended to mirror the diffuse and dynamic nature of the process of open design. It is an assumption of the researchers that quality production values will inspire the community members to contribute, and own the process. An example of the branding is shown below, with the logo and colours used throughout:

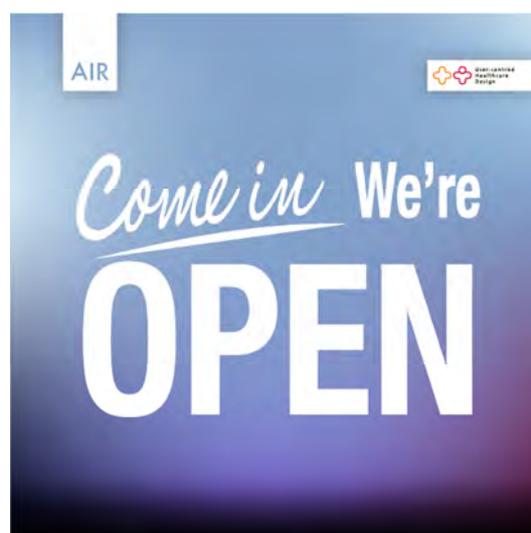


Figure 2 – Logo and colours for the first case study

In order to allow the community members to develop their ideas, and facilitate the design process each member is sent a welcome pack that contains stationary traditionally associated with design activity. This welcome pack is branded a 'design toolkit', and is modelled on the ideas of Toolkits for Innovation and Design (Franke & Piller 2004), which aim to allow people to 'un-stick' the ideas they have, and communicate them to others. An example of the welcome pack is shown below:



Figure 3 – Example of the welcome packs distributed to community members

Recruitment for this case study has been conducted extra to the National Health Service (NHS), with invitations to participate posted through Public and Patient Involvement (PPI) websites, blog posts, and emails to community representatives of large Cystic Fibrosis communities. This research is ongoing, but the most successful recruitment techniques have involved actively developing a relationship with a 'champion' for the project (a person we found by emailing a large Cystic Fibrosis social network), and posting calls on a Tumblr³ blog. Currently, the community has 4 active members, with 2 prototypes produced. The latest member of the community was recruited by another member of the community, without involvement from the researcher, suggesting that the community itself is gaining some momentum.

Conclusion

Open design offers an opportunity to include more users of medical products in their design, and to also allow for innovation to come from those same users. There are potentially substantial benefits to this process; promising innovations and products that are more fully suited to those who have to use them, and in creating a community of users who can support and aid the development of new products. However, a fully open-source development process may appear daunting to medical product developers, with questions remaining about ownership of ideas, the commercial implications for manufacturers, and the how such a process might be related to 'in-house' design activities. It is the purpose of this research here to explore some of these questions, by putting these ideas into practice, and reflecting on the outcomes as they appear.

³ www.tumblr.com is a successful social blogging platform

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KEYNOTE PRESENTATION

New challenges for Health IT – design fit for life

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KEYNOTE PRESENTATION

Abstract

Technology is seen as the critical enabler for moving care out of clinical settings into patients' hands and homes, and for empowering people to be active in their own health and well-being. This presents a radically different design space for health IT and for health practice; it fundamentally challenges our notions of patient, clinician, care and home. Designing good functional systems to support (self) care practices will not be sufficient in its own right to promote the uptake and use of these systems at home. There is a whole range of other design concerns we also need to be sensitive to. Here we focus on designing for integration into everyday spaces, routines and social context, and designing for active participation, entailing collaborative sensemaking and engagement. We conclude with a call on designers to be more reflective practitioners to ensure that the new health technologies we design are actually fit for everyday life.

Keywords: design, everyday life, healthcare, health ICT, integration, interaction, self-care, telecare, telehealth.

Introduction

Governments worldwide, and in the developed world in particular, are facing increasing challenges to deliver health care services and spending increasing proportions of gross domestic product (GDP) on health care. For example, the United States spends 17.6% of gross domestic product (GDP) on health care (CMS.gov⁴; figure for 2009), and the average in the European Union (EU) is 7.4% (Eurofound 2009; figure for 2004). The demands are predicted to be even greater in the future due to an increasingly aging population (from 600 million people aged 60 and over in 2000, to 1.2 billion by 2025) where people are living longer and require more healthcare services to deal with chronic illnesses (United Nations 2002).

It is no surprise then that ICT is being seen as a key enabler for improving both the efficiency and quality of care. This is reflected in trends such as national initiatives to set up electronic medical record infrastructures, e.g., the UK NHS Connecting for Health program (2011), previously started as the Npfit in 2002; the Canada Health Infoway (2011) established in 2001; the US program, started in 2009, to digitise the country's health care system (Singer, 2009); the National e-Health Project in Australia (e-Health, 2011); and the Connected Digital Health program in Denmark (Digital Sunhed, 2010).

ICT is seen as even more critical in addressing the care needs of the aging population and particularly of chronic diseases. A key plank in the strategies to meet this challenge is to move care out of costly institutions, such as hospitals, and into the community and people's homes – the focus of interest in this paper. This has advantages not just for the care of older people and chronic diseases but for the wider population, with a push to greater involvement of people in the management and monitoring of their own health. New configurations of ICT, often framed as telecare, telemonitoring, telehealth and/or mobile health services, are being proposed to support this increasing move to self-care and supported care in the community and at home (Dept of Health, 2005).

The challenges of moving care into the home however should not be under-estimated. In this paper, we explore some of these design challenges, focussing particularly on: designing for integration into the spaces, routines and social contexts of everyday life; and designing for the consequences of patient empowerment, shifting to a model of collaborative control and interpretation, and designing for active engagement. Before going on to discuss each of these, we first outline the ways in which hospital care and home-care are qualitatively different for the purposes of the design focus.

⁴ https://www.cms.gov/NationalHealthExpendData/25_NHE_Fact_Sheet.asp

From the hospital to the home as a site for care

It can be tempting to think that moving care from the hospital into the home is simply a case of re-location e.g., of moving (a more compact usable version of) the renal dialysis machine from the dialysis unit to the home so that the 'same' dialysis takes place but now in a different and more comfortable setting. However the hospital and home are very different settings and care plays out in very different ways.

In the hospital, care is delivered in highly structured and regulated ways, reflected in the divisions of labour among different care professionals with specific roles, in different dedicated sites (such as wards, operating rooms, radiology etc), in relatively well-defined clinical pathways, care processes/workflows and, ideally, in evidence-based decision making about care protocols. People encounter hospitals via care episodes, time-bounded by admission and discharge. Within an episode, the person who enters the hospital becomes a 'patient', dislocated from their usual everyday life contexts, with their health condition taking the prime, arguably almost the only, focus. They are allocated a bed in a unit, and are the recipient of care processes at times and choosing of the healthcare professionals. Discussions of ICT in hospital, and similarly General Practice (GP), reflect this, putting the emphasis on supporting the work of clinicians and related care and administrative functions. This, understandably to some extent, renders patients as largely invisible and passive recipients of care in a tightly orchestrated institutional setting.

Yet getting even basic ICT 'right' in this institutional setting has proved to be a challenging task. The move to electronic health records is a case at hand (see, for instance, Black et al., 2011; Greenhagh et al., 2010; Kaplan and Harris-Salamone, 2009; Public Accounts Committee Second Report, 2009; Rozenblum et al., 2011). This is despite significant investments and efforts tracing back to the late 1960s when Weed (1968) proposed one of the early electronic health records; and despite this being a relatively well understood domain, with care episodes bounded in space (the hospital setting) and time and with relatively well-defined processes, workflows and information flows.

Moving towards self-care and care in the home increases exponentially the challenge to get ICT 'right' and it is not a simple matter of re-location of care functions. The ways in which the home and hospital vary are diverse. The home is not an extension of the hospital; it is a place for living and for supporting all aspects of life, including health but also many other aspects e.g., relationships, social interaction, creativity, leisure, work and so on (Pink 2004). The person can play multiple roles simultaneously, not just that of 'patient'. In the home, control shifts from the care system and the clinician to the person. The home is also often the site for multiple inhabitants, where engagement with the home space is shared and often contended. The care network can involve not just professional carers but also, and often more critically, the informal care network of family and friends. While ICT designed for institutional settings can assume certain

infrastructures and supporting skills sets, none of these can be assumed at home. Even further, the rhetoric of self-care presumes an ability and willingness to actively participate in disease management and/or health and well being monitoring. Such a normative account of active participation might not always be the case (Aarhus et al, 2009; Holstein and Minkler, 2003).

The ICTs currently being developed and/or installed in homes are diverse. They can range from applications on mobile phones, e.g.: to monitor activity levels (Consolvo et al, 2008) or to support blood sugar management for diabetic patients (Aarhus et al, 2009); to function-specific devices such as a home renal-dialysis unit or an oxygen machine; to packages of devices to support monitoring of physiological parameters such as blood pressure, weight etc that can also be directly communicated to a care provider (Aarhus and Ballegaard, 2010; Barlow et al, 2006); to wireless sensor networks in homes that monitor activities of daily living and safety and security, with remote monitoring and escalating responses when abnormal patterns are detected (Lee and Dey, 2011).

In short, shared care and self-care at home pose very different design challenges, even if some of the core health needs appear functionally similar to those in a dedicated care setting. We argue that technologies designed for use in hospital and related settings need to be 'fit for care', where a medicalised model of care is appropriate. However technologies designed for use at home, even if for the same or similar functionality, need to be 'fit for life' and medical models of care are unable to take account of the huge complexity and diversity of lived experiences at home. The challenge is to design systems that can be appropriated and integrated into everyday life as decided by the person not dictated by the medical system. We go on now to discuss two particular design challenges, for integration and for sensemaking, drawing on diverse case studies from literature and projects with which we have been directly involved.

Some Design Challenges

Challenge: Design for integration

Designing technologies to be fit for life, not just fit for care, means designing for technologies to fit into the practical aspects of everyday life. Here we discuss the challenge of integration, particularly into everyday spaces and routines, and everyday social contexts.

Integration into spaces and routines

A first but critically important point for basic acceptance within the home space is that *aesthetics and appearances matter*. The direct re-location of 'grey boxes' and medical devices that look 'at home' in a hospital do not look 'at home' at home. As noted by Blythe et al (2005) in a study investigating experiences of technology to support an ageing society, "many older people strongly resist the installation of telecare

monitoring technology”, commonly complaining that “we do not want our homes looking like a clinic or a hospital” (p. 678). Palen and Aaløkke (2006) similarly tell a compelling story of one of their participants in a study of medication management at home. This woman had recently become sick and required a number of medications. However she did not want her visitors to think she was getting frail and sick and so chose to conceal her medications inside her piano stool (similar to one shown in Figure 1), replacing her sheet music. Being able to manage appearances was important to her and being in charge of her own space enabled her to develop innovative strategies to manage this appearance.



Figure 1: A piano seat, similar to that used to hide away medications to manage both the aesthetic appearance of the home and the appearance of the self to visitors as not being sick.

This leads to a second point, which is the ways in which *spaces and their associated routines become utilised as part of care strategies*. For example, medication management and spatial strategies have been evident in studies of care in the home but play out very differently to a hospital setting. Whereas medication delivery in a hospital is managed by the clinicians using strict time-based schedules, patients at home are more likely to make use of spatial arrangements to manage medications, e.g., by putting the morning medications with the kettle or the evening medications in the bedside table (Palen and Aalokke, 2006). The schedule for taking of these tablets is not so much associated with a strict time but a location and time dependent activity such as making the morning cup of tea or going to bed. Community health care workers visiting the home learn to ‘read’ the spatial arrangements and temporal routines of the patient’s home “to infer an elder’s state of health and ability to manage medication” (Palen and Aalokke 2006, p79). Piras and Zanutto (2010) also describe how people’s use of Personal Health Records at home is a “spatialised activity that is inextricably interwoven with the everyday routine and objects” of the home.

A third point is that *space is a precious limited resource*. As part of the Motivating Mobility project to develop interactive technologies for home-based post-stroke rehabilitation, we conducted various in-home studies with participants (Axelrod et al, 2009). While the brochures for many smart homes and living labs show organised neat spaces with ample bench space and clear floor space, we found homes where every

surface was fully utilised e.g., for the display of precious objects, or for functional uses, and with very little free space. While some spaces appeared to be 'messy' or cluttered to us as outsiders, each object and piece of furniture had its own story and were precious to their owners. Other homes were beautifully and aesthetically furnished with everything clearly in its place. We also found homes where rooms that had to be re-purposed to meet the changing health and mobility needs of the person, e.g., where a kitchen now doubled as a bathroom or a lounge room as a bedroom. We had to radically re-think both the potential size and the aesthetics of any device we were going to design to support self-motivated rehabilitation at home.

Fourthly, *space is a contended resource*, especially when the home is shared by others. For example, one of the post-stroke rehabilitation systems we designed for a particular participant was a tangible chess game that was supposed to make use of the TV to display the game board. The motivation for this, decided with the participant, was that it would be more engaging and feel less like interacting with a computer. However after a very short time we had to return with a laptop for the display, thus now also requiring precious table space, because the TV became a point of conflict and negotiation between the participant and his wife who did not want to miss her favourite TV shows just because her husband wanted to do his exercises (Balaam et al, 2011).

Integration into relationships

This last example highlights another key challenge when designing for care at home and that is, *designing for integration with the broader social network* around the person. We can contrast this with the hospital setting where the patient is dislocated not just from home but also from family and friends in order for their health care to become the sole object of focus. This is captured well in the stereotypical image of a patient alone in their hospital bed. In the home, there is the broader social network to consider, whether this is other people living in the same house, or extended family or friends. Much of self-care and home-based care, especially involving older people and children, necessarily entails the involvement of others. To design for care at home, we are not just designing for a single 'user' but for the "extended 'user' network" (Fitzpatrick et al, 2010, p.50). To design in relation to this social context we first need to identify who are the key members of the network and their roles. Negotiating this network can also involve negotiating different and often competing agendas. Again referring to the Motivating Mobility Project, we found many instances with older couples where the partners were particularly keen for their stroke-survivors partners to participate in our studies and were often more highly motivated than the stroke participants themselves, for example pushing the person to undertake more exercises than they wanted to (Balaam et al, 2011). We also had an instance of a younger woman, Sophie, who had had a stroke, who was trying to balance being a mother to a small child she could no longer manage independently, and who had her own mother (grandmother) living

with her to provide care support. Unpacking these relationships and negotiating the different motivations of all players can be an emotionally fraught and difficult task.

More practically, designs have to take account of the very functional role that many in this extended care network will need to play in *supporting the use of technologies in the home*, e.g., to set up and put away, and to trouble shoot as required. For example, we built a sensor-based tangible toy with balls for Sophie to play with her son while also doing her rehabilitation exercises (see Figure 2). However we hadn't anticipated the burden we had placed on the mother (grandmother) of our young stroke patient to retrieve the balls from the room. This happened because there ended up being conflicts between what Sophie set herself as a target for the number of balls to roll, and the attention span of her young son who would get bored before she reached her target and toss the balls around the room rather than hand them back to her.



Figure 2: Interactive game designed for dual use as a game with a child while at the same time supporting upper limb rehabilitation movements for a post-stroke person.

Challenge: Design for active participation

The language of a medical model of care is often framed in terms such as compliance, and control, where the gold standard is to deliver care processes against ostensibly objective evidence-based criteria and where necessarily the clinician is the expert. The shift to more of a self-care and shared care model also creates shifts in the loci of expertise and control and engage the patient (and often their extended network) as active participants in care. This in turn has implications for designing in new ways to support active participation.

Designing for collaborative control and interpretation

Moving technologies into the hands of patients and asking them to monitor and record their own health status moves patients away from being passive 'bodies' monitored by professionals in a care setting, to being active participants in their own care process. To maintain the 'usual order' of things, it could be

tempting to hope that this is just about delegating data gathering to the patient, data that can then be communicated to and interpreted by the professional care provider for 'business as usual'. This is not the case however. Moving technologies into the hands of patients is also moving the locus of control, challenging notions of compliance, and requiring new methods for interpretation for collaborative sense-making.

The role of patients with chronic diseases in helping to manage their own health information and to collaborate with physicians and other carers in interpreting and making sense of their lived condition is receiving increasing attention (e.g., Bardram et al., 2005; Mamykina et al., 2008; Andersen et al., 2010).

Examples of applications and devices that have been developed and deployed to support longer-term interactions between a patient living with a chronic condition and a clinician include: MAHI, a mobile health monitoring application for people with diabetes and a web-based portal enabling them to share information with a care provider (Mamykina et al., 2008); a videophone system for consultations in patients' homes on diabetic foot ulcers (Larsen and Bardram, 2008); a web-based eDiary and video consultations for pregnant women with diabetes (Aarhus et al., 2009) rehabilitation at home (Balaam et al., 2011); and applications aimed at promoting healthy living, e.g., UbiFit Garden (Consolvo et al., 2008).

In all of these cases there is evidence of the benefits of such self-monitoring for *educating and empowering the patients*, enabling them to become more knowledgeable collaborators in their own care not just recipients of care (Bardram et al., 2005; Mamykina et al., 2008; Andersen et al., 2010). Storni (2010), for example, unpacks the impacts of such education and empowerment for young diabetic patients, showing how they diversely appropriate self-care technologies to enable greater autonomy and control, and doing so in a way that now "goes beyond the simple measuring to calculate how many units [of insulin] to inject; its appropriation takes the form of a deeper entanglement with the intricacies of real life where doctors are no longer in the picture". Here he is referring to young patients pushing the limits (from a clinical perspective) of their insulin levels in order to maintain as normal a social life as possible: "From being an instrument of compliance, the glucose meter has become a means of self-management and self-determination where the levels of glucose can be tweaked and adjusted to gain increasing control over the disease" and a means to enable managing the appearance of a normal social life.

There is also evidence of self-care technologies *transforming the relationship between the patient and the doctor*, changing the division of work and the location of work. This changes the power and knowledge relations between them and bridges home and hospital in new ways (Bardram et al., 2005; Aarhus et al., 2009; Andersen et al., 2010). For example, the emergent need to engage the patient in the collaborative interpretation of the data is illustrated in the case of an IMD (specifically an implantable cardioverter-

defibrillator (ICD) for remote cardiac telemonitoring). Here Andersen et al (2010) found that the clinicians needed more information than just the numbers wirelessly transmitted from the IMD to make sense of the numbers. To support this, the researchers provided a web-based application called myRecord to enable patients to provide more of the missing socio-technical data and to collaborate with the physicians in interpreting their data.

These sorts of experiences challenge clinicians to *re-think their notions of compliance and control* and to embrace the patient not just as a source of their own data collection but as having rights to also engage in the interpretation of that data and to co-determine how that data is practically implicated back into their everyday lives and experiences. It also means accepting that sometimes the patient will say no where the clinician, and more 'objective' evidence-based standards, might want them to say yes.

The move to self care moves the locus of control and the right of interpretation and action into a continuously negotiated collaborative relationship between the patient and the clinician, and moves health away from being a single focus of concern to being one of many entailed in the messiness and complexities of everyday life. Designing for care at home needs to support these shifts in control and interpretation.

Designing for active engagement and reflection not just surveillance

A different challenge around interpretation of data arise in the increasing turn to ubiquitous technologies and wireless sensor networks, e.g., as part of 'ambient assisted living' (AAL) scenarios. Here, much more so than in self-monitoring scenarios mentioned previously, the approach is to passively monitor the patient in their home (often talked about as monitoring activities of daily living (ADLs)), and have this data read and interpreted by someone else (e.g., the family in the case of Digital Family Portraits (Mynatt et al., 2001) or by some machine learning approach or remote monitoring service in more mainstream services). This is in contrast with the collaborative model supported by the IMD and myRecord combination above.

In recent work on the final evaluation of an in-home AAL system as part of the eHome project⁵, we found many instances pointing to the need to move the design of AAL systems away from passive monitoring to one of shared control, interpretation and opportunities for reflection. For example, one participant lived alone and so didn't bother closing the bathroom door when she took a shower. She could see however that there was a sensor detecting door closing and she was worried that 'whoever was looking at the system' would think she didn't shower or look after herself. This reflects the same concern for managing self-presentation as we saw earlier in the piano stool example. Another participant, when asked to fill in a paper

⁵ Eva Ganglbauer, Florian Guldenpfennig and Geraldine Fitzpatrick collaborated with Marjo Rauhala on a qualitative study as part of the final evaluation of the eHome deployment. <http://deutsch.ceit.at/ceit-raltec/projekte/aal---ehome>; http://www.aat.tuwien.ac.at/ehome/index_en.html;

diary about her movements, did not know what was meant by a question about whether she went outside. The diary was for the researchers' use to validate the sensor data as this was a prototype; the woman knew there was a sensor above the door to her apartment but she said she did not regard herself as 'going out' unless she actually went outside the building, not just outside her apartment into the corridor or to the garden. For yet another woman, seeing the data she was recording about her cooking habits (used to check that the sensors on the stove top were working) prompted her to reflect on the fact that she wasn't cooking enough and she used this as a stimulus to change to better cooking and eating habits.

These examples point to the needs of participants to be more actively engaged in the interpretation and sense-making of data about their own lives. It also points to the potential of using the same data sources not just for external monitoring and surveillance for safety and security but also as a source of reflection and engagement for the people themselves. Other recent work on embedded sensors in the home for monitoring activities is also starting to explore how to engage the older person themselves in promoting their own awareness of activities, here specifically around medication and phone use (Lee and Dey, 2011).

Moving Forward – Designing technologies fit for life

Our concern in this paper has been to reflect on some of the new design challenges⁶ that arise when we move care out of the hospital and other institutional care settings into people's hands and homes. The economic imperative for needing to do so is clear and compelling. The case for *how* we do this however needs much more thought than might be immediately obvious. It is not just a matter of re-locating technologies designed for institutional care into this new setting. It is a matter of fundamentally re-thinking how to design technologies fit for life, not just for care; while at their core they might be functionally equivalent to institutional technologies, they need to be able to be appropriated and integrated by people into their everyday lives and spaces and social contexts.

This shift to self-care and home care also fundamentally challenges our very notions of patient, home, clinician and care. The patient is no longer a sole focus defined in terms of a healthcare problem to be solved but is an autonomous individual making the necessary adaptations to maintain quality of life, where health needs sit among a whole complex of everyday life concerns, and where they can become active participants in their own care. The home is not an extension of the hospital but is a private sacred safe space, where the occupants are in control and where being surrounded by their own 'stuff' matters. The clinician is no longer

⁶ There are of course many more challenges that are beyond the scope of this paper to discuss, for example: the challenge to design for the diversity of participants (styles, ages, preferences, socio-economic circumstances etc); the challenge to design for changing needs, whether between morning and evening as someone tires, or over the course of weeks and months as conditions improve or worsen; the challenge to design to motivate and encourage active participation when the incentive is left to the person to engage; and so on.

just the controller or monitor of care but needs to embrace new roles of being a guide, educator, coach and collaborator. This in particular challenge current notions of care and where the locus of control resides for managing care, interpreting data and making moment-by-moment sense of the lived experience of integrating health issues along with other often competing concerns of daily life. This calls on whole new models of care to be designed, not just new technologies.

This shift doesn't just challenge us to design health technologies in different ways. It challenges our very design practices and calls on us as designers of these technologies to be much more critically reflective practitioners, e.g., whose voices are we listening to, whose values are we inscribing into the systems, and what normative models of participation and care are we inscribing by design. It challenges us to understand how the apparently simple design decisions we make can have profound influences in how the people we are hoping to support in care are able to live. Given the scale of the challenge posed by an aging population and chronic diseases, this is a significant societal responsibility, to design technologies that really are fit for life.

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Distraction and attention: health, nature and art in the GROVE project at NHS Greater Glasgow and Clyde's New Stobhill Hospital

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Abstract

The paper will draw on a key case study, GROVE, the art and architecture strategy recently completed in NHS Greater Glasgow & Clyde's multi-award winning New Stobhill Hospital. GROVE was developed by poet and artist Thomas A Clark and Andy Law, architect, Reiach & Hall, Edinburgh. In GROVE Clark and Law focused on the experience of 'waiting' in hospital. Their aim was to make waiting a reflective experience and to counteract the anxiety associated with hospitals.

Clark and Law argue that the New Stobhill Hospital is a single work of art, and this is demonstrated by the 'composing' of spaces within the unifying theme of 'A grove of birch in a forest of larch'. The artworks within the architecture that make up GROVE all represent or relate to nature, including short poems installed on walls and windows by Clark, as well as visual artworks (paintings, installations, video) by collaborating artists. For example, across the outpatient clinic waiting areas a poem, a series of videos and installations contribute elements within the architecture to create a sequence of distinctive spaces.

Keywords: health, distraction, attention, art, nature

Distraction is an increasingly important concept in healthcare, often a justification for the inclusion of public art within capital projects. Distraction therapies are a documented aspect of pain management (Diette et al 2003). The beneficial effects of views on nature (Ulrich 1984) and environmental interventions in everyday activities (Cimprich & Ronis, 2003) are also documented. Kaplan (1995) differentiates between voluntary and involuntary attention and argues that the involuntary fascination aroused by aspects of nature has restorative effects on attention. Distraction, attention and fascination are linked concepts. This paper argues that design for health needs to move beyond 'distraction' as a guiding concept to understand 'fascination' and the restoration of attention as key benefits that can be delivered by art and design. Art is increasingly included as an important functional, not merely decorative, part of healthcare buildings. Specifically it can be included to support wayfinding (Huelat, 2007, p.9), to address patient dignity and to provide distraction (Ulrich, Quan, Zimring, Joseph & Choudhary, 2004, p.21).

This paper sets out to suggest that whilst distraction is a useful function within healthcare, it is too general a term, and that there may be reasons to focus on the idea of fascination and in particular 'soft fascination'. Attention Restoration Theory, as developed by Stephen Kaplan (1995), argues that soft fascinations, including specifically the way aspects of nature attract our involuntary attention, restores the ability to give directed attention to tasks.

GROVE, the art and architecture strategy recently completed in NHS Greater Glasgow & Clyde's multi-award winning New Stobhill Hospital, is a case study that is relevant to this argument.

GROVE was developed by poet and artist Thomas A Clark and architect Andy Law (Reiach & Hall Architects). They commissioned four visual artists Ken Dingwall, Andreas Karl Schulze, Olwen Shone and Donald Urquhart as collaborators. The author was the project manager for the GROVE project; brought in to coordinate the installation of the works. The project was funded from a range of sources including the Scottish Arts Council, NHS Greater Glasgow and Clyde's Endowments, the Staff Lottery as well as contributions from a wide range of faith groups.

In GROVE Clark and Law focused on the experience of 'waiting' in hospital. Their aim was to make waiting a reflective experience and to counteract the anxiety associated with hospitals.

Law commented that the patient attending a clinic or waiting for a scan ought to be in an environment which enabled them to prepare for the 'meeting,' and that this ought not to be a noisy, cluttered and distracting space, but rather one in which the environment promoted quiet reflection and preparation.

A time of particular stress is any period of waiting. The mind can wander. Worry and doubt can grow. However waiting can (and should) be seen in a more positive light than this. It is a time for thought, for reflection, for preparation. (Law, 2010, p.61)

Clark and Law understand the New Stobhill Hospital as one total artwork comprising architecture, landscape, poetry and art. This is demonstrated in their statement framing the GROVE project in the New Stobhill Hospital which articulates the rationale for including art in addressing this challenge,

It is our understanding that art in a hospital should contribute to a healing environment.

The new hospital is set within an apparently random planting of silver birch trees. Open courtyards are planted with larch trees and surfaced with natural larch boarding. The theme of woodland light and shade is continued within the building by means of installed painting, video and poetic texts.

It is a grove of larch in a forest of birch.

In consultation with the architects, Clark placed a series of his own poems onto the glazing and walls of the new Hospital. The four commissioned visual artists developed their works in response to the poems and locations.

Clark's poems are clearly in the tradition of Concrete Poetry, an international movement with a number of key practitioners in Scotland (including Clark). Edwin Morgan, Scotland's poet laureate, said,

...the concrete poem isn't meant to be something you would come across as you turned the pages of a book. (Most concrete poems still are, but that is not the ideal.) It would rather be an object that you pass every day on your way to work, to school or factory or office: it would be in life, in space, concretely there. (as cited in Cockburn & Finlay, 2001, p.19).

The focus of the project was on waiting and therefore most of the art is installed in waiting areas or routes to and from waiting areas. For example the two poems, A YELLOW FLAG UNFURLED BY THE SEA and THE DIFFERENCE THAT ONE COLOUR MAKES TO ANOTHER, are in the waiting areas for key busy departments on the main Arcade (see fig 1. For further visual documentation of GROVE see Fremantle & Sands 2011).



Fig 1. Thomas A Clark, 'Untitled (Waiting Areas),' (2009) Various Media, New Stobhill Hospital, Photo Luigi di Pasquale courtesy of NHS Dumfries and Galloway.

The poem ABOVE THE ROOFTOPS THE SKY is installed in the main Imaging waiting area in juxtaposition with works installed by Ken Dingwall.

The art installed in the main sequence of 13 waiting areas (see fig. 2) on the arcade of the New Stobhill Hospital are composed of:

A: a poem by Clark etched into the glass which takes the form of a list of twenty six indigenous tree names, spread across the waiting areas,

B: a series of what one might call ambient films of the play of light and shade in amongst trees in woodland settings by Olwen Shone,

C: and elements of an abstract composition of small coloured fabric squares on the white walls by Andreas Karl Schulze.



Fig 2. Thomas A Clark, Andreas Karl Schulze, Olwen Shone, 'Untitled (Waiting Areas),' (2009) Various Media, New Stobhill Hospital, Photo Luigi di Pasquale courtesy of NHS Dumfries and Galloway. Clark's poetry is engraved on glazing out of sight to left; Andreas Karl Schulze' installation can be seen on the rear section of the right hand wall and Olwen Shone's moving image work is on the screen on the back wall.

In other waiting areas more descriptive poems are closely juxtaposed with visual art elements as exemplified by A BRIGHTNESS IN A STILLNESS, GLADE where Clark's poem and Donald Urquhart's installed painting sit together (see fig. 3).



Fig 3. Thomas A Clark, Donald Urquhart, 'Six Landscapes,' (2009) Various Media, New Stobhill Hospital, Photo Luigi di Pasquale courtesy of NHS Dumfries and Galloway

Finally the visual artist Donald Urquhart, who won a number of awards for his design of the Sanctuary at Edinburgh Royal Infirmary, designed the Sanctuary for the New Stobhill around Clark's poem HAVING THE BRIGHTNESS AND STILLNESS OF A WOODLAND GLADE (see Fig 4.).



Fig 4. Donald Urquhart, Thomas A Clark, Andreas Karl Schulze, 'A Place Apart (Sanctuary),' (2009) Various Media, New Stobhill Hospital, Photo Luigi di Pasquale courtesy of NHS Dumfries and Galloway

This suite of installed artworks is intended to operate in various ways to bring nature into specific spaces. The artworks are not the only relationship between the new hospital and nature. The architects designed the building with courtyards which are planted with larch trees, and they designed a landscape which has an "apparently random planting of silver birch trees" which surrounds the hospital. The hospital is adjacent to Springburn Park and the entrance from the hospital to the park was redesigned, including artworks, in a parallel project. Finally, some parts of the hospital have views out to the Campsie Hills to the North of Glasgow. It is therefore important to recognise that the artworks are an element of an overall scheme, and that they are not a substitute for views of nature. Rather than being a direct experience of nature, they highlight aspects of nature, perhaps evoking positive experiences and memories, engaging the imagination.

The GROVE project demonstrates the ambition of architects and artists to address the stress of waiting by means of the representation of elements of nature through artworks installed in an healthcare building, as well as by providing views of nature. Artworks, even about nature, and actual views of nature are categorically different. That difference should not be elided, although both do conform to the criteria of attracting involuntary attention, otherwise described as soft fascination.

Soft fascinations may share characteristics with distraction, but what is of specific interest about soft fascinations is their restorative impact on attention.

Distraction, in everyday use, can have a negative connotation: “I missed my stop because I was distracted.” “I burnt myself because I was distracted.” But a literature and practice has developed within healthcare around distraction and the positive function it can have (Diette, Lechtzin, Haponik, Devrotes & Rubin, 2003). Distraction Therapy has been developed within paediatric healthcare specifically (e.g. Great Ormond Street Hospital). Art, design and multimedia technologies are deployed to provide distraction in Imaging departments (e.g. Royal Hospital for Sick Children, Yorkhill, Glasgow) and treatment rooms (e.g. Royal Aberdeen Children's Hospital). It can take the form of imagery applied to treatment room walls, projections of moving images onto ceilings, films projected in such a way as they can be seen from inside Imaging scanners. The documented benefits are: reduced use of pain medication; reduced requirement for anaesthesia; quicker treatment times, and reduced stress.

But distraction when generally used as a catch-all to justify art and design in healthcare becomes very vague. What constitutes a useful distraction in a waiting area? A painting, a photograph of days gone by, a television (often on 'mute')?

Law (2010), the architect for the New Stobhill Hospital, argues against a general use of distraction in hospitals on the following grounds,

It is sometimes argued therefore that distraction is required in hospital waiting areas. This does not seem reasonable. The purpose of a visit to hospital is not to escape issues, but to address them, mentally and physically, and distractions are unlikely to make a positive contribution. ... In order to address difficult issues most people will naturally seek out a 'quiet' place to think. Sitting by a favourite window, walking along a beach, looking out to sea, sitting on a park bench, staring into a river, gazing into a fire. These are all places for restful contemplation which releases the mind to engage in the sort of introspective thought required to address personal situations.

Law's argument, whilst not specifically referencing Kaplan's Attention Restoration Theory, is broadly in alignment with it.

Kaplan (1995) argues that we have two forms of attention: voluntary attention and involuntary attention. Kaplan argues that prolonged mental effort, paying attention to something, leads to fatigue, but specifically a fatigue of the capacity for that form of directed attention. Kaplan's concern is to understand the ways that we restore our ability to direct mental effort, or attention. He identifies the fundamental importance of attention in terms of human effectiveness, problem solving capacity, and self management. He argues that our capacity for attention is restored by the exercise of the other form of attention: involuntary attention,

and he cites experiences that take our attention which might be characterised by the loss of a sense of time, and being absorbed in something.

Kaplan argues (1995) that certain sorts of environments, and he makes his case around natural environments, provide a form of fascination that restores our ability to focus our attention. He also argues (Kaplan, Bardwell & Slakter, 1993) that museums also provide restorative experiences. He differentiates these from what he terms 'hard fascinations' which have the same capacity to capture attention, but not necessarily the same capacity to restore. A wide range of research, including Ulrich (1984) and Cimprich (2003) provides evidence of the therapeutic benefits of views and use of nature.

Kaplan identifies four characteristics of natural environments that he argues are key:

Firstly, 'being away' by which he means that the environment you enter into is away from everyday cares and concerns. Whilst the greenspace around the New Stobhill Hospital may be familiar to the users of the Hospital, the artworks bring in different, abstracted, generalised or framed construction of nature that is away from the everyday.

Secondly, 'extent,' and here he means that the environment is one you can enter into and spend time in, move around and explore, at least conceptually. The park adjacent to the New Stobhill Hospital has, without doubt, extent in the sense that Kaplan uses it, and the artworks provide a different sort of extent, one to be explored with the imagination. Interestingly the concept of coherence of the environment is also highlighted, and in this case the GROVE project, distinct from many art in healthcare projects, has a coherence spatially, being woven together by Clark's poetry and by a small group of visual artists making multiple works.

The third characteristic of natural environments that he highlights is their capacity to attract the attention whether that is light moving on leaves in woodland, cloud patterns in the sky, sunsets, etc. Whilst the hospital as described above provides both near and far views of nature; the artworks, whether the poems or the visual art, capture specific moments of precisely the sorts of experiences Kaplan is highlighting.

Finally he talks about compatibility, which is articulated in terms of the compatibility between our needs and purposes and the environment or context that might provide some restorative benefit. In this respect, Law and Clark formed a judgement that a grove in a woodland was, at least metaphorically, appropriate. If the alternative was to select for instance high mountains, around which one could equally envisage poems and artworks, one can see it might be less compatible with a hospital environment.

This short summary of Kaplan's argument demonstrates its apparent coherence with the approach taken by the team developing the GROVE project. It demonstrates the potential for an art and architecture approach to address the problem of stress associated with waiting. It demonstrates a number of tactics which conform to the general outline of Attention Restoration Theory and in particular the provision of soft fascination within a healthcare setting.

Therefore in conclusion the aim of this paper has been to argue for a more nuanced identification of priorities for art and architecture strategies. There are good reasons for use of distraction therapies in hospitals particularly (but not exclusively) in paediatric contexts, but that the less than rigorous use of the idea of distraction misses out on a much more useful approach to thinking about the role of art and design in hospitals and healthcare.

If we accept that 'soft fascination,' as manifest in both nature and art, has a valuable role in restoring our ability to direct our attention, and that it's useful to be able to direct our attention (i.e. that we are not passive subjects of healthcare, but rather need to be active, prepared, engaged), then clearly a more nuanced and sophisticated approach to the concept of distraction, unpacking it to include soft fascination, should inform art and architecture projects in healthcare.

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Your Map or Mine: visualising involvement for the development of eHealth projects

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Abstract

Framed within the participatory design perspective and the Socially Responsible Design approach, we believe that design has a responsibility towards society (Papanek, 1985) and should involve all actors. In our view, the preparation of a new research proposal should therefore always start from a multi-actor perspective. This paper describes how different mapping sessions with all stakeholders (patients, nursing staff, doctors, companies, policy makers) were organised to develop a eHealth research project, dealing with the creation of smart textiles used for self-management in chronic diseases (Textures for Care). This mapping tool, self-developed in the MAP-it-project, brings all stakeholders to an equal level, both verbally as well as visually, thus enriching the communicative possibilities. The mapping toolkit creates a common language between participants with different profiles, backgrounds and expertise who not necessarily share the same 'language'.

Keywords: participatory design, socially responsible design, mapping, eHealth

Introduction

This paper describes how a new research proposal - Textures for Care - was formulated, starting from a multi-actor perspective⁷. The proposal deals with the creation of smart textiles used for self-management in chronic diseases (and diabetes in specific). In a preparative trajectory, several mapping sessions with all stakeholders (patients, nursing staff, doctors, companies, policy makers) were organised to allow a multi-actor perspective to take on a distinct form. The goal of these mappings was to identify the needs of caregivers, industry, policy makers and self evidently to gain insights in the way patients experience their condition. Research group Social spaces (www.socialspaces.be) took –together with two other research institutes – the lead in a preparative trajectory⁸ aimed at the formulation of Textures for Care.

Social Spaces is a cross-disciplinary research group of the MAD-Faculty (Media, Arts & Design Faculty – Genk, Belgium), operating within a context of art, design and reflection. Social Spaces' goal is to create social, participatory, but also imaginary and functional designs for various (often neglected) groups within society. The main focus of the research group is to amplify participation and critically reflect on the hybridity of the digital and physical. Social Spaces explores and experiments with the social character of art, (new) media and design. These experiments lead to the creation of amongst others, alternative media interfaces, participatory art and design, social and interactive textiles and the development and reshaping of methods within design research.

All projects are set in the framework of social and participatory design and focus on socially responsible design, two approaches that form the starting point of this paper. Subsequently, we will concentrate on MAP-it, the mapping toolkit we used in the preparatory trajectory of developing the research proposal. As we will discuss more in detail, MAP-it is a very effective method to carry out research projects that are framed within a **Socially responsible design** and **Participatory design** approach, since it creates a common language among all stakeholders and concentrates on uncovering the deep-seated aspects like the social and societal relevance rather than the utilitarian aspects.

Socially responsible design

The pioneer of this design tradition is Victor Papanek, who, in the seventies, wrote 'Design for the Real World: Human Ecology and Social Change' (1985). This work was a pamphlet against design being preoccupied with "confecting trivial 'toys for adults', killing machines with gleaming tailfins, and 'sexed-up' shrouds for typewriters, toasters, telephones, and computers". Against this extreme utilitarian, conformist

⁷ The involvement of many different actors in the (design) process

⁸ This trajectory was spread over the year 2010-beginning 2011

and gimmicky design, Papanek wanted to focus on the fact that each designer should take into account hers/his environmental, social and moral responsibility.

Throughout the years the reception of Papaneks Design for the Real World has received quite some criticism due to - amongst others - his lack of providing a variety of techniques for “good design” (as opposed to pinpointing on what “bad design” is) and his depreciation of the element of aesthetics in design (Valtonen, 2006). In recent years the design field has seen a renaissance of Papaneks ideas, as there is a renewed interest in social, ethical and moral implications of design.

In later years Papanek focussed more on the methods a designer should use to let the ones one design for participate in the creation process: “The biggest challenge for designers, architects, and engineers these days is to develop a language, a method of actually letting people participate in the design and architectural and technological processes.” (Victor Papanek’s research, n.d.)

Papanek design approach is exemplified by his story on the creation of a transistor radio for the third world (Papanek 1972). The radio consists of a used tin can and uses no batteries, nor current. The burning of wax, wood, paper & dried cow dung in the tin can will generate enough energy to make it work for at least 24h and at little cost. Papanek was highly criticised for the “ugliness” of his radio (it was a mere used tin can of soda). He however narrates the story of people in Indonesia who were not only able to use this radio but also to “modify” it to their aesthetics needs. According to Papanek, “This is a new way of making design both more participatory and more responsive” (Papanek, 1972, p. 74).

Most of the projects at Social Spaces start from this non-utilitarian view on design. Our aim is not to create merely functional, short-term or aesthetic design solutions, but to design with a view on the integration of environmental, political, social or ecological context in our research projects and methods used. By making use of such a holistic approach we try to make design research more socially relevant and, conversely, make social, economic and artistic sectors more adapted to the world of experience of its target audience.

In 2011 Social Spaces started a cross-disciplinary research project called ATOM. ATOM stands for A Touch of Memory and aims at creating a meaningful and intelligent network of objects and humans for people with dementia. It starts from the objects from a person’s personal past and uses the so-called Internet of Things technology (a self-configuring, wireless network of interconnected objects). The dementia syndrome is very heterogeneous of character: people with dementia suffer from a wide range of symptoms and differences exist in the rate at which their abilities decrease (Cohen-Mansfield, 2000) or how people will cope when confronted with these symptoms. Bharucha et al (2009) concluded after an extensive literature review that most of the intelligent technologies developed for people with dementia mainly targeted younger people

with non-progressive brain injuries. Moreover, Bharucha et al noted that little testing in an early design phase of the systems is actually done by people with dementia. To be able to create new and modify existing products for people with dementia, an approach putting the person with dementia and their context more central in the research and design/development is a central issue. To be able to integrate the person with dementia and his context of daily life, we rely on methods coming from social and participatory design.

Social and participatory design

In the seventies the computerisation of the workplace was on the rise with the introduction of new IT systems without taking into account the real situation or the existing habits of employees. The Norwegian steel and metal workers union contacted some researchers to help to create IT environments to improve the workers workspace and the tools at hand. A set of language games was developed to enable that software developers and employees to better understand each others and that together they would design systems that suited users' needs (Nygaard, 1979).

Later, this so-called participatory design, was not only concerned with the actual end-users of a product, but tried to involve other stakeholders in the design process. As diverse as the stakeholders, so diverse is the field of participatory design, drawing inspiration from various angles such as sociology, psychology, anthropology, etc. (Muller, 2003). Participatory design can thus not be considered as one theory, approach or paradigm, but rather is an umbrella term for various forms of design which all pay attention to what a end user and different stakeholders "have to say". All elements in the field of participatory design feel that designing is a social thing, where the design of the design process is as important as the design of an artefact itself (Brandt, 2006).

Some of the forms of participatory design are amongst others community architecture and co-design. Alexander and Turner are the key figures of community architecture. Turner, a British architect, was inspired by squatting movements in Peru and believed that housing was best managed by those that dwell in it. In his work "A Pattern Language: Towns – Buildings – Construction" (1977) Christopher Alexander tries to empower people to design, build and shape their own surroundings by creating a "pattern language", a generative grammar consisting of 253 patterns. Each pattern can be seen as a building block in the creation of a building, a residential area or a town and thus the society these architectural constructions are set in. All patterns have been developed with a strong participation of those who is designed for. Co-design revolves around the equal involvement of end users and experts in the design process and came about in industrial and architectural design (Sanders, 2008). While there is a strong focus on designing together with end-users, co-design is also linked to the process of designing beyond the borders of one's discipline (Huybrechts, 2011).

One of our projects 'Carefree Living in the Elderly Care' asked the question what design can mean for the care of the elderly and vice versa. and how media can create a more carefree way of living for the elderly. A multidisciplinary team of designers, artists, professional care takers and residents of a living and care centre for the elderly worked in close collaboration on this project which resulted in both a series of concrete design solutions and an exhibition travelling to various centre for elderly care where the confrontation of these future designs were recorded. A holistic approach was chosen using role-play, contextual interviews and an analysis of cultural probes. A theatre walk through the care centre played with what was real and what was fake: professional actors mixed seamlessly with the residents, designers and care takers and performed their role; moments set-in-scene intertwined with 'real', daily life acts and led to a bizarre as well as a touching experience. The constant mix between reality and fiction helped the designers (and the other "players") to be confronted with and reflect on being "old". The contextual interviews, following after this performance, let designers conduct interviews with the residents using photographs, souvenirs or any given object when visiting them in their room. This very personal set-up made the reflections more real and personal. In the cultural probes research the designers tried to collect subjective experiences. Through visually attractive packages of postcards, notebooks, stickers,... older residents were asked to write down their comments about objects, draw pictures etc. These packages were later analysed by the multidisciplinary team and would give rise to reflection on life as an elderly citizen and the daily life in a care centre. These attempts to come "closer" to the ones you design for and let them being part of the design process are essential elements of the social and participatory design strategies we use at Social Spaces (Huybrechts, 2007).

Mapping for insights

A shared interest for design, the user and sensory technology among three research partners looking for a field of application within the context of healthcare formed the motivation to set up a preparative trajectory for the development of a fundamental research proposal. Often the creation of those proposals starts from the idea of one scholar and doesn't involve the end-user in setting the boundaries and the direction of the research. However since our research is grounded in the participatory design perspective, we engaged not only the end-users but all stakeholders in the delimitation of the research.

The societal challenge within the health care sector of non-communicable diseases (NCDs) was taken as the starting point for the development of this research proposal. Non-communicable diseases - chronic conditions that do not result from an acute infectious process – have become the biggest health challenge for the 21st century (WHO, 2002). According to the World Health Organization (WHO), NCDs such as cardiovascular diseases (CVD), cancers, chronic respiratory diseases and diabetes account each year for 60%

(35 million) of all deaths (WHO, 2005). Since this specific field of NCDs is far too broad to study as an application domain within one project, we decided to organise different socio-technical workshops with a variation of stakeholders within the care field to let them guide how we best limit the research scope of the application domain. We chose for this approach since we believe that fundamental research should originate from actual user needs and thus should start with the involvement of users and other relevant stakeholders.

A first round of workshops explored the needs and problems within the context of ubiquitous computing and the rise of non-communicable diseases. The goal of this first workshop was gaining some insights in the different diseases that could benefit from applications using smart textiles. Different stakeholders (patients, doctors, nurses, industry, policy makers, researchers, technical partners, etc.) were asked to think firstly on different diseases that are a growing problem in the current health situation. In the second round of the brainstorm, the different needs of patients - suffering from the diseases mentioned above - were mapped. Finally those needs were concretised and possible applications using smart textiles were suggested.



Figure 1: Textures of Care workshop

When analysing the results of the brainstorm, one disease immediately stood out: diabetes. It was cited by a number of participants during the different workshops as a growing health issue that could benefit from applications using smart textiles. A second round of workshops was organised with patients, representatives from the diabetics association, nursing staff and diabetes educators to gain more insights in the disease. In a first phase of the brainstorm, the participants were engaged in a meeting to brainstorm visually, triggering them by this method to gain a deeper insight in the wants and needs of diabetics. During the brainstorm, the participants mapped out the different problems diabetics could encounter in the different contexts of everyday life (at home, at work, in public space) and simultaneously placed the icons of the different sensors that could help to overcome those problems. We used icons (Figure 2) as a way of visualising and explaining the technological complexity in an comprehensive way. In a second phase, the participants were asked to map out (the icons of) the sensors that could be usable on a drawing of a person and reflect on possible

applications. The participants particularly touched upon topics such as technology not always being adapted to the style of patients, technology is not being accessible for all forms of digital literacy and the need for a high level of patients' responsibility and reflection. This workshop resulted in very specific questions from all parties involved, which led to the formulation of the project proposal.



Figure 2: Three examples of sensor icons (respiration, pressure, brain activity)

In both phases we used MAP-it, a mapping method to mediate participatory design processes. More specifically, it is a toolkit that is designed to address the fact that people from different profiles, backgrounds and expertise do not necessarily share the same 'language'. In this case, participants with a more medical background shared a table with non-professional users or stakeholders. The MAP-it toolkit contains icons and background maps that are open and adjustable and it intends to construct a common language among participants. This language – which is new to all participants – aims to create a different dialogue than every participant is used to in her/ his own context. MAP-it's 'unfamiliar' character enables everybody to join the conversation on an equal level (Schepers, Huybrechts & Dreessen, 2011). The MAP-it toolkit consisted of a more abstract background map during the first series of workshops, since the goal was more explorative. In the second rounds of workshops however, we used a cross section of a house, an office and school environment as background map (Figure 3). We deliberately chose this everyday life, non-threatening situations that everyone could easily relate to as a trigger for the conversation. Another important element of the toolkit are the icons that in this case represented different sensors (Figure 2). This visualisation proved to be very effective during the workshops to make technological complex objects very tangible for a mixed group of participants, all coming from different backgrounds.

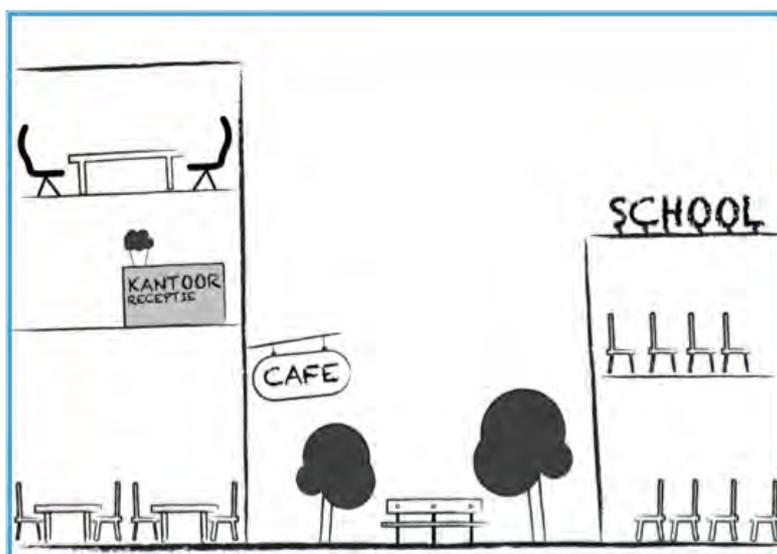


Figure 3: An example of a background map (school and office environment)

Based on the insights we gathered in the different mapping sessions, we formulated the proposal Textures of Care. Although not all research questions were directly dealt with in the mappings, some crucial questions were integrated in the proposal. A topic raised by a number of participants (patients as well as nurses, doctors and educators) was the need for personalisation of medical appliances. They all felt that little or no attention is given to the aesthetic aspect of most technologies or objects, designed within the context of health. For this reason, we included the aspect of personalisation as an important research question in the Textures for Care proposal. While this question focuses on the aesthetic assets of the system, a second research question deals with the adaptiveness of the system by the user: When and how can a system communicate -about a person's health- with his environment? To what extent can and may a user define the way in which a system communicates?

Discussion

The research project 'Textures for Care' was defined in a participatory manner, involving a multitude of stakeholders in formulating the scope of the research. We used MAP-it, a self-developed participatory method, to gather all stakeholders around the table and start the discussion using a common language (icons and background maps). This easily accessible tool is one example of the different ways projects are conceived and executed by the social spaces research group taking a multi-actor viewpoint as starting point. By using these participatory and social design methods we try to embed a socially responsible design approach in our daily research practice.

Taking into account a multi-actor perspective is time consuming: the recruitment of participants, the execution of these participatory and social design methods and the analysis of these actions require quite

some time and effort of the research team. Needless to say that the amount of time needed is proportional to the number of stakeholders that can be defined. Moreover, the challenge to take into account a multi-actor perspective also asks for a research team with multi-disciplinary competences: a 'cost' which can not always be made for each project.

On the side of the user we see challenges in the extrapolation of the individual needs and wishes of those involved in the described participatory processes. As has already been noted by Bodker (1994, p. 216) "a forum for co-operation between the directly involved participants and their different peer groups or organizations [...] [is] often missing."

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Therapeutic Daylight for Hospital Patients: A Search for the Benchmarks

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Abstract

To evaluate the therapeutic potential of daylit in-patient rooms, it is important to know the characteristics of daylight objectively (e.g. intensity and duration) which might support patient health effectively and are merely different from lighting requirements for visual purposes, such as viewing objects and doing work or movement. In the absence of a suitable standard, the upper and lower limits of daylight recommended by previous researchers to support patient health and comfort were selected for verification as the benchmarks of therapeutic daylight for hospital patients. Therapeutic daylight was defined as the level of daylight that can support patients to recover quickly. A field survey was conducted to collect real-world patient data from an existing hospital building. Clinical and demographic information were collected from hospital records. The amount of daylight that a particular patient might experience on the head during his/her stay in the bed was estimated by calculating the average ratio between two indoor data loggers: one installed at the back wall of patient bed (head side) and the other kept on vacant beds at the location of patient head. Based on the amount of daylight experienced, the sample patients were grouped under three categories and their post operative length of stay (LoS) inside in-patient rooms were compared using Multiple Linear Regression (MLR) analysis. The coefficient estimates of the developed MLR model (adjusted R square = 0.516, F = 40.931 (Sig. < 0.001)) shows that while holding the other explanatory variables constant (provision of outdoor view, rent of the rooms, mean arterial pressure, heart rate and diabetes mellitus), being in lower daylight group (below 190 lx) adds 42 hours ($t=3.096$, P value=0.002), and being in higher daylight group (above 2000 lx) adds 29 hours ($t=2.094$, P value<0.037) in patient post operative LoS in hospital rooms with respect to the group experienced the moderate levels of daylight (between 190 – 2000 lx). It was concluded that the range of 190 – 2000 lx can be regarded as effective daylight intensities within which positive health outcomes are more likely to occur, and architects could use this benchmark for therapeutic daylighting design.

Keywords: therapeutic daylight, hospital patient, length of stay (LoS), multiple linear regression (MLR), standards.

Introduction

To make an objective assessment of the subjective issues related with therapeutic effect of daylight on hospital patients, some level of simplification is necessary. In the absence of any accepted scale for the measurement of therapeutic effect of daylight, contemporary research (e.g. Gochenour et al., 2009 and Pechacek et al., 2008) consider effective circadian rhythm (biological events that occur at regular intervals) as an indicator of therapeutic effect of daylight. It is also admitted that, in addition to circadian rhythm, multiple mechanism are engaged in improving performance of hospital patients under daylight environment (Lockley et al., 2006), and still researchers are struggling to identify those mechanism (Nelson et al., 2003). The exploration of the complete and accurate biological mechanism as the effect of daylight is somewhat outside of the scope of this paper. As it is very difficult, if not impossible, to isolate the effect of daylight on circadian rhythm from other physiological and psychological mechanism, this research focuses on evidence than the mechanism to identify the therapeutic effect of daylight on hospital patients. This research considers reduction of patient length of stay (LoS) in hospitals as the therapeutic effect of daylight. The objective of this research is to test the range of daylight intensities within which patients LoS are expected to be reduced referred from literature. This paper comprises two main parts: a review of previous literature to identify the benchmarks of daylight intensities within which patient LoS inside in-patient rooms are expected to be reduced; and the field investigation for the verification of the benchmarks identified from the first part.

Identification of the benchmarks from literature

To incorporate therapeutic effect of daylight in the architectural design of hospital in-patient rooms, it is important to know the intensities of daylight that may support to reduce patients LoS in hospitals. A review of the existing lighting standards and recommendations for hospital in-patient rooms was necessary at the beginning of the research. Table 1 presents a comparison of some current recommendations (ADB, 2009; SLL, 2008; CIBSE, 2002 and IESNA 2000) on general internal lighting for hospital wards and single bedrooms.

Table 1: Recommendations for lighting for hospital words and single bedrooms.

Lighting Purpose	Maintained Illuminance (lx)			
	ADB (2009)	SLL (2008)	CIBSE (2002)	IESNA (2000)
General lighting	100		100	75-200
Local lighting for reading	150	300-520	300	200-350-500

Lighting for simple examination		300-520	300	
Lighting for examination and treatment		1000	1000	
Night lighting, observation lighting	5	5-10	5	
Lighting for bathroom and toilets for patients			200	

Most of the lighting and photobiology publications are focused on artificial lighting sources (Pechacek et al., 2008) to meet the visual needs, including the recommendations presented in Table 1. It is recognised that even artificial light and daylight might have the same intensity level; the properties of artificial light and daylight are different with respect to human perspective. Individuals accept less daylight compared to artificial light to do the same visual activities (MIT IAP, 2008). The physiological and psychological effects of lighting are especially different from these two sources of light. Therefore, the standards for daylight and artificial light should differ for both visual and health purposes.

Identification of the lower limit

Threshold values defined by the outcomes of photobiology research, in terms of intensity, timing and spectrum of light for effective circadian rhythm (MITDL, 2011); can be tested to verify the benchmark for therapeutic purpose. Pechacek et al. (2008) first attempted to provide some objective characteristics of daylight for circadian efficacy applicable for healthcare facilities. Pechacek et al. (2008, p.7) developed this system of equivalencies where *'an inferred radiometric spectrum of a known light source is multiplied by the circadian action spectrum [C(λ)] curve to determine a circadian weighting [W-C(λ)]'*. To account for the variability of the changes of daylight in apparent colour temperature with time of day, orientation and weather conditions, D65 (ASTM, 2006) was assumed for south, east, and west orientations, and D75 (ASTM, 2006) for north orientations in their research. Pechacek et al. (2008) validated that the same circadian power will be achieved with 190 lx daylight for south, east, and west orientations, and 180 lx for north orientations with an uncertainty of ±10 to 20 lx, when daylight will be transmitted through a double-pane, clear, low-E window. The timing and duration of daylight exposure are also important for circadian system. The timing was fixed from 06:00 AM to 06:00 PM with duration of 12 hours average daylit period (applicable for most of the locations) on patients' eyes. The details of the system are available in Pechacek et al., (2008). The paper (Pechacek et al., 2008) later received the Taylor Technical Talent Award (TTTA, 2009) from the Illuminating Engineering Society of North America (IESNA). Gochenour et al. (2009) also applied the proposed index to evaluate the circadian potentiality of daylit space in residential buildings.

Although, Pechacek et al., (2008) work is a significant advance on evaluation of the therapeutic effect of daylight, it is not beyond limitation and criticism (Gochenour et al., 2009). Pechacek et al. (2008) derived the action spectrum from the response of fixed doses of monochromatic light based on the studies of night-time melatonin suppression. The response to polychromatic light, for example daylight during the daytime, is still not entirely understood. There is still gap in knowledge to set appropriate values for regulating individual's circadian rhythm, and other physiological and psychological systems from photobiology. Pechacek et al. (2008: p.5) admitted that their method presented used off the shelf technology and the findings should not be taken as an absolute measure of circadian efficacy or health potential because *'the precise definition of the human circadian action spectrum [C(λ)] is still underway'* and the model predictions needs to be tested. The test of Pechacek et al., (2008) recommendation (if minimum 180/190 lx of daylight around patients head can provide circadian stimulation to patients) is beyond the scope of this paper, however, if 180/190 lx daylight can be considered as lower limit of therapeutic daylighting to reduce patient LoS in hospitals is one of the interests of this study.

Identification of the upper limit

Identification of the upper limit of therapeutic daylight is critical, as higher intensity of daylight needs to be incident on the patient retinas to start biological stimulation inside the body which might create visual discomfort. After reviewing the published findings, Nabil et al. (2006: p.905) provided a detailed classification of daylight intensities based on the data from field studies on occupant preferences and behaviour that considers the *'propensity for excessive levels of daylight that are associated with occupant discomfort and unwanted solar gain'*, the results being summarised in Table 2. Nabil et al. (2006) concluded that, daylight illuminance in the range 100–2000 lx are potentially useful for the inhabitant of a room.

Table 2: Classification of daylight intensities based on occupants' preferences and behaviour (Nabil et al., 2006).

Daylight illuminances	Occupants' preferences
lx < 100	insufficient daylight as sole source and needs significant amount of additional artificial light
100 – 500 lx	effective daylight as sole source and can be used in conjunction with artificial light
500 – 2000 lx	desirable or at least tolerable level of daylight
lx > 2000	likely to produce visual and/or thermal discomfort

Rogers (2006: p.13) proposed that the threshold of potentially glary conditions depend on the design illumination of a space and '*a patch of illuminance at least 10 times greater than the design illuminance typically represents an occurrence of direct daylight that could potentially cause glare and other visual comfort problems in a daylight space*'. ADB (2009), CIBSE (2000) and Nabil et al. (2006) proposed minimum 100 lx; IESNA (2000) recommends 75-200 lx for general lighting and Pechacek et al. (2008) proposed minimum 180/190 (± 10 to 20) lx on patient head for circadian support. Based on different sources, according to Roger's (2006) proposal, glary conditions can vary from above 750 lx to 2000 lx. Many researchers suggest that much higher light levels – in excess of 1000 lx – are needed to stimulate biological systems compared to the visual systems (Middleton et al., 2002; Baker, 2000; Zeitzer, 2000; Muneer, 2000). Hence, above 2000 lx, which is the level likely to produce the visual and/or thermal discomfort found by Nabil et al. (2006), is more acceptable as the upper limit of therapeutic daylighting. The discomfort indexes proposed by Nabil et al. (2006) and Rogers (2006) are based on office and classroom environments and the values are needed to be further verified before recommending for hospital environments. In this research, 2000 lx and 190 lx of average daylight level around patients head were selected to be verified from the real world field data as the benchmarks of therapeutic daylight for hospital patients which could reduce their LoS inside in-patient rooms.

Verification of the benchmarks from field

Methodology

A field survey was conducted to collect real-world patient data from an existing hospital building (Square Hospital, Dhaka, Bangladesh; Figure 1). Data collection comprised two phases. In the first phase, 31 indoor data loggers were fixed at the back wall of each patient bed (head side) at the cardiac inpatient unit (Figure 2) for one year. The indoor data loggers were fixed on the wall at 2000mm height from floor level to avoid shadow on sensors due to movement of patients and hospital staff during work (Figure 3).



Figure 1: Case hospital building- Square Hospital Ltd., Dhaka, Bangladesh (courtesy:SHL).

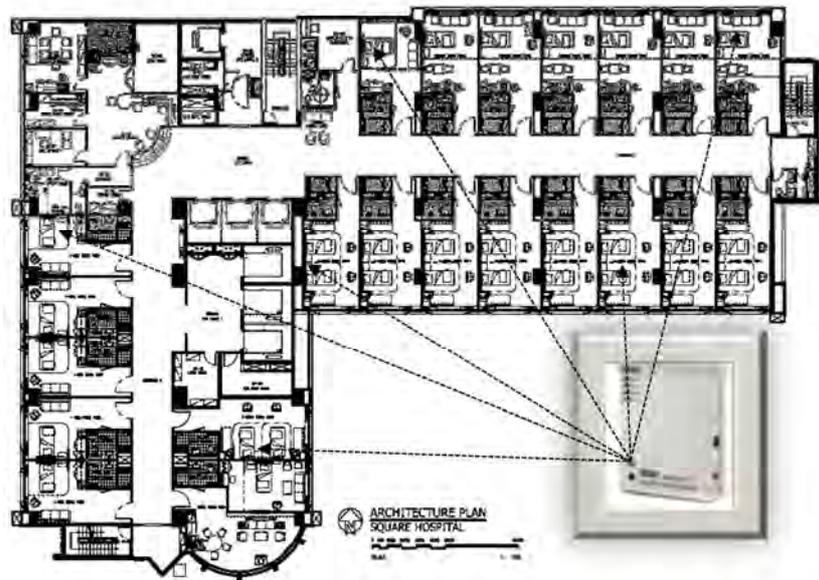


Figure 2: Architectural plan of study space- Cardiac Inpatient Unit located at tenth floor, where indoor data loggers were installed (courtesy:SHL).



Figure 3: Location of indoor data logger(source: Joarder et al., 2010).

During observational studies, the researcher noticed that most of the heart surgery patients were lying with their spine on hospital beds after coming back from Cardio-Thoracic Intensive Care Unit (CTICU) to the cardiac surgery unit. Doctors also advised that patients are instructed to lie on their back without creating any pressure on chest and should not rest on sides, particularly on left sides. To identify the amount of daylight that a patient receives on his/her retina, additional data loggers were kept by rotation (as there were always some patients on the in-patient unit) on vacant beds at the location of patient head for 24 hours (Figure 4). In the absence of the patients, the data loggers on the beds recorded the amount of daylight that a patient might get while lying on the bed. An average ratio between two data loggers (one on the bed and the other on the wall) was estimated for each bed of the cardiac in-patient unit. The estimated ratio for each in-patient bed was multiplied with the reading of the data loggers installed on the wall for one year to calculate the amount of daylight that a particular patient might experienced on head during his/her stay in the hospital bed. Based on this calculated amount of daylight, the sample patients were grouped in three categories. The first group contained the patients who had experienced lower levels of daylight (below 190 lx) in the maximum time of their stay inside in-patient unit. The second group contained the patients who had experienced moderate levels of daylight (between 190 lx to 2000 lx) in the maximum time of their stay inside in-patient unit. The third and last group contained the patients who had experienced higher levels of daylight (above 2000 lx) in the maximum time of their stay inside in-patient unit. The second group was taken as reference and their post operative LoS inside in-patient rooms were compared with other two groups. A Multiple Linear Regression (MLR) model was developed to understand the functional relationships between the patient LoS and daylight level at patient head in presence of other (clinical, demographic and environmental) variables listed in Table 3, to observe what might be causing the variation in the patient LoS.



Figure 4: Placement of additional data loggers on a vacant bed.

Table 3: List of variables primarily considered.

Clinical variables (unit)	Demographic variables (unit)	Environmental variables (unit)
Patient LoS (hour)	Gender	Room type
Systolic blood pressure (mm Hg)	Age (year)	Provision of outdoor view
Diastolic blood pressure (mm Hg)	Weight (Kg)	Rent of the room (Tk/day)
Mean arterial pressure (mm Hg)	Height (cm)	Room temperature (°C)
Heart rate (beats/ min)	Body mass index	Relative humidity (%)
Respiratory rate (resp/min)		Daylight (lx)
Body temperature (°F)		
Saturation of peripheral oxygen (%)		
Fasting blood sugar (mmol/l)		
Fluid balance (ml)		
Ejection fraction value (%)		
Smoker		
Hypertension		
Dyslipidaemia		
Diabetes mellitus		
Myocardial infarction		
Transient ischaemic attack		
Bronchial asthma		
Stroke		
Cerebral vascular diseases		
Chronic renal failure		

Data collection and analysis

A total number of 263 post-operative patients, who underwent a Coronary Artery Bypass Graft (CABG) surgery and experienced varying lighting conditions at their stay in hospital rooms, were selected as sample

for the study. At the beginning of field investigation, sources of clinical data which will be used as variables in statistical model were identified. Clinical data (e.g. LoS, blood pressure, body temperature, heart rate and respiratory rate) and demographic information (e.g. age, gender and BMI) were collected from case hospital patient record. This research ensures compliance with the Data Protection Act 1998, and was checked by an Ethical Advisory Committee. The objectives of the research were informed to the hospital authority, and researchers took approval prior to start survey.

The first phase of the study started on 21 July 2009 at 00:00 and ended on 31 July 2010 at 23.00 while illumination values above patient beds were obtained by the readings of indoor data loggers (Figure 3) as described in Section 3.1. After completing the first phase, the second phase took place during 9 September 2010 to 18 September 2010. The amount of daylight that a particular patient might experience on the head during his/her stay in the bed was calculated following the method described in Section 3.1. The collected data were used to determine the effects of upper (2000 lx) and lower (190 lx) limits of therapeutic daylight, identified from literature review in Section 2, on patient LoS. The hypothesis of this particular study was that, patients LoS will be higher if they spent most of their hospital stay time under lower and higher level of daylight environment compared to moderate level of daylighting (190-2000 lx).

Development of MLR model

The dependent variable of the model was the patient LoS in hours. For each observation, a total of 31 possible explanatory variables were considered at the beginning listed in Table 3. To determine the multicollinearity between explanatory variables, that may bias the standard error, generate wrong sign and implausible magnitudes in the coefficients (Chin et al., 2003), Pearson Correlation among the primary selected explanatory variables were analysed. The most significant variable from the correlated variables was separated to develop a suitable statistical model. For example, mean arterial pressure (MAP) was significantly correlated with weight, height, body mass index (BMI), age, gender, systolic blood pressure, diastolic blood pressure, respiratory rate, fluid balance, smoking habits and hypertension, and the correlated variables were dropped from the model. In the next stage, a stepwise regression analysis was conducted among the short listed non-correlated variables to select the “best” set of explanatory variables, and insignificant variables were eliminated from the model, such as myocardial infarction (MI), ejection fraction (EF) value and dyslipidaemia. Table 4 presents a sample summary statistics of the variables considered in the final MLR model. The information of lighting was incorporated in the model by two-categorical variables represented by lower ($lx < 190$ lx) and higher ($lx > 2000$ lx) daylight group of patients with respect to moderate (190 – 2000 lx) group, mentioned earlier. Finally, four environmental variables and three clinical variables were selected for the MLR model. The final set of variables, their coefficients (B), standardized coefficients (Beta), t-statistics together with the *p-values* are shown in Table 5.

Table 4: A sample summary statistics of variables included in the MLR model.

Variables	Min/ NO.	Max/ NO.	Mean	Std. Deviation
Patient LoS in hour (dependent variable)	48.00	666.00	109.63	61.67
Lower levels of daylight (lx<190 lx)	Yes (11)	No (252)	-	-
Moderate levels of daylight (190 – 2000 lx)	Yes (241)	NO (22)		
Higher levels of daylight (lx>2000 lx)	Yes (11)	No (252)	-	-
Provision of outdoor view (POV)	Yes (210)	No (53)	-	-
Rent of the room	3500	17500	4655.89	1658.44
Mean arterial pressure (MAP)	60.00	110.57	85.85	6.34
Heart rate (HR)	72.00	120.00	91.03	7.79
Diabetes mellitus (DM)	Yes (107)	No (156)	-	-

Model interpretation

The analysis of the MLR model (Table 5) shows that four variables increased patient stay time inside in-patient unit, and three variables were responsible for decreasing the stay time (POV, MAP and HR). Six variables (lx<190, POV, Rent, MAP, HR and DM) were highly significant (less than 1%) and one variable (lx<2000) was significant at a level of four percent in the MLR model. The column of un-standardised coefficients (B) provides the values for explanatory variable for the MLR equation. Expressed in terms of the variables used, the estimated MLR equation can be written as Equation 1 (adjusted R square = 0.516, F = 40.931 (Sig. < 0.001)).

Table 5: MLR Model to confirm the range of daylight for therapeutic purpose.

Explanatory variable	Un-standardized coefficients (B)	Standardized coefficients (Beta)	t- statistics	p-values
Constant	242.596		4.959	<0.001
lx <190 lx	42.337	0.138	3.096	0.002
lx >2000 lx	28.592	0.093	2.094	0.037
Provision of outdoor view (POV)	-24.079	-0.157	-3.340	0.001
Rent of the rooms	0.013	0.353	7.363	<0.001

Mean arterial pressure (MAP)	-1.392	-0.143	-3.238	0.001
Heart rate (HR)	-0.965	-0.122	-2.795	0.006
Diabetes mellitus (DM)	71.310	0.571	13.120	<0.001

* *Dependent Variable: Patient LoS in hour; R Square =0.529; adjusted R Square =0.516; F = 40.931 (Sig. < 0.001).*

$$\begin{aligned} \text{LoS} = & 242.596 + 42.337 (lx < 190) + 28.592 (lx > 2000) - 24.079 (POV) \\ & + 0.013 (Rent) - 1.392 (MAP) - 0.965 (HR) + 71.310 (DM) \end{aligned} \quad (1)$$

It is evident from the developed MLR model (Equation 1) that the stay time of the patients for two daylight categories used as explanatory variables, were significantly higher compared to the reference group who experienced moderate levels of daylight in the maximum time of their stay inside in-patient unit, therefore, confirmed the recommendations of previous research (e.g. Pechacek et al., 2008; Rogers, 2006; Nabil et al., 2006; 2005). The coefficient estimates show that while holding the other explanatory variables constant, being in lower daylight group adds 42 hours (t=3.096, p value=0.002) and being in higher daylight group (lx>2000) adds 29 hours (t=2.094, p value=0.037) to patient LoS in hospitals compared to the group experienced moderate levels of daylight.

Therapeutic and intuitive judgement confirmed the validity and practicality of mathematical signs in the model (Equation 1). A view to the outdoor may help to reduce the LoS of patients (t=-3.340, p value=0.001) agreed with the finding of past researchers Ulrich (1984) and Joarder et al. (2010). It is logical that in a modern and expensive private hospital such as Square Hospital, Dhaka, patients with better economic conditions are more intend to stay in luxury rooms with higher rent till their complete satisfaction to recovery compared to the patients with less affording capabilities who prefer to stay in economy rooms (i.e. shared rooms) and tend to leave the hospital earlier with a reasonable recovery status of their health with doctor's consent. The impact of the rent of the room which reflects patients' economic capabilities, thus, have a strong influence on LoS in hospital (t=7.363, p value < 0.001).

Medical judgements also confirmed the validity and practicality of the mathematical signs of the clinical variables. Due to the influence of anaesthesia during open heart surgery, the blood pressure and heart rate are usually reduced compared to patients' normal state (Neto et al., 2004) when they come back to the cardiac surgery unit. The patient recovery process accelerates with the increase of blood pressure (t=-3.238, p value=0.001) and heart rate (t=-2.795, p value=0.006) to normal stage, as a result, stay time in hospital is reduced. It is logical that patients with diabetes will take more time (Morricone et al., 1999) compared to non-diabetes patients to recover (t=13.120, p value < 0.001).

Conclusion

In work paper, the experiments were conducted to collect data from field to develop MLR model to confirm the daylight intensities within which patients LoS inside in-patient rooms are expected to be reduced (defined as therapeutic daylight), identified from literature at the beginning of the paper. The analysis of photobiology and daylight literature reveals that a minimum of 190 lx might needed to be incident on patient retinas to stimulate circadian rhythm and illumination higher than 2000 lx might create visual and thermal discomfort. The estimation of MLR model (Equation 1) emphasised that the CABG patients who experienced higher (above 2000 lx) and lower (below 190 lx) levels of illumination in the maximum time inside in-patient rooms, stayed significantly higher (extra 29- 42 hours) times than the patients who experienced moderate levels of daylight (190-2000 lx) in the maximum time of their stay in hospital rooms. It was concluded that the range of 190-2000 lx can be considered as the benchmark for therapeutic daylight intensities within which reduction of patients LoS are more likely to be happened. Architects and designers could use this benchmark to design daylight in-patient room, supportive to patient clinical recovery in hospitals.

The specific limitation of the methodology applied in this research was that, the ratio between two data loggers was calculated for one day data but considered for the whole year. As the ratio was calculated in absence of patients, hence the effect of patients' behaviour on blind adjustment and artificial light control was not possible to include. As, the estimated values of daylight were not directly used in the MLR model and only used to group the sample patients under three categories, the deviation from exact value have little impact on grouping patients (for example, the patients experienced average 500 lx or 1500 lx will fall in the same moderate daylight group). The research might be replicated by taking samples from different types of patients other than CABG to confirm the presented results.

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Resident user perspectives for the elderly care home guidelines

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Abstract

This paper presents resident related findings from the research project Constructing Wellbeing in Elderly Care organizations, design and management as key elements (2009-2012). The project researches wellbeing influence and the interconnectedness of social, managerial, physical, spatial and aesthetic dimensions in the elderly care home environments. Data collection has appropriated images from existing care homes for group discussions with elderly people. The individual and deep end user experience has further been opened out appropriating earlier anthropological studies within care home residents in Finland and in Denmark. (Koskela 2004; Kofod, 2008)

Care home design needs to bridge the gap between staff members' quality of care paradigm and elderly residents' everyday living experience. Care home design guidelines have typically related to quality assessment emphasizing measurable care elements. New US. based resident quality of life assessment emphasizes resident autonomy, dignity, individuality, privacy, meaningful activity, enjoyment, relationships, comfort, security, functional competence, and spiritual wellbeing (Kane et

al. 2003; Cutler et. al 2006). Quality of life demands as environmental observables describe life enriching features, function enhancing features, resident environmental controls and personalization. (Degenholtz, 2006) New care home concepts enable each resident's individual quality of life, personal autonomy and daily functioning (Kane et al 2007).

The COWELL elderly user information supports the individual quality of life features with concrete notions of home and such elements as nature that the elderly find important in the delicate differences making a care home a pleasurable living environment instead of an institution. The research specifies stigma, dignity and identity as issues connected not only to the physical elements but to a service process where resident intake consists supporting the residents in their sorrow having to give up the past life and belongings, getting to know the residents past, their personal requirements and life style tastes and applying these in the individual resident life.

Keywords: elderly, care homes, guidelines, assessment, atmosphere, affordances, experience concepts

Introduction

This paper presents findings from the Academy of Finland funded research project Constructing Wellbeing in Elderly Care organizations, design and management as key elements (2009-2012). The project in total has studied the interconnectedness and wellbeing influence of social, managerial, physical-spatial and aesthetic dimensions in the care home environments. One part has been problematizing the elderly care home design guidelines from the resident perspective by viewing current Finnish, US and UK guidelines and assessment tools and their application through care home design reality and stakeholders. The effects of care home solutions are further reflected through Finnish focus group experiences about existing care home images implicating solutions for positive care home atmosphere and concepts through well thought physical elements, characteristics and affordances. The emerging care home evaluation and development tools draw attention to the resident quality of life which, from the resident point of view, concerns issues such as identity preservation and stigma. As an elderly user experience input this paper presents elderly workshops' responses for possible care home residency concretizing the quality of life producing care home environments and items in the eyes of the elderly themselves.

Existing elderly care home guidelines

The official care home guidelines in Finland by the National Authority for Medicolegal Affairs 2009 are to ensure the minimum quality level in quality assessments. Typically also the physical environment evaluation is conducted by people from health care background. The Finnish physical guidelines emphasize the necessity of barrier free environment, possibilities for joint activities, minimum resident room size, single rooms, adequate equipment and furniture, technical and functional safety, storage rooms, hygienic requirements, air conditioning, possibilities for cultural and other activities and outdoor staying. The environments should fulfill the demands for pleasurable, safe, home resembling, activating living, support privacy and functionality. Concretely this refers to activity equipment and activities, joint happenings, possibilities to eat together and supporting the relatives' collaborating visits. Self-regulation, privacy and participation are emphasized even with weak functional abilities.

InformeDesign (US.) interior designers' care home guidelines are based on research articles about interior solutions (InformeDesign 1999-2009). General guidance points to home resembling conditions and atmosphere, small enough households, meaningful objects, informal furniture and materials and replacing symbols of institutional care. Specific guidance includes safety equipment, efficient lighting and barrier free solutions. Mobility and activity possibilities are emphasized as well as environmental signage, places to rest and stimulating, changeable nature and culture features. Outdoor and nature activities and seating are seen as important. Everyday necessities are supported by easy bathroom conditions and small person per

bathroom ratios. Room personalization with furnishings, memorabilia and own control provides privacy. Socialization is ensured with shared communal space, joint but intimate eating and semi-private visiting or activity areas. Considerations of differences in resident cultures and personalities, cognition and fatigue are included.

The requirements provide guidance in the general level but the challenge for the care home design is the diversity of the users: mental disabilities, physical fragility, demographics, lifestyle, religion and original nationality. Restrictions in applying even the basic guidelines stem from the use of existing facilities, equipment, furniture and economical limits. Controversial demands rise through the diverse stakeholders: elderly clients, care personnel, cleaning and facility caretakers, residents' relatives and friends and private or public management. The environment should be home resembling but also provide assistance, accessibility and fulfill health care and hygienic demands.

Official regulation provides functional care home demands through the above described multidimensional requirement background. However, environmental elements also associate to psychological needs creating emotional experiences and meaning construction. These are often expressed as feel attributes or category descriptions referring to the publicly accepted care homes' values, emotional and social-cultural aspects such as comfortable, friendly, safe and homey. As guidelines these remain vague and their application is left to the mercy of the designers' and assessors' cultural concepts and preferences where professionals' perspectives might differ significantly from the elderly resident perspective. Is the residents' homely comfort or the health and safety applied as the prominent requirement? Comfort can be randomly glued over a health care environment resulting in an unauthentic feel. Research results show contradictions of safety and health regulations with the resident quality of life measures. In the UK care homes with high provision for safety and health, residents had diminished possibilities in enjoyable activity, moving around and immediate environment control. (Parker et al. 2004).

The responses for existing care homes' images

Kyttä's (2003) environmental psychology model describes pleasurable living environment through physical, social and emotional offerings or affordances looking at the suitable community feeling, aesthetics, safety, recreation and residents' activities. To capture all this design needs to bridge the gap between functional environmental elements and their emotional and meaning based experience. The COWELL study year 2009 searched for the bridging possibilities eliciting pleasure reactions to images from existing care homes' public spaces in focus group type of discussions. Small focus groups of 3 to 5 persons were held for two groups of elderly users, one for care home management, one for care personnel and two for designers. The chosen

images presented environments from two public and two private care homes in Finland. From each a picture of the public living room, dining room, bathroom and corridor facilities was presented.

The results clarify a pleasurable, warm and respectful middle zone: the well thought, homey and comfortable setting with domestic furniture, items and plants, warm colours and good lighting. Care homes filled with devices, messy information boards, differing styles of furniture and stimulation material are fuzzy and associate disrespect. Assistive devices stimulate experiences of disabled stigma, cleaning items communicate about dirty environment where constant cleaning is necessary and children's items refer to children's level residents. On the other hand too bare environments with cold colours and lighting, public space items and settings present displeasing, boring and even scary atmosphere reminding of the healthcare institutions. When domestic quality is demonstrated in a former hospital ward with odd selection of home furniture the end result may be weird, fake and disturbing rather than pleasurable.



Figure 1. Pictures 1.-3. Describe the disturbing space with clutter, pleasurable domestic care home setting and bare, cold corridor with institutional connotations.

The environmental solutions offer affordances described by Norman (1999) for certain kind of behaviour or experiences that are interpreted through culturally constructed understanding. In the discussions respondents saw physically, socially and mentally connected positive or negative affordances. The settings provided ideas of physical activities and social meetings. Mental affordances were pictures reminding of pleasurable things, enjoyable nature views or empty spots for nice things. A suitable solitary setting afforded peaceful meditation or with a view an opportunity to peacefully observe others or outside life.

The respondents' socio cultural experience elicited from the existing care home pictures certain conventional categories representing both private and public, even very institutional environmental concepts. Concept can be described as a unit of meaning built from typical concept's characteristics and producing emotional atmosphere experience. For private space the perceived categories were home, mother's home, old person's home, living room, home garden, cellar, lobby and animal barn. Public space categories were hotel, motel, hostel, shop, kiosk, health spa, school, industrial or other workspace

restaurant. Institutional categories were healthcare centre, hospital ward, army courtiers and even a jail. The categories were interpreted from a single strong item such as a food distribution desk's metal railings referring to a jail or from the whole bare and cold atmosphere relating to institutional atmosphere. The public and institutional categorisation was directed to negative and the private to positive but not as a thoroughly consistent dichotomy.

As a means to find out positive concepts the focus group participants were also asked to choose pictures of a pleasurable environment. The participating elderly chose mainly pictures of gardens even in winter time. The pictures had flowers, walking paths, seating and possibilities for eating outside. For the elderly the nature relationship seems to play much more important role than the guidelines propose.



Figure 2. Garden sceneries adapted from the pleasurable care home environment choices. Drawings Mari-Sofia Kuronen.

The resident quality of life approach

The UK National Minimum Standards for Care Homes for older people focus on service users' quality of life, residents' everyday preferences, personal and health care needs. The approach includes privacy, dignity, autonomy, choice and lifestyle preferences relating to the environmental solutions such as comfort, safety and privacy in their bedrooms with their own possessions around them and semi-public domestic spaces offering social, cultural, and religious activity possibilities.

Year 2010 published 'evolve' rating (Lewis et.al.) for older people's living environments in the UK states universal requirements such as personal realization and choice, dignity and privacy, comfort and control of your environment, personal care, social support inside building and social contact outside as the first ones to

be inspected when evaluating the elderly homes. Only after that come the typical functional and other older people's requirements such as accessibility, physical and sensory support, dementia support, health and safety issues, security and support for care staff.

New US. care home resident quality of life assessment by Kane et al. (2003) focuses on autonomy, dignity, privacy, meaningful activity, enjoyment, relationships, comfort, security, independent functional competence and spiritual well-being. Cutler et al. (2006) assign assessment to observing function-enhancing or life-enriching features, resident environmental controls and personalization. Life Enriching Features include outdoor views, seating, telephones, flowers, living plants, movable chairs, media equipment, religious items, games, animals, pictures, newspaper, work spaces, computers, exercise and skill equipment. The interest lies in solutions such as distances between individual rooms and bathrooms, corridor clutter and noise or the absence of life-enhancing features. The assessment is conducted from the resident's point of view: their rooms, units, nursing facilities composing elements into indices relevant to quality of life. A separate item can influence several quality-of-life domains: inadequate ventilation, low light or poor controls are relevant to dignity, privacy, comfort, security and functional competence. Degenholtz et al. (2006) further remind that as trade-off the lack of life-enriching features in vicinity may be substituted by having them further if the residents reach them. The similar trade-off does not work in terms of function-enhancing features. The care support points to the importance of the service process for the total experience. When fragile the garden serves you only if someone takes you out.

These American approaches have led to the Green House concept solutions: individualized, person-centered planning empowering the staff for maximizing each resident's quality of life, personal autonomy and daily functioning. Instead of good care the whole concept, the following design and service are supporting the residents' good life and lifestyle. Comparison results (Kane et al, 2007) show higher resident quality of life measures in these solutions than in a conventional nursing home when considering physical comfort, functional competence, privacy, dignity, meaningful activity, relationship, autonomy, food enjoyment, spiritual well-being, security, and individuality.

Due to ethical hindrances with mentally fragile residents the elderly care home resident user experience is rarely studied. Kofod's (2008) Danish longitudinal investigation was about the transformation process when you have to leave your own home and move into a care home. In Finland a care home manager Koskela (2004) used game methods to question if her residents felt the care institution was a home or rather resembled army barracks. These studies reveal resident ideas of their own home and a care home connecting the meaning of home to identity, autonomy, control over your own activities and social relationships. In a care home what, when and with whom you accomplish are transferred at least partly for

other people to decide. The feeling of respect is an extremely sensitive question. Stigma can be caused by others seeing your personal hygiene care or others eating messy and you feel considered similar. Losing your identity and life history is connected to worries about your important belongings you cannot take with you. At a mental level this means unfolding your old life and thinking if it matters at all in the care home. The residents' critique towards the staff members connected to their lack of interest about the residents' life history vital for their sense of identity.

Elderly user workshops for care home preferences

To search for the real user perspective content for the quality of life guidelines the COWELL research organized two workshops in North Karelia October 2010 with people aged 60+. In these workshops there were together 57 female and 10 male elderly respondents. These people or their relatives were suffering from physical or cognitive problems, they had relatives in care homes or were home care givers. In addition to the quality of life features in the UK and US care home assessments the elderly answers about the care home residency can be linked to framework from the well-being psychology described by Miller and Kälviäinen (2006) emphasizing effective, predictable and involving action, satisfying social interaction and mindfulness, physical involvement and enjoyment.

In the workshop results the financial affairs were considered as the most important for retaining the feeling of own control and decision making. You should be allowed to decide about your own money, handle your bank account, possessions and property. Even if unrealistic with the residents' disabilities also car and car keys were considered important. On the whole there was consideration how the decidable things depend on your condition. The elderly emphasized that before incapable of deciding yourself you should do your care will and explain your desires for treatments, affairs and burying.

The participants wanted to retain decision rights with practical, every day issues such as wake up times and toilet visits. The environment was hoped to support resident's independent functioning even with difficult disabilities. The decision making question concerned also care behavior: to be asked how you want to do things and when you need help. The care staff should act friendly and normally, not in a patronizing or I know best style. The differences between the resident personalities and habits and the care home practices should be reconciled.

Autonomy related identity needs included the continuation of own habits and daily rhythm. Deciding about private issues related to autonomy. Monetary affairs, personal life discussion, care documents, funeral organizing, correspondence and phone calls were considered private as well as hygienic care, toilet visits,

dressing, hairdresser, and morning coffee. Even semi-private activities such as daily newspaper reading, watching TV, shopping and own celebrations were private for some respondents.

Many results from choosing pictures describing pleasurable care home settings relate to social interaction: easy chairs surrounding a small table as a conversation place or a dining table for an outside dinner with candlelight. Visitors, relatives and old friends, are vital. It was important to take your own address book and mobile phone containing the phone numbers for friends to the care home. Furthermore it was considered desirable to take part into the care home activities. Joint eating, coffee, reading newspapers, general socializing and joining together for special celebrations such as Christmas were seen as communal activities. Also information events, sharing news, watching TV, hobbies and physical activities, playing games or enjoying cultural performances had social nature.

Wished for social interaction included comfortable and cozy joint spaces, flexible timetables, a choice of socializing and freedom to move around. The care plan containing relatives' information from the cognitively disabled residents' social interaction was seen as important. Relatives or friends were hoped to be received in own rooms with no restricted visiting times. A possibility to talk with your relatives and nurses was considered important. Meeting other residents could happen in the communal space which should have room also for birthdays and other celebration.

Things to take along into a care home included own familiar books such as the car repair book helping to remember the joy of the past skill. Own music and song books with familiar songs and a piano pointed to meaningful musical activities. Own working table and trash bin, computer and Internet access were references to intellectual activities. Craft hobbies promoted people to take with them self-made things, craft tools and materials such as hammer and nails.

Decorating your own room according to your own taste and resembling your old home was considered important. Retaining memories related to own memorabilia: photos, paintings, craft textiles, wall clocks, soft toys, and family heritage. Continuing your own life was ensured with own clothes, underwear, night gown, slippers, jewelry, doing your typical make-up and hair do. Own hygienic care and eating objects, a rocking chair or your favorite easy chair with snooze blanket, own carpet, a chest of drawers, television, radio and a coffee maker were blocks of building a normal life setting. Nature elements such as flowers and plants were cherished and some elderly also wished they could bring their pets into the care home.

Preserving identity included even the re-constructive activity of writing your memoirs. A more general wish was the continuation of the earlier pleasurable activities even if not available in the care home's normal program: crafts, drawing, building bottled ships or houses out of matches, collecting stamps, nature trekking

and fishing. The elderly appreciated also enjoyment of favorite music, books or television and radio programs. Even decorating your own environment related to the importance of nature with planting your own or shopping table plants and flowers.

Mindfulness and involvement references exist in the outdoor picture choices of pleasurable care home environments. These pictures presented beautiful gardens with plants, flowers, bushes, walking paths and seating offering possibilities for strolling, sitting outdoors, enjoying the garden and being involved in constructive, even physically demanding activities.

The popular joint activities for a care home included crafts, singing and baking and other household related activities. Physical activities were dancing, gym sessions, gymnastics and relaxation. The cognitive activities consisted of telling memories together, games, crosswords and sudoku. A wise notion was that the residents' life experience skills should be utilized for organizing the activities.

As nice and refreshing surprises the elderly saw visiting artists and associations presenting music, poems, plays, dances or fashion shows. The elderly also hoped to see young people's performances and visiting animals. Different kinds of trips such as nature trekking, sports events, swimming hall visits, art exhibitions and concerts were also popular. Even such short outings as a garden grill party or a visit to a country house were mentioned. Also individual outings were considered when relatives or friends take the residents to places special just for them.

On spiritual life support music, religious meetings and activities organized by outside session keepers were mentioned. Some elderly considered a possibility for church visits important. Reading could be organized with a reading circle, literature available and visits to the local library. It was also pointed out that people need support with their own lines of thought and religious propaganda should not be force-fed. For religious type of groups there was a wish for agreed timetables to choose when to participate.

The elderly wanted a separate space even in the communal district for thinking in peace. For the resident rooms the elderly hoped for a door sign "no visitors" to signal a wish to be left alone and a door bell for visitors asking entrance. There should also be a possibility to lock the door. The resident well-being should be guarded with regular nurses' visits and the residents should have a security phone.

Referring to existence as a person, not an inmate the chosen pictures included images of delicious food, nostalgic country house kitchen, garden table settings, indoor spaces with well thought colors and décor. The examples of the elderly chosen environments point to respectful, beautiful and meaningful environments for everyday life activities, socializing and relaxing. A domestic atmosphere was hoped for

with the resident possibility to influence the menu and participate in the everyday chores. The answers about nice surprises related to considering the residents as valuable individuals: rewarding residents or remembering their birthdays and name days.



Figure 3. Two adaptations of the nostalgic style environments chosen by the workshop participants as pleasurable care home environment. Both of the pictures also included the idea of meaningful social interaction and joint tasks such as crafts and cooking. Drawings Mari-Sofia Kuronen.

Conclusion

When searching for guidance to create positive care home atmosphere reflection should be directed on the application of the existing guidelines. The visual interview results show that it is possible to find some translations how environmental elements and characteristics bring pleasurable and positive feel experiences, affordances and categorization. The quality assessment perspective is crucial: the results are different when evaluated from the resident quality of life compared to the efficient care perspective.

The elderly user information supports the individual quality of life features with concrete notions of home, identity, dignity, privacy, meaningful activities and independence added with nature elements that the elderly find important. Common guidelines cannot take into consideration the personal taste and lifestyle requirements of all the changing residents even if in practice the environment is not a separate entity but entangled with the individual resident's living habits. The intake process to the care homes could include information tools about the resident's identity and their personal requirements, everyday routines and environmental taste. Compared to suggestions from customer taste defining framework from Kälviäinen (2002) it could include pictures from the residents' own homes and surroundings, real life situations, information about their family, everyday life habits, tasks and timetables, occupational and cultural

background, hobbies, roles, meaningful identity and value issues, meaningful objects, lifestyle inclinations, social networks, and interaction habits. The staff should be interested in supporting the elderly in continuing their preferred life style even when in the care home. The general understanding for the positive care home atmosphere should be integrated with the real residents' personal life history and home concepts.

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Embodied textiles for expression and wellbeing

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Abstract

To date, experiences with technical textiles have largely been focused on performance related aspects of a fabric developed for specific applications such as sports, health or safety (Shishoo 2005), and methodological problems remain with the techniques employed to measure what is a complex of effect and affect (Bartels 2005, Jordan 2000). However, there has been little in the way of empirical research into personal human experience with technical fabrics in context, with the notable exception perhaps of Entwistle who examines in depth the kinesthetic properties of particular garments, resulting in heightened awareness of the body (Entwistle & Wilson 2001) and Candy, who analyses feelings of well being and the performance of socially meaningful demeanours (Candy 2007a, Candy 2007b). We wish to extend this embodied view of textiles in order to realise the potential of smart and technical fabrics and sensory environments as tools for wellbeing, mental health and personal expression. This paper describes the work of an interdisciplinary group of practitioners and researchers investigating the development and application of textile stretch sensors on the body (Breedon et al 2008), figures 1 and 2. Understanding that such tactile products and materials may offer beneficial contexts for in-the-moment and expressive therapeutic techniques (Jones 2010, Jones & Wallis 2005), we describe the early stages of our collaborative development of an evaluation framework based on person-centred principles and outline the future work planned.



Figure 1. Visual resources and samples in development

User Centred Design, textiles and tangible interaction design

Design recognizes the agency of users in appropriating products for their own purposes, and is aware of the ways in which the situated actions of users often transcend the intentions embedded in products (Suchmann 1987). User-centred approaches such as Participatory and Co-Design seek to bring products closer to user lifeworlds through addressing the unequal power relationship that can exist between the designer-as-expert and the user-as-passive-consumer (Sanders 2006, Lanier 2010). At the same time a growing emphasis on services means design is moving from user-centred to human-centred models (cf IDEO 2011, Sangiorgi 2011). In all of these models, the agency of the user or client is evident in the *process* of design. We propose that there may be a way to complement this by focusing on user meaning-making with the *products* of design. This approach means explicitly leaving space for users to define the expressive and even pragmatic functions of an object. In many cases this will challenge the central assumptions of seamlessness and fitness-for-purpose that characterize products intended to become a part of *productive* life. In contrast, in this model, the design process is not working towards a solution, but a context for exploration as part of an *expressive* life (Hallnäs & Redström 2002).

To inform the development of our ideas, we are looking at person-centred theory and practice and in particular, we are focusing on the non-directedness of Rogers' theory as a condition for therapeutic encounter as a way of designing for wellbeing (Levitt 2005). Person-centredness has not been entirely absent from UCD: Ann Light draws on Rogers practice to conduct 'explicitation interviews' with individual users in Human Computer Interaction research (HCI) (2006), while Wilde and Andersen's recent Owl Project has inverted the normative design process, creating 'design probes' to encourage 'magical thinking' (2009). As interest builds in the potential for tangible, as opposed to screen based interfaces, for designing for user experience, the goals, processes and evaluation methodologies of interaction design are also being re-examined through Craft's interest in material; for examples, the reader is directed to Wallace's work in McCarthy et al (2006), White's approaches to Interaction Design (2012), and Kettley's work in distributed computing (2011).

Textile Design offers a natural opportunity for contributing to this paradigm shift, although until recently, much development with smart fabrics and technical textiles have been focused on the performance related aspects of fabrics developed for specific applications such as sports, health or safety (Shishoo 2005). In the Textile Design literature there is research into the complex of effect and affect that textiles afford (Bartels 2005, Jordan 2000), which would benefit the development of novel interactive textile systems. In the sociology of clothing, Entwistle examines the kinesthetic properties of particular garments, and the resulting

awareness of the body (Entwistle & Wilson 2001), while Candy analyses feelings of wellbeing and the performance of socially meaningful demeanours (2007a, 2007b).

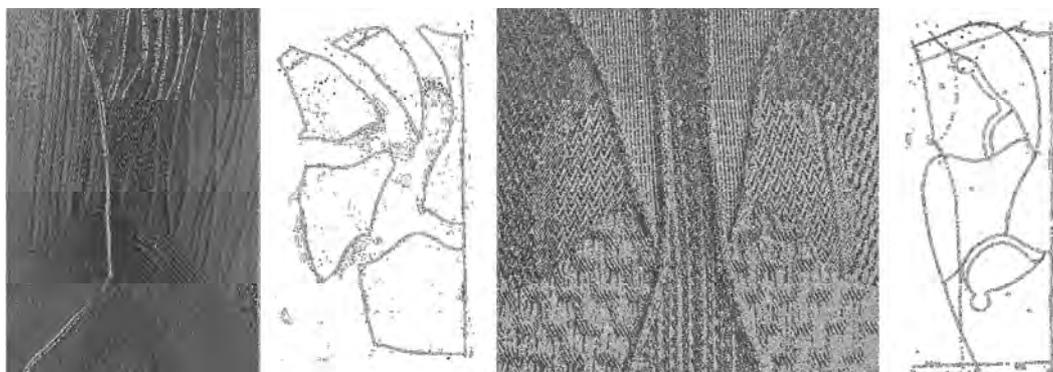


Figure 2. Details of the embroidered (l) and woven (r) backs with pattern cutting approaches to the spaces between segments

Our work with stretch sensing on the body

Over the past two years, textile designers in knit, weave and embroidery have been collaborating with an interaction designer and pattern cutter at Nottingham Trent University to investigate how methodological knowledge informs interdisciplinary practice (Glazzard & Kettley 2010, Kettley et al 2011). Deliberately working from a Craft perspective, applications and functions were left undefined while fabrics incorporating novel stretch sensing fibres were developed, allowing the textile designers to approach the new material according to their own aesthetic concerns (including weight, handle, texture and pattern for example). The common visual reference used was the musculature of the male back, selected in response to our association of the stretch sensor with ligaments in the body, figure 1. The outcomes of this work included a series of garments referred to as ‘the backs’ as shown in figure 3.

The backs have demonstrated the potential for professional craft and design practice to add value to the development of interactive systems (Kettley et al 2011), although they do not currently incorporate a full circuit and there is no output as yet. This reveals the inversion of the design process, as the normal concerns of what design is for and what it does give way to the value of materiality and the body.



Figure 3. The 'backs.' L to R: embroidered, knitted, woven garments with stretch sensors

To continue the work now means to bring it to users (dance therapists, learning disabled artists, and disabled dancers) and to use it as a starting point for further requirements generation (to use the language of interaction design). The key methodological point to stress here is that we wish to generate rather than define requirements, and to put in place a methodology that values emergent and hard to articulate benefits as well as instrumental, pre-defined goals. These concerns have come out of the first author's interest in craft as a design methodology, and find resonance in the evaluative framework developed by Jones (2010, Bayliss et al 2007, Wallis et al 2010). The next section describes Jones' work with participatory arts charity Salamanda Tandem and the changing landscape of service provision in care.

Therapeutic expressive practices – Salamanda Tandem and the changing context of care

Salamanda Tandem is a group of artists and producers, who have been working for over twenty years in the Nottinghamshire area in participatory performance arts. The remit of the organization is to develop socially engaged participation methods and sensory performance "in order to inspire and help people, from all areas of society, to harness their creativity in order to improve their quality of life and that of people around them" (East Midlands Participatory Arts Forum 2012). Led by Creative Director Isabel Jones, the group includes artists, musicians, composers, architects and academics, and is funded by Arts Council England and Nottinghamshire County Council Arts Team. Until recently, organisations like Salamanda Tandem would typically deliver workshops and services through day care provision in fixed locations. However, funding structures have been radically changed through the personal budget system, and day care centres are no longer the cornerstone of this type of activity. Instead the disabled person and their care staff and family become responsible for choosing therapeutic interventions which may be delivered in a range of environments including the home (Dilnot Commission 2011). *Valuing People*, a policy for services to learning disabled people (Department of Health 2001) and *The National Framework for Older People* (2001) appeared to point to a philosophy of person-centredness underpinning all health care provision in the UK. However,

over the last decade progress has been slow and relevant research, for example *Valuing People Now* (2009), has shown that person-centredness is not easy to achieve. More than this, although the term has come to mean different things in different care practices, and misunderstanding across disciplines is a significant issue (Freeth 2007).

A person-centred approach based on Rogers' theories (1990, Freeth 2007) requires wholesale attitudinal change in a social care and health system founded upon a deficit model of disability, and upon illness being the root of a 'problem', rather than individuals holding the source for a 'solution' (Patterson & Joseph 2007), just as the design process introduced above requires a conceptual shift from its own deficit model based on the identification of user 'needs'.



Figure 4. Living Room, Rufford, January 2011

Amongst practitioners there are concerns about how some of our most vulnerable people might 'be offered a personalized care plan' (Department of Health 2008, p. 47). The non-directive emphasis of person-centred practices depends on listening and empathy, which need to be sensitively employed to help service users make informed choices in tandem with their care networks. Jones' specialism is in this kind of listening, which may also be non-verbal. As part of the work at Salamanda Tandem, a set of principles and values have been established, driving the development of facilitative methods and structures to support the practices of individual development and wellbeing (Jones 1993). One of these structures is 'moment by moment evaluation', which has been shared through the Foundation for Community Dance (Jones, 2010). Here the arts practitioner deploys a high level of reflexivity, and through establishing mutual exchange and non-verbal dialogue s/he can enable each individual to expand their potential and become an active partner in expressive production. Such an approach to evaluation seeks to remain true to the ethics of person centredness while introducing rigour to the evaluative process (Patterson & Joseph 2007).

As an example of Salamanda Tandem's practice, *Living Room* provides a context for expression and performance co-created by profoundly disabled or vulnerable people. Here the team of artists attempts to create a flexible and sensory interface that is dynamic and sufficiently two way to deal with the multiplicity of human interaction (Hodgetts & Jones 2007), figure 4. The following section describes the coming together

of the new team of movement specialist (Jones), interaction designer (Kettley) and textile designer (Downes) and the early insights these moments have provided.

Sharing practice and informing future research

The theoretical and evaluation framework is being developed through a series of framed discussions, forums and a theoretical literature review. Methods to date have included a shared *Living Room* workshop at Rufford in January 2011, the *12 Provocations* debates facilitated by Salamanda Tandem (12 Provocations 2010), and recorded handling sessions with the backs and textile samples at Nottingham Trent University in July 2011. In addition, Jones conducted a sensory design seminar with masters students on the Smart Design framework at Nottingham Trent University in the autumn of 2011, which Kettley recorded towards this research. While such discussion may not normally be considered a research method, we find it referred to in the person-centred literature as important to the development of learning and new knowledge (Kelly 2008 p15), and consider it similar in approach to the conversational conference as a powerful means to facilitate real interdisciplinarity (Callaos 2009).

Living Room

In January 2011, Sarah Kettley and Tina Downes contributed to one of Salamanda Tandem's invited practitioner workshops held at Rufford in Nottinghamshire. The purpose of this was in part to experience the space, its physicality and mixed media and opportunities for interaction, but more importantly, to experience first hand Jones' approach to facilitating expression – her practice. Using movement, voice and gesture, she works to include participants without dictating. The option not to take part is always given, with clear and simple actions made available – for example, sit outside the grass circle to indicate your non-participation. This personal experience of non-directivity was important for beginning to understand the potential it might have in design, and how it might be explained to others in the textile design team.

12 Provocations

In October 2010 Salamanda Tandem launched the *12 Provocations* on line (12 Provocations 2010). Each Provocation starts with one of the organisation's working principles and a text that acts as a stimulus for dialogue (Jones 1993, 2010). Joining the debate are a group of experienced practitioners and researchers from the fields of health care, education and the arts, who have been exploring the ethical values and aesthetics necessary to enable creative expression for a wide spectrum of people. Kettley attended the Provocation on authenticity on 30th March 2011; the session was organized around Boal's principles of the Theatre of the Oppressed (2002) in which two participants enact a discussion around a provocation, and others are invited to comment on the action, and respond with new directions. One of the themes to

emerge was the ways in which an evaluation thought process sited within the practitioner may move quickly outwards and back through collaboration, acting rather like a feedback loop, embedding meaningful change in the design and actualization of participatory experiences. One insight to emerge from this was that authenticity may be seen in the generation of an embodied dialogue between the original idea and what is emerging – the ‘warp and weft’ of the old and new.

Handling session, July 2011

Isabel Jones visited the University to discuss how the textile work undertaken so far might be developed in line with the sensory environments facilitated by Salamanda Tandem. Although this had been planned as a ‘handling session’, it quickly became more involved, with Jones putting the garments on in turn and moving around the space in response to them. The videos captured were ad hoc (figures 6-8), but have been important in informing our discussions around embodied interaction with textiles on the body, particularly at the point where expression and wellbeing intersect.



Figure 6. Embodied responses to the embroidered back

Isabel’s clearly articulated bodily responses to the three garments demonstrated the importance of the quality of the space between textile and body for kinaesthetic awareness and subsequent action. One of the outcomes of the early research had been to illustrate how textile knowledge differs across processes, and how these differences become embedded in the final outcomes (Kettley et al 2011). The three backs were made to the same pattern, but different processes produce different material properties, and each garment thus has its own character – each is a distinct *actant* in the anthropological and Actor Network sense of the word (Molotch 2011 p102). Isabel described in words and movement the embodied reaction she had to these qualities; in the captured video footage it is easy to see how the embroidered piece is looser on the body and leaves gaps between the skin and the fabric, the knitted garment is very forgiving but touches the skin almost constantly, while the woven piece is very strong and fits closely to the body at all times. In response to these different presences, the human actor feels and moves differently.



Figure 7. Embodied responses to the knitted back

In addition to the interaction with the physical pieces, Isabel shared videos of her practice with a severely learning disabled child in a standard soft play space as provided by a day centre. In this we were able to see in action the non-verbal communication of dancer and child, as well as the one-dimensional treatment of texture in the room. This is not unusual; textiles have been under represented in this field, with vinyl being preferred for ease of manufacture and wipe clean capabilities (Gaudion 2010). However, early outcomes of research in Scandinavia (Cappelen & Andersson 2011) suggest that a wider range of formal qualities such as texture and flexibility may be beneficial for what Caldwell has termed *intensive interaction*, the close mirroring of client action or sound which brings the actor, carer or therapist into the child's world, as in Isabel's practice and theory (Caldwell 2008, Jones 2010 pp70-73)



Figure 8. Embodied responses to the woven back

Towards a collaborative framework

These responses to the physicality of the stretch garments and the qualities of the fabrics were a promising start, but several questions remain: who will be wearing the garments? How can they become part of expressive and therapeutic practices? How can such fabrics become part of a sensory environment such as *Living Room*, and what is the relationship with the body then? In addition, Isabel is exceptional in her ability to articulate what for most people would remain implicit responses to formal environments. How can this

work contribute to the development of a framework for evaluation when the majority of users' responses will be non-verbal? Many learning disabled people are exceptional in their ability to be in-the-moment, but more standard evaluation procedures rely on prediction, in setting criteria, and post-evaluation. Dominant cultures of evaluation in health and wellbeing, and in craft and design, are often based on the object that results from the activity: craft in its modernist guise is concerned with quality and craftsmanship; design likes to closely define a problem and a user group with a shared demographic or lifestyle in order to fit a product to its purpose; the National Health Service finds Cognitive Behaviour Therapy (CBT) useful because of its approach to diagnosis and its finite timescales and demonstrable outcomes (although whether it is effective in the long term is questionable, and it is certainly not a fix-all solution (Durham et al 2005)). But as the Provocations and others have shown (12 Provocations 2010, Hollingsworth 2011), this type of practice, in which the client is as much the artist as the facilitator, there is a blurring of the art form, making predefined criteria difficult to pin down, and ownership is radically redistributed, challenging modernist ideals of the individual artist as the genesis of a work. Further, psychotherapy and CBT are concerned with different scales of 'improvement' in a client, relying on the interpretation of 'an expert', and clear changes in client behaviour respectively. We find the processual focus of person-centred theory and practice more suited to our emphasis on the quality of in-the-moment experience of the client, and to our concerns for equality of power in the relationship between all performers (Walshaw 2008). Here we discuss briefly four themes which are emerging from and informing the framework of our collaborative practice, these being: *the relational artform*, *security in performance*, *modalities of communication*, and *reflection*. Further themes are expected to emerge, and need to be examined, in future work.

A relational framework in understanding the artform

Steve Hollingsworth refers to a framework of relational aesthetics in his sensory environments for Artlink (2011). This allows him to conceptualise the work as 'art' at the same time as shifting focus from the object to the facilitation of relationships. While the objects within the space, and the space itself, are key to what happens and what is experienced, they are not where value lies in this process. Rather, the aim is to provide the necessary scaffold for a shift in perception. As in Salamanda Tandem's practice, the artist becomes a catalyst, supporting others' creation of their own narratives and identities.

Security in performance: providing the context and reading the signs

In providing a regular Tuesday group of "strange sounds and other worlds", Hollingsworth is careful to offer both routine (in the repeated weekly format) and change, in the media of the sensory space, which may often be determined by chance and low budgets (2011). Routine and repetition at different scales is useful in both providing security and acting as an expression empathy: "In a world of scrambled sensory information

when he used a repetitive behavior he knew what he was doing.” (Caldwell, in McIntosh & Whittaker 2000, p21). However, sometimes it is not movement but stillness which can indicate or give peace; in Isabel’s accounts of themed practice in a school (in this case the theme was the second world war), it was the listening to and reciprocity towards body language that allowed one disturbed child to find his place. According to Kelly (2008 p18), talking and not talking during therapy sessions is equally important, and the cues should be taken from the (child) client.

Modality of communication, supporting bodily interaction beyond sight alone

We are in danger of becoming “lazy lookers” in the way that we perceive the world, and that in the West in particular we have become over accustomed and over reliant on sight as the dominant sense (Hollingsworth 2011). This is supported by other artists working in hybrid practices involving robotics and artificial intelligence, who question what perception is. Anna Dumitriu takes the famous provocation, ‘*What is it like to be a bat?*’ (Nagel 1974) and asks scientists ‘*What is it like to be a robot?*’ In challenging creators of autonomous systems to experience the world through the standard ‘senses’ they build into their machines, she asks them to rethink consciousness. In her own exploratory performances, she removes and restricts her own senses, binding her limbs, masking her eyes and anesthetizing areas of her skin. In this way she becomes highly conscious of her own moment-to-moment assessment of the space around her.

We believe that textiles may offer a new palette of sensory focal points beyond the inclusion of textiles in a long list of ‘crafty’ materials a practitioner may take along with them (eg Walshaw 2008). One classic sensory approach we may look to in therapy is sandplay (Woodhouse 2008), although this is not covered in great depth in the person-centred literature (it has instead been historically informed by Jungian practices, e.g. Soble 2011). Although she does not use the term evaluation, Woodhouse talks of the need to ‘listen with the whole of herself’, using all her senses and intuition to work effectively for and with the client (2008, p31). This description of empathic moment-to-moment evaluation echoes the framework developed by Jones (2010).

Reflection

The cornerstone of Jones’ evaluative practice is that of reflexivity. Often thought of as learning from a previous experience in order to take learning forward into new projects, Jones is careful to show how reflection happens in three phases: *before* an activity, drawing on all previous experience; *during* an activity in moment-by-moment evaluation; and in summative evaluation *after* the event. Her model of evaluation takes into account the various stakeholders in the process, including the practitioner and client of course, but also the network of carers, staff, peers and external bodies (2010 pp59-73), figure 9.

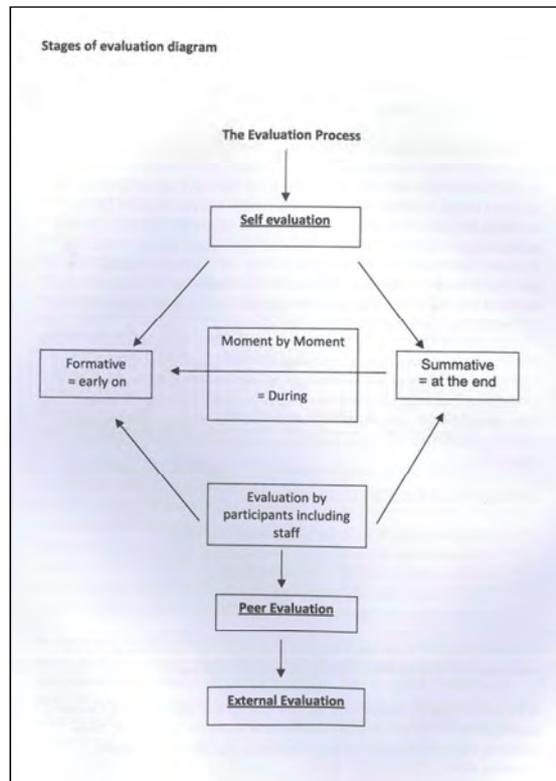


Figure 9. Jones' stages of evaluation

In our evaluations we want to avoid reifying gestural meaning or processes (whether ours or participants'). We are so used to meaning apparently belonging to the past, being dependent on it and defined by our received ideas of styles of movement and disciplinary expression that we find ourselves challenged by our participants to rediscover real meaning as it is, in Peter Brooks' words, "checked in each man's own present experience" (1968, p15). Perhaps the ultimate test of our sensory environments will instead be evidence of a "true unspectacular intimacy" that emerges from quiet, security and confidence (Brooks 1968, p22).

Conclusion and future work

Through our discussions we have begun to build a common language and have been able to recognize shared concerns despite working in different creative disciplines. The theoretical framework for evaluating textiles and wearables for therapeutic interventions will continue to develop throughout 2011 and 2012, including through new instantiations of *Living Room*, sensory dance performances, and sensory space exhibitions. We are developing research questions based on the framework and will look at how participants work with or experience the textile objects and environments: for example, do they become communicated with or through, and what makes the difference? We wish to further our understanding of how such textured objects may be both 'designed' and 'open', acting as scaffolds for expression. Lastly, we are interested to know how such open objects might then be used by care professionals to build training in

empathic and intensive interaction techniques, increasing skills in recognizing, sharing and developing individuals' sensory language. It is patent that many, even simple, objects, are useful to the skilled and empathic practitioner (Jones 2007), and that the key ingredient of the therapeutic encounter is not so much the 'toys' but what the facilitator or counselor brings to the interaction (Kelly 2008, p14). Further, we expect to be able to continue to discuss this non-directive way of working in interaction design as part of the interdisciplinary nature of the project.

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Using qualitative people-centred co-research methods to enhance innovation within ‘medical model’ research design

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Abstract

To date, the biomechanics community has had limited success in communicating complex biomechanical data and analyses outside its field. This may be symptomatic of its approach to public and patient involvement (PPI). The authors, having considered the visualisation and presentation of these biomechanical data from a user-centred perspective, have created an innovative prototype software tool to visualise objective dynamic movement data. Evaluation of this tool through PPI has shown it to improve communication of complex mobility data in an accessible manner for non-biomechanical specialists and lay people. Its continued development, by a multi-disciplinary team, as a therapeutic intervention for rehabilitation, has highlighted the problematic issues of: a) conventional randomised-controlled trials (RCT) design and the different models of research and metrics favoured by different disciplines within the team; b) the interpretation and application of PPI using either design or scientific methods; c) the acceptance or challenging of assumptions and conventional practice; and d) the idea of open innovation. This paper describes how research originally conceived in a 'medical' mode using quantitative outcome measures from a set of RCTs has evolved to use a mixed methods approach. A complementary qualitative methodology was introduced at points before, during and after the RCTs, using people-centred design methods. This helped challenge assumptions within the team, enabled innovation and facilitated more in-depth evaluation of the effects of the changes in the rehabilitation process for patients and health professionals.

Keywords: People-centred, co-research, qualitative design, healthcare, innovation

Introduction: context of the research

For many physical rehabilitation issues a biomechanical understanding of the problem and its solution is essential (Durward, Baer & Rowe, 1997). However, despite almost 40 years of research the biomechanics community has had limited success in communicating complex data and analyses to other disciplines and to lay people. This issue provided an opportunity to investigate the potential of applying visual design methods to help 'unlock' the complex information for other disciplines in healthcare.

In an initial study, the authors developed a prototype visualisation method designed to assist in the understanding and the improvement of appropriate movements during rehabilitation (Loudon & Macdonald, 2007; Macdonald *et al*, 2007). A subsequent study (envision, 2009) investigated the ability of professionals from different disciplinary backgrounds and lay persons to understand example visualisations of complex biomechanical information on the functional capabilities of older adults. This research found that through the use of visualisation techniques, data which would normally have been incomprehensible and required specialists in biomechanics to interpret could be understood by both lay and non-biomechanics professional audiences. Further, the visualisations were shown to enable new cross-disciplinary dialogues about the data between the professionals and lay members (Macdonald, Loudon & Docherty, 2009).

To evaluate the feasibility and efficacy of visualisation methods to improve rehabilitation services, visualisations of biomechanical data are being tested in a third study (envisage, 2011) through a series of five Phase II randomised-controlled trials (RCTs) exploratory, as defined by the MRC and will follow MRC guidelines for the evaluation of complex interventions (MRC, 2008). It is in this current study that an interesting and productive tension has emerged between the conventional scientific design of RCT trials and the different models of research favoured by different disciplines within the team. This tension embraces: i) the interpretation and application of public and patient involvement (PPI) and the implications for the development, definition and integration of qualitative methods as part of the overall methodology; ii) the acceptance or challenging of assumptions and conventional RCT design practice on the development of the visualisations for the individual work packages (WP); and iii) the opportunities for an open innovation approach through PPI and how to continue innovation and development of visualisations not only before but also during the trials. In this case the open innovation paradigm assumes that 'external' ideas (i.e. in this case ideas from patients and therapists) as well as 'internal' ideas (i.e., from the members of the research team) can be used.

Initial study design: original outcome measures

Returning to the problem referred to above of the difficulty the biomechanics community has had in communicating its research successes outside its field, this may be symptomatic of the community's

approach to PPI and how it tends to regard 'subjects' in a study of this kind. The study, being led by a bioengineer, originally defined the outcome measures predominantly through the functional outcomes and quantitative metrics familiar to that discipline. The original specification of the RCT design tended to measure subjects through biomechanical metrics such as walking velocity, motion generated through activity, joint movement and kinematics. Issues such as motivation, confidence and quality of life were to be measured using standard questionnaires or self-reported using activity diaries.

To address the 'envisage' team's main hypothesis that *"visualisation of biomechanical data will enhance health and rehabilitative healthcare by mediating between users, carers, clinicians and healthcare practitioners, and in so doing enhance ... physical mobility and independence ..."* the research design was also to include an over-arching qualitative study. This would use structured interviews and focus groups of the participants and healthcare professionals consulted in the WPs to review the success, or otherwise, of the visualisations in improving rehabilitation and any problems with implementation.

While the importance of the qualitative study to the overall project was recognised, it was not fully integrated and was seen originally as a parallel activity, evaluating the results primarily at the end of the trials. Influential to the authors' approach to developing and integrating the qualitative work package into the study were findings in Lewin, Glenton & Oxman (2009) which discussed the use of qualitative research within RCTs of complex healthcare interventions. *"Complex healthcare interventions involve social processes that can be difficult to explore using quantitative methods alone. Qualitative research can support the design of interventions and improve understanding of the mechanisms and effects of complex healthcare interventions"*. They found that qualitative research within an RCT is still relatively uncommon and the examples published to date have largely been poorly integrated. As they conclude: *"Most of the qualitative studies were carried out before or during the trials with few studies used to explain trial results."*

Focus groups: using survivors and therapists to guide development

Although the authors had developed and evaluated a prototype visualisation method in previous studies, to guide the initial development of the visualisations for the RCTs it was essential to understand how these might be perceived by and be of value to both patients and therapists for specific areas of rehabilitation, such as post-stroke or post-knee surgery. In designing a patient-centred approach, Savory's (2010) model was considered. Savory usefully describes four idealised strategies into a framework to discuss four main categories of PPI in healthcare research: A) PPI strategies that focus on the participation of patients with the primary purpose of collecting data; B) a broader-based PPI strategy involving data collecting from a wider range of stakeholders; C) a patient led strategy where the mode of PPI is complex with them being involved

in the design, conduct and analysis of the research; and D) where there is widespread public involvement in translative research.

The normal practice of the biomechanics community would have been to deploy the strategy A (PPI strategies that focus on the participation of patients with the primary purpose of collecting data). The authors, being concerned with patient/people-centred design approaches, wished to challenge this practice and to broaden the approach to also include strategies B and C. In the previous work (Macdonald, Loudon & Docherty, 2009) the ability of the visualisations to mediate discussions between lay people and professionals was identified. However, the research did not investigate in detail if there were any differences in how the visualisations were perceived and understood by lay participants and professionals.

To investigate this for the present research, two focus groups were held for the WPs concerned with stroke: one with stroke survivors; the other with stroke rehabilitation professionals. The questions centred around: i) how to communicate to the patient what physical movements or exercises they had to perform and why they had to do these in a particular way to assist setting goals; ii) how to track and communicate the progress of the patient through their programme of rehabilitation; and iii) how to help motivate the patient to persevere with their rehabilitation programme.

Topic guides were used to explore each of these areas for the problems and difficulties encountered during rehabilitation, and how explanatory visual materials could best be used to mediate discussions between therapists and patients, illustrated in the following figures (Figures 1, 2, 3, 4 and 5).

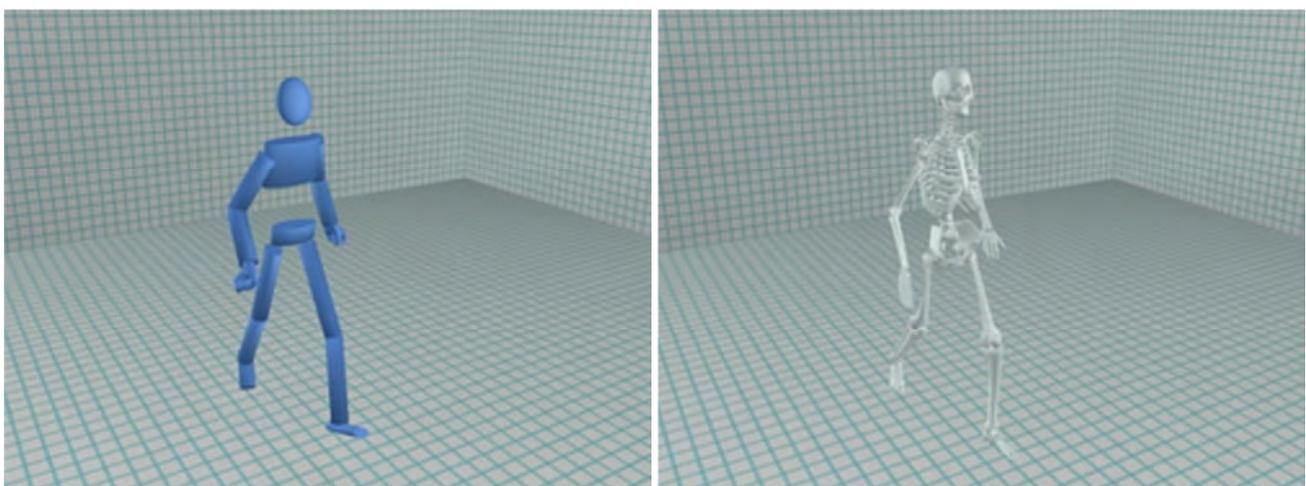


Figure 1. Appearance of the figure: whether this should be a (left to right) i) 'stick', ii) 'skeletal', or iii) 'realistic' figure.

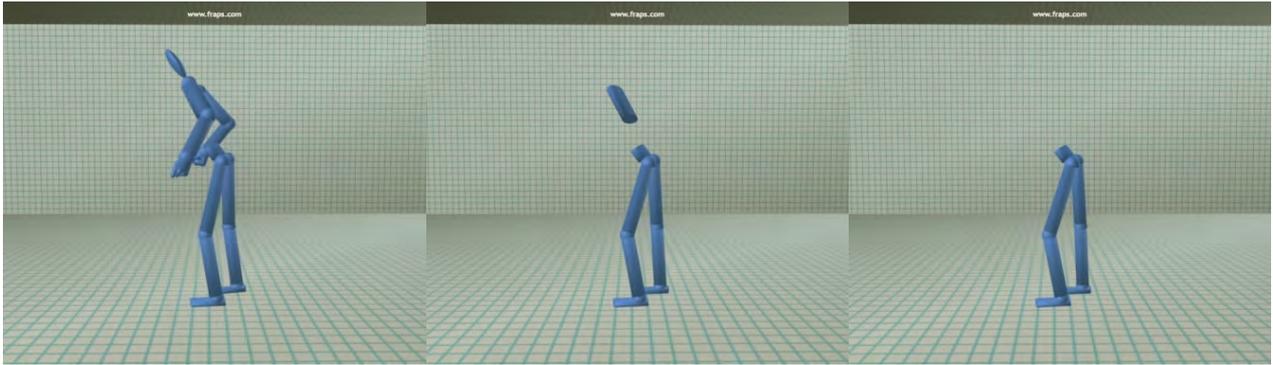


Figure 2. Whole or part body: whether (left to right) i) the total body figure should be used or ii) and iii) only relevant body figure segments.

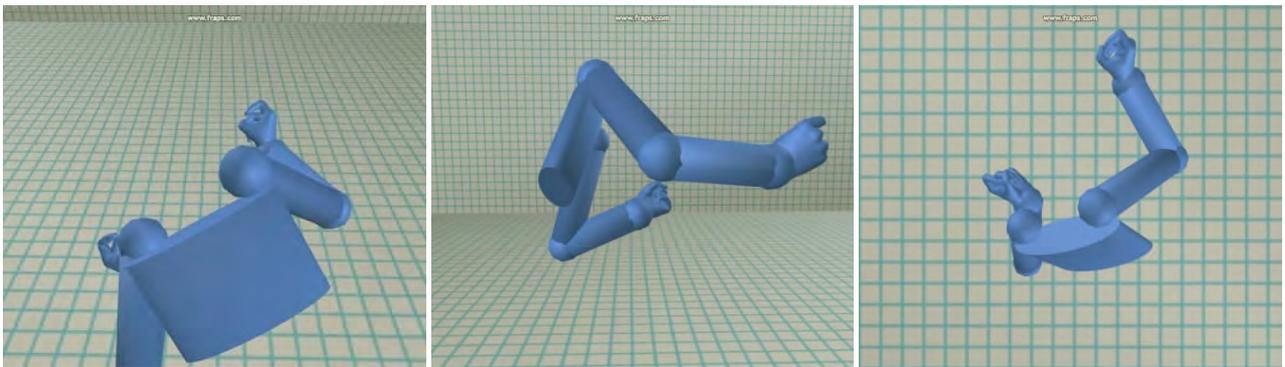


Figure 3. Viewpoint: whether this should be (left to right) from i) the side, ii) behind or iii) above when viewing movements.

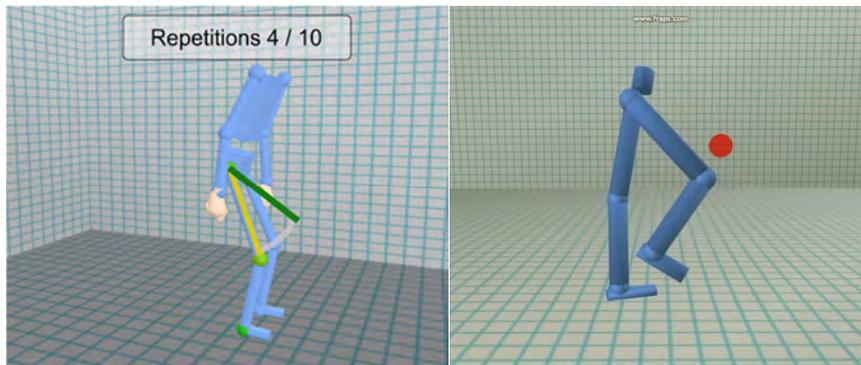


Figure 4. Overlay information: exploring what kind of graphic overlay information would help (left) i) achieve correct angles during movements, or (right) ii) correct positions with reference to a target.

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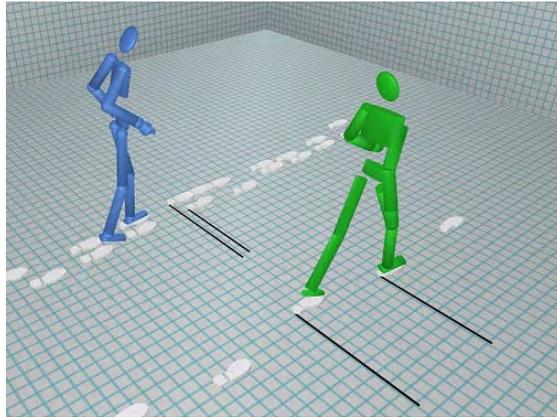


Figure 5. Comparative progress: how best to convey progress, e.g., by showing video files of visualisations side-by-side comparing previous with current movement quality, or to show improved progress with step length and symmetry overlay information.

The focus groups were important in highlighting the survivors' issues and, for example, the sensitivity required in showing stroke patients the extent of their difficulties through visualisation at a hugely distressing period of their life. For example, in showing the last of the above sets of visualisations concerned with progress (Figure 5), one unexpected finding was the potential for a chosen type of representation in reconnecting the stroke survivor with an earlier, perhaps painfully recollected, stage of their rehabilitation. One's physical rehabilitation journey is also an emotional one embodying the achievements and setbacks of the past and also the hopes and fears for the future. This highlighted to the team that the experience of the therapist will be key in deciding what should (or should not) be shown and when, with sensitivity to the patient's situation. One's motivation to continue with rehabilitation therapy involves psychological issues and challenges which may not have been explained from the original functional outcome measures referred to earlier.

These findings highlighted the sensitivity required in the design of the representation of the figure and managing how the patient sees their own movements. For example, in their initial rehabilitation session the patient may not have been able to see before the severity of their movement problems in a clear objective manner. The same movement, shown using different types of figure representations, has a potential for eliciting a different emotional response for each type of representation. This kind of response from the focus groups sessions informed the design of the software to enable the appropriate representation of the figure to be selected from a number of options by the patient and/or therapist, an innovation in the visualisation tool. The patient's progress through their rehabilitation, which can be complex, will also require to be sensitively handled. There may be periods of rapid improvement, but also times where improvement is limited, or there may be intermediate reductions in capability. The approach taken in response to this sensitive area has been to make the tool flexible in how progress is communicated to the patient and to give

the therapist control over when and how progress is communicated. A potential advantage of the visualisation tool in this scenario is that the progress can be communicated objectively by the tool, rather than by what may be conceived by the patient as the subjective opinion of the therapist. The benefits this may provide for the interaction between the therapist and the patient will be explored in the research and during the RCTs. (Loudon, Carse & Macdonald, 2011)

Integrating qualitative methods into the RCT design

Findings such as those mentioned above strengthen the case for mixed methods in RCTs, for a substantial qualitative dimension to the study to both i) guide the development of and ii) evaluate the effectiveness of the intervention. As a consequence the qualitative dimension to the RCTs was designed with the following stages and methods:

- pre-trial interviews: eliciting patients' and therapists' views before the start of the patients' rehabilitation
- during trial observation: observing how patients and therapists use the visualisations during rehabilitation
- post-trial interviews and focus groups: eliciting patients' and therapists' views about their rehabilitation experiences and relating the quantitative trial outcomes to these experiences

At each of these stages patient, carer and professional perspectives on the visualisation tools, rehabilitation interventions and overall service implications are being explored using a combination of observational data, interviews and focus group discussions. Using as an example those WPs concerned with stroke, the researchers were interested in the following kinds of detailed questions:

- In upper and lower limb stroke rehabilitation for acute stroke patients, could visualisation of compensatory movements and biomechanical measures of movement quality improve upper and lower limb motor relearning for acute stroke patients?
- In diagnosis and fitting of an ankle-foot orthosis (AFO) in late stage stroke, could objective visualisation of the effect of AFO tuning on complex and inter-related gait parameters improve clinical decisions and hence patient outcomes? Could visualisation of the benefits of wearing an AFO to patients make them more likely to wear the orthosis?

- There were a number of questions that the individual WP researchers wished to ask, and these were challenged and evolved using the design process and qualitative data from the focus groups. These questions evolved into a set of over-arching questions for each of the WP RCTs.

Discussion

Lewin, Glenton & Oxman's (2009) findings show that current biomechanical RCT study design practice has largely centred on acquiring quantitative data from subjects (Savory's Strategy A). Although this kind of data might be able to give some indication as to the 'what', e.g., improved walking rates or more controlled movements, it is not useful in determining the 'why', e.g., motivational issues or how the visualisations were perceived and understood. This highlights not only the need for other (i.e., mixed) methods to be introduced into traditional RCT design but also the differences in epistemological viewpoints between scientists and designers. As a consequence, the first task for the qualitative design researchers in the team was to question the conventions, perceptions, methods and approaches used by the scientists, engineers and technologists in the team whose preoccupation had previously been primarily with the technologies of position sensing, motion-capture as well as the quantitative outcome measures.

These outcome measures, referred to in 2 above, were determined clinically and primarily for comparison in the literature. The problems encountered by the 'subjects' of the research were assumed at the outset of the study. However, walking velocity may be a key indicator clinically, but the participants' needs were considerably more complex, as characterised by those emerging during the focus groups.

Developing the scripts for the focus groups helped create synergy between the different disciplines. This process and PPI helped develop a growing awareness of the importance of understanding how people comprehend what they are viewing, of what should be shown and of how the visualisation might be used to assist in the process of rehabilitation therapy, in measuring progress and for improving motivation to continue with certain exercises. The process of development and integration of the qualitative methods and questions helped create new kinds of relationships between the quite different disciplines in the team, e.g., between the software engineer, designer, biomechanist and qualitative researcher to integrate the different methods into a more coherent overall mixed methods design. This closer involvement of different disciplines working together with survivors and therapists also facilitated a more open process of innovation, through consideration of survivors' and therapists' views, in the development of visualisations for each WP trial, i.e., suggestions for what should be seen and how this should be presented.

Arguably, development work such as this should not be conducted within an RCT. However, as the visualisation method is innovative within this rehabilitation context, the mixed methods approach *within* the

RCT has enabled the team, using visualisations, to solicit useful feedback pre-trial and to develop this further for the trials themselves. If the traditional design and structure of a conventional RCT had been used, this may have stifled innovation, whereas using a people-centred design methodology, which is iterative, some issues have been clarified and an improved prospective solution has emerged through the iterative and participative process. This approach has helped move the research towards a more open innovation approach pre-RCT and helped to shift perceptions within the team from a model where research is conducted *on* 'subjects' to one concerned with co-research *for* and *with* 'people'.

Conclusions

If such a mixed methods approach is not yet commonplace in RCTs then, as in this envisage project, the practicalities of working out the integration of these methods into a coherent methodology would take time for any team. The experience of this project team at this stage suggests that the normal three year RCT project plan would benefit from some additional time for: i) exploration of the problem early in the project; ii) a mixed methods approach to be developed in the study design and the means for integrating disciplines that are methodologically very different; iii) exposing researchers to 'real people' early on in the process to establish a dialogue about the problems people face through sufficient user-group involvement, and particularly in piloting with user representatives before the RCT commences to determine the optimum format and content of visualisations to be used in trials.

However, the epistemological tensions within envisage still prevail: RCTs tend to reduce the variables and remove context to allow scientific comparisons whereas people-centred approaches are regarded by designers as necessary to understanding context and experiences as lived. The team of researchers are willing to live with and learn from these differences, and their impact on the RCT outcomes and project findings through this approach.

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Service innovation in hospital nutrition healthcare through co-design

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Abstract

How does one inspire innovation in public sector healthcare service delivery when faced with sectoral inertia due to the scale and complexity of the challenge? This paper describes an approach and the means used to design a new prototype food service to address malnutrition in vulnerable older adult hospital patients. The co-design process used was based on the ideas that tacit knowledge, experience and insights can be readily mobilised if provided with the appropriate means and encouragement and that innovation comes from creating a blend of ideas from multiple sources. A set of design methods was adapted and used to empower, train, inspire, facilitate and guide not only non-design members of the research team - including food scientists, nutritionists, medical sociologists, ergonomists, and technologists - but also the range of individuals concerned with hospital food and nutrition, i.e., key stakeholders and a 'food family' of staff, carers and older people's representatives. From this approach, of 'skilling-up' non-design professionals with some of the methods and processes used by designers, key insights and ideas emerged which led to a set of service principles and opportunities for development. The collaborative development process was guided by a set of service narratives which not only helped to develop shared understanding across the team, but also to generate specifications for each element of the new food service. This process led to a demonstration prototype which includes new products, technologies, environments and procedures, with the ultimate aim of raising the profile of food and thereby improving nutrition.

Keywords: Service innovation, healthcare, co-design, hospital nutrition, older adults

Introduction: context of the research

The unacceptable scale, significance and economic consequences of malnutrition in older hospital patients within the UK's National Health Service (NHS) are well documented elsewhere (BAPEN, 2003; European Nutrition for Health Alliance, 2005; Age Concern, 2006). Previous isolated interventions, e.g., the Better Hospital Food Programme, have tended to focus on specific areas of food provision or on guidelines for ward staff to assist with patient meal times. Despite numerous such interventions and guidelines, a 'joined-up' approach to the provision of adequate nutrition to older people in hospital had not previously been considered. Although tools and processes are in place to screen for malnutrition, the current food provision system is unable to adequately monitor food, nutrient and fluid intake on an individual basis, nor does it provide an audit trail of accountability to ensure patients' individual nutrition requirements are being met.

In response to these issues, the 'mappmal' researchers, funded through the cross-research council's New Dynamics of Ageing programme, wished to consider the hospital food and nutrition system as a whole, to include new foods, new products to assist the supply and delivery of food, new staff procedures, conducive settings for eating and, where appropriate, to exploit state-of-the-art technologies (New Dynamics of Ageing, 2012).

The mappmal team comprised a range of academic disciplines (i.e., food scientists, dietitians, social scientists, ergonomists, technologists, computer scientists, clinicians, speech and language therapists and designers) from four academic institutions (Newcastle University, The Glasgow School of Art, University of Reading, and Loughborough University) and involved a food family (FF) (i.e., food producers, caterers, ward staff, nurses dietitians, physicians, speech and occupational therapists, carers, and older people), and key stakeholders (KS) representing the NHS, relevant charities and regulatory organisations.

Hospitalfoodie

Three and a half years' work by this team resulted in the 'hospitalfoodie' demonstration prototype. A nutrition management system is accessed through touch-screens at the patient bedside and staff interfaces. Tailored menus enable personalised food provision allowing ordering closer to eating times. Six smaller energy- and nutrient-dense 'mini meals' per day are provided, supplementing existing catering systems with ward-based food provision using a new 'mini-meal' trolley.

The system is designed to engage all types and grades of staff in the process and raise the profile of food provision as part of total patient care. At each meal, nutrition intake is monitored through an innovative 'wipe away' food monitoring application linked to a nutrition composition database. This is intended to facilitate screening for malnutrition, calculate individual nutrition requirements and monitor each patient's

achievement of targets. In the event of a shortfall, alerts will prompt time-limited actions allocated to a designated staff member, building accountability, providing performance data for auditing requirements and facilitating increased management of food and nutrition.

Questions and challenges

While the nutritional issues remained paramount throughout the research and development (R&D) process, this paper focuses on the role of designers working within the multidisciplinary team. The main questions and challenges facing the designers are outlined here and discussed below.

1. How could the inclusion of designers help the healthcare team 'think differently' about the problem and potential solutions?
2. Where were the opportunities for design interventions in the current food service to minimise malnutrition?
3. How could designers help inspire innovative patient-centred thinking in public sector healthcare service delivery particularly when faced with sectoral inertia due to the scale and complexity of the challenge?
4. How could they develop or adapt design methods and activities to engage and 'skill up' i) the other researchers in the research team and ii) the FF and KS as part of the R&D team to utilise their tacit knowledge and experience, and their insights and ideas for improvement?

Methods, tools and approaches

Due to the recent and rapid growth of activity in the service design field, a rich resource of methods, tools and case studies is now available to designers. Design-led approaches have been piloted to help the NHS 'think differently' about how healthcare services could be delivered. For example, Cottam & Leadbeater (2004) explore innovation in approaches to diabetes management. Bate & Robert (2007) provide a user-experience-centred response to the NHS system reform programme, set out in the Department of Health's (2005) patient-led plan. The NHS Institute for Innovation and Improvement has been exploring the use of service designers in the redesign of healthcare services (Design Council, 2008), and Pickles, Hide & Maher (2008) discuss practical methods of working with patients to redesign services. Tassi (2009) provides a tool summarising useful methods, as do Stickdorn & Schneider (2010) who along with Meroni & Sangiorgi (2011) provide a number of useful and relevant case studies. A number of service design consultancies also make their methods and case studies available on-line such as Engine (2012) and thinkpublic (2012).

The team’s designers surveyed recent literature and exemplars from this field for approaches, methods and tools appropriate to the mappmal project to both engage participants and to make ideas and concepts more tangible through an iterative R&D process using mock-ups and working prototypes. The types of activities, the methods selected and used and the main stages in the process are summarised in Table 1.

Table 1: Activities and methods used at key stages in the development of the demonstration prototype.

Key Stages	Methods
1 Identifying issues with the status quo and opportunities for improvement	Ethnographic studies in 5 NHS hospitals Interviews (n=52) with FF and KS Sensory testing of existing hospital foods Mapping of existing food journeys
2 Analysing, visualising and validating findings	Mapping of existing food journeys Thematic analysis and visualising of issues Validation of findings (workshop 1)
3 Conceptualising and co-design	Identifying opportunities and stimulating new thinking (workshop 1) Idea generation and scenario building (workshops 1 & 2) Service prototyping (workshop 2)
4 Iterative co-design and development	Determining core elements Building narratives and scenarios Prototyping of new interfaces Evaluating early system concepts with FF & KS (workshop 3) Evaluating early interface prototypes with FF & KS (workshop 3 & user testing session) Evaluating early food supply and delivery system (workshop 4)
5 Communication through demonstration prototype	Demonstration prototype - working simulation of key elements Exhibition design Conference presentations (n=6) Website design

Co-design and open innovation

Across the diverse disciplines in the mappmal team there was a need for greater in-depth understanding of the problems and needs of the patients receiving - and the staff delivering - the service. A significant difference from previous ‘nutrition’ initiatives was the deployment of a co-design process together with an ‘open-innovation’ approach. The open innovation paradigm assumes that ‘external’ ideas (i.e. in this case ideas from the FF and KS) as well as ‘internal’ ideas (i.e., from the members of the mappmal team) have value, that innovation can result from creating a ‘blend of ideas from multiple sources’ (Young Foundation,

2010) and that tacit knowledge and experience can be readily mobilised if provided with the appropriate means and encouragement. In this regard the FF and KS and non-design members of the research team represented a previously under-exploited resource for R&D predicated on the idea that it is not only designers who can design and use design methods.

The characteristic of the methodology deployed in mappmal was its participative, co-design approach using a variety of design methods in workshop-based activities. Insights and ideas were developed through a series of iterative workshops involving the FF and KS using visuals, simulations, mock-ups and prototypes. The design methodology was not stand-alone but was integrated into the overall project methodology and so was subject to robust scrutiny by the clinical, healthcare and social-science research disciplines in the team. This process also helped create a strong and effective social dynamic within the research team.

Thinking differently

How was 'thinking differently' facilitated as the basis for identifying service improvement opportunities? This was achieved through a mix of methods and activities. Our first such activity asked the FF and KS to suspend 'NHS-type thinking' and imagine the ideal mealtime experience which might be delivered by different types of service providers, i.e., a consumer lifestyle-orientated technology company, a food supermarket chain owned by its employees, or an armed services logistics corps, each highly focused on their customers' needs and expectations. To assist this activity, clear principles by which each of the above organisations delivered their services were provided in a set of 'prompt cards'. Following a facilitated brainstorming session, storyboards of the new mealtime experiences were created by the FF teams to integrate and demonstrate their ideas. Coughlan, Fulton Suri & Canales (2007) highlight the benefits of creating early physical and 'experience' prototypes of ideas generated by participatory design workshops, using methods such as role-playing and scene enactment, "...giving permission to explore new behaviours...". This 'discovery' phase allowed the FF, KS and mappmal team the first insights into alternative possibilities for innovative and improved nutrition management and food services. From an analysis of these and other workshop activities, key insights into the requirements and ideas for a new food service emerged. These were formalised into a set of service principles and opportunities for a new food service concept which would be iteratively developed and prototyped for feedback at further workshops.

People-centred thinking

According to the team's medical sociologist the nature of the existing service is one of "... transitory people doing interrupted work ... everybody is in transit all the time doing something on the way to doing something else". Particularly where there are a large number of different healthcare and clinical staff

involved in the delivery of the service to acutely ill individuals, this can result in a form of myopia in appreciating how service users actually experience a service. However, an effective and efficient service should be user-friendly for all those involved in the delivery and receipt of that service. Mapping the 'big picture' of food journeys from interview data and developing an understanding of the patients' mealtime experiences were initial objectives. For the design team, the second of these objectives was confounded by lack of access to acutely ill patients due to practical and ethical issues. Patient-centred thinking was achieved through the combination of methods summarised in Table 1 and which have been discussed in some detail previously by the authors (Macdonald, Teal & Moynihan, 2010a, b; Macdonald, Teal, & Rice, 2010). In summary, the use of ethnography, visual mapping techniques, personas and mealtime scenario-building using photos of vignettes compiled from hand-sized toy figures helped the team and FF to understand more clearly some of the problems with the current status quo from both staff and patient perspectives.

One method which was particularly helpful was the 'narrative' technique which helped the team understand the very human aspects (from each of the patient, ward staff, clinical staff, nutritionist, catering manager or hospital manager perspectives) of the emerging prototype system. To help develop the service concept a set of 'food service narratives' was scripted that reflected the core nutritional goal of ensuring that calorie, protein and fluid intake met individual daily targets. These narratives, describing nutrition-related events during the daily life of a patient's hospital stay from admission to discharge took three forms. The first was a set of simple text documents which enabled the narratives to be easily edited by all members of the research team and were used to reach team consensus.



Figure 1. Illustrated service narratives as used in PowerPoint®

The second was a modular set of illustrated PowerPoint® storyboards which visualised typical scenarios (Figure 1). These explored the supporting role that various service elements and technologies played in responding to individual patient nutritional needs, for monitoring intake and prompting appropriate food and drink options. In this way, the requirements of, e.g., ordering and monitoring technologies, and the role

and frequency of delivery of new, specially designed foods (developed by the food scientists in the team) could be specified. From the patient and nursing staff perspectives it was also important to visualise how the service presented itself to – and welcomed - the patient, helped in the selection of meal options and in creating a stimulating, attractive, and non-medicalised experience. This version of the narratives was used by the team’s sociologist in further interviews with the FF and KS to reveal any issues with the new service concept.

The third version of the narrative was used by the team to communicate the hospitalfoodie concept as part of the demonstration prototype exhibition shown at a series conferences which were used to solicit feedback (see section 4.2). For the final conference presentation in the series, a professional quality version of this narrative was commissioned by the team (Figure 2) which was also used on the project website (hospitalfoodie, 2011).



Figure 2: Stills from the professionally commissioned narrative video. (Images © Peter Baynton 2011).

The hospitalfoodie prototype

Prototyping elements of the system

Visuals, enactment, mock-ups and interactive prototypes were amongst the range of methods used to make ideas and concepts more tangible, allowing the mappmal team, FF and KS to identify issues and opportunities for improvement and innovation. For example, a number of ideas were considered for monitoring nutrition intake before a concept for a ‘wipe-away’ app was selected as showing the most potential (Figure 3). The rationale for and testing of this app is described in detail in Comber et al (2012). In similar fashion, the preferred versions of the patient-facing (Figure 4) and staff-facing menu systems resulted from the iterative mock-up and prototyping development process.

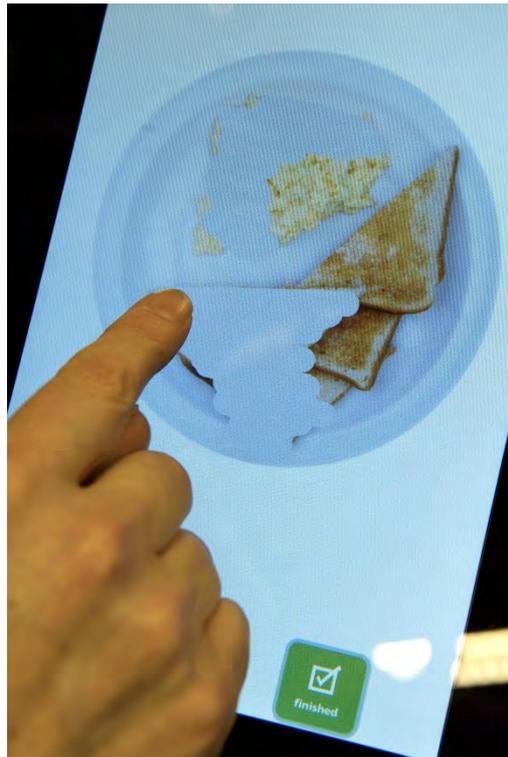


Figure 3: The user 'wipes away' food items eaten based on a visual assessment. The app is linked to a nutrition database calculating nutrients and calories consumed.

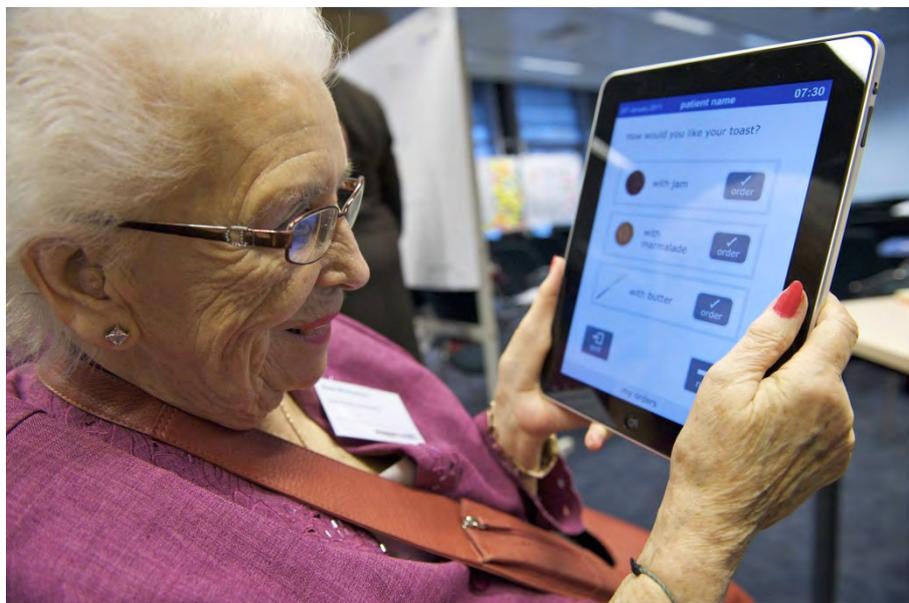


Figure 4: A food family member provides feedback on an early version of the patient menu interface at one of the FF and KS workshops. Photo © Cate Gillon 2011.

Communicating the concept

In the final phase of the project the system was exhibited as a demonstration prototype (Figure 5) at a series of four key conferences representing key stakeholder communities, i.e., geriatrics, gerontology, design-for-

health and nutrition. This was designed to solicit further feedback by providing: i) an overview and explanation of how the system worked as a whole, its key features and attributes and how it addressed key nutritional issues; ii) prototype interactive interfaces designed both for staff and patients; and iii) an illustration of how the system would supply and deliver 'mini-meals' through specially designed foods and a mini-meals trolley. Feedback was solicited through a set of postcards each of which focussed on a particular aspect of the prototype, e.g., 'mini meals' and 'ward food provision' and through a comments form via the hospitalfoodie website.



Figure 5. Delegates interacting with the touch-screen interfaces in the demonstration prototype exhibition. Photo © Cate Gillon 2011.

Conclusions: the contribution of design

At the end of this process, what, in the view of the other researchers in the team, did designers bring to and contribute to the project? The perceptions of some non-design members in the team have helped reveal the value of design in this context. For example:

“As a non-designer I now have a knowledge and understanding of creative ways of expressing ideas and concepts visually to make them more tangible and facilitate understanding. The design methods that have been employed ... have created the threads that link the key elements of the prototype together. The design element of the project has also introduced me to a new variety of means to facilitate engagement with key stakeholders to elicit feedback”.
Dietitian and project lead

“Until I started working on [the project] I had no understanding of what service or process design meant, nor participatory design, nor iterative design. I think at the end of three years I now find it hard to imagine how truly multidisciplinary teams working on a multilayered problem can get anywhere without a designer on board. To me designers can visualise ideas and communicate them to a wide audience in a way most disciplines cannot, but perhaps more importantly they can see how a full system should fit together to work well in a way isolated parts of a system cannot.” *Food scientist*

The contribution made by designers in this context is clearly different from - but complementary to - that made by the scientists and social scientists in the team. This project demonstrated the designer's translational abilities, using an evidence-base generated by the other researchers, and ideas generated by

the FF, KS and mappmal team through the participative co-design process, to give tangible form to new ideas and concepts through mock-ups and working prototypes in an iterative R&D process. This process helped build the specification for the system. The demonstration prototype is now (at April 2012) at the stage where, with further development work on the interfaces and software system, it can be taken forward for testing in simulation trials and ward trials.

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The decentralized social networking systems towards mobilizing actions of citizenship and solidarity against cancer

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Abstract

The goal of the present study is mapping the nature of possible contributions of participatory online platforms in citizen actions that may contribute in the fight against cancer and its associated consequences. These platforms are usually associated with entertainment: in that sense, we intent to test their validity in other domains such as health, as well as contribute to an expanded perception of their potential by their users.

The research is based on the analysis of online solidarity networks, namely the ones residing on Facebook, Orkut and the blogosphere, that citizens have been gradually resorting to. The research is also based on the development of newer and more efficient solutions that provide the individual (directly or indirectly affected by issues of oncology) with the means to overcome feelings of impotence and fatality.

In this article, we aim at summarizing the processes of usage of these decentralized, freer participatory platforms by citizens and institutions, while attempting to unravel existing hype and stigma; we also provide a first survey of the importance and the role of institutions in this kind of endeavor; lastly, we present a prototype, developed in the context of the present study, that is specifically dedicated to addressing oncology through social media. This prototype is already available online at www.talkingaboutcancer.org, however, still under development and testing. The main objective of this platform is to allow every citizen to freely build their network of contacts and information, according to their own individual and/ or collective needs and desires.

Keywords: Networking, Web 2.0, Design, Cancer, Citizenship

The effects of decentralization

Manuel Castells refers to the new social model based on networked individualism. He clarifies, however, that this does not correspond to a collection of isolated individuals. Like Chris Anderson, he argues that individuals construct their physical and virtual networks, based on their interests, values, affinities and projects. But due to the flexibility and power of Internet communication, online social interaction has an increasingly important role in the global social organization (Shirky, 2010; Surowiecki, 2007). Although they are different from physical communities, online communities are not less intense in uniting and mobilizing (Castells, 2001, p. 161)⁹. The great advantage brought by the new social tools was what the social scientist, Seb Paquet, quoted by Shirky, called a "ridiculously easy group formation" (Shirky, 2010, p. 55).

Furthermore, the virtual world is not divorced from the physical world. The development of communication in society is a hybrid one, acting as a material support of networked individualism (Castells, 2001). But in this networked society, where citizens have been gaining increasing prominence, what kind of effects can they cause on the so called dominant groups? Already in late 1990, Ignacio Ramonet, in his book "The Tyranny of Communication", stated that the power is no longer exclusively identified with political power. According to him, that power tends to be more on communication (media) than in action (politics) (Ramonet, 1999, p. 39). Ramonet also refers decentralization and this passage from a vertical, hierarchical and authoritarian power to a horizontal, networked and consensual power (Ramonet, 1999, p. 39). This leveling of the power to communicate is transforming not only a market that is increasingly global, but also many professions and in different areas.

Despite all this flattening and democratization of media, which is the real increase of power comparatively to the institutions? Are the institutions and the traditional mass media losing power of influence? What changes of behavior have brought the new information technologies to autonomous health management?

It matters now to understand the true importance of the new technologies in health care in Portugal and in particular in oncology: who uses them, for what purposes and the role they play on the individual management of the disease, by the citizen. This analysis will be based mainly on a series of interviews that are currently being developed in the IPO of Oporto to oncologic patients and their families (in the area of pediatrics); in the recent report "The Relationship between ICT, users, Professional staff and Technological Networks in Health Management Information"¹⁰, from Project "SER – A Saúde em Rede", from the Centre for

⁹ Look at the recent events in Portugal, with the expression "Geração à Rasca", or internationally, with the social upheavals in Arab countries.

¹⁰ This report is one of the research components of the project SER – A Saúde em Rede –, developed at the Centre for Research and Studies in Sociology (CIES – Lisbon University Institute), with the support of Calouste Gulbenkian

Research and Studies in Sociology, coordinated by Rita Espanha; and though the critical observation of sample pages and groups on social networks in the area of oncology.

The role of the Internet and decentralized platforms in the area of Health and Oncology

Interviews with parents and patients in IPO, Oporto

During the month of April and May 2011 a series of interviews with patients and parents was carried out in the pediatric ward of the IPO Oporto in order to understand how they process the information regarding the personal issues of the disease. In this paper, we present the main aspects to highlight from the 25 interviews already carried out (5 patients and 20 parents of patients)¹¹. It should be noted that this universe of respondents is not intended to be a representative sample of the Portuguese population affected by pediatric oncology. The aim was to obtain a specified and small but significant portrait of this universe and find possible relations with other studies and cases. More specifically, in these interviews we seek above all to know:

- how they clarified their doubts about the disease and to what means they resorted to;
- how to confront and manage personal research with the national health system, especially its professionals;
- if they search for information on the Internet and how;
- and, in individuals who are registered in social networks, what is the role of these networks in the daily management of the disease.

Firstly, it is notorious a high and consensus trust in the national health system, in their professionals and in the hospital itself, as shown by the result of the assessment made by the interviewed concerning the degree of confidence in the doctor for the treatment of their disease (or child, depending on the interviewed). On a scale from 1 to 10 the result was 9.44, while the hospital was only slightly below in 9.04. There is a similar consensus regarding the level of clarification given by the doctor to parents and patients. They all considered being well informed and that this contributed to the high level of trust in their doctor. An answer to their questions and anxieties is clearly what patients and families value most. Despite this high sense of confidence and clarity, more than half of respondents (seventeen people) points out that the channels of communication with the hospital (via email, website or phone) to clarify small doubts could be optimized.

Foundation. The report was completed and submitted in April 2011. Research team consists of: Rita Espanha (Coordinator), Rita Veloso Mendes, Rui Brito Fonseca and Tiago Correia.

¹¹ The large difference in the number of parents interviewed comparatively with the patients was due to the fact that only patients aged over 13 years were interviewed. The vast majority of patients were under age.

The main concerns and questions appear in the initial stage of the disease. Sixteen of the interviewees claim to have conducted research on the Internet, and most of them state that it was only in the early disease diagnosis, yet half of these sixteen, admitted it was a very general research and virtually insignificant. At large, they admit that the search results turn out to be negligible, due mainly to the following reasons: the information is abundant and dispersed, the language is too technical, and / or because the answers confirm the information given by the physician. But one of the main reasons cited by those who conducted research on the Internet is the specificity and characteristics of each disease and treatment and the high degree of clarification and follow-up they claim to have from the health professionals, are a major reason for a non-exhaustive exploration in the universe online.

In our perspective, although the vast majority gives up early researching about the disease, this does not mean that the Internet plays a minor role and that should be devalued. On the contrary, because it is a quick and easy way to search for information and used mainly by the younger generations, the Internet certainly tends to win an increasing importance over the years in obtaining answers to the doubts of those who relate directly or indirectly with oncologic diseases.

In summary, with these interviews it was evident the high degree of confidence expressed by patients and family members in the national health system and its professionals. The demand for information on the Internet always appears as complementary and in all cases, the interviewees assume they do so because of the need to find more answers and support, before a serious situation where doubt, fear and even panic are high. There seems to be no direct relationship between the surveys and the trust they place in healthcare professionals. Although most research is done at an early stage and focused on the disease, fewer than a dozen admits making occasional research – small and sporadic doubts that usually confirm the answers given by nurses and doctors.

The importance of sharing and exchanging experiences with other parents and patients is quite pronounced among the interviewees. Twenty-three of the twenty five interviewees say that they are quite interested in knowing cases similar to their. However, the existing dispersion is evident in the research done on the Internet as well as the lack of references. The vast majority do not remember the sites they consulted. As already mentioned, the research was done primarily by the search engine, and there is no oriented search.

One last note worthy of mention: the site oncologiapediatrica.org is unknown to the vast majority of parents and patients, regardless the fact of being supported and managed (in part) by the IPO of Oporto.

The horizontal system and the construction of a network focused on the individual problem of the citizen

We are witnessing a lack of institutional spaces of public utility related with cancer to help bring citizens of the institutions through a greater interaction. However, in addition, there is a heavy growth of communities connected to the Internet in pediatric oncology. They are especially visible in *web 2.0* platforms and social networks. These sites are used for a variety of approaches, ranging from simple sharing of testimonies, in a personal blog, to creating the solidarity movements in social networks like Facebook. Campaigns like "Help Aline Coelho", "Together for Teresa", "Helping Afonso" or "Helping Marta" are possible examples, with noteworthy results. These campaigns, created mainly in order to sensitize society to the voluntary enrollment in the Bank of Bone Marrow Donors have been a significant phenomenon of civic mobilization and solidarity, through the Internet.

The first major Portuguese phenomenon was the "Helping Marta" campaign. In January 2009, four year old Marta was diagnosed with Acute myeloblastic leukemia. With all the treatment possibilities exhausted, the only solution would be to get a compatible marrow donor (Ramos, 2009). Since then, family and friends joined forces and launched an online campaign to get a donor for this child. According to Maria João Dray, Marta's aunt, the most striking in this campaign was that many of the countless people who responded to the request did more than the blood tests (Domingues, 2009). People discussed and sent new forms of help, forming a strong chain of solidarity, through various means, including the page created on Facebook.

On May 22, Marta was able to find a donor. Although not knowing whether there was a direct relationship between the movement and the appearance of the donor, we must highlight the efficacy of these campaigns to mobilize citizens. The wave of solidarity generated in social networks, have greatly contributed to the increase of people registered in the Portuguese Bone Marrow Donors. Lima Duarte, President of the Portuguese Association Against Leukemia (APCL), considers the case of Marta "paradigmatic" since it made the national registry of donors increased in some 13 000 people (LPM, 2010). This campaign for Marta moved and mobilized the whole country, and had great prominence in the social communication. This time the media highlighted the incredible mobilization of national citizenship and solidarity that a small group of people achieved through the use of social platforms on the Internet.

In order to enhance the site www.oncologiapediatrica.org and test it in a horizontal system, in September 2009, a project page was created on the social network Facebook. The experience has been positive. In the first six months of operation, the great momentum that this type of system can create was confirmed, especially when it refers to a network such as Facebook, with over 350 million users worldwide¹² (Ribeiro,

¹² Data refer to December 2009 and were presented by Javier Olivan, responsible for the internationalization of the Facebook service, in a public interview with the Journal Público, on 16 December of that year. He added that in Portugal there are over one million active users of this network, but as he points out: "(...) what is most impressive is the speed at which Facebook is gaining users in Portugal. In September it had only half a million. That is, in three months the

2009). Contributions on the page are freely made by the many visitors. The immense publications issued by the many users (more than five thousand) did not record any insulting, provocative or disrespectful publication (Martins, 2009). Facebook, in addition to its great popularity, has also been a testament on how the current decentralized social platforms can help increase solidarity and citizenship, as exemplified by the outcome of the various campaigns carried out in this social network to collect new Marrow Donors. But beyond this kind of campaign we want to know the real relevance of social networks in the fight against cancer. Despite the fact that the anonymous citizen and the institutions have the same tools to communicate on the network, can they have the same level of mobilization and influence?

We selected four institutions of reference in the field of oncology that are on Facebook: Acreditar Association, the Portuguese Association Against Leukemia (APCL), IPO Oporto and the Portuguese League Against Cancer (LPCC). The level of investment in the pages and its success is quite uneven. The data are referenced to the 3rd of May 2011. That day, the numbers of users' followers of every page were in the case of Acreditar of 16.402, IPO of Oporto was 2.338, of APCL were 98.686 and of LPCC were 365.93813. The great success of the LPCC page is easily explained by the major investment and momentum applied to it. The publications are regular and mainly used for news, testimonies, and awareness campaigns and to publicize events. It is visible the careful management of the information.

Please note that the page is used not only as a means of communication but also of interaction with the users. It is customary to see LPCC answers to questions put in the comments. In addition there is a global communications campaign, where initiatives are communicated and articulated through various means, being Facebook one of the privileged means. The photo on the profile page is normally used to pass messages of awareness and solidarity; not limited to just put the logo of the institution.

This quite active attitude of the League on the Facebook explains the success of the page. A completely opposite attitude is displayed by the Oporto IPO. From January to May 2011 there has been no publication posted by this hospital. The page allows followers to publish on the mural where messages of support, appreciation and dissemination of initiatives are frequent. Interaction with users is also lacking – there was no visible response from the hospital to any messages from users. Despite the absolute inactivity of the page from the IPO, it has a regular attendance from the followers who amount (until the 3rd of May, 2011) to 2.338¹⁴.

number of users doubled. And compared with the beginning of this year, when there were only about 100 000 profiles, the number of Portuguese users has increased ten times" (Ribeiro, 2009).

¹³ Although there is no record of the founding date of each of the pages, we know that all they have at least more than one year of existence, given that we follow and analyze since January 2010.

¹⁴ From 2 pm to 4 pm, on the 3rd of May, 2011.

The other two pages of the institutions under review, the Association Acreditar and the APCL have a great dynamism in their pages, which also explains the many followers they have. However, there is a major difference to the page of the LPCC, which is the number of followers and participations. This fact is partly explained by the global campaign, in other media, like traditional media, that the League has on its page.

The two opposing examples of Facebook pages, LPCC and the IPO from Oporto, two institutions of reference in the field of oncology, demonstrate the importance of institutional credibility of these media – especially the page of the IPO, that despite not having any kind of activity from the hospital maintains a page with many followers, and with a regular participation – and the major influence that publicity continues to have in traditional media, with the example of the LPCC.

The two pages we created on Facebook of the sites OncologiaPediatria.org and FalarsobreCancro.org are two other examples that apart from reinforcing the previous argument show the great mobilization that Pediatrics causes. In both cases there was a regular activity, with dissemination only in Facebook. In just four days the page OncologiaPediatria.org got more followers (161 followers) than the page FalarsobreCancro.org; in their six months of existence, i.e., the current 131. The 6.452 followers in Facebook of OncologiaPediatria.org are a testament of how much attention and solidarity pediatric oncology attracts from citizens. The FalarSobreCancro.org despite having a regular activity on the page shows a great difficulty in attracting followers. Compared with the example of the IPO one realizes the importance of the corporate brand, even in decentralized networks, in which citizens and institutions have exactly the same tools.

Thus, despite its growing weight, learning about health through new technologies have not led to a reconfiguration of information sources already in place, nor of the relationship that individuals have with the health systems. Even among those who depend most on the Internet, the range of this feature does not replace or compete with the knowledge imparted by health professionals or by those closest (Espanha et al., 2011).

The platform FalarSobreCancro.org

It should be noted that these networks such as Facebook, are not thought to explore specific clinical content, such as those from cancer.

Attempting to fill this gap, a new platform was build, available at FalarSobreCancro.org (or TalkingAboutCancer.org) in late 2010 with a more decentralized structure. It is a public and gratuitous site, targeted at all people and institutions interested in fighting cancer in several areas: clinical information, testimonials, statistics, contacts, solidarity networks. It is intended as a privileged means of access to

knowledge and experience exchange between all the oncology community, patients, family, friends, health professionals, researchers and volunteers.

The main purpose is to allow every citizen an opportunity to freely build his network of contacts and information, according to his own needs and desires, individually and / or collective. Although the site is already reachable on the Internet, is still under development, therefore it is premature any kind of results assessment. It should be noted, however, that it was on purpose to use Facebook as the sole disclosure platform – as we saw earlier, it only has (as of May 3rd) 131 followers. The still embryonic stage of the platform and its poor disclosure has contributed to the little current activity of the platform.

Conclusion

As it turned out, the increasing freedom of access to information related to oncology and global interaction that is achieved on the network, these advantages are recognized and can be exploited by the individuals. This means that the individual has (or may have) more autonomy and responsibility in his decisions. The collective wisdom and intelligence, mentioned by Tim O'Reilly and Rosental Alves (O'Reilly, 2005, Santo, 2009a), have been growing in many online communities, especially in social networks. Should one continue to look at this new manifestation suspiciously as if it was a parallel and marginal reality? Certainly not: the significant increase in the National Registry of Bone Marrow Donors is an indication of the importance of these networks. These media are also sought in order to obtain, share and exchange all kinds of information. But beyond the recognized potential of these means for mobilizing actions of citizenship and social solidarity, what is their true value for the problem of cancer?

In this article, we sought to demystify spells and stigmas concerning decentralized platforms, with primary focus on social networks; to assess the importance and role of the institutions in supporting these initiatives and, finally, argue about the relevance and importance of this kind of platforms as a possible bridge to approach cancer problems.

The major institutions and healthcare organizations can no longer limit themselves to communicate, they also need to interact. Thus the National Health System and its professionals will be better prepared for this new reality in which the user tends to be more informed. It is known, however, the impossibility for the institutions to monitor the gigantic set of information in the online communities and respond to all requests. And, as put to evidence in this article, the Internet and especially the social networks seem to have still a residual importance in managing the individual health of the citizen. However the tendency seems to be growing, in addition to the fact that Internet and social networks have proven their high relevance in the mobilization of citizenship activities.

However, it is already visible a greater concern of the institutions in being present on these decentralized platforms, namely Facebook. Institutions such as the Portuguese League Against Cancer, the Portuguese Association Against Leukemia or Association Acreditar, maintain an increasing activity in this network, with more and more users and in 2011 in Portugal, it is the social network with more users (Marktest Group, 2011).

Despite the effectiveness of these more mainstream and popular social networks, on matters related to cancer, it is believed that new models can be studied with a design, tools and services appropriately conceived for that purpose. For example, a website that provides comprehensive information on medical services and the national health system, in oncology, a central space in a network where the citizen can access and clarify his doubts.

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'Let me show you what happens as I get from A to B':

Way-finding Design, Visual Ability & 'Way-finding Hot-spots'

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Abstract

The built environment currently fails to support people who have a visual impairment (Barker, Barrick, Wilson, & Royal National Institute for the Blind, 1995; Jokiniemi, 1998). The task of way-finding within a public building is raised as a particular problem (Arthur & Passini, 1992). The building, described as an 'assault course', threatens independence, well-being and causes a 'serious threat to independence and full social integration' (Barker, et al., 1995, p. 10). Goldsmith (1997) recognises this as a form of Architectural Disablement.

This doctoral research, based within architecture yet exploring across various disciplines, coins the term '*Way-finding Hot-spot*'. It explores the events and occurrences (both positive and negative) which are experienced, and therefore influence and impact, on a journey around a building. Participant evidence along with an innovative methodology has been essential in highlighting the importance of way-finding design. Ten participants (with varying degrees of visual ability, different ages and forms of disability) undertook a 'Way-finding Scenario' composed of purposeful conversation (Burgess, 1982) and a way-finding task.

This paper presents scenario-based findings and a framework of design considerations evidenced as stages of a *Way-finding Journey*. It discusses logistics and presents narrative, logs, trace and visualisations from *Way-finding Scenarios*. It begins to generate dialogue in the design of systems suitable for a diverse range of way-finders. It creates a case for application of this knowledge in professional practice and education across disciplines of architecture and design as well as in areas of occupational therapy, rehabilitation, policy-making and academia.

Keywords: Way-finding Journey, Visual Ability, Architectural Model of Disability, Architecture, Participatory Research

Introduction

The task of way-finding through a public building is an activity that we all regularly engage with. It is the pursuit associated with arriving at a meeting on time, the meandering through a shopping centre on a Saturday morning or the exploring of a museum. As a person-orientated process, way-finding is the cognitive, behavioural and strategic task of planning movement through space (Arthur & Passini, 1992). It is knowing what course of action is needed to reach a destination (Downs & Stea, 1977; Golledge, 1999).

Way-finding is not a process we are always conscious of undertaking (Downs & Stea, 1977), however awareness is particularly drawn to it when the way-finder is immersed in a new or altered set of surroundings, becomes disorientated, or recognises that they are lost. This is when a form of way-finding communication is needed and when a way-finding plan to reach the destination is required.

However:

What if you were not able to use current forms of way-finding communications (signage etc.) because you couldn't see what they say? Would you be able to identify and find your way to the entrance of the correct building? Would this be an enjoyable experience free from hazards? How would you begin to find your way to your destination? Would you feel you had the opportunity to explore your surroundings? Would you be able to find the toilets and know what to do in an emergency?

This paper discusses the experiential components of a *Way-finding Journey* around public buildings as uncovered by way-finders who have a range of visual impairment. It reviews the research context in relation to way-finding, presents the innovated methods used to capture way-finders experiential data, introduces the participants, provides a brief insight of findings, and finally, considers the research contribution advanced by this study.

The Research Context: Way-finding and Visual Impairment

The importance of understanding way-finding, in terms of process and design, is validated by a wide range of literature spanning across a broad spectrum of disciplines (such as urban design (Lynch, 1960), geography (Golledge, 1999), cognitive psychology (Downs & Stea, 1977), architecture (Arthur & Passini, 1992), graphic design (Berger, 2005), etc.). Generally, each researcher and practitioner has been interested in how people way-find through the context of their surroundings. Each has contributed to the way-finding debate in defining the roles of memory, cognitive mapping, spatial awareness and information processing. They have considered how we use our senses, form a plan of action, and execute that plan to reach a destination. Some have been interested in understanding processes of way-finding (e.g. Arthur and Passini's (1992) *Information Processing Model*) whilst others have developed theoretical structures (e.g. Appleyard's (1970) *Coding*

Structures of the City). However, in current way-finding research and practice there is a lack of holistic understanding (based on both positive and negative experience) which incorporates a range of visual ability and is in relation to a real-world setting (Kitchin, 1997). There are few participant evidence-based studies of way-finding within a public building. Furthermore, there are no studies of *real-life* experiences of way-finding undertaken by *real-life* Participants who have a range of visual ability.

In recognising this gap in current knowledge a major Research Question was formulated: *What are the design issues (both positive and negative) revealed by participants who have a range of visual ability as they way-find in a large public building?*

This study investigated the 'real life' way-finding experiences of people who have a range of visual ability. The objective was to provide an insight into the issues and joys way-finders encounter as they undertake way-finding journeys through public buildings.

Methodology and Method Design

This architectural research, which adopts a multidisciplinary approach, is positioned within the post-positivistic paradigm. Rather than following a traditional line of hypothesis-testing, it is inductive in its approach as the purpose is to gather experiential way-finding narrative. In adopting the social model of disability (Oliver, 1990) (when working with people) and the architectural model of disability (Goldsmith, 1997) (when building understanding of a Way-finding Journey) a Case Study was employed to investigate the holistic way-finding experience.

Case Study: The Way-finding Scenario

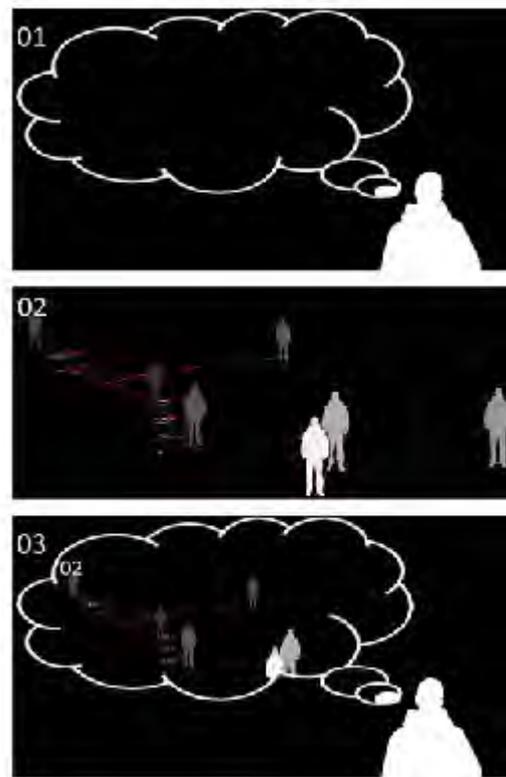


Figure 1: The Way-finding Scenario composed of three sequential Phases – Phase 1: Purposeful Way-finding Conversation, Phase 2: Way-finding Task and Phase 3: Post-Task Purposeful Conversation.

Building on knowledge of ethnographic methods, a new method, *The Way-finding Scenario* (Figure 1) was designed to evaluate both pre-existing memories of way-finding and the experience of participants undertaking a Way-finding Journey specific to this research (i.e. a case study of participant way-finding tasks within a public building). It comprised three sequential phases:

Phase 1: Purposeful Conversation. The method of purposeful conversation (Burgess, 1982) was utilised in the initial phase as an unobtrusive way to gather narrative and provide insight into the participant's existing memories of way-finding experience. (The conversation framework evolved continuously through each participant conversation and included topics such as: way-finding experiences, orientation and mobility training, way-finding technologies, becoming lost, emergency situations and accidents).

Phase 2: The Way-finding Task. Within Phase 2, each participant undertook a way-finding task within a large public building. They were asked to find their way from a starting point (the wall bounding the site of the building) to a destination point (an office within the given building). Each participant was asked to undertake the task as they normally would when visiting an unfamiliar building (e.g. if he/she normally asked at the reception for directions than he/she should ask the receptionist in this building for directions).

The task was not run on a timed basis and each participant carried a small digital video camera at hip height throughout their way-finding task which captured and recorded the complete journey. This 'way-finding trace' was then charted onto the floor plans of the building with each participant's location at every second in time plotted and all way-finding encounters experienced on the journey (e.g. accidents and pauses) captured.

Phase 3: Post-Task Purposeful Conversation. Employing the same purposeful conversation technique as utilised in Phase 1, Phase 3 was implemented immediately following the way-finding task to gain insight into the participant's experience during the Phase 2. The conversation was flexible in structure whilst being controlled in conduct to encourage participants to talk about experiences of way-finding in the task that had recently been undertaken. Participants also talked about previous way-finding experiences, memories of which were prompted by events and occurrences during Phase 2. The purposeful conversations were recorded using a Dictaphone, transcribed by the researcher and, along with the way-finding trace, were analysed.

Through analysis of the purposeful conversations and the way-finding trace, it emerged that there were events (temporal/spatial and positive/negative) which impacted on participants' Way-finding Journeys. Analysis of these events, coined '*Way-finding Hotspots*', was vital in providing understanding of the holistic way-finding experience across a range of visual ability. The participants – The Way-finders – who undertook the way-finding scenario will now be introduced.

The Way-finders

As opposed to others (e.g. Unwin (2009)) who concentrate on the elements of a building), the focus of this study was the experience of the Way-finder (i.e. the Way-finders experience of encountering the elements of a building). In adopting this egocentric position, experiential data relating to way-finders' Way-finding Journeys was captured. Ten Way-finders (Figure 2), five males and five females, took part in the Way-finding Scenario and they each had their way-finding stories to tell. As a diverse group the Way-finders' age range varied from the youngest, Adam at 20 years old, to the oldest, Alfie at 60-70 years old. They each had varying degrees of visual impairment which came about at different times in their lives and had received varied amounts of orientation and mobility training, with some having undertaken none at all (Alfie, Emma, Jack, Grace, Lily and Ben).

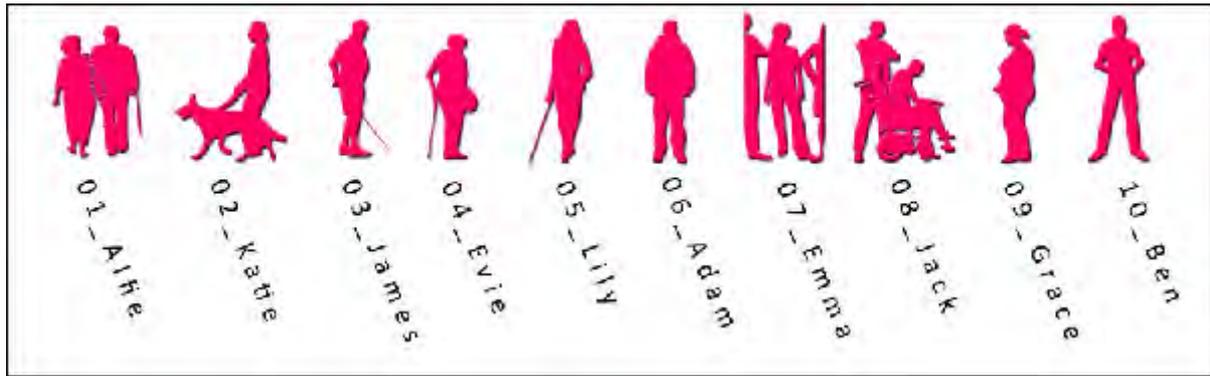


Figure 2: The 'Way-finders' who undertook the Way-finding Scenario.

Alfie lost his sight completely in his late 50's and explained that he could *'see nothing'* and is *'in total darkness all the time'*. Although stressing that he *'never leaves the house without someone else to help'*, he explained how he utilised the cane to inform others that he was blind and *'to hit off things to make sure nothing gets in the way'*. Katie lost her sight in her early 20's and is *'totally blind'*. Although having *'some sense of shadows'* she stressed, *'I have no useful sight at all when I am out and about'*. Katie has a guide-dog, Bruno, and identified that because of him she is *'a very competent person at being able to get out'*. James has been *'blind since birth'* and although registered blind, has *'some useful vision in terms of getting around'*. He explained, *'It depends on how tired I am, where I am, how much attention I am paying to what is going on around me, on the light, what I am doing.'* James has trialled various way-finding aids, however favours the roller cane which enables him to *'feel the whole surface area on the ground'*. Evie, who uses a sliding cane, has a degenerative visual impairment and explained that she has peripheral vision, is highly sensitive to light, has double vision and wears tinted glasses. Lily, who used a cane, started to lose her sight when she was thirteen due to a degenerative condition and explained, *'I can only see things really close to my face'*.

Adam wears prescription lenses, has *'no working iris'* in his eye and is sensitive to light as well as being *'quite short-sighted and registered partially sighted'*. Emma has no vision in her left eye and a small amount of vision in her right eye. Emma preferred an *'occasional borrowed elbow of a friend'* and only utilised her cane if she *'goes into panic mode'*. Jack *'can only see 'tunnels' in the middle bit'* and cannot see anything using his peripheral vision and stated, *'I can only really see straight ahead.'* He wears corrective lenses and also explained, *'I use a wheelchair all the time and Dave, my helper, is always with me and helps me get around buildings.'* Grace explained that her sight is corrected with lenses while Ben stated that he has *'no visual loss at all.'*

The Way-finding Scenarios generated a large amount of person-centred experiential data and way-finding trace. In analysing these way-finding experiences a rich and powerful insight into the holistic knowledge and

tacit expertise of these ten Way-finders and the community of people with a range of visual ability has been depicted.

Discussion of Findings: The Experiential Charting of a Way-finding Journey

The findings of this study concluded that regardless of visual ability Way-finders find it challenging, and sometimes impossible, to reach their destinations within public buildings. However, regardless of whether the destination was reached and the Way-finding Journey was completed, there were numerous Way-finding Hot-spots which impacted on Way-finders emotional and physical well-being. Negative Way-finding Hot-spots were defined by the Way-finders as being the ‘tricky’ (Katie, Jack, Evie) parts of a journey when they become ‘lost’, ‘frustrated’ (Emma, Adam and Lily) or ‘injured’ (Katie). They were the points when the Way-finder became distracted or when there was no access to way-finding communications when trying to establish where to go. Busy spaces or unpleasant encounters with staff and having to rely on others throughout the journey were also highlighted as negative way-finding hotspots. Positive examples of way-finding hotspots were the joyful easy parts of the journey which were either made by chance or were deliberately sought out by the Way-finder. These included the times when there was a pause in the journey to chat with a friend encountered along the way or when something of interest (e.g. artwork) was discovered along the route. The feelings of achievement, overcoming challenges and arrival at the destination were also identified as positive Way-finding Hotspots.

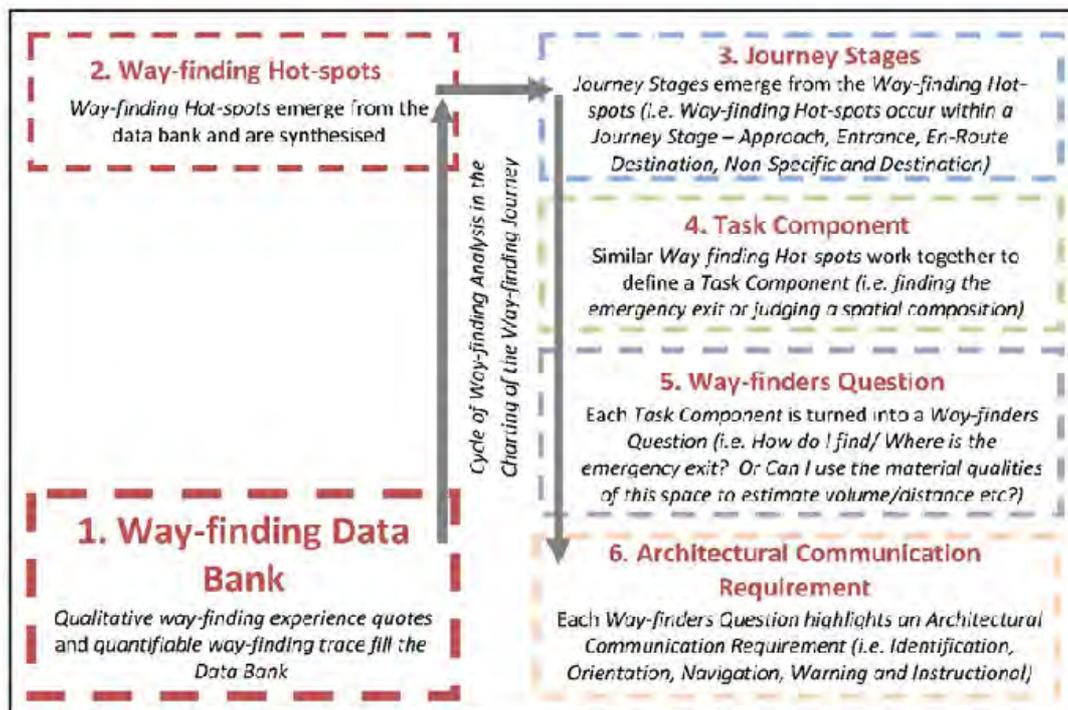


Figure 3: Cycle of Way-finding Data Analysis in Creating the Way-finding Journey. The Way-finding Hot-spots were analysed as a hierarchy of Task Components and Architectural Communication Requirements.

Analysis evidenced that the fluid and continuous movement through a building - the Way-finding Journeys - are filled with positive and negative Way-finding Hot-spots. The Way-finding Hot-spots were analysed as a hierarchy of *Task Components* (figure 3) which occurred within one of the following Journey Stages:

- Journey Stage: **Approach** - encompassed external tasks which occurred between arrival at the site boundary and reaching the building entrance.
- Journey Stage: **Entrance** - encompassed tasks which occurred between entering the building and the immediate experience of welcome and reception.
- Journey Stage: **Non-Specific** - encompassed tasks which were not specific, particular or exclusive to a definable Journey Stage (e.g. Approach).
- Journey Stage: **En-Route Destination** - encompassed tasks which occurred whilst Way-finders undertook the task of deviating from the original route.
- Journey Stage: **Destination** - encompassed tasks which occurred whilst Way-finders undertook the final steps in reaching the Destination.

Each of these Journey Stages arose iteratively through the process of analysis and together they define *The Experiential Charting of a Way-finding Journey*. The *Task Components* were further analysed to establish what types of provision the Way-finder required to support them in undertaking the Way-finding Journey. Framed as a series of Way-finders Questions, the identification of *Communication Requirements* (figure 3) was the result of this secondary analysis. At different points within their Way-finding Journey Way-finders need five specific types of communication: Identification; Navigation; Orientation; Warning; and Instruction.

The Experiential Charting of a Way-finding Journey: Examples

To provide insight into the process and rich findings of this study, two examples of Way-finders' experiences will now be extracted from the complete Way-finding Journey and described. Figures 4, 5 and 6 also illustrate specific descriptions of way-finder's experiences.



Figure 4: Katie's Way-finding Hot-spot which was described during Phase 1: Purposeful Way-finding Conversation. Katie explained: 'He won't go up stairs if they are open in any way or if they are made of glass. He can't see where to put his feet, so he just refuses.'

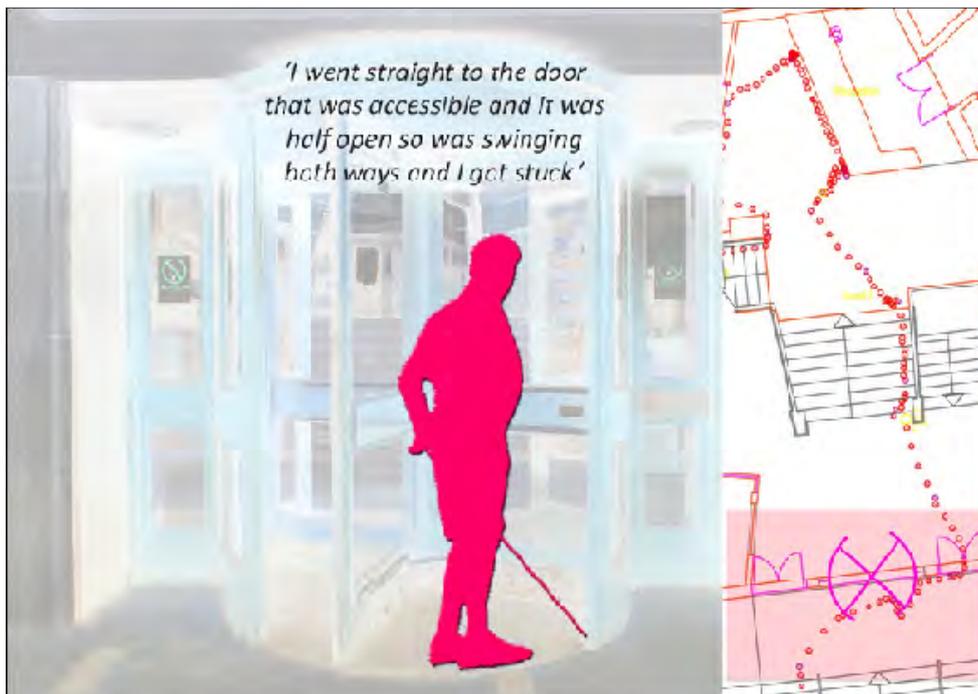


Figure 5: James describing his Way-finding Hot-spot as experienced and recorded within Phase 2: The Way-finding Task and talked about during Phase 3: Post-Task Purposeful Conversation.

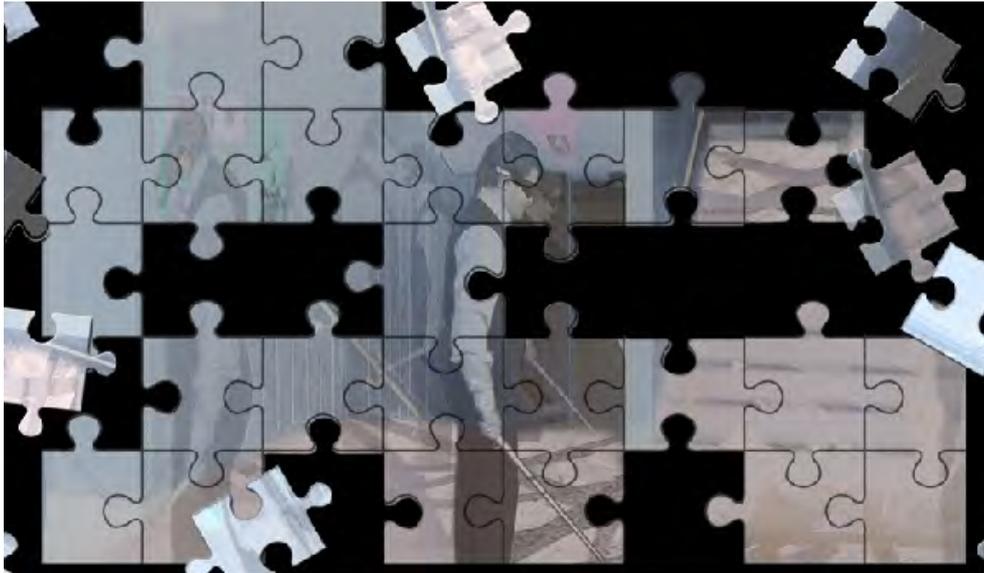


Figure 6: Adam described his general experience and strategy of way-finding through a building as: 'It's like a jig-saw...I can't see very well so way-finding for me is a task of grasping at all the other information... all the smells and everything I can touch...then I have to add it all together to be able to find my way through it all.'

Example 1 - Journey Stage: Non-Specific

Within the Journey Stage of 'Non-Specific', the top-level task, *Negotiating a Change in Level* was found to be composed of four sub-tasks, 1) Using Stairs, 2) Using Lifts, 3) Using a Ramp and 4) Using Escalators and Moving Walkways. In exploring further the task of **Using Stairs**, Katie explained: *'It is often a common misconception that blind people can't use stairs... but for me there is no other way. Bruno (guide-dog) doesn't like lifts. You just have to be careful.'*

The following six Way-finders Questions were highlighted by the Way-finding Scenario in relation to using stairs: *How do I get to the stairs? Where am I on these stairs? Is this stair going up or down? Is this a stair or a landing? Are there any hazards on these stairs – where are they? and How do I get to the handrail?*

Therefore five main communication needs were highlighted: Navigation communication to enable Way-finders to find the stairs; Orientation communication to enable Way-finders to orientate and mark-out the stairs; Identification communication to enable Way-finders to differentiate between a landing and stair; Warning communication to enable Way-finders to avoid and deal with hazards on stairs and; Navigation communication (*'place your hand here'*) to enable Way-finders to find and use the handrail.

Example 2 - Journey Stage: En-Route Destinations

Incorporating 'En-Route Destinations' into a Way-finding Journey was found to be subject to a Way-finders' confidence. It involved a Way-finder taking the decision to deviate from the primary journey, reaching the En-Route Destination, and then making a plan to way-find to the original Destination. In this study it was

found that Way-finders with more visual ability were more inclined to leave a primary way-finding route. However, it was also identified that all Way-finders will undertake *En-route Destinations* if afforded information to answer: *If I break the journey can I get back on the original route again?* The task of *Breaking the Journey* was composed of three sub-tasks: 1) making discoveries and having a rest, 2) using the toilet and 3) exiting in an emergency.

In exploring further the task of **Using the toilet**, it was highlighted that Way-finders need communications to be able to: find the toilet/disabled toilet, identify and enter the appropriate gendered toilet, and instructional information to use bathroom fixtures and fittings. When trying to find the toilets in an unfamiliar public building the reliance on someone else to either guide, or give directions to the toilet were highlighted as the standard practice for the Way-finders in this study. Lily highlighted that in many cases going to the toilet was not an option for her, as she feared getting lost if she deviated from her principal journey route. Way-finders Question: *'Where are the toilets?'* was dependant on identification communication and navigation communication.

Interestingly, a two-part Way-finding Hot-spot regarding the use of the disabled toilet was highlighted by Way-finders. Previous research (Bichard, Hanson, & Greed, 2008) found that people with visual impairment preferred not to use the disabled toilet because they are too spacious, however this study found that using the disabled toilet was often the only choice for several Way-finders in this study. Alfie explained this reason, *'My wife takes me to the toilet so we have to use the disabled toilet...she can't be going into the males now can she?'*

Way-finders experience has provided rich insight crucial for enhancing the understanding of Way-finding Journeys around buildings. Through full analysis of the Way-finding Scenario data, Way-finding Journeys around buildings have been evidenced as being emotional and physical roller-coasters full of excitement, anxiety, joy, frustration, uncertainty and achievement. They impact on a Way-finder's physical safety, independence and emotional well-being.

Conclusion

All Way-finders, inclusive of diversity of need and range of impairment (visual or otherwise) should, at the least, be able to find their way to their chosen destinations. This study has highlighted the experiences (positive and negative), expectations, *Way-finding Hot-spots* and way-finding requirements of people who have a range of visual impairment. It has found that the building environment needs to communicate to the Way-finder, as Katie explained *'It needs to give us little clues'*.

Through presenting a varied insight of person-centred experience and expectation of Way-finding Journeys, this research illustrates a method to enable architects and designers to empathise with users of their buildings. It identifies the shifting dynamic of mood and confidence as captured through the notion of *Way-finding Hot-spots*. Instead of providing prescriptive design recommendations it analyses the holistic experience of person-centred way-finding. It develops a framework for architects and designers to not only enable, but also enhance, experiences of way-finding by building users who have differing visual and sensorial needs and begins to establish design briefs for future research.

With further design consideration, Way-finders can feel secure and enabled if the surroundings give them confidence. A building which provides clear communication to Way-finders, with varying visual and sensorial needs, will offer an independent experience which is richer than simply the facilitation of arriving at a destination.

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**Wellbeing in Healthcare Environments:
A Human-Centered Design Research Approach to Improving the Cancer Patient Experience during
Radiation Therapy**

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Abstract

Healthcare and medical products are often designed with the singular focus of providing the best treatment available to patients. However, research has shown that this treatment-based approach does not result in quality care. There are many factors that play into making a healthcare experience patient-centered, and this paper explores the use of human-centered design research to understand this experience. This paper presents a case-study of a Radiotherapy Department at a University Hospital, where we used patient survey, observational, and narrative data to gain awareness into the patient experience during radiation therapy. Our research shows how the current radiotherapy environment is anxiety provoking to the patient, and how insights gained from the written and visual stories of the patients' experiences were used to develop a design solution that improves the patient view in the treatment room with the intent to make this space more patient-centered and inviting. In conclusion, this paper argues that designing for the patient experience and their emotional wellbeing is a crucial aspect of any healthcare service.

Introduction

In this paper we present a case-study of the Radiotherapy Department at Norrlands University Hospital (NUS), where we have taken a human-centered design research approach to researching the cancer patient's experience while undergoing radiation therapy. This approach is comprised of a variety of research methods, all focused around the following two questions: How do healthcare services, products, and spaces impact the emotional wellbeing of the patients that interact with them, and how can we understand and design for these emotional experiences?

This paper aims to show how human-centered design research can be used to mediate the treatment-focus of healthcare and medical technologies to understand and design for holistic patient experiences. We first look at the history of healthcare technological development and the importance of a person-centered care climate to set the stage for our research in the clinic. We then discuss the implementation of a patient-centered research approach within the clinic, involving surveys and journals, observational studies and cameras. We then go on to analyze the data we gained through these research methods to understand the patient experience, looking specifically at anxiety and the patient-centeredness of the environment. Taken together, we will attempt to show how these different research approaches can provide us with an increased awareness of the patient experience and how this insight can lead to designed change within the treatment room that considers both the patient's experience and point of view.

Background

Medical technologies are designed with the intention of improving patient health, with each new development aimed at improved detection and treatment offerings. However, patient well-being is rarely considered in this equation. The field of medicine has typically taken a very quantitative approach to healthcare, focusing on the immediate needs of treatment versus experience (Mah & Guenther, 2011). Healthcare facilities have been designed for the doctors' needs in identifying and treating the patient requiring medical attention. These spaces are dominated by various equipment and technologies which the doctors rely upon to diagnose the patient's condition and provide treatment. Unfortunately, the medical devices and technologies used to provide the most accurate and up to date diagnostics and treatments possible often unintentionally relegate the cares and experience of the patient as non-essential consideration. The best treatment option places emphasis on curing the patient to the exclusion of everything else, including the patient experience.

Findings from a growing body of research on experiences of illness, treatment and care have shown that healthcare care based purely on this biomedical perspective is unable to generate satisfactory or even

acceptable care from the patient perspective (Edvardsson et al, 2008; Edvardsson et al, 2006). This research highlights the importance of taking into account the subjective experience of the individual and how such a view constitutes a person-centered approach to care that can promote well-being. Person-centered care stands for the practice of valuing the person and those caring for them, treating people as individuals and thereby assessing and meeting individual needs of patients rather than meeting the needs of staff, using the perspective of the person and creating a positive social environment in which the person can experience wellbeing (Brooker, 2007).

Patients undergoing curative radiotherapy receive daily radiation treatments over a period of several weeks, for duration of up to two months. This means that these patients have a high level of exposure to the care environment, making it very important to understand what their experience is like and how it can be improved. This paper aims to show how human-centered design research can provide insight and understanding into patients' emotional experiences during their healthcare interactions, and show how the insights gained can be used to drive patient-centered design change within these environments.

Methodology

Three different research methods were used in our research to gather data about the patient experience. Quantitative methods were used to gather data about the radiotherapy patient population at NUS, while qualitative and design methods were used to get more detailed information about the patient experience within the clinic and while undergoing treatment. The rationale behind using this type of research approach was to gather data with differing perspectives in the attempt create a holistic understanding of what is it like to undergo radiation therapy.

Our quantitative survey, comprised of two previously validated surveys – the State-Trait Anxiety Inventory Form Y (STAI-Y) and the Person-centered Climate Questionnaire (PCQ) – in addition to demographic questions and treatment specific questions, was used to generate a baseline understanding of the patient population undergoing radiation therapy (Spielberger et al, 1970; Edvardsson et al, 2008).

For our qualitative studies, we conducted short-term ethnographic fieldwork at the clinic for a period of two months, comprised of in-depth observations of the patients and interviews with the staff (Hammersley & Atkinson, 2007). We documented our findings through extensive fieldnotes and used salience hierarchy to analyze the data recorded (Emerson et al, 1995; Wolfinger, 2002). This approach enabled us to create a detailed analytical account of the patients' experiences within the clinic, and gain insights into their physical and emotional experience of radiation therapy.

Thirdly, we used design probe kits to look at the patients' experience recorded through their own words and images (Mattelmäki, 2006). The design probe kit was comprised of a daily journal and a camera, and included open-ended questions about the treatment experience (See Figure 1). The stories gathered from the completed journals and cameras within our probe kit allow us to gain insight into the daily lives and personal experiences of the patients while they are undergoing radiation therapy, while minimizing our impact on these experiences.



Figure 1. Design Probe Kit

The research presented in this paper was conducted at the Radiotherapy Department of the Norrlands University Hospital (NUS), in Umeå, Sweden. Our research protocol was approved by the NUS ethics board (Dnr 2010-371-31M), and follows the ethical rules and guidelines set forth by the Swedish Research Council. All patients being treated with radiation therapy with curative intention at the NUS Radiotherapy Department were eligible for participation in our study, and interested patients were invited to document their experiences using our Design Probe kit.

Analysis

Looking first at patient responses to our questionnaire, we found that one out of every six patients undergoing treatment reported that they experienced some level of anxiety while in the treatment room. This finding was supported by STAI-Y scores (i.e. their state anxiety level) which were a mean of 10 points higher for patients who reported experiencing some anxiety during treatment than those who did not. In addition, patients who reported experiencing some anxiety also reported experiencing a less person-centered climate through the PCQ survey. However, while the survey data was able to numerically quantify the percentage of the patient population experiencing anxiety and tell us that they experienced a less person-centered climate, it was unable to tell us what was causing these feelings, when they were being experienced, or why.

This is where our ethnographic fieldwork within the clinic became very helpful. During our observational studies, we had the opportunity to view multiple patients being fitted with fixation devices for treatment (See Figure 2). These devices are used within radiotherapy to provide reproducible patient positioning from one treatment appointment to the next. Unfortunately, they also seem to trigger patient anxiety.



Figure 2: Patient fixated for treatment in a head mask

One patient was observed discussing with the nursing staff about how the mask had triggered feelings of anxiety and claustrophobia when it was being worn, despite this individual not normally having any problems with enclosed spaces. In a follow-up interview, the nurses explained to us that the patient had used breathing relaxation techniques to stay calm and avoid panicking. In this interview we also learned that these masks frequently cause feelings of anxiety in the patients, and that in order to alleviate some of these feelings, the nurses often need to alter the masks in different ways to make them tolerable to the patient. This can be through cutting eye openings in the masks to allow the patients the ability to observe what is going on around them and communicate, or adjusting the fit in other ways. Our observations led to the identification of the fixation device as one trigger of anxiety in patients undergoing radiation therapy.

Building upon these findings, the self-reported material collected from the Design Probe journals provided us with rich descriptions of patient radiotherapy experiences that were otherwise unattainable through the questionnaire and observational methods. Drawing on material gathered from 14 different patients, we looked for stories that would support our understanding of the role of the fixation device in causing anxiety.

In the journal of a patient who reported suffering from claustrophobia, we found a description of her experience with the face mask: *"I had a panic attack the first time. I could not handle being trapped in the mask. Then the staff modified the mask so that it didn't put pressure on the neck. The next day I asked to them to make eye holes for me, which they did. Now it's ok."* This statement, supported by our observational findings, suggests that the care staff form a tightly intertwined relationship with the treatment technology,

and the negative emotional impact of the equipment is often balanced out through the actions of the nurses. Through the example of the fixation device, we can see that the nursing staff mediates the anxiety provoking and claustrophobic nature of this technology through physical intervention, softening its restraint and making it more tolerable for the patient.

In her book, *The Logic of Care*, Annemarie Mol, discusses how the technologies involved in medical treatment are generally considered to be mere 'instruments' and a means to an end, but they also often have unexpected effects (Mol, 2008). Mol suggests that 'good care' involves the care provider's constant endeavor to adapt these technologies to their needs. From the examples provided in this paper, we can see that in the context of Radiotherapy, the nursing staff shoulders the burden of providing both treatment, and emotional and physical support to patients during radiotherapy in order to mediate the patients' 'unexpected' negative responses to the treatment technologies.

Design Solution

Taking our analysis a step further, we dug into the details provided in the patient journals about the radiotherapy experience to look for ways that we might begin to intervene in this environment and make it more person-centered. From the patient journals, we discovered that many patients emphasized in the design probe materials that there is a lack of visual stimuli during treatment. One patient wrote that she wished she had *"something in the ceiling to watch during treatment,"* while another patient wrote that she spends her time in the treatment room *"counting the tiles in the ceiling."* This finding was reinforced by images of the treatment room ceiling taken by the patients with the cameras that were part of the probe kit (See Figure 3).

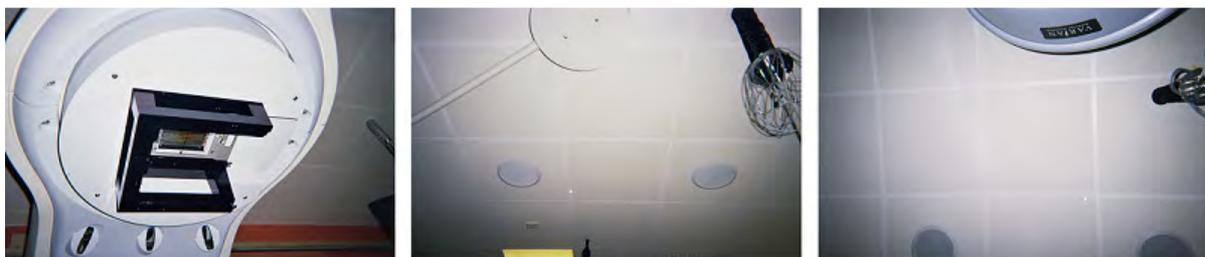


Figure 3. Patient photographs of their view while lying on the treatment table

This insight pointed to a means for mediating the anxiety caused by the treatment technologies, and the concrete details provided by the patients in their journals and photographs provided a place to leap from research into design. Based upon the insights gathered through our patient-centered research, we chose address the issue of the bare ceiling in the treatment room and find a design solution that would engage and

distract patients from their immobilization-based anxiety within the treatment room. Since the patients reported the treatment room as being cold, uninviting, and a space predominated by technology, we decided to bring nature imagery into the room.

Previous research has shown that exposing patients to interesting and distracting environments through video and sound can have a beneficial impact on their hospital experience, especially if the imagery is nature imagery. It has long been known that views of natural landscapes provide a strong positive health effect in patients (Ulrich, 1984; Velarde and Tveit, 2007; Malenbaum et al, 2008). These health effects include short-term recovery from stress or mental fatigue, faster physical recovery from illness, and long-term overall improvement on people's health and well-being. In addition, Miller et al. (1992) found that burn patients exposed to scenic imagery through videos during dressing changes reported significant reductions in ratings of pain intensity, pain quality, and anxiety.

Working directly with the treatment room nursing staff to find a design that wouldn't interfere with their normal workflow, we arrived at a final solution using projection to screen video of clouds moving in the sky upon the ceiling of the treatment room (See Figure 4). The video provides visual stimulation for patients, and a place to focus their attention during treatment. The patient view is transformed from a static, unchanging landscape of ceiling tiles, to a dynamic colorful visual of nature.



Figure 4. Ceiling Projection Intervention

Initial findings from the impact of the implemented design have shown that patients look for a focus point in the treatment room, to ground them during each visit and help them relax. The video intervention can be used as this focus point for some patients, and removal of the video imagery impacts these patients' ability to relax during treatment. However, more research needs to be done to assess whether this intervention actually decreases anxiety in this patient population.

Conclusions

Person-centered care has been argued to be essential in ensuring patient wellbeing during their healthcare experiences, but in order to provide this type of care we must first be able to understand the factors influencing this experience from the patient's perspective. Using three different methods to research patient experience in this paper, we looked for indicators to help us determine whether the radiotherapy experience is currently meeting patient's needs and providing a patient-centered environment.

The quantitative data gathered from the patient questionnaire provided data showing that anxiety is prevalent within a significant portion of this patient population. This information suggests that anxiety is something that needs to be addressed within radiotherapy treatment and one way to do this is to increase the person-centeredness of the clinic environment. However, the questionnaire data taken alone provided us with very little insight into the details of the patient experience, and this method is incapable of giving us any further information about where, when, how or why these patients experienced feelings of anxiety.

While the ethnographic fieldwork was helpful in identifying one cause of patient anxiety, the fixation device, it was the design probe material that was crucial in clarifying why this technology triggered anxiety. The probe kits were instrumental in constructing understanding around the role of anxiety in the patient experience because they gave us access to the patient voice, which showed that the fixation device triggered feelings of claustrophobia for many individuals.

The design probe kits have demonstrated that they are a highly valuable tool for gathering insight into healthcare experiences from the patients' perspective, a critical aspect of generating a patient-centered approach to care. Patient interviews is another technique that could be used for acquiring access to the patient voice, however the design probe kit is unique in that it provides multiple mediums for capturing experience, both verbal and visual. Regardless of the method implemented to capture the patients' perspectives, patients are our best tools in understanding the radiotherapy experience because only they can tell us what it is really like to go through the treatment process.

This paper demonstrates how medical technologies designed to treat disease can produce 'unexpected' negative effects in patients, such as anxiety. Furthermore, our research findings suggest that the care experience within the Radiotherapy Department at NUS is highly dependent upon the nursing staff to mediate the negative impact of the technology on patient experience. It can be argued that providing and receiving care within radiotherapy could be very different if these technologies incorporated patient-centered perspectives into their design, or if the environment was designed to be more person-centered and distract the patient from the technology.

The ceiling projection design intervention that arose out of this research is just one potential solution for diminishing the 'unexpected' effects of the fixation device and creating a more person-centered environment. While this paper focused upon the fixation device as a cause of anxiety for patients undergoing radiotherapy, the material gathered from the design probe kits shows that this is just one factor that plays into the creation of the patient experience. There are many other aspects that can influence patient anxiety and perceived patient-centeredness of the environment, and these factors work together to create a positive or negative patient experience. Design for patient wellbeing and care needs to go beyond providing the most advanced treatments to include consideration for the patient as an individual and their experiences. This paper demonstrates that human-centered design research can be a useful tool in providing insight into the patient experience as well as identifying areas where change can be implemented.

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Beyond a Spoonful of Syrup: understanding physical barriers to medical packaging

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Abstract

It is estimated that 50-70% of patients in the USA do not take prescribed medication properly, and thus it is suggested that 125,000 people with treatable illnesses die annually in result – patient noncompliance is estimated to cost the United States \$100 billion per year (Wertheimer, 2003). Additionally, older patients take much more medicine than younger people because of the increased rate of health problems with age – on average an older person takes four or five prescription drugs and two over-the-counter (OTC) drugs every day (Merck, 2004).

The subject of patient-compliance, i.e. whether a patient takes their medicine as instructed, is extremely complex. One of the reasons that a patient does not comply with drug treatment is that they encounter obstacles associated with packaging (Fuente et al., 2009). Evidence suggests OTC drug misuse is high among older persons (Lumpkin, 1990). Ineffective packaging and labelling can result in a number of compliance errors including: “wrong drug, wrong dose, wrong time of administration, dose omission, wrong patient, extra dose, [and] wrong route of administration (Vidt, 1997).”

The authors recognise that whilst packaging access for older people is a complex issue combining, physical, cognitive and psychosocial issues more understanding is needed of each of these issues. To that end the authors have undertaken a study using focus groups, video ethnography, surveys with patients and pharmacists and detailed ergonomic analysis (including motion capture) to understand the physical issues surrounding access to medicines. This presentation discuss some of those results found and looks at some proposed design solutions for improved compliance and produces some recommendations for the future direction of medical packaging.

Keywords: accessibility, packaging, ageing, inclusion, barriers

Introduction

Child Resistant Closures (CRC's) are applied to packaging in order to prevent young children from gaining access to harmful contents, most commonly seen in the storage of medicines which when ingested by a child can be extremely dangerous and cause poisoning.

Regulations on the supply of highly toxic medicines such as Aspirin and Paracetamol, were first produced in the early 1970's (US, Government, 1970). These regulations led to the production of child resistant packaging firstly with reclosable bottles and more recently the introduction of blister packs. Child resistant packaging for products containing Aspirin, Paracetamol and Iron have become mandatory in the UK since October 1st 2003 by means of a statutory instrument, the Medicines (Child Safety) Regulations (2003).

The 'Push and Turn CRC' is the most widely used design of child resistant closure. This requires the lid to be pushed down onto the body of the bottle before the threads align and the top can be unscrewed. The instructions for these actions are usually indicated on the lid, (as shown in Figure 1).

This design uses the concept of 'false affordance', for example if there was a flat plate at chest height on a door, one would assume that in order to open the door it needed to be pushed, this would be a true affordance. A false affordance uses sights, sounds and textures to complicate a task. A child might think to turn a bottle top but they are unlikely to be able to read the instructions which inform the user to depress the top first. Undertaking two actions simultaneously is inherently difficult for any child under 51 months old, they would find it very hard to push down the lid and then turn it even if they were shown how to open the bottle.

This solution requires a cognitive approach; the mental process of knowing, including aspects such as awareness, perception, reasoning, and judgment. This CRC is effective in preventing children from accessing a bottle's contents but it has also been found that elderly people struggle to use it due to the force and dexterity required. Consequently, another possible major problem contributing to child poisoning is a lack of openability of CRCs since users often decant their medication into non-CRC bottles for ease of use (Wilkins S., 2001).

However, in the UK these types of closures systems have fallen out of favour largely due to legislative pressures that have seen these types of systems replaced with blister packs similar to those shown in Figure 2.



Figure 1: Typical 'Push and Turn Closure'



Figure 2: Blister Pack

in the development of Child Resistant packaging, some exceptions were made, principal amongst these was the exclusion of unit dose packed products, for example medicines packed in blister packs. As discussed earlier, in the early 1970s when this direction was first formulated blister packs were uncommon but the converse is true today and now more than 50% of prescription drugs are dispensed in easy open blister packs and represent a real danger of child poisoning (Wilkins, 2011) and 80-90% of all solid medication sold in Europe is packaged using blister packaging (Pilchik R, 2000).

Progress has been made towards developing inexpensive and effective child resistant blister packs and some examples are shown in Figures x.3 and x.4, and there is a now European standard (EN 14375) against which they can be tested.

However, the development of Child Resistant blister packs is complex, there is for example, disagreement as to the definition of an opening. How many units need to be extracted before the pack is considered to be open? In the United States every medicine is accorded a 'toxicity value' so for some, a pack is considered open when one unit is extracted, whilst for others up to nine tablets need to be accessed before the pack is regarded as open.

Within the European Union, there is no common regulation for medicine packaging however standard setters have defined an opening for blister packs in EN14375(6) as 'more than eight units'.

As a packaging system for medicines and a range of other products the blister pack is excellent, it incorporates a perfect seal preventing contact either with the atmosphere or other products and permits dispensing with no risk of contamination at the retail level.

Whilst there are examples of CR blister packaging (see Figures, x.3 and x.4) within the European Union CR blisters are uncommon and EU manufactured prescription drugs for the US market are often dispensed in containers with traditional CR closures and currently there is no truly effective CR blister pack in which the pharmaceutical industry can have confidence, both for its child resistance and its ease of opening by adults (Wilkins, 2011).



Figure 3. Everest safe-Pak, CR Blister pack



Figure 4. Comply-Pak, CR Blister Pack

Work by de la Fuente and Bix (2010) tested six different CR and non-CR pack designs, including examples of a CR and non-CR blisters. These packs were tested on three different groups:

- people with disabilities
- older adults
- children

The work has been developed as the authors believe that current testing protocols are flawed (de la Fuente, 2010, Bix, 2009) and an understanding of users abilities will allow the development of improved CR designs, improving compliance whilst reducing accidental poisoning.

The researchers undertook a series of tests including strength, dexterity and anthropometric measurements. They concluded that to include people with disabilities, a CR pack design should not rely on the use of pinch strength. Further, the study suggested that when finger strength and dexterity are required, user ratings for that particular pack design tend to be low. Indeed, the researchers suggest that hand-finger dexterity cannot be used as a mechanism to exclude children as there are no significant differences in dexterity between children and adults. They go onto suggest that hand anthropometrics (the difference between adult and children's hand size) is likely to be the best way forward. Work by Yoxall (2008) showed that simple changes in geometry can produce improved access to CR bottles whilst excluding children. A CR bottle was developed that used the "affordance" principles described earlier, and encouraged users to use their palms rather than finger dexterity to open the closure (see Figure 5). Whilst a possible solution, the bottle is bulky and more expensive than current designs, moreover as discussed earlier, CR bottles have largely been replaced by non-CR blisters.

In order to aid the development of CR blister packaging that is both effective and meets the requirements of all users, it is essential to understand how users currently use blister packaging. Following on from the work by de la Fuente and Bix (2010) in this project we wanted to investigate in more detail, hand anthropometrics, dexterity and cognition with respect to non-CR blisters with the principal aim of aiding the development of more inclusive CR blister packaging.

To this end a series of experiments were undertaken to understand the use of current blister designs.



Figure 5. Modified CR bottle

Methodology

In order to develop a more detailed understanding of how blister packs are accessed, several experimental methods were used to assess the ease of access of this form of packaging. These were:

grip analysis

dexterity analysis

motion capture analysis

In this study, all 57 participants undertook the Classification Analysis and 45 participated in the Dexterity Test. An older cohort of 8 participants took part in the Motion Capture. The group of 57 participants had approximately the same number of male to female participants (28 female, 29 male) and covered a spectrum of age groups; with the youngest participant aged 21 years while the oldest was 91 years old (mean age 45 years). Two forms of non-CR blister pack were used in the experiments, one with a round tablet shape and the other with a capsule shaped tablet.

Classification Analysis

Previous work by the authors had developed a classification for the types of grips used in accessing food packaging (Yoxall et al., 2007). This classification became useful in identifying how people use and manipulate packaging and which grip types they prefer (Rowson, 2011). An attempt to categorise opening techniques of blister packaging does not appear to have been previously undertaken.

Methodology

As with the earlier references, participants hands were measured, they were then asked to open a pack and their opening technique photographed. Two different pack types were studied one with a rounded tablet and the other with a capsule format.

During the testing, participants were firstly informed that they would be asked to remove a tablet from the blister pack and were asked to give verbal consent to allow the recording of their hands as they carried out the motion. When asked to open the blister pack, participants were asked to open the blister pack as they usually would. They were not told that they would be timed, to ensure that they would perform the motion as they usually did. After opening both types of blister pack, hand measurements were taken from both hands. The measurements included hand length (a), hand width (b) and individual finger lengths (c) as shown in Figure 8.



Figure 6. and 7. User opening standard blister

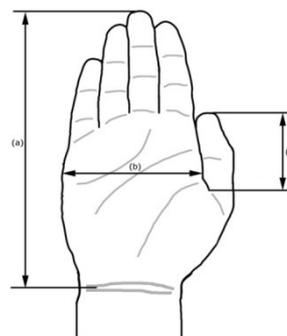


Figure 8. hand measurement schematic

Dexterity Test

Purdue Pegboard Tests have been a standard method for measuring dexterity for over 70 years (Figure 9). The Purdue Pegboard Test is a test kit invented by Joseph Tiffin, Ph.D. from Purdue University (Tiffin, 1948). The test was originally designed to select applicants for labouring work.

The Purdue Pegboard tests two types of dexterity; macro- and micro- dexterity. Macro-dexterity is defined here as the overall movement of the entire arm(s); that is the ability to move the fingers, wrists, hands and elbows. Micro-dexterity in this context refers to fine-finger movements; that is the ability to perform complex motions with primarily the fingertips.



Figure 9. Purdue peg-board test

The receptacles (cups) at the top of the board contain, from left to right: 25 pins, 40 washers, 20 collars and 25 pins. The test assumes that the participants are right-handed; therefore when a left-handed person takes the test, the instructions have to be swapped accordingly, as well as the placement of the sleeves and washers in the pegboard.

The Purdue Pegboard test claims its can be used for numerous other purposes; while the more well known experiments have tested for the presence and/or extent of brain damage, learning disabilities and dyslexia (Tiffin, 1948).

Test Methodology

There are four individual tests that were carried out using the Purdue Pegboard. For all of the tests, the participant was sat at a table that was at a comfortable height.

Test One (Right Hand) - The first test involved the participant using their right hand to pick up a pin from the right hand cup, and then placing the pin into the topmost hole on the same side. This step is repeated with

another pin from the cup, which is then placed in position just below the first pin, and so on. The test was timed to see how many pins could be placed in 30 seconds.

Test Two (Left Hand) - The second test is identical to the first, but performed with the left hand, the left hand cup and the left hand side of the board.

Test Three (Both Hands) - The third test was similar to the previous two and involved using both hands to simultaneously pick pins from the both cups and place them down the right and left hand rows simultaneously. Only the number of pairs of pins placed in this test is recorded.

The scores for Left + Right + Both Hands are added together to give an overall score of macro-dexterity.

Assembly Test - The final test to be performed was the assembly test. Depending on the dominant hand of the person performing the test, the arrangement of the collars and washers sometimes had to be exchanged as mentioned before, so that a more reliable result could be obtained from the test. The assembly test involved picking a pin from the cup on the dominant hand (DH) side of the board, then placing it at the top of the DH row, then using the other hand to place a washer over the pin, followed by a collar with the DH and finally a last washer with the other hand.

The first three tests are performed within a time limit of 30 seconds and the final assembly test in 1 minute. The participants were asked to work as rapidly as possible during that time. The scores from the first three tests are added together to give a combined score for macro-dexterity, while the assembly test gives the micro-dexterity score directly. At this point of the study, hand measurements were taken in the same fashion as outlined earlier in the Classification Analysis (see section x.2.1).

A trial was carried out on two people to ensure that the student would be able to conduct the test properly. Instructions were read out to the participants as they were written in the manual. After performing two trials it was realised that a few changes had to be made by to the instructions and method used when carrying out the study. Some adaptations were made to the instructions after performing some trials.

- The addition of, "*I shall ask you to...*" to the beginning of each of the tests descriptions, as when the original instructions were used participants felt the need to act upon the instructions as they were read out.
- The second change made to the instructions was a countdown to the start of the tests, as the participants in the trial felt that just asking them to begin the test was too sudden.

As a means of identifying the Dominant Hand of the participant, they were asked if they were either right handed or left handed, and then they were asked which hand they write with. The first question was to determine what hand they perceived was dominant, while the second question was used to determine which hand performs an obvious high-dexterity skill such as writing (Tiffin, 1948). This was due to the fact that a large number of left-handed participants had been taught and brought up to write with their right hands.



Figure 10 and 11. Purdue-pegboard test

Motion Capture

Introduction

Optical motion capture systems have previously been used to understand packaging access (Fair et al, 2008) of vacuum lug jars used for sauces and pickles. To better understand if and why people may have trouble complying with their blister packaged medication, it was decided that an optical motion capture investigation would be the best way of determining such a problem.

The setup (see Figures x.12) used involved a Hawk Digital RealTime System that consisted of seven Hawk Digital Cameras connected to a computer running Eva Real-Time software. The Hawk Cameras are specifically programmed to record only infrared light and are mounted with an array of infrared Light-Emitting Diodes (LEDs); whose intensity can be controlled. The cameras are all connected to a computer, running EvaRT 5.0.4, which allows the computer to store and process all the captured data to give a precise and accurate positioning of the object of focus and allows the user to view the object from any angle (point of view).

As the cameras only register infrared light, reflective markers are used to capture the motion of the participants' hands. markers were placed on participants hands as shown in Figures x.13 and x.14. due to limited time available and the complex nature of analysing the results, this investigation was only open to people aged 55 years and older, as the main aim to see if any difficulties faced when opening blister packs could be examined in detail.



Figure 12. Motion-capture set-up

Figure 13. Motion Capture calibration

Figure 14. Hand marker set-up

Before any tests could be carried out, the equipment had to be calibrated to ensure correct reading and relaying of data from the cameras to the computer. Calibration had to be performed on both the hardware and software. For the hardware calibration, the cameras are prepared and positioned to focus at a specific point in the test area. The position of each of the cameras relative to the area of interest is measured and entered into the program to help the computer stitch together all the two dimensional movements recorded by each camera to create a three dimensional representation of the movements recorded.

The cameras are able to operate in a range of 1 – 200 fps. It was decided due to the nature of the project and after consulting with experienced users of the software that a frame rate of 120 fps would be suitable to give a detailed enough motion capture without requiring too much time to post-process the data.

To ensure that the software was working correctly, several trials were conducted using three voluntary participants. The participants were seated a table in the centre of the workspace for the investigation. Reflective markers were placed on all the joints of all the fingers and two additional markers on the centre of either wrist.

The motion capture is carried out in a dark space to improve the quality of the capture. Therefore when recording the participants, it was necessary to switch off all the lights in the room (though the infrared LEDs do emit a faint visible light). It was noticed during the trials (and also during the technique analysis) that the thumb, index and middle finger performed most of the work when opening the blister pack and that the ring finger and little finger were used to either support the packaging or were curled out of the way.

Results and Discussion

Grip types and classification

When analysing the footage it was noticed that each of the participants mainly used one hand to perform the actions required to remove the tablet from the blister pack, therefore this hand was labelled the active

hand. The other hand merely aided the active hand by supporting the blister pack or catching the tablet as it fell, therefore this hand was titled passive hand.

Even though the methods (or techniques) associated with each of the grips have been outlined below, the key information was the positioning of the hands at the beginning of the initial motion. There were four grips that were recognised during the categorisation investigation. They are outlined below as follows.

Grip One (The Hold and Push)

This grip involves using the thumb of the active hand to push the tablet out of the blister, while the passive hand is used to grip the packaging (See Figure 15). Once the blister is broken, the tablet is usually taken out using the other fingers of the active hand. In some cases, once the blister is popped, the pack is flipped over to provide easier access to the tablet and to prevent it falling out. Positioning of the thumb varies, with some participants applying force to the edge of the blister, while others press down on the centre of the blister.

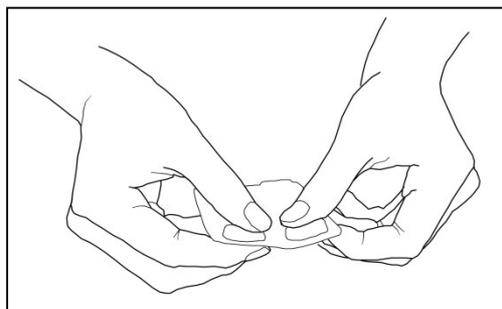


Figure 15. Grip classification number 1

Grip Two (The Hold and Pierce)

In this grip, one hand is used to grip the blister pack while the thumb of the active hand is used to score a cut into the foil (see Figure 16). After the foil is pierced, either the passive or active hand is used to push the tablet out from the packaging. A sharp fingernail is not required to break through the foil, just an adequate amount of pressure. A number of participants mentioned that the method is easier to perform on blister packs that have a stiff backing material. This grip is very similar to Technique One. The hands are positioned in an almost identical way, but with the blister pack held in a flipped (reverse) manner.

The tablet is generally levered out the blister pack by using a twisting motion of both wrists. Some participants used

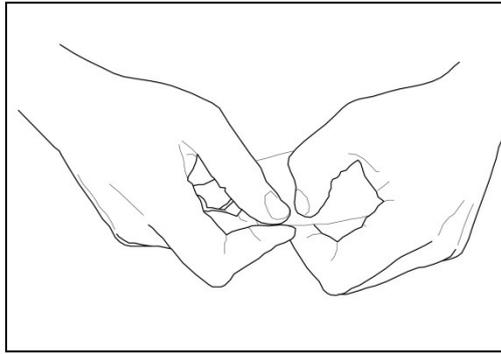


Figure 16. Grip classification number 2

Grip Three (The Reverse Hold and Push)

This grip is very similar to Technique One. The hands are positioned in an almost identical way, but with the blister pack held in a flipped (reverse) manner (see Figure 17).

The tablet is generally levered out of the blister pack by using a twisting motion of both wrists.

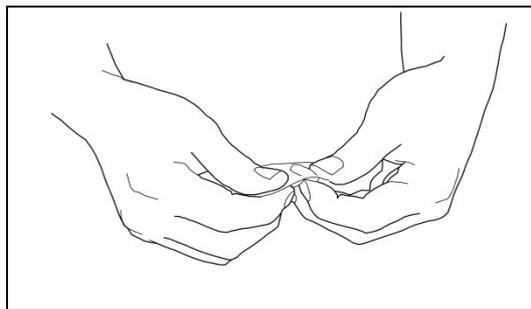


Figure 17. Grip classification number 3

Grip Four (The Single Hand Push)

This grip uses one hand to hold and open the packaging, while the other hand is held below the blister pack to catch the tablet once it falls out of the pack (see Figure 18).

The active hand uses the thumb to push the tablet out of the blister while the index and middle finger provide support; one finger on either side of the thumb.

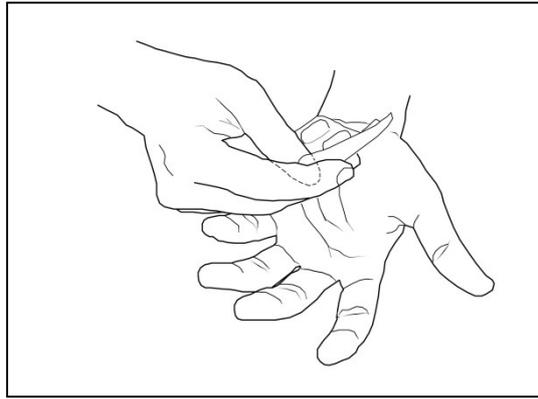


Figure 18. Grip classification number 4

Summary

As can be seen from Figure 19, the most popular grips used were Grips 1 and 3. The use of Grips 1 and 3 was spread across all the age groups. While the techniques associated with both grips were similar, those that used the technique linked with Grip 3 were generally faster, as they were not as worried about dropping the tablet with their method.

Grip 2 was generally used by the older participants; the youngest being 30 years old. The technique related to the grip seemed to require the least effort, but generally took a longer time to perform than those using Grips 1 and 3. Speaking to one of the participants who had developed severe arthritis, she said she developed this method herself, as it made the process of removing tablets much easier.

Only two participants demonstrated Grip 4, both of whom were in the 18 to 25 years old age group. But as both participants struggled slightly to perform the technique associated with the grip, it is clear why very few of the participants utilize such a method.

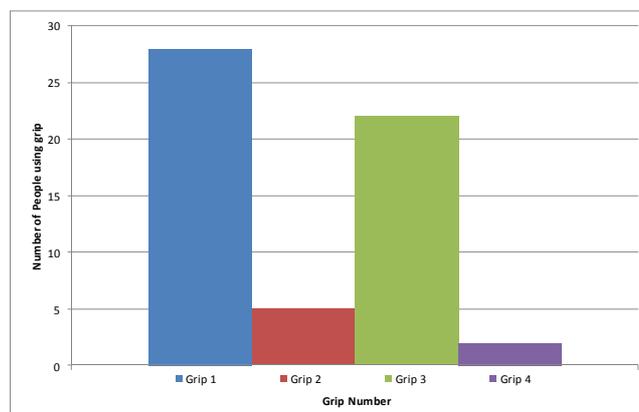


Figure 19: Graph of grip styles user versus number of participants

Figure 20 shows time taken to open access one tablet (both tablet and capsule) against finger length in mm. From the data in this study there seems to be no correlation between finger length and time taken to access the contents. Further Figure 21 shows little correlation between dexterity and hand size.

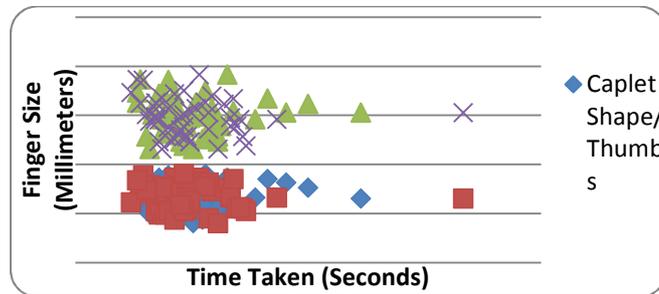


Figure 20. Graph of finger size versus time to access blister content

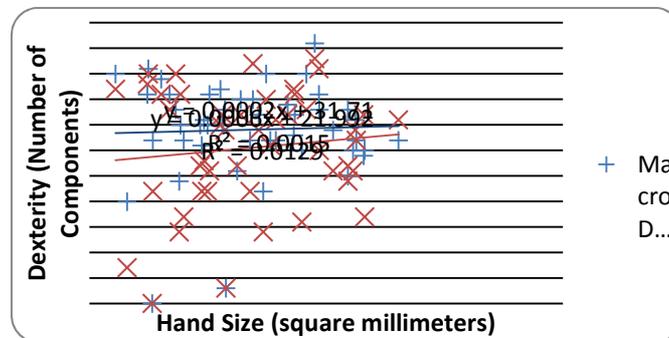


Figure 21. Graph of hand size size versus dexterity

Dexterity Analysis

From the dexterity data and hand measurements collected during this investigation the following graphs were produced.

As can be seen from Figure .22, there is a clear decline in the general level of dexterity between the young and old participants. This decline with age is seen to be far more rapid in the case of micro-dexterity than is seen with macro-dexterity.

Analysis of Results

The trend seen in Figure 22 is to be expected as when one gets older, motor control function of the hands begins to drop and physical conditions such as arthritis tend to start manifesting themselves (Latash, et al., 2000).

While all the dexterity data collected is useful; as it was verified that age has a big effect on the ability to perform fine finger movements, it was still unclear how that could be linked to the ability of the participant

to remove a tablet from the blister packs. Out of all 57 participants involved in the study, only 2 people (Participants 40 and 54) mentioned and demonstrated difficulty when opening the blister packs and performing the dexterity tests (indeed, work by Bix, 2009 also showed that participants that would nominally be excluded from pack testing protocols could successfully open screening CR and non-CR packages). Therefore to try and identify the minimum level of dexterity upon which opening blister packs becomes a problem, the data was normalised to the slowest participant. Participant 40 (Age: 74, Female) suffers from peripheral neuropathy as well as arthritis and scored a 3 in both the macro- and micro- dexterity tests. Participant 54 (Age: 84, Female) suffers from Chronic Obstructive Pulmonary Disease and mild arthritis and scored a 20 in the macro-dexterity test and 7 in the micro-dexterity test. Both these individuals have their medication decanted out of blister packs and placed into non-CR bottle packaging on advice from their GP. This level of performance could then be used to determine a level or 'score' at which blister packs were seen to perform badly and alternative solutions proposed.

Hence, a simple methodology was developed to normalise the dexterity data and develop an 'Accessibility Score' (Equation 1). This score was calculated by taking the average of the time taken to remove tablets from a blister pack (T_{av}) and then multiplied the value obtained against the average dexterity scores (D_{av}). To reduce the effects of cognition on opening times all participants were given an identical pack to open prior to being tested.

$$A.S. = T_{av} \times D_{av} \quad (1)$$

The accessibility score was then plotted against age as shown in Figure 1.23. A clear trend can be seen in this Figure where accessibility score decreases gradually with age. Participant 40 and 54 can be spotted on the graph with scores of 7 and 9 respectively. The other participants that scored below 10, while not possessing any physical disability, were aged 76 and 81 years old respectively; and commented that although they faced no major problems opening blister packaging, it did require effort to extract a tablet.

Therefore using this information it can be assumed that anybody with an Accessibility Score below 10 will have trouble opening blister packaging.

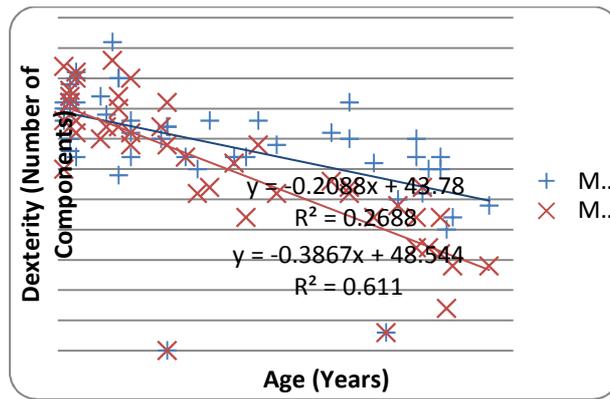


Figure .22. Graph of dexterity versus age

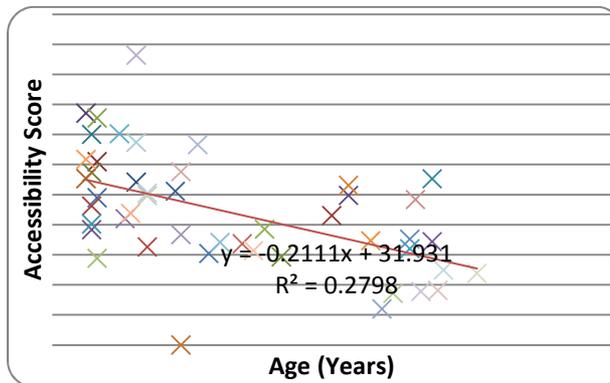


Figure 23. Graph of accessibility score versus age

Motion Capture Analysis

The following charts are displacement – time graphs generated with the data collected from the motion capture investigation. Each of the lines represents one of the markers as shown in Figure 14. The finger displacement using Grip types described earlier is shown in Figures 24-x.26.

The results show significant differences in finger movement between the different styles. The graph for Grip style 3 clearly shows the way in which the tablet is extracted through the bending of the blister. Of interest is how little relative movement there is between fingers, in contrast to Figure 25 showing the opening using Grip type 1. Here, whilst the motion of the fingers is similar the difference is relative motion is more pronounced. Motion capture analysis for Grip style 2 shows significant differences in finger motion when compared to the other grip styles.

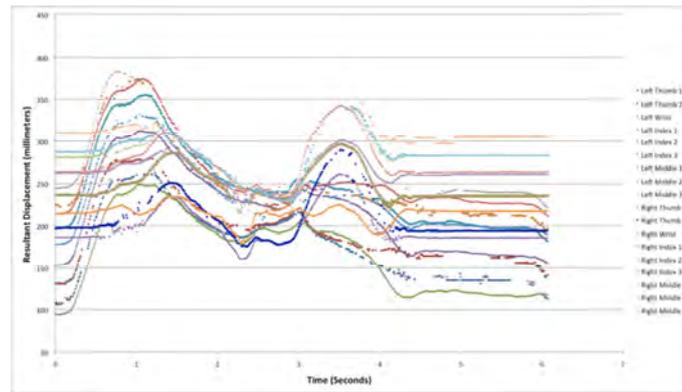


Figure 24. Motion capture results for Grip type 1

Discussion and Conclusions

A consumer's ability to access packaging is influenced by either a user's strength, dexterity, cognition or a combination of these factors. Work has been ongoing in understanding these issues for food packaging by a number of researchers (Su et al, 2009, Vorbij, 2002, Yoxall et al, 2010), however for CR packaging detailed understanding of issues surrounding ease of access is less well researched.

de la Fuente (2010) and Bix (2009,) have undertaken a series of experiments looking at design exclusion of CR packaging, either in the testing protocols or the designs themselves. Obviously for CR packaging to work, it has to exclude children whilst including adults some of whom are likely to have disabilities and impairments. Difficulty of access is a known issue relating to patient compliance and there is a growing body of literature surrounding older users and their difficulties in accessing medical packaging.

De la Fuente (2010) indicated that due to the loss of strength and dexterity in older users, cognition and hand anthropometrics were the most likely way forward for development of CR packaging. Within the EU single dose blister packaging dominates and the authors have attempted to understand in more detail the issues raised by de la Fuente with respect to non-CR blister packaging with the aim of informing the future direction of CR packaging.

In this study, the authors used experimental techniques and informal interviews to assess dexterity, hand anthropometrics and cognition. There were several key points to note:

- All users including those with very poor dexterity could actually access the packs. However for some users the time taken was considered so prohibitive that their GP prescribed their medication be delivered in non-CR bottles.

- By combining this time limit with a dexterity analysis we were able to develop an accessibility score. This score could be used to aid the development of CR blister packaging and could be useful as a design guide for other types of packaging.
- Packaging dexterity and ability to access the contents did not seem to be related to hand size. This suggests that for blister packaging hand anthropometrics may not be the most straightforward solution to developing CR blisters.
- None of the participants tested, read the instructions printed on the foil side of pack prior to opening. This instruction was similar to Grip style 2.
- Users demonstrated four distinct grip styles with two styles dominating. The lesser used styles (termed Grip Style 2 and 4 in this analysis) were user developments after struggling to access packaging. Of interest was that from motion capture analysis Grip Style 2 requires significant finger movement.

This research suggests that the development of a truly effective CR blister is a complex problem. However a methodology is proposed that will at least provide new designs with a benchmark to assess their effectiveness.

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Methods for collective creativity in experience design processes for health(care)

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Abstract

Design research projects situated in the domain of health(care) can aim for social innovation. In that case, design researchers want to invent products, services or systems that will be valued and adopted by health(care) contexts (Pepperell & Punt, 2001). Usually, such projects are quite complex and demand a joint creation process between many different stakeholders. In any project it is indeed important to create a joint experience between the involved stakeholders and facilitate communication amongst them. The field of experience design focuses on designing and/or shaping joint experiences of people. In order to design these experiences, the designer must empathise with the users and imagine what it is like to live the life of the user (Huybrechts, 2007). Methods of collective creativity can help the designer to actively involve in the life world of relevant target groups (Sanders, 2001). This paper describes how the research group Social Spaces 'designs' collective creative methods for health(care) contexts in which empathy, imagination and the creation of a common language play an important role. These features are crucial for designers to touch upon the experiences of participants in health(care) projects, engaging them in a joint social innovation process. While the design of collective creative methods is certainly not new, their application in health(care) contexts can be explored more thoroughly. Social Spaces experiments with using artistic techniques in designing these methods for collective creativity, having advantages in a health(care) context.

Introduction

Social Spaces (www.socialspaces.be) is a cross-disciplinary research group of the Media, Arts & Design faculty, part of the Faculty of Art and Architecture of the University of Leuven. Social Spaces consists of about fifteen researchers, designers, engineers and artists and operates within a context of design and artistic research with strong roots in digital design and art, audiovisual and product design. Its goal is to create social, participatory, but also imaginative and functional designs for various (often neglected) groups and contexts within society.

This paper illustrates how Social Spaces mediates **collective creative design processes in social innovative health(care) projects**, wherein **the creation of a shared experience** (between users and between users and designers) was the main objective. First, in “Carefree living in the elderly care”, performance was used to mediate a collective process between design researchers, students, elderly, caregivers and a theatre group. Second, for “A Touch of Memory”, Social Spaces organised a workshop using personas portraying people with dementia. Finally, in a workshop for “Textures for Care”, participants playfully mapped problems that people with diabetes encounter in everyday life.

This paper describes how collective creative design methods can make the experiences of participants in innovative health(care) projects tangible. This helps designers and researchers from different disciplines, but also user groups, to open up communication and speak a common language. Additionally, sharing experiences takes the participants out of their comfort zones, allowing the designer to empathise and imagine what it is like to live the life of the user or the other way around. Firstly, we take a look at the concept of experience design in the framework of social innovation processes. Subsequently, we discuss how grasping the viewpoint of other perspectives can be facilitated by using collective creative design methods. Next, we discuss above-mentioned projects to illustrate how collective creative processes were mediated, with the creation of an experience as a central concern. Finally, we draw some conclusions for further discussion.

Experience design in social innovation processes

Social innovation processes are complex and demand that people adopt and value what designers create for them. Therefore, designers try grasping the viewpoint of various stakeholders and empathise with them by involving them in joint creation processes.

Experience design is an appropriate approach to facilitate health(care) questions and phenomena, often being very personal and intangible. The experience design field is concerned with engaging in stakeholders' life worlds. It deals with researching, designing and/or shaping experiences of people in relation to their

environment. Its goal is to grasp and create meaning and emotion, changing man's complex experience of the environment in the process of changing a certain aspect of that environment (Shedroff, 2006). By addressing these experiences, experience design can transcend the current dominant functional or narrow aesthetic models in the field of design. It aims for socially and culturally relevant solutions rather than, for example, functionality. Experience designers design experiences *with* people that can change as their needs and desires shift. To make these experiences as successful as possible, the designer must imagine what it is like to live the life of her/his user, going further than satisfying practical market demands and answering to emotional questions (Huybrechts, 2007).

Next to this personal and intangible character, health(care) innovation processes have a second important characteristic: they involve a complex set of stakeholders, like health(care) workers, engineers or designers. These disciplines usually use standard solutions and neglect the possibility of engaging in creative cross-pollinations for finding innovative and people-oriented solutions. When experience design is combined with a participatory approach, this field is able to deal with the complex constellation of stakeholders in health(care) projects. For the designer, this means that she/he has to grasp the viewpoint of several complex stakeholders and conjoin them. The experience designer needs to go beyond the 'abstract user' and engage in participatory set-ups, addressing a diversity of people (McCarthy & Wright, 2004) (Buchanan & Margolin, 1995).

Collective creative design methods that focus on sharing experiences can help the designer to do so. They aid in capturing the viewpoint of the user and in working in participatory set-ups. We now take a closer look at these methods.

Collective creativity (in experience design)

In experience design processes that focus on social innovation, methods of collective creativity play an important role. According to design researcher Liz Sanders (2001), **collective creativity** takes place when bisociation – i.e. the process of joining and combining previously unrelated and un-associated ideas – is shared by two or more people (Koestler, 1964). Sanders states that collective creativity can lead to more culturally, socially and commercially relevant results than individual creativity does. Therefore, *“all people who touch and are touched by the 'product' that is being designed should play a role in collective creativity”* (Sanders, 2001, p. 1).

Generally, participants in a collective design process comprise two groups: 'makers' and 'users'. The makers include members of development teams from marketing, engineering, design, etc. The users include patients, people who shop for or end up using the product. However, the users – usually non-designers – are not used

to express their creativity and therefore need to be provided “with experiences and tools so that they can exercise their creativity and participate directly in the design process” (Sanders, 2001, p. 2). Additionally, a large part of the makers are unfamiliar with expressing creativity as well.

Methods of collective creativity can take both the makers – (experience) designers – as the users out of their comfort zones. They create a common language, levelling the participants in the design process. This reduces participants’ uncertainty and provokes mutual learning. Collective creativity facilitates participation, leading to a better articulation of different perspectives and knowledge, and consequently to new insights. It allows the experience designer to gain a better understanding of her/his users and grasp their viewpoint in a better, grounded manner (and the other way around). Therefore, experience design-related fields often apply well-known collective creative methods, such as generative tools (Gage & Kolari, 2002).

Generative tools are a collage toolkit, created by Sanders. The kit functions as a make-tool, visualisation and storytelling method. The toolkit has an artistic, expressive nature that challenges assumptions and encourages mutual learning. Participants use certain components of the toolkit to express their feelings about a specific question. Different forms like collages, visual and verbal components are combined in various ways. The toolkit makes tangible what is difficult to express and grasp. When used in groups, the toolkit can help shift from a verbal to a collective, visually expressive exchange of ideas (Sanders, 2000).

Inspired by existing experience design methods and combining elements from other contexts, Social Spaces searches for ways in which collective creative methods can facilitate social innovation in health(care) projects (see Figure 1). Sanders stresses that the format of the collage, derived from the artistic domain, allows freedom to express emotions. Social Spaces explores this artistic perspective in developing its own collective design methods for social innovation in health(care) projects. Three of these explorations are discussed next.



Figure 1: Collective creative method used by research group Social Spaces

Collective creative (design) methods in Social Spaces' projects

The collective creative methods Social Spaces designs and researches, allow participation of diverse stakeholders and create a shared experience about a certain health(care) question. The main goal of these collective creative methods is to create an intense, common experience for all stakeholders involved. This way, the debate is opened up, communication is enabled and an imaginative meeting between the makers' and users' wishes and needs is facilitated. Methods derived from the artistic domain were found to be particularly effective in achieving this. They trigger people's emotions and bring the not immediately visible problems in and underlying solutions to health(care) questions to the surface by visualising them with, for instance, video portraits (Huybrechts, 2007). The collective creative methods Social Spaces designed were thus inspired by existing experience and collective design methods, but also enriched with elements from artistic contexts like theatre, as was the case in the first project we will discuss.

“Carefree living in the elderly care”

In “Carefree living in the elderly care”, funded by the Flemish government and the province of Limburg (BE), students of the Department of Health Care and the Media, Arts & Design Faculty teamed up with care centre *St. Jozef*, theatre group *Bad Van Marie* and health foundation *Wit-Gele Kruis*. Together, they researched how media can be used to make the lives of people in the elderly care more 'carefree'. In an innovative manner, a multidisciplinary team (of elderly, caretakers, designers, students and teachers) experimented with new methods to actively involve elderly in the design process.



Figure 2: Performance workshop for 'Carefree living in the elderly care'

Within this project, Social Spaces collaborated with *Bad Van Marie* to organise a performance workshop in which students and teachers performed role-plays, using the setting of the residential elderly home (see Figure 2). The home was turned into a theatre stage, wherein professional actors, personnel, older people and designers – both professional researchers and students – took part. The participants, except for the professional actors, were not aware of which were real-life and which were fictive situations:

A number of residents told “their” stories, like a man who told about his wife, who had died. Finally, each of the groups was left behind in the recreation area, where they were able to participate in a game of bingo (Janssen, 2007, p. 88).

This unique form of performance created a defamiliarising situation, increasing the attention of all participants and providing the ideal starting point for the design team to empathise with the people they were designing for. The designers were challenged to think and act like elderly and were confronted with physical and/or mental limitations. Using this form of collective creativity, they gained “*a deeper insight into the way in which older people move and interact with space and objects*” (Demuynek, 2007, p. 74).

In the field of design, performance is a way to experience situations in the everyday lives of, for instance, elderly (Janssen, 2007) (Iacucci, Iacucci & Kuutti, 2002). Although design research is mostly based on empirical facts, imagination is unbearable. The people whom the designer designs for often cannot express themselves or put their needs into words. Therefore: “*design researchers have to think beyond the reality that is being studied*”, imagining what it is like to live the life of an elderly person (Janssen, 2007, p. 86). The designer can then make things that otherwise stay invisible, visible. With the help of performance, intuitions and emotions are touched upon in a way that cannot be achieved by traditional design means alone, such as prototyping.

“A Touch of Memory” (“AToM”)

The multidisciplinary project “AToM” – funded by the Flemish government (IBBT) – studies the development of new ICT applications for people suffering from dementia. The project aims at connecting the design of ICT applications to elements from the personal past to improve autonomy and independent living. “AToM” uses the Internet-of-Things as context and starts from a participatory design strategy, including people suffering from dementia, their partners and caregivers.

In a preparative workshop, four groups of participants – specialised in design, health(care) and technology – participated in a **performative role-play** in which they each were ascribed a **persona**. These personas were sketches of fictional persons, varying in age, sex, stage of dementia, etc. The participants had to find a technological solution for the problems the personas were dealing with in their daily lives.

Personas – the method used in this workshop – are:

fictional users, often based on real people, who represent the end-users during the design process. (...) If sufficiently detailed, they can help to create empathy with the end-users and provide in-depth insight into their needs and lives (Goodman, Langdon, & Clarkson, 2007).

Like performance, working with personas requires some form of **imagination** and creates **empathy**.

Although the personas are based on actual user data, the real-life end-users are usually not involved in the process. Unlike the previous example, there was no actual communication between the designers and end-users during the workshop. The brainstorm was merely used as a means of gaining a multidisciplinary insight into the experiences of the users.

“Textures for Care”

Thirdly, the project proposal “Textures for Care” deals with the creation of smart textiles used for self-management in chronic diseases. It focuses on the current strategic bottlenecks concerning the conceptual and technological design of smart textile solutions in general and for self-management in care (specifically, for diabetes).

During a preparative workshop, a cross-section of a house was used. Participants (patients, nurses, policy makers, etc.) were asked to talk about issues people with diabetes encounter in their everyday life. Simultaneously, participants placed icons of sensors – i.e. devices that measure physical factors (like temperature) and convert them into tangible signals (like sound) – on the map, illustrating how technology could offer possibilities for people with diabetes in specific situations or for specific problems (see Figures 3 and 4).

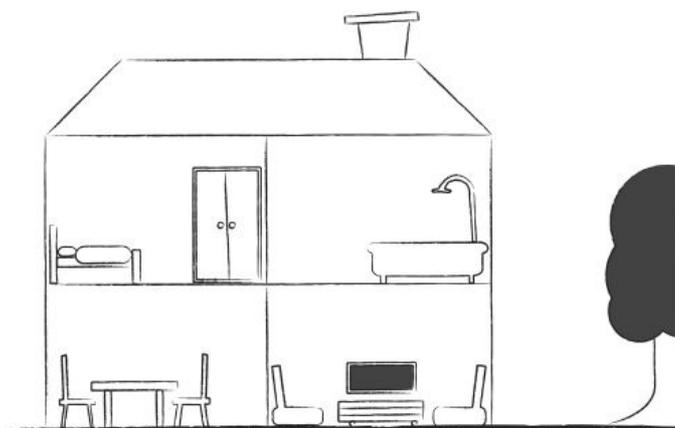


Figure 3: Cross-section of a house used in the 'Textures for Care' mapping workshop



Figure 4: Icons of sensors used in the 'Textures for Care' mapping workshop

The mapping methodology (www.map-it.be) was used to visualise a process in space and time. The resulting maps captured real-world situations of people with diabetes. This workshop gave the participants a glimpse of what it means to suffer from diabetes, each addressing the 'user' from their own expert background. It helped them to – collaboratively – understand, explore and communicate technologies that could possibly solve some of the patients' problems.

Comparable with the other projects, the focus on empathy during the mapping workshop was important. However, the main motivation for using the mapping method for this particular workshop was **the creation** of a common language between the participants, all coming from different disciplines, backgrounds, etc., to talk about their experiences and express their feelings and thoughts. Using playful icons enabled the participants – instead of communicating in their own jargon – to create a collaborative visual language. Like Sanders's generative toolkits, this language was not rigid. Its artistic character left room for the participants' own interpretations, wishes, ideas, etc.

Discussion

Social Spaces' health(care) projects always start from the creation of an experience, which is very intense for all stakeholders involved and stimulates a different type of communication between them. This combination of 'grasping the viewpoint or experience of the stakeholders' and 'opening up a collective debate' by using an 'unfamiliar kind of communication' is used to innovate in health(care) contexts and, as we have shown, can lead to interesting results.

To create a shared experience between the stakeholders, Social Spaces uses collective creative methods borrowing elements from the experience design field. As discussed in the exemplary research projects, all collective creative methods Social Spaces uses aim for the creation of empathy. For instance, the workshop for "Carefree living in the elderly care" involved performance to create empathy and gain a better insight in the everyday lives of the elderly.

The goal to empathise was combined with the intention to confront different stakeholders in the health(care) innovation projects in a participatory process. By 'designing' a different kind of communication

via collective design methods, designers and different stakeholders are enabled to speak a common language. This takes both the designer and the stakeholders out of their comfort zones. The mapping methodology in the “Textures for Care” workshop, for instance, used visual icons, translating the frameworks of the stakeholders into one common language.

To enable a different kind of communication - and thus stimulate innovative solutions - artistic methods that defamiliarise and stimulate the imagination, are used. **Imagining** the aspects in the projects that were difficult to envision or to talk about for all participants (including the designers) played an important role. This was particularly the case in the workshop for “AToM” in which the participants had to imagine what it is like to experience the problems the personas – portraying people with dementia – were dealing with in their daily lives.

Putting these conclusions into practice, Social Spaces keeps on designing, testing and using artistic approaches to collective design methods within the field of health(care). The research group always involves the three discussed aspects in their experiments with collective methods: empathy, a common language and imagination. We experienced that the use of artistic approaches in designing these methods is not evident. Health(care) contexts are delicate contexts that can benefit from imaginative ways to bring people together. However, methods often proved not to be entirely appropriate for a context and needed to be iteratively redesigned. Designing more artistically to inspire collective methods for social innovation in health(care) contexts, requires continuous redesigning and evaluation. Therefore, Social Spaces hopes that, by sharing their methods, other designers and researchers will also appropriate them for a variety of participatory contexts and that this will result in modified, surprising and possibly improved design methods.

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Eliciting Therapist's Views to Inform the Design of an Advanced Functional Electrical Stimulation Rehabilitation Tool.

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Abstract

Purpose. Rehabilitation technologies to support recovery of upper limb function after stroke, such as Functional Electrical Stimulation (FES), require the involvement of therapists in prescription, set-up and use, yet there are few reports on the involvement of this group in the development of new FES devices. This paper reports on the involvement of therapists in the development of a requirements specification for a new upper limb FES rehabilitation system.

Method. A series of advisory group meetings was used to gather data from 11 senior therapists. 5 meetings were held over 12 months. Information was elicited on current upper limb therapy practice, types of functional tasks and practice schedules, feedback on a mock-up graphical user interface (GUI) and options for bio-feedback. Thematic analysis was applied to the transcribed data.

Results. The data fell into three categories: 1) factors that contributed to the design requirements; 2) design requirements; 3) external factors affecting adoption. A ranked set of design requirements was elicited and verified.

Conclusions. The study identified a number of complex challenges associated with moving such technologies into clinical practice, including the limited time available to set-up such devices. Therapists also recognized the potential improvements to their practice that could be gained with the use of appropriate technologies.

Keywords: Stroke, rehabilitation, upper limb, rehabilitation technology, therapy, design requirements, software development.

Background

Upper limb impairments are very common following stroke. Reports show that 85% of stroke patients will have an impaired upper limb on admission, and of these only around 50% will ultimately recover useful functional movement (Wade et al, 1983; Sunderland et al, 1989). Reduced function and an inability to carry out activities of daily living leaves over 50% of patient's dependent on others (Wolfe, 2000) with a reduced long-term quality of life (Patel et al, 2006).

In recent years rapid progress has been made in our understanding of the mechanisms that promote recovery of upper limb function after stroke (Foley et al, 2008). Important characteristics include high intensity, voluntary-initiated practice, that is varied and task-oriented, together with patient feedback (Krakauer, 2005). One intervention that is showing significant promise as an adjunct to physical therapy for the recovery of upper limb function is Functional Electrical Stimulation (FES). Traditionally, electrical stimulation for the upper limb used systems which delivered repetitive stimulation using pre-set timings (cyclical stimulation), but this approach resulted in a reduction in impairment, and limited impact on function. A number of studies have demonstrated significant clinical benefit with systems in which the onset and termination of stimulation is patient-controlled, either from sensors located on the hemiplegic upper-limb (Hayward et al, 2010; Mann et al, 2011; Chan et al, 2009) or by the contralateral limb (using buttons for example), or where a therapist triggers stimulation to assist with the movement at appropriate points (Popovic et al, 2009; Thrasher et al, 2008; Hedman et al, 2007). Even when severely affected acute stroke patients, with minimal movement in their affected arm, undertake intensive functional task practice, using therapist-triggered FES, significantly improved clinical outcomes can be achieved (Thrasher et al, 2008).

This evidence suggests that functional improvements from FES may result from its use in supporting voluntary-triggered, task-focused practice, which has led to an increased emphasis on how stimulation is controlled. Devices that are triggered by therapists are not a practical solution if patients are to perform highly intensive practice. By contrast, devices that are triggered directly from body-worn sensors have the potential advantage of not requiring constant therapist support for their use. Accelerometer-triggered FES uses the change in an arm or finger-located accelerometer signal that results from voluntary movement to initiate or terminate stimulation. Although studies that have used accelerometer triggered stimulation show significant promise (Mann et al, 2011), the devices used to deliver the stimulation can be difficult and time consuming to set-up. Complex upper limb tasks usually require multiple stimulation channels which compounds the problem of long set-up times. In addition, such devices have often required specialist and hence costly training for therapists (Tresadem et al, 2007). These issues, among others may limit the future

uptake of FES devices into healthcare settings and provides the rationale for the development of a new advanced FES Rehabilitation Tool (FES Rehab Tool).

The FES Rehab Tool is being developed by a multi-partner consortium to address the limitations with current FES devices described previously. One of the main aims of the project is to enable therapists with no software skills to quickly and easily set-up an individually tailored library of upper limb FES-supported tasks for each patient, together with the corresponding bespoke FES controllers.

The goal of the authors' part of the study was to design a graphical user interface (GUI) that would guide the user through the set-up process, yet shield him/her from the complexity of controller design. Although the long term goal is to also produce a device that patients could take home, the focus of the work reported here was on a device that is to be set-up and used in a clinical environment. Therefore, it was important that therapists' views were sought early in the design process (Wilson et al, 1997). Although there has been a growing realisation of the need to involve service users in the design of assistive devices, there have been relatively few studies that have documented the process of involving therapists in design.

Methods

Identification of Therapists

It was important to elicit views from individuals who represented the range of therapists that could ultimately be using the device. Eleven senior therapists were recruited (2 males & 9 females) including: 6 physiotherapists & 5 occupational therapists working with neurological patients on a daily basis. The group composition was one expert user of FES, four novice users, and six therapists with no prior experience of FES. The therapists were treated as equals in the design process, allowing the design team to work alongside therapists in a collaborative manner (Daly et al, 1997). The group facilitator and researchers were healthcare practitioners who had an in-depth knowledge of the environment that the therapists operated within and could act as a conduit between the design team and the therapists.

Description of the advisory group meetings

Initially, a literature review was conducted, to inform the planning of the meetings and to help formulate objectives. A total of 5 therapist advisory group meetings were held, over a 12 month period, in order to gather data to inform the design. Each meeting was video recorded and two researchers also took field notes. A combination of semi-structured group discussions, case studies and presentations were used to focus the discussions. An overview of the meeting aims is provided below in *table 1*.

Table 1: Aims of advisory group meetings.

Meeting Aim

- 1 Overview of project goals, exploration of current practice in upper limb rehabilitation, types of patients who may benefit from the device, and perceived barriers.
- 2 Identification of suitable functional tasks, ways in which FES might be used, compilation of practice schedules.
- 3 Gaining feedback from therapists on the GUI.
- 4 Exploration of the type of bio-feedback most useful for therapists and patients, identification of the most suitable format.
- 5 Verification and ranking of design requirements

Data Analysis

Thematic analysis (Boyatzis, 1998) was used to analyse the data in order to identify the key themes that emerged during the meetings. The stages of data analysis were as follows:

Stage 1: Transcribing the raw data from meetings 1 to 4 (carried out by each of the 3 researchers independently). **Stage 2:** Summarising and extraction of initial themes (each researcher independently). **Stage 3:** Reviewing of initial themes and coding to form 'higher order' themes (collectively). **Stage 4:** Connecting, ordering & re-coding the themes to establish relationships between themes in relation to the design of the FES Rehab Tool (completed with the design team). **Stage 5:** Corroborating and legitimating coded themes (with therapists and by referring back to the literature). After each meeting the data were transcribed, coded and categorised under the existing themes or new themes were included if there was sufficient data to support its inclusion. The process was iterative in nature with the raw data being periodically reviewed against the themes to ensure their validity. During this process, a list of design requirements was compiled. The requirements list was extracted from the themes and therapist's direct quotes. The meeting at which the design requirements emerged was also noted (**table 2**).

Results of Thematic Analysis

Three broad categories of themes were identified (higher order themes): 1) Factors that contributed to the design requirements 2) design requirements 3) external factors affecting adoption. Beneath these higher order themes a number of sub-categories emerged (**Table 2**).

Table 2: Higher order themes and sub-categories

- | |
|---|
| <p>1. FACTORS THAT CONTRIBUTED TO THE DESIGN REQUIREMENTS</p> <ol style="list-style-type: none">1.1. Patient presentation, including patients who would benefit from FES.1.2. Current treatment approaches & beliefs1.3. Patient motivational factors1.4. Organisational influences |
|---|

- 1.5. Adoption issues as design inputs
- 2. DESIGN REQUIREMENTS**
 - 2.1. Set-up and user interface
 - 2.2. Patient biofeedback
 - 2.3. Patient adaptation including within sessions adjustments
 - 2.4. Performance feedback for therapist
- 3. EXTERNAL FACTORS AFFECTING ADOPTION**
 - 3.1. Adoption issues independent of design

Table 3: FES Rehab Tool – Ranked therapist design requirements with importance scores

FES REHAB TOOL - Therapist design requirements with importance scores (when used in an in-patient setting) 0 = not important; 1= mild importance; 2= moderately important; 3= very important; 4= extremely important							
	Meeting	0	1	2	3	4	Total
Takes less than 30 min to set-up	1, 3					6	24
Allows adjustment of device parameters in accordance with patients progress	1, 2					6	24
Device is comfortable to wear	3					6	24
Electrodes are easy to apply & position	1, 2					6	24
Sensors are easy to apply & position	3					6	24
Triggers stimulation on & off reliably	3					6	24
Stimulation is comfortable for patient	3					6	24
Patients are able to practice on their own where appropriate	1, 2					6	24
Device functions and interface are easy to understand	1, 3					6	24
Easy selection of muscles to be stimulated	1, 2				1	5	23
Device is easy to put on	3				1	5	23
Effective co-ordination of muscle stimulation (where multiple muscles involved)	3				1	5	23
Easy to adjust settings once administering treatment	3				1	5	23
Adjustable stimulation settings (e.g. frequency)	2, 3				2	4	22
Choice of functional upper limb tasks	1, 2				2	4	22
Sensors are easy to select and adjust	3				2	4	22
Stimulation intensity easily adjusted	3				2	4	22
Adjustable ramp settings	3			1	1	4	21
Wires unobtrusive - wireless preferred	3			1	1	4	21
Guides the user during the set-up process & highlights any incorrect parameter settings	1, 2, 3			1	1	4	21
Device is easy to take off	3				3	3	21

Able to be used to treat a variety of patient presentations	1, 2				4	2	20
Aesthetically acceptable to patients	3			1	2	3	20
Intuitive set-up process that follows a natural & logical order with minimum redundancy	1, 3			1	4	1	18
Bio-feedback serves to motivate the patient	1, 3, 4			1	4	1	18
Provides performance data that can inform treatment parameters & outcome measures	1,3			1	4	1	18
Good battery life	3			1	4	1	18
Choice of bio-feedback methods tailored to suit each patient	1, 2,4			3	1	2	17
Choice of sensors e.g. movement sensor, EMG, goniometer	2, 3, 4			1	5		17
Compact & portable	1, 3			1	5		17
Automated processes wherever possible (1 none response)	1, 3			1	2	2	16

Discussion

Only the factors that contributed to the design requirements and actual design requirements will be discussed.

Factors that contributed to the design requirements

Patient presentation, including patients who would benefit from FES

Therapists reported that they continued to see a wide range of patient presentations in clinical practice. They concurred that patients who recovered quickly and were left with only a mild to moderate level of functional limitation were discharged into the community at an increasingly rapid pace. Hence the patients that remained as in-patients were those with more severe and complex presentations. When asked, *“What type of patients do you feel this system might lend itself to?”* One therapist stated, *“Would have thought initially of patients at quite a high level, with more minimal impairment..... But having listened to this, if you did get a little bit of shoulder movement you could incorporate it into the arm treatment at that stage.....”* (PT 1). This was a good example of how the focus group discussions had encouraged the therapists to consider approaches they might otherwise not have considered (Creasy, 2008).

The ability to stimulate either single or multiple muscles with the aim of achieving single or multi-joint movement to assist task achievement for a broad range of patient presentations will be required. However, there are obvious challenges with using voluntary triggered stimulation as the lack of voluntary involvement in the task, which would be characteristic of the more severely affected group of patients may limit clinical benefit.

Current treatment approaches and beliefs.

In the second advisory group meeting, when discussing the case studies, the therapists were clearly comfortable with the notion that FES could work alongside a traditional 'hands-on approach' and that the two facets of treatment could be used simultaneously during treatment sessions: *"The therapist could work proximally around the shoulder with FES being used to elicit hand opening" (PT 2)*. They expressed a wish for the new FES device to offer therapists a choice of functional tasks. Interestingly therapists felt that patients viewed rehabilitation of the upper limb in the acute setting as less of a priority in comparison with regaining mobility: *"As therapists we want to treat the upper limb as much as the lower limb but we are led by the patient and it is often not their priority in the early stages" (PT 3)*. However, once patients were discharged into the community it was felt that this perception changed. *"After a couple of weeks reality sets in and they think, what's going on with my arm?" (OT 1)*.

Patient motivational factors

The motivation of patients and maintenance of motivation at a sustained level was a recurring theme across all of the advisory group meetings. A number of therapists commented that: *"The more severe patients tend to lose motivation as they're unable to use their arm and hand functionally" (OT 1)*. The importance of using goal setting as a means of helping to motivate patients was highlighted. One therapist commented that: *"It's all about matching patients expectations. If there's a mismatch they'll lose motivation" (PT 4)*. All the therapists agreed that patient motivation was essential if positive rehabilitation outcomes were to be achieved. *"We all work on success don't we?" (PT 4)*. Patient motivation is a complex phenomenon and the negotiation of goals between therapists and patients is used as an empowerment tool (Maclean et al, 2000; Levack et al, 2006). Therapists agreed that there was potential for using the FES Rehab Tool to provide visual or auditory feedback to assist with sustaining patients' motivation.

Organisational influences

The organisational influences on rehabilitation, particularly for the upper limb, were frequently remarked on during the meetings. The comments highlighted the impact this was having on therapists' approaches to rehabilitation: *"There is mounting pressure to get patients through the system and out of hospital beds" (OT 2)*. The length of time that patients are exposed to rehabilitation interventions is becoming shorter with the therapists reporting that it is not uncommon for patients to move from the acute to community setting within 2 to 3 weeks of stroke. The discussion emphasised the major challenges facing the designers of the FES Rehab Tool and other rehabilitation devices aimed at a similar population.

Adoption Issues as Design Inputs

The organisational influences above demonstrate the need for any new device to be portable in order to allow transfer across a number of health economies, which in themselves are often viewed as barriers to adoption. Devices that are low cost, easy to use and therefore do not require expensive and time consuming training for therapists, will help to overcome some of the adoption barriers. Many current assistive technologies that move with patients across health settings, such as walking sticks, or walking frames, are relatively low cost devices and require little training of therapists. The FES Rehab Tool will be a more complex piece of equipment and, although the need for training will be reduced as far as possible, it is inconceivable that therapist training will not be required.

Design Requirements

Set-up and user interface

With the pressures of a heavy caseload and the rapid turnover of patients highlighted by the therapists, set-up time and ease of set-up were high priorities for therapists. Therapists' views on set-up time were as follows: *"Depended on whether this was a one off investment that would be more automated on subsequent occasions....Also, if it meant I could leave a patient to practice independently allowing treatment of more patients that would make a difference"* (PT 2). However, in spite of these potential benefits, therapists were still keen to stress that *"30 minutes is the absolute maximum set-up time and ideally the less the better"* (PT 1). One therapist summed up the groups views that there needed to be *"A balance of level of complexity versus ease of set-up"* (OT 3). This view was reinforced when therapists ranked set-up time as one of the most important design requirement (**table 2**).

Patient biofeedback

The therapists advocated the following requirements for extrinsic feedback to the patient: *"Needs to provide both visual and auditory feedback for patients to cover the range of patient deficits that might be encountered"* (OT 3). Clearly the method in which feedback is provided is important, be it a *"motivating voice"* or *"a green light"*; *"Sometimes actually having an audible sound might just help"* (PT 2) (for patients with hemianopia). Bio-feedback for patients was discussed at length in meeting four when therapists were provided with a range of possible options for the types of sensor data that could be used as extrinsic feedback. When faced with these options one therapists advocated a *"pick and mix approach"* (PT 4) as a pragmatic way forward. The importance of bio-feedback cannot be overstated, not only for the effective re-learning of sensory-motor skills, but also to ensure patients remain motivated. However, there remains a paucity of evidence regarding what type of feedback is best suited to particular situations (Van Vliet & Wulf, 2006).

Conclusions

The therapist advisory group meetings have provided some guidance on therapists' needs for the next generation of upper limb FES devices, such as the proposed advanced FES Rehab Tool. Set-up time (maximum of 30 minutes) featured strongly in their discussions as a result of the limited time therapists have available to them for treatment purposes. Associated with this is the need for both the software and hardware aspects of the device to be easy to learn and use, thereby minimising the time needed for training. This inferred the need for the device to be readily programmable with respect to, for example, the functional tasks prescribed, co-ordination of movement phases, and FES parameters. However this should not require the therapists to have specialist software skills. The advisory group repeatedly expressed a desire for a system that allowed sensor based measurements to be used for both patients (bio-feedback) and therapists (performance monitoring). Further research will be required to establish whether more sophisticated FES devices, such as the proposed advanced FES Rehab Tool, can be made sufficiently usable to become practical tools for the re-training of upper limb function in everyday practice.

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Designing health: The role of phenomenology in integrating physical, mental and social well-being within healthcare design

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Abstract

If health is defined as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” (World Health Organization, 1948), the scope of healthcare design changes dramatically. The Designing Health paper as a result of this statement, aims to illustrate ways in which mental and social health can be incorporated into contemporary medical practice, it describe anecdotally how phenomenology is used as design methodology. An excerpt from the Designing Health thesis, it is a glance into the authors contextual inquiry, design research approach and methodologies. It presents the merits of phenomenology when applied to the subjective topic of illness.

Design interventions throughout this paper focus on the grey areas of how a sick person feels when ill, and how a designer could create an environment where they feel the best that they can. The paper shows some of the outcomes from the interviews, prototypes and experiences conducted, and how this design research was interpreted into tangible products. The goal of this broad research technique was to find the nuances in various health fields in order to extract and create ways in which they could be applied in medicine today.

Although there are many design opportunities in healthcare, this paper focuses on ways mental and social health can be improved during interaction with the mainstream medical system. Designing Health, is based on scientific evidence which has shown the benefits of distraction (Johnson, 2005), humour (Martin R. , 2007), sleep (Mystakidou, 2007)and social networks (Rutledge T. R., 2004)during times of illness or traumatic events, not only during short term recovery, but, in the long term health of the individual. Stress and anxiety are detrimental to healing, and recovery times, Supportive design (Ulrich, 1990)is explored as one of the ways to facilitate better mental and social health during an illness.

Keywords: Mental health, social health, experience interventions, product design, humor, distraction, social interaction, design research, Patient Centered-Care

Introduction

Designing Health is a paper built upon the definition of health adopted by the World Health Organization (WHO) in 1948 which has not been amended since. The definition (World Health Organization, 1948) views health holistically as an interrelating system with social, emotional and physical components. Today, such all-inclusive views of health and medical treatment are commonly associated with Complementary and alternative (CAM) medical practices such as Ayurveda or Traditional Chinese Medicine (TCM). Mainstream medical practice, seen as allopathic in approach often concentrates on the physical symptoms or complaints. Today we have a booming \$825 billion pharmaceutical industry today (IMS Health , 2009) which supports this approach to curing illness.

There is a shift however, on the mainstream medical front to transition towards a Patient-centered care (PCC) commonly found in the CAM sphere of medicinal treatment. Patient empowerment is a primary component of these fields [CAM and PCC], as is the commitment to address the mind, body, and spiritual aspects of health. (Maizes, Rakel, & Niemiec, 2009)

Evidence wise PCC has been found to lead to enhanced patient satisfaction, better outcomes, improved health status, and reduced utilization of care (Mauksch et al., 2008; Stewart et al., 2000; Williams et al., 1998). What also separates PCC from a more allopathic approach of taking a pill, sealing a wound and providing tools allowing for adaptation until convalescence completes, is that it takes into account underlying causes, inclusive but not limited to mental, social and spiritual factors. Although it is early to tell the success of PPC as a system; on the patient-side studies have found (Mauksch et al., 2008; Stewart et al., 2000; Williams et al., 1998) that such discussions and interventions that include social or mental health significantly change outcomes. Essentially my argument within this paper is, that because each of us is a balance between mental, social and physical health, maybe we should as designers reconsider our criteria for Designing Health.

Contextually 58.8 million lives around the world are lost yearly due to lifestyle diseases. The most common reasons for mortality in one of the most recent (WHO, 2009) statistics were high blood pressure (13% of all deaths), tobacco use (9%), high glucose (6%), physical inactivity (6%) and being overweight or obese (5%). *Figure 1.* These factors are seen to increase the likelihood of heart disease, diabetes and cancers. They affect all countries across all income groups and are predicted to increase significantly in the next 5 to 10 years. What this alarming statistic shows is that our current approach to health is not working for millions of people globally. Despite constant the advances of medical science to find the cures and vaccines, an approach like PCC could be a viable partner in tackling, social and mental health within a mainstream medicine framework.

PCC and design for it would support a holistic healthcare approach incorporating preventive medicine and chronic illness.

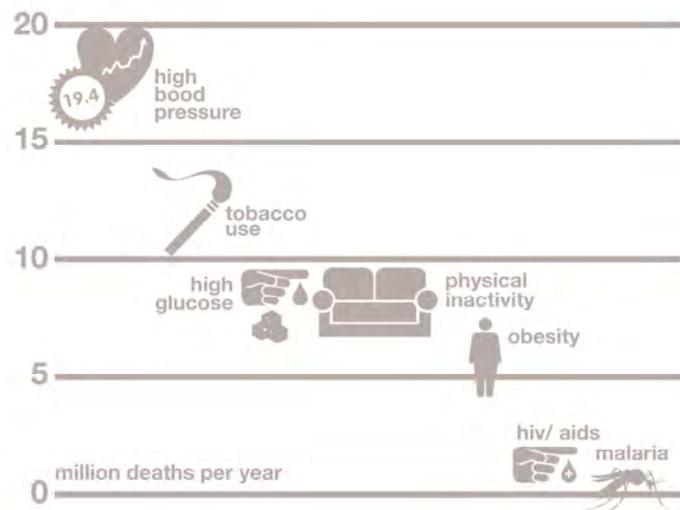


Figure 10. Info graphic representing leading causes of death globally calculated from World Health Organization (2009), (CNN, 2009)*child only statistic available, (UNAIDS, 2010) and (WHO, 2010)

Methodology

This paper touches upon how phenomenology and co-design principles were integrated into the methodology of designing for holistic health. Similarly to emotional health and perceptions of pain phenomenology has the advantage of focussing on the 1st person perspective. It is subjective, intimate and internalised, and for that reason for me as a designer, very interesting. Experience is a central theme of this paper, so apart from extensive literature review (theory-based research), excursions, interviews, workshops and treatments (practice-based research) are incorporated within the design methodology.

Among the conclusions of this paper, is the finding that small interventions can make a big difference in a person's sickness experience. Designing Health, is based on scientific evidence which has shown the benefits of distraction (Johnson, 2005) humour (Martin R., 2007), sleep (Mystakidou, 2007) and social networks (Rutledge T. R., 2004) during illness or a traumatic event, not only the short term recovery, but, in the long term health of the individual. Stress and anxiety are detrimental to healing, and recovery times, Supportive design (Ulrich, 1990) is explored as one of the ways to facilitate better mental and social health during an illness. Within the context of this paper, humor, social interaction and positive distraction are seen as tools that the designer can utilise to influence the experience of illness, in the process making it healthier.

The context of health today and speculative design implications

According to the World Health Organizations' report titled *Global health risks: mortality and burden of disease attributable to selected major risks*, non-communicable diseases (NCD) are becoming an ever increasing threat to life globally (WHO, 2009). Not only are NCD's increasing, but these diseases also have the highest DALY(Disability-adjusted Life Year) or level of burden. Although it can be argued that non communicable diseases in the developed world are much more documented and monitored than those in developing ones. This is an alarming world trend that lifestyles are the leading risk factor globally for premature death, and a major contributor to burden of care.

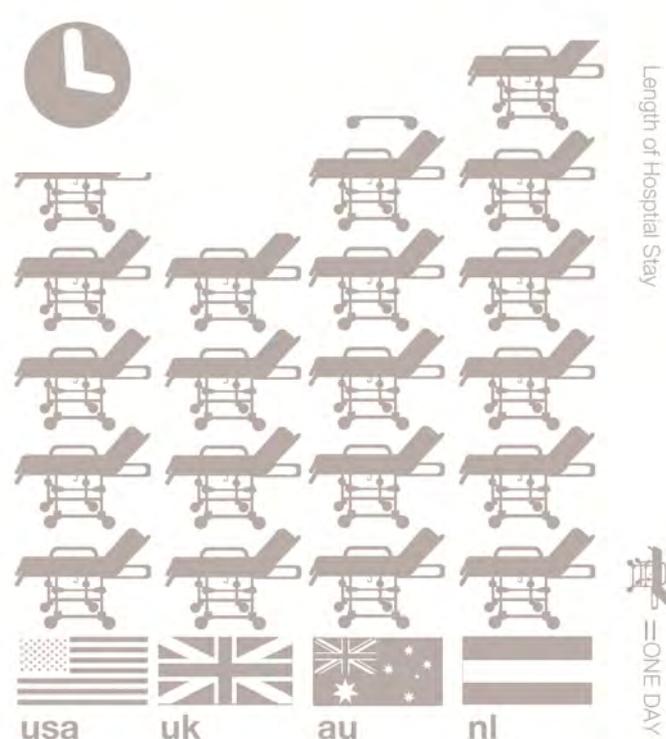


Figure 2. Average hospitalization times for the USA, UK, Australia and Netherlands. In the USA the average Hospital stay in 2008 was 4.6 days (US Department of Health and Human Services, 2011). In the UK for 2009 the Median stay in hospital was 1 day, although once fully admitted Children 0- 14 stayed 2.2 days, those aged 15-59 had on average 4 days and people over 60 stayed 7 days. (HES Online, 2009). In Australia Same-day separations were 57% of the total, having increased by an average of 4.8% each year between 2004–05 and 2008–09. The average length of stay for overnight admissions was 5.2 days (Australian Institute for Health and Welfare (AIWH), 2010). In the Netherlands the average length of stay was 5.8 for women and 6.0 days for men (Centraal Bureau voor de Statistiek (CBS), 2010). The overall trend is that time in hospital is decreasing.

Coupled with this increase in unhealthy lifestyles, another trend emerging across the Western world is declining hospitalization times. *Figure 2* Shows average hospital stays in the US, UK, Australia and the Netherlands. Individuals today are less likely to be admitted into hospital care initially, and, in the last decade advances of minimally invasive surgical techniques such as laparoscopy, keyhole surgery and others like the PATH® Tissue-Preserving Technique (Neel M. , 2009) there have been great reductions in recovery time and post-surgical pain management. These advances strengthened by those of the cosmetic surgery industry have created an increase in outpatient procedures (National Centre for Health Statistics (NCHS), 2009) and even 'lunchtime' surgeries. What these developments have enabled is a patient/consumer driven demand for market healthcare models, anesthetics and systems for patient self-management of post-operative pain.

It is my belief, and as a designer I can only say this as an observer, that the future of medicine quite easily fits in the home. With technology as an enabler, the onus may very well shift from external or outsourced care, to a patient centered and patient initiated system. This is something that may be fast tracked in order to help the mainstream medical system tackle the issue of the increasing aging population. Patients will need to adapt as recovery time shifts out of the hospital and increasingly into the private home. They will have to either rely on self-funded, private health care, or their own social networks to facilitate recovery.

For this reason the concepts investigated in the Designing Health thesis, and this resulting paper focus on the hospital and the home, and hope to integrate mental and social health. Based on the premise that in order to change lifestyle, behavior must be altered. Designers should consider using education, advocacy, cognitive and non-cognitive attributes and support from social networks fit into their healthcare design process.

Designing health : the concepts

The final tangible outcomes of Designing Health, will only be briefly mentioned in this paper to build a framework for the underlying methodology. There were two selected final outcomes, and in the development of the project many experimentations and seed ideas.

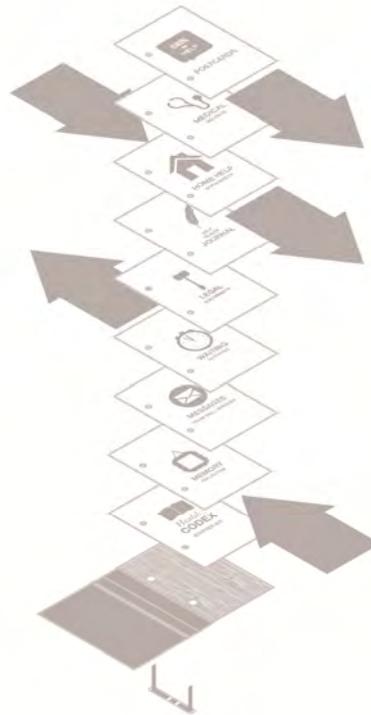


Figure 3. *Still from animation.* Schematic of Health Codex. Showing the flow of each section.

One concept from Designing Health is the Health Codex (Figure 3 & 4). It allows you to capture your own health history. Which to make the distinction very clear; is very different from your medical history. As something that follows you through your illness experience, it is compiled by its owner the and in essence it contains what they feel is important to them. They can monitor all the aspects of their health, use humour to ask for help, organise their social health care network, and keep their medical records and legal documents. The Codex can even contain distractions and games to do while in a waiting room. Or cards and well wishes from friends to cheer you up when you are on your own.



Figure 4 Photograph of open Health Codex

The second concept titled Landscape linen (Figure 5 & 6). Landscape linen aims to create conversation and distraction during illness because having visitors whether at home, or at hospital is beneficial to your recovery (Rutledge T. R., 2004). The landscape linen consists of a flat sheet and pillow use piezoelectric sensors to monitor your health, and a blanket provides positive distraction and social interaction. The blanket can be used individually, collaboratively or competitively. Starting as a soft textured print on bamboo fleece, washable markers allow it to be filled in and built upon during each visit. Primarily this blanket is for interaction activities between friends, keeping the patient in bed, and the provision of an escape from the world of sickness.



Figure .5 Schematic illustration of Landscape Linen



Figure 6. Photograph of Product in use. Tester is Elizabeth, a 60 year old woman with Rheumatoid Arthritis in her hands, she is filling the blanket out with her daughter.

Examples of phenomenology as design methodology

Phenomenology is a philosophical term which focuses on a person's perception. This includes studying the structure of various types of experience ranging from perception, thought, memory, imagination, emotion, desire, and volition to bodily awareness, embodied action, and social activity, including linguistic activity. It is based on personal experience.

Phenomenology provided me with the richest insight into the world of illness, and for this reason it is the way I chose to approach my research. It was my belief that I couldn't be expecting to create new sickness experiences without having any base experiences to build upon. For this reason, I searched for new experiences to test and, for contact with people who had stories to share with me. I would like to put an emphasis the word stories, and storytelling within this paper. Design research within the setting of this paper was not in any way quantitative, vaguely qualitative, and highly interpretable.

Phenomenology in design research enabled a looser definition of design research, one which facilitated the main goal of design research for inspiration. Contextual inquiry provoked designs and theories which were later validated through literature review and structured interviews. Over the course of a year, as part of this project, I managed to compile a collection of experiences, both my own and those of others. I began this collection by doing an experience review my own sickness experiences. This included things I did (or my parents did) during my childhood illnesses and accidents, my hospitalizations, and all my most recent illnesses. The prompt for looking into this Designing Health topic for my thesis was the not-so-trivial Chickenpox I contracted at 26. I did an analysis of what worked for me and what didn't. Armed with this I could compare what I had experienced to the experiences of others, to an extent I created a baseline.

I chose to approach asking others in a more novel way. Talking about health was generally awkward enough, so I tried to see if I could change the experience of talking about it a little. I created an interview kit, Refer to Figure. 7. to take with me for one-on-one chats. Armed with this kit and my questions I talked to pharmacists, doctors, scientists, acupuncturists, Ayurveda practitioners, medical designers, people with chronic illnesses, as well as, anyone I knew that was sick at the time. I am pleased to report that this approach enabled me to collect 18 out of 18 fully filled questionnaires and a notebook full of personal stories, which not only inspired me but motivated me throughout the design process. What they shared with me was often very insightful and personal. And although they had deferring opinions on how to cure a cold, I found all of them agreed that the experience of being ill can have more than a physical impact and that social support can be a precursor for a speedy recovery.



8

Figure 7 Interview Kit

Social support came up a lot in conversation, from people with a toothache to those with chronic illness, everyone I talked to mentioned that it was their family and friends that they would rely on to help them in the event of illness. These findings, although common sense supported my literature review findings, and gave me real world examples to design for. Currently there is an increasing amount of research being done on the relationship between social health and physical health outcomes. Among other things, having social relationships has been found to reduce morbidity (Brummett, 2001& Rosengren A, 1998& Williams, 1992), improve cancer survival rates (Eli, 1992& Welin, 1992), Increase immunity (Lee, 2001), and lower blood pressure (House, 2001).

Throughout this process I also endeavored to experience new things, and aggregate them according to my prior evaluation of what worked and what didn't. I tried acupuncture and Ayurveda treatments. I visited a blind restaurant, sat in several waiting rooms and looked at fascinating medical exhibitions all around Europe.

I watched many documentaries and films, and read many books, including self- help ones on how to deal with cancer or other negative diagnoses. Basically, I immersed myself in the topic.

Designing health tools

Humor, positive distraction and social interaction are the design tools used in both of the concepts mentioned previously. Humor, despite its perceived triviality in the medical framework, has been found to relax tense muscles (Fry, 1989), boost the immune system (Berk L., 2001& Berk, 1989) and increase pain tolerance (Cogan, 1987).

The list does not end there, humor has also been associated with decreasing anxiety (Lefcourt, 1995), Stabilising mood fluctuations (Martin R. A., 1983), Enabling the brain to rest (George, 1995) enhancing communication (Blazer, 1993), creativity (Miller, 1983), memory (Lyubomirsky, 2005) and morale (Provine, 2000). 50% of cancer patients use humor to adjust to a cancer prognosis (Bennett M, 1999). Therapeutically humour is a natural response to stressful life situation. These findings for humor are also reflected in those for positive distraction, which has been linked to reduced pain perception (Johnson, 2005), and social interaction which to an extent naturally facilitates both humor and distraction.

Humor, positive distraction and social interaction are by definition fully experiential and subjective. My argument in this paper is that health and illness is also based on these principles. Philosophers and academics such as Merleau-Ponty (1962) and more recently Carel(2008) have argued for using phenomenology to observe and better understand the experience of illness.

One example of testing theories

All this time I was building and testing models, among the many prototypes, I made fifteen paper prototypes for the landscape linen blankets that I tested both in the Netherlands and Australia (Figure.8) The experience of the test was positive overall. Most of the testers, particularly those in hospital where open to doing something new to pass the time. The prototypes themselves, where also a prompt for participants to talk about their frustrations and share personal stories (an additional research opportunity). Individuals at home, despite their illnesses, had difficulty staying in bed, continuing to try to multitask while ill. The product test was particularly successful during visiting hours in hospitals. The simple paper prototype seemed to enable an easier flow of communication. One tester which was pregnant, really enjoyed having the product when her younger child visited, giving them something to do while the whole family waited. The atmosphere around the patients with the prototypes seemed a little lighter; this was noted by the staff. One particular tester, Lucy a 79 year old woman dying of breast cancer and in the Palliative care Unit at St. Johns of God

Hospital in Geraldton, spent three hours with her daughter and son in law completing a prototype. They said they enjoyed doing something together.

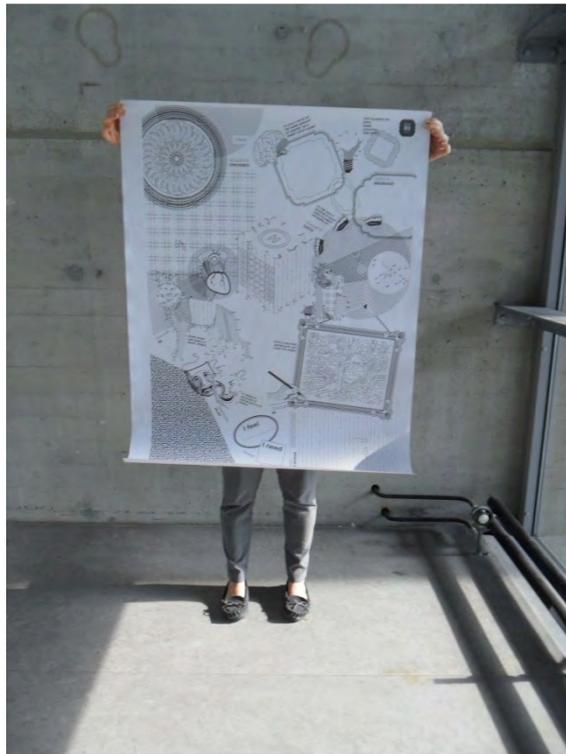


Figure 8. One of the paper prototypes.

This quick testing helped verify the concept, and reveal certain flaws. The sizing was an issue for particularly small individuals, and those with limited vision or movement. Women and children were the most receptive, men found it difficult open up to the idea, this may have been a cultural or gender specific barrier for the concept. Man said they would prefer a book format while digitizing the product was also suggested. In any case, it moved the ideas forward, and helped in making design decisions this in turn, pulled to concept in the direction of the Health Codex discussed before.

Conclusion

Health is something very private and personal, and, although physical health can be tested, measured and scientifically proven, mental and social health falls within the grey area of lived experience and subjectivity. Although we can empathise with people who are ill, even if we have the same illness, our experience of it could be entirely different. Mental and social health perception is built up over time with our life circumstances and past experiences, which is what makes it individual, unique and very complex.

The use of the World Health Organization definition of Health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (World Health Organization, 1948), makes designing for health considerably more intricate. New factors, or perhaps old forgotten factors such as the Humors personality traits have to be account for, and all of these can vary in significance from one person to another.

In order to change a sickness experience, and include mental and social health into contemporary medical practice more of a Patient centered-care approach (PCC), Designing Health, as a research project had to hand control back over to the end user. This began during its initial research, by selecting phenomenology as a design research methodology, and continued throughout extended immersion and testing. The PCC model is integrated in both of the final proposals, Landscape Linen and Health Codex and hopes to empowering individuals to change the way they choose to approach both illness and health. The role of the designer in this project is that of a researcher and mediator, able to provide a selection of tools whether physical or immaterial for use in the event of illness. The role of the end user, is to, if they so wish, use any of the tools that they feel suit their needs so that they can improve their overall health and wellbeing.

Transparent communication and discussion of taboos needed to be addressed in order to Design Health effectively, and for this reason the project was done with the assistance of people from all the different sides of health. This project was inspired by chronic illness sufferers in Amsterdam, built upon through conversations with designers, scientists, engineers, artisans, physicians, psychologists, and alternative medicine practitioners. It was tested in homes and hospitals in the Netherlands and Australia, and it could not have be done otherwise.

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Science, technology & design: harnessing copper's antimicrobial power – a review.

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Abstract

There is now no doubt that copper and copper alloys possess the strongest antimicrobial efficacy of all common materials under normal indoor conditions. This is leading to the adoption of copper alloys for touch surfaces such as door furniture, handrails and trolleys to reduce contamination on frequently touched surfaces and help reduce infection in healthcare environments. Copper's efficacy has been demonstrated both in the laboratory and, more pertinently, at a set of eight geographically diverse clinical trials. The latest results and new experiences from these trials will be reported here.

There is general acceptance that high environmental bioburden will tend to increase infections, but the case has, perhaps surprisingly, to be proven. In 2010, the Department of Health turned the spotlight on the influence of the environment on the incidence of infection. A selected review of the existing evidence will be presented.

In the UK to date, there have been a small number of early adopters of Antimicrobial Copper, and a case study will be presented of one such specialist unit, the brief being 'to set the gold standard for infection control'. This will work through conception, choice, installation and use to maintenance.

In order to support the understanding and deployment of copper alloys, a technology rich website has been developed to act as a global resource. This will be introduced and key areas for designers and architects will be highlighted.

Keywords antimicrobial copper, healthcare design, architecture

Introduction

This paper reviews the existing science behind the intrinsic antimicrobial efficacy of copper and copper alloys, suggests how it may be deployed and identifies barriers to adoption.

The Healthcare Associated Infection (HCAI) problem

The UK Health Protection Agency (HPA) (2012) states that healthcare associated infections (HCAI) are:

Infections resulting from medical care or treatment in hospital (in- or out-patient), nursing homes, or even the patient's own home. Previously known as 'hospital acquired infection' or 'nosocomial infection' the current term reflects the fact that a great deal of healthcare is now performed outside the hospital setting.

In their most recent publication on the subject the World Health Organisation (WHO, 2011) explicitly recognise that accurately quantifying the scale of HCAs is extremely difficult due to different collection techniques and associated expertise. They settle for the statement that “*hundreds of millions of patients suffer from HCAI every year worldwide*”, whilst acknowledging that this is likely to be an underestimate. This is not just a statistical exercise however: WHO state that in Europe alone HCAs lead directly to 16 million additional hospital days and 37,000 deaths. They further estimate that *direct* financial losses alone amount to in excess of € 7 billion.

WHO's *Clean Care is Safer Care* campaign to reduce HCAI rates, launched in 2005, has focused on hand hygiene but well before this date there was awareness that the hospital environment had a role in infection transmission. This awareness has increased as more work has been undertaken to verify and attempt to explain how the care environment plays an important role in cross contamination and risk of acquisition. Dancer (2007) provides an excellent review of the specific problem of methicillin-resistant *Staphylococcus aureus* (MRSA) in hospitals and highlights the lack of science as a major barrier to understanding.

Globally there have been a number of guidelines and initiatives (UK Department of Health, 2004) (Sehulster et al, 2004) aimed at addressing cleanliness of the environment and subsequent transmission of infection, but most suffer from a significant limitation: the extent to which cleanliness may be measured or, more specifically, quantified (Mulvey et al, 2011). Perhaps understandably then, the focus has shifted to the efficacy and development of cleaning and disinfection agents and, more recently, to the process of cleaning itself. In parallel to these streams of endeavour there are a few technologies that show promise with regard to their intrinsic fungicidal, bactericidal or antimicrobial characteristics; copper is one of these.

Copper Context

In 1983 an observant medical intern Kuhn, at Hamot Medical Centre in Pennsylvania, USA, noted a surprising lack of bacteria on brass door knobs during an incidental training exercise for their cleaning staff (Kuhn, 1983). Subsequent and more detailed investigations in the hospital and laboratory confirmed the efficacy: copper disinfected itself in 15 minutes whilst stainless steel and aluminium showed heavy growths even after three weeks. Taking this starting point the Copper Industry, through the International Copper Association (ICA), has sponsored research into the efficacy of copper and, probably more importantly in practical terms, copper alloys, since 1985.

Since 1985 significant research effort has been directed into understanding various aspects of the efficacy of copper: reproducibility, speed and extent of activity, effect of humidity, temperature, soiling, contaminants and mechanisms. This is relatively new science and, whilst the work is ongoing, the results show broad spectrum and continuous efficacy under a variety of conditions. With this basis, investigations have successfully moved to the clinical (as well as other identifiably hazardous) environments.

Test Protocol

Fundamental to the scientific effort has been the development and establishment of a suitable laboratory protocol to simulate typical indoor conditions and contamination events that might pertain in a hospital, school or office environment. Keevil and co-workers (2006) demonstrated such a test, developed from existing standards for disinfectant evaluation. A material coupon is inoculated with about 10 (Kuhn, 1983) colony forming units (CFU) of a live microbe in a 20 microlitre droplet of carrier solution. This is then aseptically spread over the surface to simulate a moist, wiping contamination event and left for a defined period under defined conditions of humidity and temperature (e.g. room conditions) before all surviving microbes are harvested from the coupon. These are then applied to a nutrient plate using standard and established microbiological techniques and incubated for 24 hours after which time the live CFUs are counted. This test protocol may be modified to test under other conditions and is sufficiently sensitive to differentiate between alloys of copper, test temperatures and microbe type as well as simulation of other environments (Michels, Noyce & Keevil, 2009) (Weaver, Michels & Keevil, 2010).

Compare this to the well-established Japanese Industrial Standard test (JIS Z 2801) which has been developed into an ISO standard (ISO 22916). A similar liquid sample is inoculated onto a coupon and this is immediately sealed with a plastic film to maintain a moist environment. After 24 hours at 35°C the surviving microbes are harvested and dealt with as before. Whilst this is used by some to infer antimicrobial characteristics of their products, Michels shows that when, for example, some proprietary composite

materials are subjected to the “Keevil test” they show no apparent efficacy, even after 24 hours. The suitability of this JIS laboratory test has also been examined by the OECD (2008) who concluded that making claims for product efficacy based upon an inappropriate laboratory test was dangerous: “*There is clearly a significant disparity between the method used to demonstrate potential activity and the normal exposure scenario.*” At best they consider this as a first level proof of principle test.

The “Keevil test” has been used to evaluate the efficacy of a number of copper alloys (see Table 1.) and subsequently has been the basis of the independent verification of copper’s efficacy on behalf of the US Environmental Protection Agency (EPA). This submission was made by the ICA on behalf of the copper industry and, following extensive evaluation, in 2008 the EPA gave copper and about 300 copper alloys the legislative right to make claims of benefitting human health.

More recent developments on test protocols have recognised that the inoculum volume used initially by Keevil et al. plays a role in efficacy. This is important because many hospital or other environmental contamination events take the form of a relatively dry touch or a small droplet impacting on a surface. In work published in 2011, Warnes and Keevil show that by reducing the carrier volume, the rate at which copper and brass demonstrated kill was reduced to 10 minutes or less.

Table 1. Pathogenic microbes showing susceptibility to copper and copper alloys¹⁴

Acinetobacter baumannii
Adenovirus
Aspergillus niger
Candida albicans
Campylobacter jejuni
Clostridium difficile
Enterobacter aerogenes
Escherichia coli O157:H7
Helicobacter pylori
Influenza A (H1N1)
Klebsiella pneumoniae
Legionella pneumophila
Listeria monocytogenes
MRSA (including E-MRSA)
Poliovirus
Pseudomonas aeruginosa
Salmonella enteritidis

Staphylococcus aureus

Tubercle bacillus

VRE

Clinical Trials

As important as laboratory results are, clinical and field trials have been undertaken in a variety of locations and environments including Chile (Prado et al, 2010), Japan, South Africa (Marais, Mehtar & Chalkley, 2009), Germany (Mikolay et al, 2010), India, UK (Casey et al, 2010) and the USA (Moran et al, 2011). Each has confirmed the translation of the laboratory science to the wider environment. They show that simple interventions like upgrading components and touch surfaces such as worktops or bed rails to a brass or bronze alloy has resulted in reductions in the level of bioburden or pathogenic contamination. Clearly the replacement of these components is not a random choice: an important part of the clinical research has been the identification of key touch surfaces within the healthcare environment.

Three clinical trials are of special note:

1. Chile: Hospital del Cobre, Calama. Calama is high in the Andes Mountains and in a desert environment where relative humidity is fairly consistent and typically less than 20%. This is important because the results for copper alloys were still excellent (typically less than 80% bioburden compared to control items and 84% less in the copper room as a whole) despite such low relative humidity. This low humidity efficacy has also been demonstrated in the laboratory^{10,13,20} and argues for better considered and standardised tests for surface materials that claim antimicrobial efficacy.
2. UK: University Hospitals Birmingham, Selly Oak. In a 20 bed Nightingale ward equipment was upgraded to copper alloys in about half the cases, the balance being retained as standard items: aluminium, steel and plastic (Casey et al, 2010) (Karpanen et al, 2012). Cleaning of all surfaces was enhanced at the request of the Trust ethics committee as a precautionary measure, though not expected, in case the installation not only failed to reduce contamination levels but actually caused an increase. Samples were taken at regular intervals, initially twice per day and in a second, longer, trial once per day. The upgraded and control components were swapped over in both trials at the half way stage to reduce bias.

The results show statistically significant effects on contamination levels: as with Calama, better than 80% reduction compared to controls. Whilst this is noteworthy in itself, these reductions were

apparent despite the additional cleaning of both copper and control surfaces. Moreover the levels of bioburden on most of the control surfaces exceeded a proposed acceptance level (Dancer et al, 2009).

This trial emphasises a further key point: that upgrading with copper cannot be perceived as a solution to the HCAI problem on its own. Rather, it is part of an “environmental bundle” that should include cleaning, disinfection and infrastructure – and systemic feedback loops to suppliers of bundle innovation.

3. USA: a three centre, Government funded clinical trial. Preliminary findings from a three year trial were presented at the first WHO International Conference on Prevention and Infection Control (ICPIC) in July 2011 and is currently being written for publication in 2012.

Results from the trial confirm the expected reduction in contamination but go further by showing a link between the key touch surface materials used in an ICU environment and the level of HCAs observed. These early results show a better than 40% reduction in HCAI acquisition in rooms in which a few key surfaces were upgraded with copper alloys. Given the scale of the problem in financial terms, this sort of percentage reduction paves the way for significant investment in innovation with the clear opportunity of a return to both the innovator and the caregiving organisations.

Product Design

There is now clear evidence that copper has broad spectrum antimicrobial efficacy and confers similar benefits to the copper alloys. The challenge is to convert this obvious potential into practical solutions applicable to hospitals and other high use areas.

So far, most clinical trials and hospital installations have focussed on simple upgrading of key touch surfaces using expedient means, for example the replacement of painted steel with a simple brass alloy in the fabrication of grab rails and the removal of ubiquitous chromium plating from the manufacturing process of bathroom fittings. Arguably these two examples represent a very pragmatic and cost effective approach to incorporation of copper in common touch surfaces. Conversely, in the Chilean and USA trials the complex cot sides were upgraded using copper by fabricating shaped covers for the existing design: a labour intensive and highly skilled task that would not necessarily be cost effective in the longer term.

Other close-to-patient components in the environment (see Table 2) are candidates for upgrade with copper or copper alloys but they require more interaction between designers and manufacturers willing to explore

alternative materials. This is one of the key points recognised in the UK NHS Estates policy document from 2002: *“it is imperative that architects, designers and builders be partners with healthcare staff and infection control teams when planning new facilities or renovating older buildings.”* Perhaps stemming from this policy, the consideration of design in reducing HCAs was the core principle of the UK based Design Council’s Design Bugs Out campaign (2009). Clearly identifying the need for collaborative working (designers, manufacturers and clinical staff) to successfully address the patient environment with new thinking, the initiative resulted in a number of innovations. Most importantly the process was appreciated by those taking part. What is, perhaps, surprising is that the need to instigate such dialogue appears to have been lacking in the various communities represented.

Table 2. List of near patient and ancillary components identified as important to upgrade with copper or copper alloy

bed or side rail
 bed-head and bed-foot handle
 actuating lever
 IV drip pole
 overbed table and handles
 wall mounted grab rail
 door handle
 cupboard, cabinet and equipment handle
 door push plate
 patient & visitor chair arm
 tap handle
 switch
 computer mouse
 computer keyboard
 trolleys and cart
 desk, counter or work top
 toilet cistern lever

Ongoing research, under the Health and Care Infrastructure Research and Innovation Centre (HaCIRIC) program, which brings together many organisations including academics, designers, architects and health and care organisations, aims to extend the collaborative approach. This is a vast initiative, self-billed as the world’s largest programme in healthcare infrastructure, and addresses a range of issues. However, it appears from the HaCIRIC assessment (2012) that HCAs are being investigated from a cleaning rather than a material perspective.

Copper alloys are considered by many industrial designers as traditional, if not old fashioned. This is despite the continued use in many delicate and high tech applications from aerospace to microelectronics.

Architects continue to specify copper alloys for landmark buildings that they wish to provide with a different look and that hope may develop a particular patina over the ensuing years. Nowadays, in all but the most polluted environments, copper alloys will take 10 to 20 years to develop a green patina and are now often supplied pre-patinated to give the impression of an aged installation.

And these materials are cost effective: many brasses are the material of choice when it comes to manufacturing complex and near net shapes or those that require machined details. In fact many standard components fitted in healthcare facilities are already produced in brass and then chromium plated; handles and taps being good examples. Other copper alloys may need to meet the demand for stainless-look materials but the copper alloy family is wide and accommodating. Clearly manufacturers also need to rise to the challenge of providing what may currently be minority or special alloys.

Information for Designers - and others

In order to make information available to all communities as well as the general public, the copper industry has recognised the need for a global stewardship campaign. This is endeavouring to address some key issues:

1. raise awareness of the depth of peer reviewed research already available on the antimicrobial characteristics of copper alloys
2. provide further reference information based upon
 - (a) interviews with researchers and clinicians
 - (b) review and summary documents
 - (c) case studies
3. ensure those considering product development and/or supply understand the, relatively simple, technical requirements through the issuing of manufacturing guidelines
4. list suppliers that can provide raw material for product manufacture as well as finished products themselves – thereby creating a manufacturing community
5. provide a form of service mark that gives confidence to designers, specifiers and the user community.

As a repository for this information and as a way of keeping up with the ever-changing research landscape, the website www.antimicrobialcopper.org has been established. This has sections on research, clinical trials and other relevant resources found by search or using the site map.

Conclusion

So the challenge is clearly presented: will the design community, manufacturers and material developers form consortia to tackle HCAs with novel approaches using one of mankind's oldest metals? If they do, how do they include health and care practitioners, Infection Control specialists and identify and engage with the real decision making bodies?

This may be the role of the academic community, to act as a coordinating force: bringing together the interested parties from design, manufacturing and the care sector. The first two groups may be easier to identify and access but the idea that a simple piece of hospital hardware can influence whether a patient develops a HCAI, is a new concept. Such a patient absorbs critical resources in terms of time, bed space and often antibiotics as well as the potential of a reduced quality of life and ongoing care costs. But who will link the value of a set of capital fittings to improved outcomes? This is arguably where the focus should be: the study, identification and development of a multidisciplinary approach from the health sector in partnership with design and supply side expertise as well as the development of a robust cost benefit model.

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**Programme promoting dignity, independence and fulfilment for people with dementia in
healthcare environments**

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Abstract

25% of people accessing acute hospital services are likely to have dementia and the number of people with dementia is expected to double over the next 30 years (National Audit Office, 2010). Hospital stays have a detrimental effect on the independence of people with dementia (Alzheimer's Society, 2009). Many people with dementia lose their independence in undertaking activities of daily living while in hospital meaning that they may not be able to return home when the acute episode of care is completed with consequent cost increases to the care system. Yet, relatively straightforward and inexpensive aspects of the design and fabric of the care environment can have a strongly positive or negative impact on the well being of people with dementia.

The King's Fund's innovative, award winning, EHE programme provides a development programme for a locally nominated, clinically led multidisciplinary teams, including service users and estates staff, and a grant for the team to undertake an environmental improvement project

A recent EHE focus is dementia and in order to help teams demonstrate the impact of their environmental improvement projects the King's Fund developed a tool for auditing the care environment. The audit tool was developed following work in mental health units, is evidence informed (3;4), has been subject to a rigorous testing process and will be available together with supportive materials to healthcare providers and others to help them to identify systematically where improvement in the physical environment is needed to enhance the quality of the care they provide to people with dementia. The tool has been designed for use in care settings such as acute medical and surgical wards, assessment units and memory and out patient clinics where people with dementia will only be resident or visiting for relatively short periods of time. It is expected that the tool would need adaptation for use in long term residential care settings.

This paper will:

- Explain the genesis of the audit tool and the rationale for its development
- Describe the focus and components of the audit tool and how it should be used
- Outline the testing process and findings
- Highlight the implications for practice for designers and healthcare providers who wish to create more supportive environments for people with dementia and their carers



Figure 1 and 2. Outpatients pre and Outpatient post

The Enhancing the Healing Environment Programme

The King's Fund is a healthcare charity that seeks to understand how the health system in England can be improved. Using that insight, it helps to shape policy, transform services and bring about behaviour change. The King's Fund's Trustees made a number of grants to celebrate the millennium. One of these grants was to provide initial funding for a programme to improve the environment of care for patients in general hospitals in London.

This grant funded the Enhancing the Healing Environment (EHE) programme which was launched by the President of the Fund, HRH The Prince of Wales in 2000. Since 2003 the Department of Health has funded the programme as part of its work to support improvements in patient experience.

The EHE programme consists of two main elements; a development programme for a multidisciplinary team and a project grant for the team to undertake an environmental improvement. The aim of the programme has been to encourage and enable clinically led teams to work in partnership with service users to improve the environment of care.

The teams of five people are nominated by their hospital trusts and need to include a nurse or other clinical professional as the leader of the team, an estates manager and patient or patient representative. Other team members have come from a wide variety of backgrounds including medical consultants, therapists and psychologists. The whole team undertake a residential training programme provided by The King's Fund to enable them to plan and manage their project. Sessions include the impact of the environment on health and wellbeing, design, the use of colour and light and the use of art in hospitals. In addition the team gain project management skills and the knowledge to enable them to consult widely about the development of their scheme. Each team has to present their proposals to their hospital board and the King's Fund before any of their project grant is released.

Over 230 teams from acute, mental health and community NHS trusts, hospices and HM prisons have participated in the EHE programme since its inception. The programme has been extensively independently evaluated (Francis, Willis, & Garvey, 2003; Waller, Dewar, Masterson, & Finn, 2008; Arthur, Wilson, Hale, Forsythe, & Seymour, 2010) and a number of publications have been produced showcasing the projects that have been undertaken (Department of Health, 2008; Waller & Finn, 2011). The programme has won a number of national awards and individual projects continue to receive national and regional recognition.

Environments for care at end of life

In 2008 The King's Fund was commissioned to develop and run a programme to improve the environment of care for patients receiving palliative care, their relatives and the bereaved as part of the Department of Health's work to support implementation of the National End of Life Care Strategy (Waller et al., 2011). Following an open application process 20 schemes were chosen which included a palliative care suite for people with dementia within a mental health assessment unit.

Environments of care for people with dementia

The King's Fund had already worked with a number of teams from mental health trusts on schemes to improve the environment of care for people with dementia (Department of Health, 2008) and this experience together with the specific environments for care at end of life programme described above led the Department of Health to commission a specific programme to improve the environment of care for people with dementia. The programme was initially opened, in 2009, to NHS trusts providing mental health services and in 2010 general hospitals were also invited to apply. Both programmes were oversubscribed and projects were chosen to provide exemplars across the patient pathway from diagnosis to end of life care and to be representative of different care settings for example general wards and outpatient departments.

Evaluation of the schemes in mental health settings

Research into the impact on clinical outcomes of the environment of care on people with dementia is sparse nationally and internationally (Davis, Fleming, & Marshall, 2009; Fleming, Crookes, & Shima, 2007). Most of the existing research has focussed on care homes. From this research nevertheless it seems reasonable to suggest that appropriately designed hospital environments for people with dementia are likely to reduce the incidence of agitation and challenging behaviour and therefore the prescription of anti-psychotic medication, promote independence, improve nutrition and hydration, increase engagement in meaningful activities, encourage greater carer involvement as well as improving staff morale, recruitment and retention all of which contribute to better clinical outcomes and a reduction in overall service costs.

Given this gap in knowledge about the impact of hospital environments on people with dementia, this phase of the Enhancing the Healing Environment programme offered an opportunity to develop understandings nationally and internationally of best practice in relation to supporting people with dementia in hospital environments.

Five of the ten mental health trusts that began the programme in 2009 were selected to receive focused evaluation support. These were purposely chosen to reflect the diversity of types of environmental transformation projects being undertaken. The overarching aims of the evaluation support were to:

- Enable the Department of Health (England) and the King’s Fund to have an evaluative overview of the impact of the investment
- Build capacity to undertake evaluation amongst the members of the five teams
- Enable the King’s Fund and the Department of Health to consider how best to support local evaluation capacity building amongst future EHE teams.

The evaluation support involved site visits by the evaluator (AM) and ongoing access to evaluation advice from her for the duration of their projects. The purpose of the support was to ensure that the teams were confident in their data collection, that data was collected on the ‘right’ things from the perspective of stakeholders locally, and to ensure local ownership of the evaluation. To enable some comparable data across the five sites each site was asked to undertake a pre and post audit using relevant sections a commercially available audit tool.

Table 1 lists the focus of each project and evaluation measures used.

Table 1

Site	Project Focus	Evaluation Measures Used
1	Transforming a dining room and kitchen facilities to improve the patient experience, increase interaction and facilitate patients and relatives being able to make drinks etc.	Relevant sections of the Audit Tool Auditing use of the dining room Analysis of adverse incidents, slips and trips
2	Developing a modern dementia assessment unit by redesigning the entrance, transforming corridors and communal spaces.	Relevant sections of the Audit Tool Capturing patient experience using a mixture of observations and interviews Auditing use of PRN medication for agitation, incident forms, and staff sickness
3	Redesigning the social and dining areas of the ward to assist wayfinding together with redesign of the garden to encourage greater independent use of the space.	Relevant sections of the Audit Tool Dementia Care Mapping focused particularly on the use of spaces and interactions between patients and other patients, their relatives and

		staff
		Review incident and falls reports and use of PRN medication for agitation
4	Transforming a community clinic into an environment fit for its purpose as a memory clinic and 'drop in' information and advice centre for people with memory problems and their families.	Relevant sections of the Audit Tool Capturing patient and relative stories Recruitment and retention of reception staff Numbers of leaflets etc collected Numbers of visits and use of space by local voluntary groups such as Age Concern, the Alzheimer's Society and carer's groups
5	Creating an open access family and carers lounge and garden within a ward area.	Relevant sections of the Audit Tool Auditing use of and observing interactions in the new family and carers room Auditing the length of time visitors spend on the ward Analysis of incident forms and use of PRN medication for agitation

Findings

Despite the ward areas being relatively new and most being purpose built, prior to the intervention there were common issues of:

- Poor signage and lack of way-finding cues
- Poor use of colour and contrast
- Unhelpful lighting resulting in glare and pooling
- Shiny floors
- Clutter and distractions
- Stark, unwelcoming spaces off long featureless corridors
- No personalisation of space
- Under-use of gardens and outside spaces

Following the development programme and environmental transformation all sites significantly increased their scores in the relevant elements of the audit tool. Particular highlights from the local evaluations for each of the sites are presented in Table 2 below.

Table 2 Highlights from the local evaluations

Site	Project Focus	Highlights
1	Transforming a dining room and kitchen facilities to improve the patient experience, increase interaction and facilitate patients and relatives being able to make drinks etc.	<ul style="list-style-type: none"> • 6 months pre intervention 5 falls and 2 disruptive incidents • 6 months post intervention 1 fall and 2 disruptive incidents • Dining room being used for many more hours each day and kitchen being used therapeutically by the Occupational Therapy team
2	Developing a modern dementia assessment unit by redesigning the entrance, transforming corridors and communal spaces.	<ul style="list-style-type: none"> • Pre intervention 13/15 patients on anti-psychotics • Post intervention 11/15 on anti-psychotics • And change in practice regarding the use of non-pharmacological approaches to managing challenging behaviour
3	Redesigning the social and dining areas of the ward to assist wayfinding together with redesign of the garden to encourage greater independent use of the space.	<ul style="list-style-type: none"> • 4 months pre intervention 87 falls, 43 aggressive instances • 4 months post intervention 71 falls, 20 aggressive instances
4	Transforming a community clinic into an environment fit for its purpose as a memory clinic and 'drop in' information and advice centre for people with memory problems and their families.	<ul style="list-style-type: none"> • Staff reported a reduction in Did Not Attends • Improved recruitment and retention of reception staff • Charity of choice for local radio station
5	Creating an open access family and carers lounge and garden within a ward area.	<ul style="list-style-type: none"> • Significant community engagement and consultation in the design • Positive comments from all stakeholders • Room seen as 'our lounge' and a destination

The intervention has also had a significant impact on the staff teams in each of the sites. This included changes in attitudes and behaviour, increased awareness and knowledge regarding the needs of people with dementia, improved morale, improved recruitment and retention and expanded local networks and profile.

Analysis and interpretation

Many of the changes noticed, appear to have occurred as a consequence of the development programme that is they began before the environmental transformation. For example changes in staff attitudes such as investing in table cloths, laying tables, and new crockery and increases in activities for patients such as the implementation of therapy hour and so in the words of one of the team members its "*not just about the paint*".

The sample selected for extra evaluation support was chosen to maximise diversity of sites, settings and projects. It is a small sample – only five sites and the data were collected by the sites to meet their local needs. No attempt was made to match sites or control case mix. The only standard part of the intervention was the development programme provided by The King's Fund. Nevertheless data from the EHE local

evaluations indicate that simple and inexpensive changes to the physical environment such as changing the colour of the toilet doors and using matt flooring appear to deliver positive outcomes in relation to the prescribing and administration of anti-psychotic medication, incidents of violence and aggression, falls, behaviour and use of space, and patient engagement in meaningful activity. By making spaces seem smaller and more familiar, and reducing the numbers of decisions that have to be made by patients in finding their way to places such as the toilet, the dining room or their own bed space seems to significantly reduce agitation.

The teams' experience of using the commercially available audit tool, which was developed for use in care home settings, in hospital environments has led the EHE team to develop and test its own quick and easy to use environmental assessment tool to enable healthcare organisations to work directly with carers to identify systematically where improvement in the physical environment is needed to enhance the quality of the care they provide to people with dementia.

Next steps

The assessment tool has been further field tested in acute hospitals during autumn and winter 2011 and was published by The King's Fund early in 2012 together with overarching design principles for creating a more supportive environment for people with dementia in hospitals.

For further information please contact The King's Fund www.kingsfund.org.uk

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Designing Healthy Services

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Abstract

This paper presentation introduces Service Design and how its processes and methods can help healthcare services to increase productivity, improve service quality and meet customer expectations (Runchie, 2010). It demonstrates the value of a Service Design approach through a case-study experience of embedding the discipline within a third sector organisation that promotes the health and wellbeing of people over 50.

Furthermore, the paper demonstrates the value of creative tools and methodologies to enable healthcare providers to innovate in difficult times. For example, training staff in idea generation techniques to help them think creatively and abandon traditional methods of service provision that are no longer sustainable. Similarly, the paper shows where existing management tools are inadequate at dealing with dramatic transformational change currently occurring in public services. For example, encouraging the organisation to prototype propositions in order to evaluate the ideas before investment is committed, as opposed to immediate implementation that was previously practiced.

The paper details how the Service Design methods encouraged front-line staff to take ownership of ideas in order to increase the chances of actual implementation and achieving results. Methods including observational research and semi-structured interviews provided staff with the opportunity to see the problem in a different way, and concurrently gave them permission to solve the problems they observed. For example, a photography activity enabled front-line staff to *_see_* the service and make immediate changes to improve the customer journey.

Finally the paper demonstrates how this approach has empowered all stakeholders to embrace change and respond pro-actively to the changing needs of their customers, as well as the challenges of the sector; how it has resulted in a culture change which will have a lasting impact on the quality of the service provision for thousands of older people in the region.

Keywords: service design, empowering stakeholders, user research, co-production, ageing and wellbeing

Introduction

In recent years, the UK's Voluntary Community Sector has played an increasing role in the provision of health and wellbeing services. The lack of availability of central and local government funding, and the close and enabling relationship Third Sector organisations often enjoy with their customers (Corrigan, 2010), has led to many health-related services being offered by non-profit organisations.

However, a volatile fiscal climate has meant navigating a clear road to service delivery is increasingly challenging. With increasing pressure on voluntary organisations to help deliver these vital services, it has become crucial that charities find sustainable solutions to deliver high quality customer service.

Age UK Newcastle, a charity that enhances the health and wellbeing of older people in Newcastle-upon-Tyne, has recognised the key role that a Design approach can play in helping them to respond creatively and pro-actively to this demand.

Through the UK Government's Knowledge Transfer Partnership (KTP) scheme, Age UK Newcastle has been working with Northumbria University's School of Design to transfer Design capability to the organisation. By embedding this knowledge within the very culture of the charity, Age UK Newcastle could improve their existing services, and also gain a skill base that would help them to develop high quality offerings in the future to continue to meet the needs of an ageing population.

This paper describes this two-year KTP that concluded in September 2011. It will describe the recent context for organisations operating in the Voluntary Community Sector. It will discuss the relevance of a Design approach to both the improvement of health-related customer services in this circumstance, as well as the transfer of knowledge to a capacity-starved organisation. It also documents how Design was used to achieve both of these aims, and the resulting impact of this engagement on the organisation and stakeholders.

Why design?

Despite the term 'design' making more frequent appearances in policy and strategy documents within the Third Sector in recent years, the Design discipline is rarely formerly engaged to help develop services. Similarly, the need to engage service users in service development is a widely accepted necessity in the work of voluntary and public sector organisations, but whilst the concept may be embraced by many organisations, the practice is often not undertaken properly (Douglas, 2011). Outside of the Design community, there is often insufficient understanding of the role Design can play. Frequently thought of as a styling activity, non-designers fail to comprehend that the approach can help organisations to understand the needs and demands of their customers, and translate these into tangible outcomes.

Design has traditionally been viewed as a commercial activity. However, as the discipline has expanded, it has moved into a new arena of tackling social issues within a service context; creating systems and services to help people and society, as opposed to selling them for commercial gains (Parker, 2010). The successes of programmes that use Design to tackle social challenges, such as Dott 07 (Thackara, 2007) and Public Services by Design (Design Council, 2010), have demonstrated on an international level that Design Thinking can make a valuable contribution to help tackle today's social and economic challenges (Schaeper et al., 2009, p24).

In the context of social issues, viewing an issue from a Design perspective has been said to bridge the gap between deductive and inductive thinking; using abductive reasoning to consider what could be (Martin, 2009). In actively looking for new opportunities, challenging accepted explanations and inferring new possibilities, thinking as a Designer can help to visualise new ways of addressing well-established problems (Martin, 2009).

Adopting this creative perspective has been termed Design Thinking (Brown, 2009); 'a discipline that uses the designer's sensibility and methods to match people's needs with what is technologically feasible and what a viable business strategy can convert to customer value and market opportunity' (Brown, 2009).

Recent studies by scholars, practitioners and government bodies have suggested that Design Thinking has 'the power to stimulate or drive innovation and transform organisations and even societies' (Kimbell, 2011). This is particularly true in the public sector, where there are several documented examples of how Design Thinking tools and methods have been applied to improve health services in the public sector (Schaeper et al., 2009, p22-31; Lee, 2010; Sangiorgi and Carr, 2009, p38-42). Schaeper et al. (2009, p26) describe their success at using Service Design approach within the NHS, citing the example of '40 changes to one clinical pathway' as evidence of how the tools can bring a new insight to pre-existing issues (Schaeper et al., 2009, p26).

It is considered that Design Thinking can help organisations to respond to the challenges faced in times of austerity 'by thinking, and doing, differently' (Runcie, 2010). Design Thinking's disruptive, creative approach can help organisations to think in a radically different way, as opposed to taking small, incremental steps based solely on what exists. Its successful application in health services made it an ideal approach to adopt at Age UK Newcastle when trying to address social delivery challenges in a more sustainable way. However, this approach is not widespread and its adoption can meet with resistance as it challenges norms and infers inevitable change.

Culture change

In September 2009, Age UK Newcastle embarked on a two-year KTP programme with Northumbria University to begin to capitalize on the Design knowledge that they had previously been introduced to through an undergraduate project. As part of that partnership, a new Design Graduate with excellent design and interpersonal skills was carefully selected and placed into the organisation to orchestrate this change from within. The graduate was supported by an academic team from Northumbria University School of Design.

The first year of this project was planned to contribute towards the overall strategy of the organisation, and define actions to be taken over the coming periods to ensure that they were meeting their customers' needs. To contribute towards this, the designer devised a project structure designed to effect culture change.

As part of this wider project structure, the Designer wanted to demonstrate the benefit of thinking differently about established social issues. The Befriending Service, which provided social contact for isolated lonely people, proved to be an ideal example of a service that had been offered in almost exactly the same way since it was first established, over 20 years previously. Currently working at capacity, and with an uncertain funding future, it provided an excellent role model to review in full view of the organisation; providing something to imitate in order to affect real systemic change.

Although not strictly a health-orientated charity, Age UK Newcastle's services play an important part in ensuring the physical and mental health and wellbeing of older people in their community. A key part of this provision are the services the organisation offers to prevent or address social isolation and loneliness in those aged over 50, of which Befriending is an integral part.

Social isolation has been identified to be detrimental to overall health and wellbeing. This can be more acute for older people who live alone, may have experienced bereavement and who may not have family and friends within close proximity. Loneliness has been proven to cause harmful physiological events (Cacioppo, 2010). Persistent loneliness leaves a mark via stress hormones, immune function and cardiovascular function with a cumulative effect that means being lonely or not is equivalent in impact to being a smoker or non-smoker (Griffin, 2010). These shocking statistics demonstrate the importance of having effective services to ensure the social connectivity and mental wellbeing of older people.

Current mindset

The Befriending team were very keen to review their service, as they had a significant waiting list that they wanted to address. However, they were very solution-focused and wanted to devise options for expansion

as soon as possible; they interpreted the demand for the service as effectiveness. They also gave little consideration to the efficiency of the offer.

To re-balance their perspective, staff were asked to articulate, and attribute a time to, every activity undertaken when delivering this service. A simple task, but it highlighted that the administration of the service was absorbing the majority of the coordinator's time. A budget analysis also revealed that the service had an organisational cost of £900 per service user, per year, a figure far higher than the team's estimates. These initial steps created amongst the team a motivation to address the inefficiencies in the service laying the foundations for undertaking a thorough research process.

Thoroughly designed research

The Befriending department previously conducted limited, infrequent research, considering it to be too costly for one so resource-strapped. The research it did conduct asked closed questions about the service and any improvements users would like to see. This structured style of evaluation provided little feedback and of poor quality, providing no guidance regarding the service's actual performance.

To prove the value of appropriately designed research, the KTP team wanted the staff to conduct as much of the activity as possible. They trained them in design research methods, so that they could understand the purpose of the techniques, and ensure that they collected the information in a consistent and appropriate way. Each activity was also designed with the staff team, focusing on the needs of the participants, and how best to elicit the information whilst providing an enjoyable experience for them. In constructing the activities with the team, they were shown that research could be thoroughly designed, and yet remain flexible and work within the organisation's ethical guidelines.

First, existing recipients of the Befriending service were invited to come to an event to share their experiences and opinions. To prompt discussion, two fictional characters were introduced and the participants asked to suggest things that could improve the characters' quality of life. By creating characters in familiar circumstances and asking participants to consider what they may need and how they could be helped, this allowed people to think about their own needs without feeling embarrassed in the group setting.

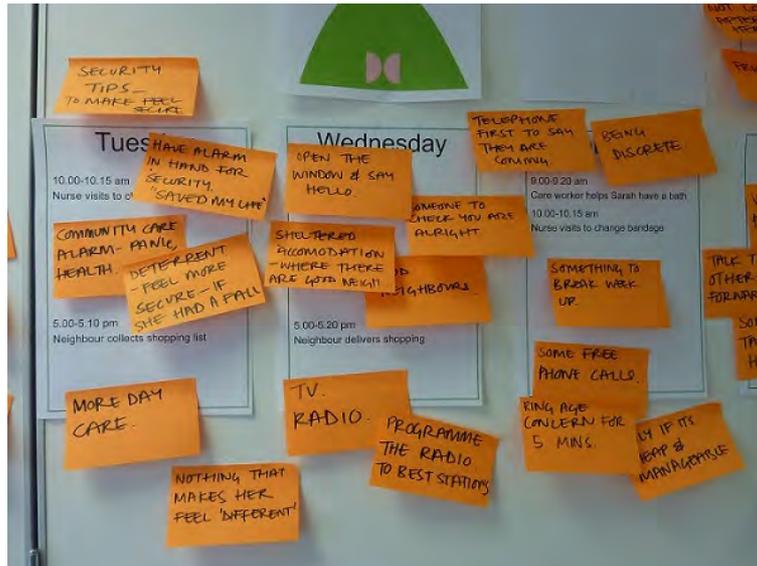


Figure 1. Suggestions made by older people on how to improve the life of a fictional older person

To elicit the opinions of people on the waiting list, and those who were unable to travel, participants were visited in their own homes and semi-structured interviews were conducted. Participants were asked to complete a diary sheet to share what they usually did on a day-to-day basis with the team, and this formed the basis of an interview; allowing the researchers to tease out the emotions they experienced without prying into their personal life. Interviewers were also given conversation tips, feeder questions and visual prompts to help them be truly responsive to the participant, whilst gathering the necessary information.

Throughout the research process, researchers were asked to gather images of the participants or things that were of value to them. The service team were initially reluctant to do this, citing the vulnerable nature of the participants as a reason not to capture any information. The KTP team encouraged them to make this departure from their usual practice and ask each participant individually; respecting their decision, rather than making one for them. In practice, what they found was that almost every older person agreed to be filmed and photographed, and actually enjoyed the attention being paid to them and their belongings, making for a rich, interesting dialogue.

The photographs were used to create profiles of each older person and capture their own personal story. This format helped to gather data regarding family and friends, their typical week, and hobbies and interests in a visually stimulating way. The profiles also helped the staff remember details of interviews, inspired them to create solutions for real people, and helped to communicate effectively the content of interviews with other team members.

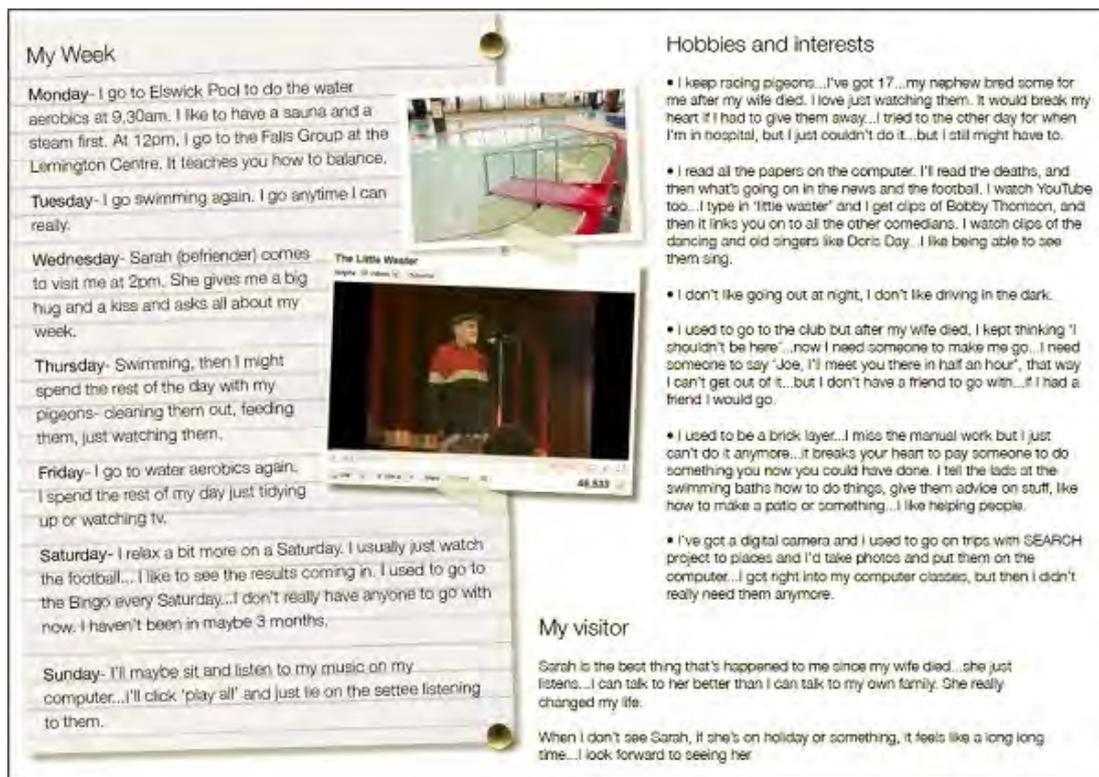


Figure 2. Example profile page created to capture richness of interviews

Doing things differently

Third sector organisations often work in partnership, but different funding bodies and management guidelines mean there is rarely comparable research data. It is therefore not common practice at Age UK Newcastle to gather and consider all data simultaneously, but this is exactly what the KTP team did!

The process helped the team to pinpoint commonalities and differences in their findings, threading the information together to form a more cohesive understanding of what they had discovered. In examining the information as a whole, staff were also able to draw some conclusions based on in-depth research, rather than generalisations. The findings were translated into four distinct areas that needed to be addressed: connecting people with genuine friends; customer progression; enhancing the existing offer and more volunteering roles. These were used to inform the idea generation stage.



Figure 3. Service Designer synthesising the findings from the research activities

Where there had previously been no research, there had also been no idea generation; Age UK Newcastle had often emulated good practice taken from elsewhere without validating whether it was appropriate for their aim, customer or circumstance. The previous stages had provided insight into the changing needs, aspirations and interests of older people, and the KTP team wanted to use the research findings to generate numerous potential service innovations to demonstrate that those needs could be addressed in different ways.

The team were asked to consider not how they could improve their service, but simply how they could fulfil its aim: offering social contact to isolated older people. In rewording the question, the KTP team gave the service team permission to think broadly, creatively and differently. Staff found that by focusing on the potential of an idea, and withholding judgement, they could take inspiration from each other and produce surprising yet appropriate suggestions. Reframing the question gave the project team permission to think broadly, creatively and differently. The profiles were then used to inspire this process, and ensure the KTP team created solutions for real people; drawing out the important information to help develop new ideas that would address their needs.

The generated ideas were then shared with staff members from across the organisation to get their opinions on which ones should be a priority to develop. From this feedback, and the knowledge gained through the previous stages, the team developed a 'Telephone Neighbourhood' concept. It suggested a way of connecting customers with other customers by forming a 'neighbourhood' that contact each other by telephone every week, whilst the group is supported by a volunteer who helps them to make connections and develop friendships. It was suggested that once the network was established, the volunteer would

gradually withdraw and the network would then self-sustain, making it a much more manageable option for the organisation in the long-term.

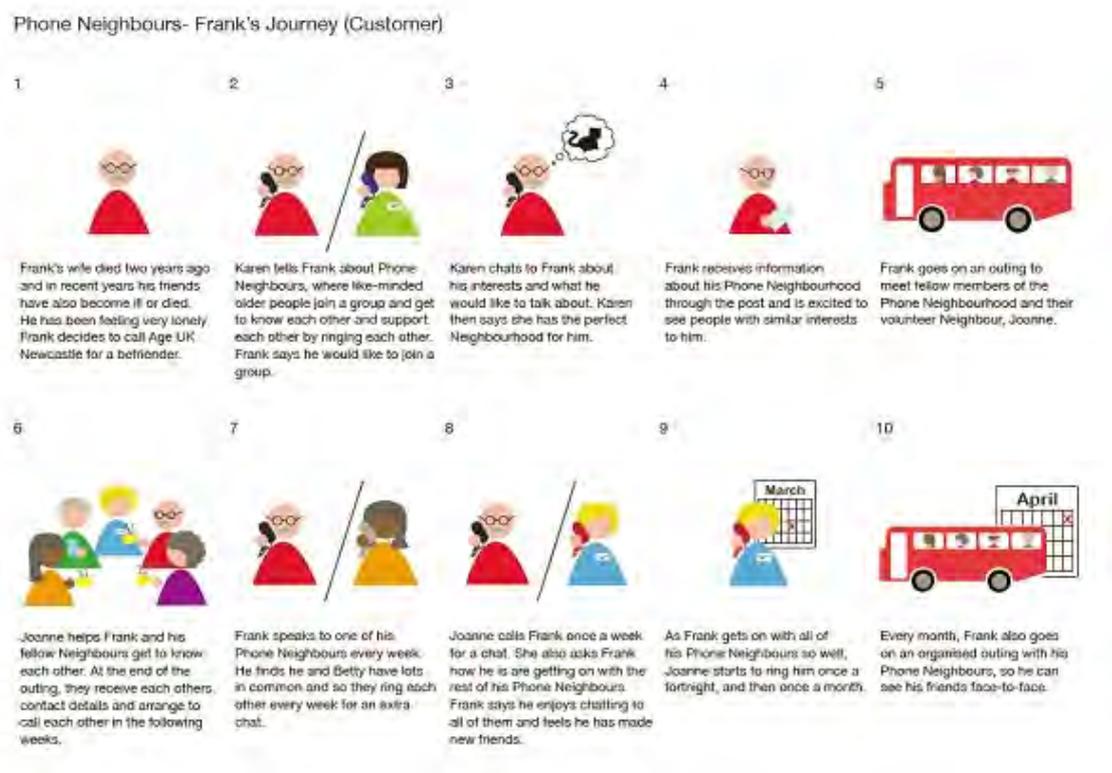


Figure 4. Customer journey storyboard for the developed service, Telephone Neighbourhood.

The concept was well received by staff across the entire organisation, which was important to ensure that it was considered an organisational initiative, rather than being segregated as a departmental offer. Additionally, some of the other generated ideas also provided inspiration for other departments and inspired them to review their current offers to older people and create more appropriate options.

Testing the water

Being such a small organisation, Age UK Newcastle had never placed much emphasis on prototyping ideas before launching them. This has often led to unforeseen issues that have proved costly to the charity. Having instilled the importance of process across the charity, the team understood the need to test the 'Telephone Neighbourhood' concept in order to judge whether or not it was an appropriate response to the research findings.

To this end, the service was piloted with a control group to check that it operated as intended. The monitoring and feedback process was carefully designed to show whether the service was both effective and

efficient, and give the team an opportunity to refine the model before launching it full scale. At the time of this paper, the pilot was still being undertaken, but with positive initial feedback.

Wider implications

Whilst the service review had resulted in a service innovation, there were also wider implications to the research findings that the design team wanted to share.

They developed a blueprint for an ideal social care service experience. . It responded to the findings that customers were not being accurately referred into the organisation, and instead were being basically assessed for a service i.e. a lonely person who was referred to Befriending by Social Services would be assessed for that service, not for any others that they might also benefit from. The blueprint highlighted the need to create a more holistic plan for a customer that would help them to reach personal objectives i.e. confidence building, in order that they would become a service provider, and not just a service recipient.

The model was shared with a wide group of stakeholders in the sector to much acclaim. By linking the more generic model to real client and service issues, the work had a more profound impact on their thinking, appealing to them on an emotional as well as professional level.

The service review was incredibly successful on a number of levels, resulting not only in an improved service offering, but also organisation policy that reflects the needs of the client group. The project work also inspired the team to apply this Service Design approach across the rest of their department. As a result, Age UK Newcastle are re-assessing all of their services and possible development options, and also seeing a Service Design approach as crucial to those reviews.

Conclusion

This programme has had a wide-reaching impact that has made Age UK Newcastle more customer-focused, more sustainable and more responsive.

The KTP team have found that using a Design approach has enabled managers, staff and service recipients to engage in service development in a different way by going on the journey together. The process provided a safe space for constructive feedback, opportunities to understand the subtleties of expectations and perceptions, and an approach for testing out new ideas as part of the design and development of services. It has been shown that Design offers both a rigour and creativity to service development, and complements more routine forms of engagement such as surveys, audits or focus group discussions.

The use of images and imaginative presentation as part of the Design process has been very effective in enabling people to get quickly to the heart of the matter. In many existing engagement processes, the use of this type of imagery, be it photographs, video or illustration, may be regarded as a luxury rather than a necessity. However, the team have shown that visualising an idea, process or touchpoint has a profound impact on a stakeholder's ability to understand the content, and also their likelihood to contribute feedback.

The team's experiences have shown that effective organisational change can be achieved by having someone in-house driving the change, as opposed to an external consultant influencing it. As an employed member of staff, the designer was a constant resource to help support the next steps of the organisational change, engaging stakeholders at pertinent times during their day-to-day activity, gradually educating them in Design Thinking methodology. They were in an ideal position to learn about, predict and respond to the changing contexts in order to produce a truly responsive approach, which is key for Third Sector organisations.

At a time when VCS organisations, and therefore the people that they help, are particularly vulnerable, the need for evidence-based practice becomes more important. The authors feel that Design Thinking offers a rigorous approach that provides the evidence base for service re-design and development, as well as the tools with which to embed this imaginative way of working.

The legacy of this project has been a culture-shift where service experience is at the core of the organisations work and staff are empowered to explore and initiate new opportunities in a methodical way. This would not have been achieved without the focus on using this new knowledge practically whilst simultaneously embedding it.

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Designing Out Medical Error (DOME)

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Abstract

The design of much equipment on hospital wards is often a cause of frustration for front line staff, and can contribute to medical error. Designs are produced for a specific role, and make no acknowledgement of the wider system of healthcare processes into which they are placed. A higher level view is necessary in order to design equipment which is fit for purpose and can contribute to improved safety and quality of care. A multidisciplinary approach has been called for in a variety of reports and academic literature.

Aims

The DOME project brings together designers, clinicians, psychologists, ergonomists and business academics from The Royal College of Art Helen Hamlyn Centre for Design, and Imperial College, London. It aims to better understand and map healthcare processes on elective surgical wards, using this as a basis for new designs which better support these processes and reduce the potential for medical error.

Method

After initial context setting research, following patients through their elective surgical pathway (fig. 1), the project focused on the patient's bed space, looking at five healthcare processes: hand hygiene, infection control, handover, medication and the measurement of the patient's vital signs. Following extensive observations and interviews, five Failure Mode and Effects Analyses were carried out on these processes to reveal where the riskiest points were, and the causes of these were investigated through expert interview. The results informed five briefs tailored to each process, and concepts were co-designed iteratively with front line staff, using simulation and testing to help further refinement.

Outputs

Six design interventions (example fig 2), ranging from hospital furniture to software were developed. The functions and features of these will be described, detailing the research insights and evidence base for each design.

Keywords: Design, Medical Error, Patient Safety, Multidisciplinary Research

Background

Medical error is never far from the headlines, and is often a hot political topic. Extensive worldwide studies have shown that some kind of adverse incident occurs in up to 10% of all hospital admissions (de Vries, Ramrattan et al, 2008), more than half of which are believed to be avoidable. The effect this has on patients, families and on staff and the financial costs of over £2billion (Gray, 2003) further increase the need to improve all aspects of patient safety.

The design of much equipment on hospital wards is often a cause of frustration for front line staff, and can contribute to medical error. Designs are often produced for a specific function, and make no acknowledgement of the wider system of healthcare processes into which they are placed. There is already extensive literature on the role of design in healthcare, errors, recovery and patient wellbeing (Ulrich, Zimring, 2004).

A higher level view is necessary in order to design equipment that is fit for purpose and can contribute to improved safety and quality of care. This involves an in-depth understanding of the wider system into which designs are placed (Buckle, Clarkson et al, 2003). A multidisciplinary approach has been called for in a variety of reports and academic literature (Gawron, Drury et al, 2006), (Karsh, Scanlon, 2007), as it is acknowledged that no one discipline can fully understand the multi-faceted nature of the problem of medical error.

Aims

The DOME project brings together designers, clinicians, psychologists, ergonomists and business academics from The Royal College of Art Helen Hamlyn Centre for Design, and Imperial College, London. It aims to better understand and map healthcare processes on elective surgical wards, using this as a basis for new designs which better support these processes and reduce the potential for medical error. The research, design and evaluation have been carried out over a three year period.

Evaluating these designs will reveal their efficacy within the context of a hospital ward. These trials aim to contribute to the evidence base around each design, validate the collaborative methodology and further expand the growing body of evidence that design can improve patient safety.

Research Methodology

During the initial phase of the project, the multidisciplinary team was immersed in the clinical environment. This was crucial for designers and psychologists to understand the context of use for many designs, and allowed an opportunity for the clinicians to view their everyday environment from a fresh perspective.

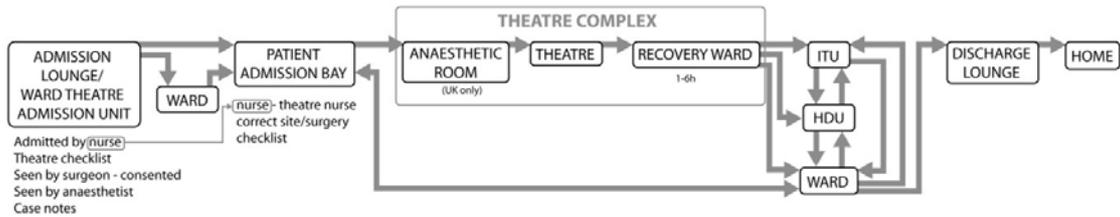


Figure 1 – elective surgical pathway

The elective surgical pathway was mapped out (Figure 1) by shadowing patients and staff. The team carried out over 70 hours of initial observations, on 5 general surgery wards, observing 60 activities. The specific focus was on 10 healthcare processes, and over 60 patients and staff were surveyed. The common framework for investigation was a focus on the hospital ward, within that the six- or four-bed bay, and within that the immediate space around the patient’s bed (Figure 2)

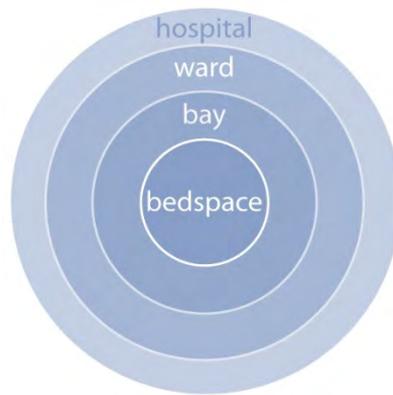


Figure 2 – common framework for research focus

The most common activities carried out in the bed space were observed, and given a hazard score using a method borrowed from industry. This combined observations, staff opinion and incident data (Figure 3).



Figure 3 – hazard scores for common processes within the bedspace

The five most hazardous processes were taken forward for further investigation. These were hand hygiene, the monitoring of patients' vital signs, infection control precautions, medication and the handover of information between staff shifts.

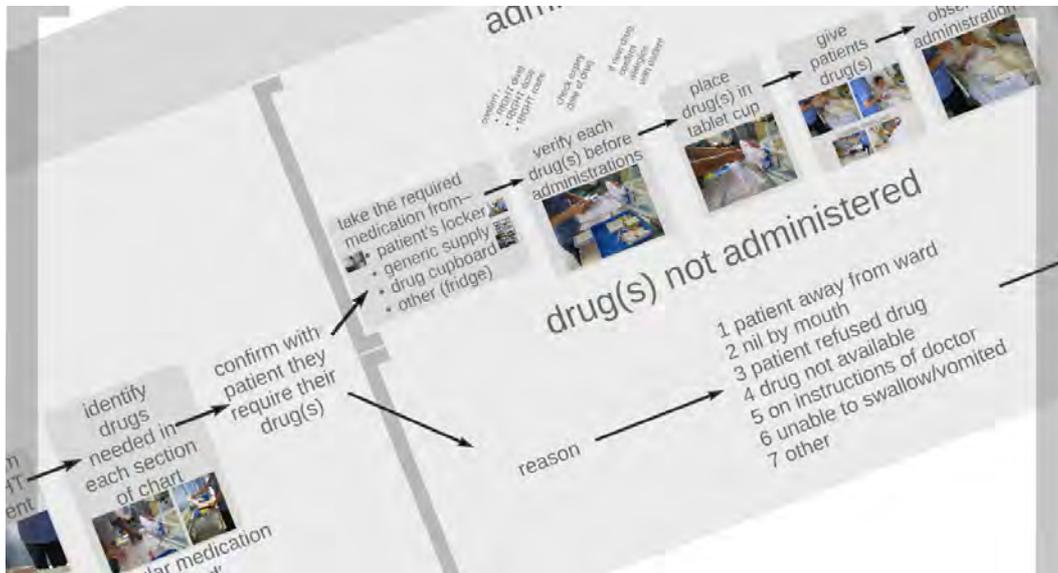


Figure 4 – detail of sample process map

These healthcare processes were mapped out through more extensive and detailed ward observations and interviews with front line staff (Figure 4). These maps were verified with process experts in each case. They were also asked to brainstorm all the ways in which each step in the process could fail. These maps and associated potential errors were carried forward for further analysis.

Running parallel with the front line clinical research, the team also visited other analogous high risk industries to learn from the way they handle risk. Various industrial sites (including mines, oil rigs, building sites and chemical plants) were visited, and this allowed clinicians and designers to see different safety processes.

Just as in healthcare, the industrial processes were mapped out (Figure 5), and this allowed comparison with healthcare process maps.

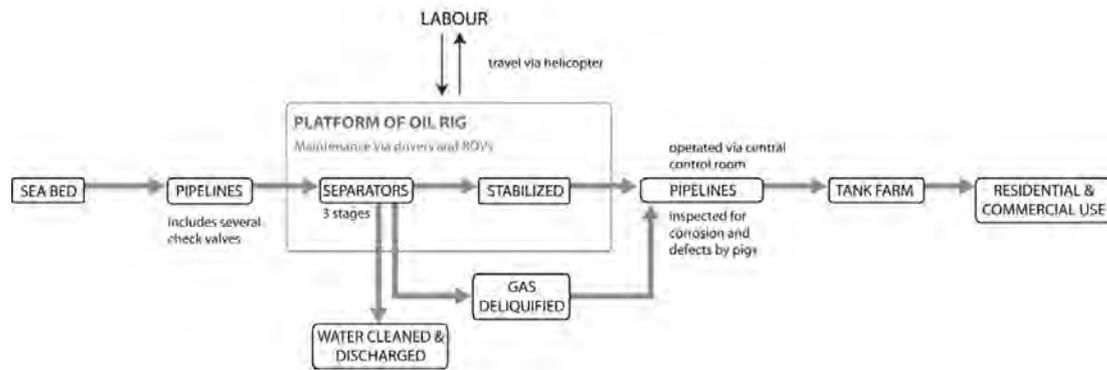


Figure 5 – sample map of industrial process

By drawing analogies through mapping, but more extensively through direct observation and expert interviews, the lessons which were applicable to industry and healthcare fell in to four broad categories:

- Improvements in task design
- Improved reminders
- Provision of equipment
- Design of the work space

These four categories were to provide a rich context for subsequent design work.

Returning to the healthcare setting for the research, the team were able to focus specifically on the healthcare process maps we had previously defined. A Failure Modes and Effects Analysis on each one was carried out. This consists of convening a small user group of patients, doctors, nurses and process experts to run through the process map, and consider each step in turn (Figure 6).



Figure 6 – group conducting healthcare FMEA

The group must reach a consensus of opinion and score each step between 1 and 4 in terms of Severity, Frequency of occurrence and Detectability. This gave an overall Hazard score, and revealed where any 'hotspots' of error lay in each process.

Once the processes had been thoroughly mapped, and their weak points prone to error revealed, a causal analysis of the high risk failure modes was carried out using the London protocol. This involves carrying out interviews with the process experts and establishing all the factors that may lead to a failure.

The systemic weaknesses are sought in the interviews by continually asking why a failure occurs until the underlying reasons are reached. Contributing factors are grouped under different headings (Figure 7).

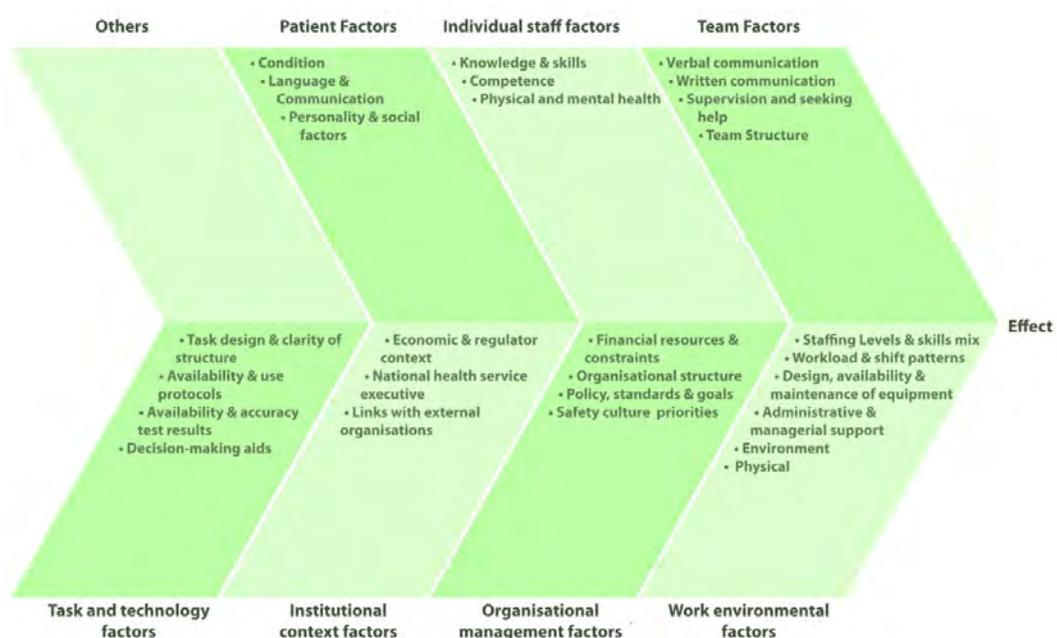


Figure 7 – sample diagram of factors contributing to error

The underlying themes from the London Protocol were grouped into areas to be tackled by design. These were then merged with the detail already gathered around the five most hazardous processes, and the result was a series of tightly defined and detailed briefs.

The definition of these briefs formed the centrepiece of the project, and was crucial in translating the research into tangible designs. They had to capture the issues emerging from the research, allow freedom of design thinking but also be constrained enough to focus on the problem.

The five briefs were around the areas of hand hygiene, infection control precautions, the monitoring of patients' vital signs, medication and handover.

Designing the interventions

The design briefs were rich with detailed context: process maps, associated errors, contributing causes and areas of focus from analogous industries. One major benefit of the length of the project was that there was time to consider all five briefs in parallel. This allowed some design solutions to overlap briefs, benefiting other processes.

Whereas previously, designers were working alongside the clinical and psychological team as researchers, now the work shifted towards concept generation. Ideas were conceived in collaboration with clinicians, psychologists and the business academics in the team.

Creative techniques were used, both individually and as a team. Brainstorming sessions were held, involving front line staff and users, as well as a variety of techniques (De Bono, 1995) which may be followed independently. This was important in involving others in the creative process, and also in introducing those who were not familiar with idea generation to simple, easy to follow methods for thinking creatively. A clear process, in line with the well defined research process, was crucial to group coherence.

By carrying out these creative activities, it was important to get a breadth of ideas for each brief. These were mapped out into various avenues for design exploration. Right from the start, the team was keen to get feedback through continual visits with front line staff (Figure 8)

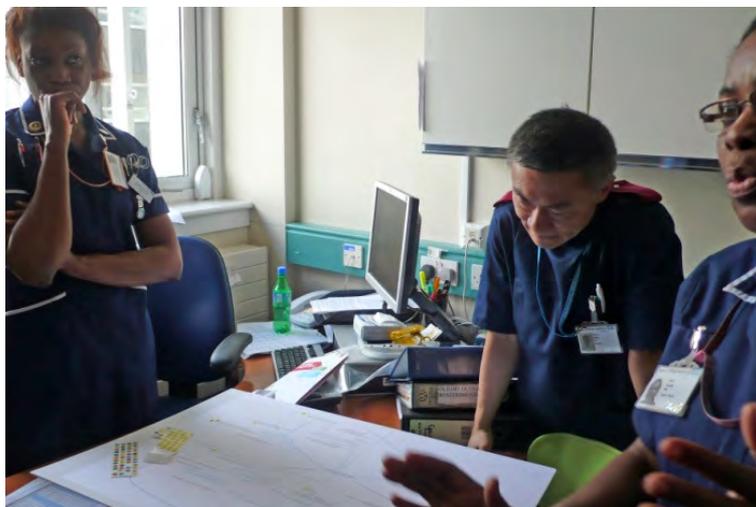


Figure 8 – feedback on ideas from nursing staff

This was done even before the sketch stage, seeking opinion on initial written concepts and functions, so that difference in sketch or presentation style would not bias early feedback.

From this breadth of ideas, the iterative feedback from patients, doctors and nurses was used to refine the concepts and select a few to be taken forward to more developed prototypes for more detailed study. This follows the more familiar iterative design

methodology, and so the critical feedback narrowed the concept range down to single selected idea for each brief. These ideas were then resolved into final prototypes for more robust clinical feedback.

For two briefs, where the design response was a tangible product, US and UK manufacturers were involved during the final development, detailed later.

Outputs

The design outputs formed a suite of interventions, all set within same context. To recap, they targeted five high risk common healthcare processes: infection control, hand hygiene, the handover of information between staff shifts, the measurement of a patient's vital signs, and medication administration.

Infection Control

During the research, the team noticed that infection control precautions, such as the use of aprons and gloves, were seen as an interruption for more pressing care processes. Looking at the location of equipment needed for common bedside processes reveals that there is rarely any order. Gloves and aprons are often dispensed outside in a corridor, the hand gel is difficult to access from the bedside, there is nowhere to put documents or waste, and the medication locker is often difficult to access.



Figure 9 – the CareCentre

The design intervention is a 'one stop shop' for all the necessary equipment for common bedside processes (Figure 9). Located at the end of the bed, it is intended to streamline staff workflow and improve access to equipment. It contains aprons and gloves, an alcohol hand gel dispenser, a medication locker, a flat surface for writing, a folder holder, a clinical waste bin and cleaning wipes. This was developed in collaboration with UK manufacturers Bristol Maid, and is now sold as the 'CareCentre'.

Hand Hygiene

Visual reminders and campaigns for visitors and staff to clean their hands have been evident in abundance on wards. However, the variety of different styles and messages contributed to an often ignored and confusing clutter on the walls. In addition, there was no focus on hand hygiene within the bedspace (most efforts targeting the entrance to wards).



Figure 10 – hand hygiene symbol

The design intervention builds on the successful National Patient Safety Agency 'Clean Your Hands' campaign. It is a simple symbol (Figure 10), taking cues from construction safety signage (evident during the analogous industries research where compliance with safety precautions is high). This simple graphic is intended to be reproduced on clear signs within the bedspace.

Handover

There is already a huge body of research into the process of handover and its associated non-technical skills (a good example is the body of work found at www.handover.eu). The team was keen to explore the physical constraints of staff handover. Often this is conducted in cramped staff rooms with insufficient seating and writing space, poor lighting and high noise levels.



Figure 11 – room in staff room mode (l) and handover mode (r)

The intervention (Figure 11) recommends the use of flexible furniture, allowing the room to be adaptable, particularly important as space is at a premium. The room therefore has two modes: relaxing seating and lighting for staff during their breaks, and more formal seating, sufficient working space and better task lighting for handover.

Vital Signs

The measurement of vital signs has three distinct problems: the existing trolley and peripherals (blood pressure cuff, temperature probe etc) can transmit infection between patients, the paper charts are difficult to plot, and they are also confusing to interpret. One important vital sign is respiratory rate, often neglected in existing practice. The current method is to observe the patient's chest movements, counting the breaths over a minute. This is particularly difficult as a clock or watch may not be visible, and a nurse looking unoccupied for a minute is frequently interrupted.



Figure 12 – new design of vital signs trolley

The new trolley (Figure 12) is much easier to clean between patients. It has a touch screen to automatically record the patient's vital signs and display them on screen, as well as recommending the appropriate course of action. This eliminates transcription and interpretation errors. Respiratory rate is measured with a simple on-screen button. This is pressed every time the nurse observes a patient breath, and the total is tallied over a minute, counted down on screen.

This design is in ongoing development with US manufacturers Humanscale.

Medication

Patients are often given drugs in an anonymous pill pot with unidentifiable tablets inside. This can be dangerous as it is difficult to identify which drugs have been administered to whom and when, and is also confusing for the patient.



Figure 13 – new blister pack design

The design intervention is a new blister pack of individual strips (Figure 13) which clearly displays all the important information about the drug. The shape also helps administration by the patient or nurse. For multiple drugs, these strips are placed on a tray (labelled with the patient’s details) which contains and displays all the information with the tablets. This involves the patient in their medication regime.

Testing

In addition to the ongoing informal feedback on all the designs, there was an opportunity to investigate more formally two of the interventions.

An early prototype of the CareCentre was trialled in a simulation ward. This was a room in St. Mary’s hospital fully furnished to replicate a regular bay in a hospital ward. A variety of scenarios (caring for a volunteer ‘patient’) were performed by frontline staff and student nurses, their actions were recorded on video and their feedback was gathered through questionnaires and interviews. 15 hours of simulations were performed in total.

Another test involved the respiratory rate component of the vital signs trolley design. The touch screen tally and countdown for easy respiratory rate measurement was prototyped as an app for an iPhone. A simulation mannequin was calibrated to simulate certain preset respiratory rates, and participant doctors and nurses were asked to use the app to measure the rate, comparing this with a control of a watch.

More extensive trials of these two designs are ongoing. Six prototype CareCentres are being trialled on wards across St. Mary’s, and a group of iPod Touch devices have been secured to vital signs trolleys to be used by staff to record respiratory rate.

These trials are ongoing, and the results will be published later this year. It is hoped that the trials will show the efficacy of the individual designs, and validate the collaborative research methodology.

Conclusion

It has been established that medical error is a widespread problem, nationally and internationally. A contributing factor is the design of much ward equipment which shows little or no design understanding of the context of use. This understanding can only be sufficiently achieved by a multidisciplinary team, allowing the problem of medical error to be viewed from all angles.

The DOME project assembled such a collaborative team, and took this broad view over a period of three years. A clear multidisciplinary methodology was pioneered: context setting, environmental focus, process mapping, error and causal analysis, site visits to analogous industries, creative techniques, ongoing user feedback, iterative idea development, prototyping and testing. This clearly defined approach meant that each team member understood the research, analysis and design processes being carried out on the project, even when working outside of their normal field of expertise.

This resulted in a suite of designs which have had user involvement throughout their development, and have gained approval from front line staff.

Formal clinical trials are ongoing, and it is hoped that the evidence gathered will prove the merit of the collaborative approach in tackling the complex problem of medical error through design.

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A concept compact city vehicle design for the disabled aging people

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Abstract

The degeneration of physical function of the aging often causes physical disability to some extent. The aging people have difficulties in getting on and off the compact car, so their chance to go outdoors increases. The present study is based on observation of six disabled aged users of light to moderate physical disability in moving inside and getting on and off a car. From the video and interviews, problems the disabled aged people encountered in using compact cars were addressed. To solve the inconvenience and difficulty elderly disabled passengers have in a compact car, a big hand bar on the side of the car door that can be controlled with the operation of car door was proposed to help them support their body. This would reduce the risk in getting on and off the car. In addition, a hand grip hidden on the ceiling can help the elderly disabled passengers move around inside a compact car.

Keywords: aging people, disabled, compact city car, vehicle design

Introduction

In recent years, the development of medical care has pushed almost all of the countries in the world into the era of advanced age (Statistics Department of Ministry of the Interior Taiwan, 2011). Aging causes the degeneration of physical functions of human beings. The behaviors of aging people change with the increase of age and the degeneration of physical and psychological aspects cause some degree of handicap. Particularly, the degeneration of motor function will dramatically affect people's activity and living habitual behavior. The aging people are not willing to go outdoors because of the inconvenience in activity and travel by transportation vehicles. As a result, they might easily lose contact with society and be unable to interact with the public.

Currently, the mass transportation tools or individual sedans are majorly designed for users of normal motor function. Take Taiwan as an example. The government concerned has provided the Fu-Kang Handicap Bus for the disabled to rent but the number of bus is a lot different from that of the disabled population. People still use their own sedan to pick up their aging disabled family members. In Japan where the advanced aging problem is more serious, many car manufacturers have made efforts in the design and development of new welfare cars. Furthermore, the Japanese government adopts some supporting measures to reduce the price of welfare cars, so that they have the most welfare in the world. However, because most people will consider to purchase regular cars, a compact city car suitable for leisure activities for local families and for picking up the disabled aging people is chosen as the target. Moreover, the electric battery is taken into consideration for the sake of environmental pollution.

Literature review

Classification of physical disability

Mobile challenge refers to the status of some people that they cannot fully utilize their ability of physical function due to the body injury. According to the grades and standard of physical and psychological handicap by the Department of Health, Executive Yuan, ROC, in 1999 and 2000, physical disability is defined as any [impairment](#) which limits the physical function of one or more limbs or [fine](#) or [gross motor ability](#). Table 1 lists the degrees of physical handicap. According to the standard and classification of handicap in Taiwan, degrees of the moderate handicap in the lower limbs include "have remarkable problems in the function of two lower limbs", "lose the ankle or above in two lower limbs", "lose the knee joint or above in one lower limb", "totally unable to function in one lower limb". Moderate handicap of the body includes "cannot stand because of the malfunction of trunk" (Disability Information Network, 2011). In this study, the aging people with light to moderate degrees of physical disability are majorly concerned. The serious handicap aging people that cannot move by themselves and need mobile assistant equipment are excluded.

Table 1 Degrees of physical handicap

Degree	Physical (the lower limbs) handicap	Physical (body) handicap
Serious handicap	Both of two lower limbs are unable to function.	Cannot sit or stand because of the malfunction of trunk.
	Lose more than half of the legs in two lower limbs.	
Moderate handicap	Have remarkable problems in the function of two lower limbs.	Have difficulties in standing due to the malfunction of trunk.
	Lose the ankle or above in two lower limbs.	
	Lose the knee joint or above in one lower limb.	
	Totally unable to function in one lower limb.	
Light handicap	Lose the ankle or above in one lower limb.	Have difficulties in walking because of the malfunction of trunk.
	Have remarkable problems in the function of one lower limb.	
	Lose all toes or malfunctions in all toes in two lower limbs.	
	Totally without function or have remarkable problems in for the hip or knee joint in one lower limb.	
	One lower limb 5 cm or more or more than 1/15 shorter than the healthy limb.	

(Source: Disability Information Network, 2011)

Compact city car

Due to the high gasoline price and economic impression, the engine capacity and fuel consumption are important factors to consider in car purchase. In Taiwan, most car manufacturers cooperate with international car manufacturers and produce models similar to those in Japan. In the definition of compact cars, the Japanese specification will be adopted. In Japan, any vehicle that is under 3,400mm long, 1,480mm wide, 2,000mm high, and under an engine capacity of 660cc is referred to as a compact car. And a small-sized car is a vehicle under 4,700mm long, 1,700mm wide, 2,000mm high, and under an engine capacity of 2000cc.

A welfare car is a special vehicle designed for the elderly, weak, and handicap in the era of advanced age. It features convenience in getting on and off the car. Japan, a country of seriously advanced age and car industry, has the most welfare cars. The development of welfare cars started after the mid 1960s and has not been emphasized until after 1990s. Since then, the number of welfare cars has increased and so has the assistant facility. After 2000, a compact welfare vehicle was introduced by a Japanese car manufacturer. Though it is space-limited, it brings great convenience to the users who have aged elders, making welfare

cars popular in public (Minoru, 2004). Currently, there is no specific definition of a welfare car in the world but any vehicle that has assistance equipment belongs to a welfare car. According to JAMA (2011), welfare cars can be divided into delivery and self-operation types. For the self-operation type, there are assistant devices for drivers of hand or foot-handicap. For the delivery type of welfare vehicles, there are rotary seat, lifting assistant seat, lifting back seat, move-in wheeler, and lifting wheeler. Most welfare vehicles are equipped with the rotary seat. Because the assistant devices need a lot of space, the price goes with the complexity of the device.

The electric car is more suitable in the urban area in that the efficiency of energy transmission of electricity driven vehicles is much higher than that of internal combustion engines, 35% for electric cars versus 8.6% for the internal combustion engines (Yoshimi, 2010). In addition, the space for the electric motor and battery needed in an electric car is also less than that for an Internal Combustion Engine. This means that more space can be saved in an electric car. Despite of many advantages for electric cars, the battery technology is not sufficient enough. The current mass-produced electric car can reach no more than 200 kilometers. Though it may be not good for long distance journey or deliver, the electric vehicle is appropriate for the urban environment and will not cause noise and exhaust.

In this study, the compact welfare city car is based upon Toyota Yaris (3,785mm length X 1,695mm width X 520mm height) without the power seat lifter. The goal of the design is to work out some assistance interior devices to reduce the difficulties of moderate handicap elders and give them more opportunities to go outdoors.

Method

The experiment conducted in this study helps to explore the feelings, difficulties and demands the aging people have in taking current sedans so as to establish the key points for compact welfare city car.

Methodology and experimental procedure

The experiment is conducted in a participatory way. Six subjects aged over 65 in different degrees of handicap took part in the experiment and survey. From observations, difficulties the elderly people have in getting on and off the cars and problems of the current cars were obtained. The experimental vehicle was first taken to the elderly daycare center and the subjects were invited to get on and off the car and sit in the car. They were asked to do the following tasks: (1) open the rear door from the back, (2) open the door and move their feet into the car, (3) step into the car in a specific position, (4) open the door and move their feet out on the floor, (5) step on the floor and leave the car. Their behaviors were taken down by video.

To understand the situation the elderly subjects get on and off the car, two video cameras were set for video shooting. As in Figure 1, Video 1 shoots the way the subject gets on the car and the action in the car and Video 2 shoots how the subject opens the door and moves into the car. After the experiment, the content was analyzed for the key frames of pictures.

Table 2 The experimental procedure

1. Subject opens the door	2. Subject enters the car	3. Subject sits in the car	4. Subject gets off the car	5. Subject closes the door and leave
				

(Source: Russian car show Тест-драйв)

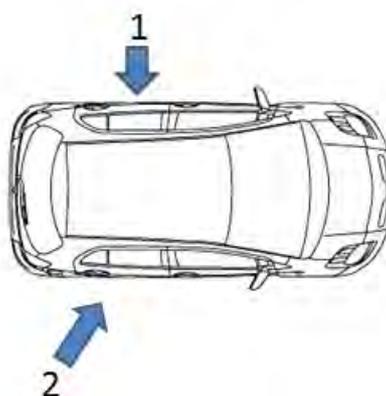


Figure 1 Positions for the video camera

Experimental materials

To make it easy for the elderly handicap subjects to get on and off the car, it is proposed to add the depth of the rear seat of Yaris. Therefore, a Toyota Wish was chosen as the experimental material because of the bigger space in the rear seat.

Physical conditions of the subjects

Among 6 elderly handicap subjects, they can be divided into three groups according to their physical conditions and walking assistant devices: crutch user, wheeler of light disabled, wheeler of serious disabled (Table 3).

Table 3 Physical conditions of the subjects

Subject code	Physical conditions of the subjects and their walking assistant devices	Physical conditions of the subjects	Walking assistant tool	Age (years)
1	Group 1: Crutch user	weak coordination due to brain surgery	Crutch	65~70
2		weakening joints and poor eye sight	Crutch	76~80
3	Group 2: lightly disabled, move by the wheeler	seated in the wheeler most of the time	Wheeler	71~75
4		weak in the right leg due to the surgery	Wheeler	71~75
5	Group 3: seriously disabled, move by the wheeler	weak and seated in the wheeler most of the time	Wheeler	76~80
6		weak in the limbs and unable to exercise	Wheeler	81~85

Results and discussions

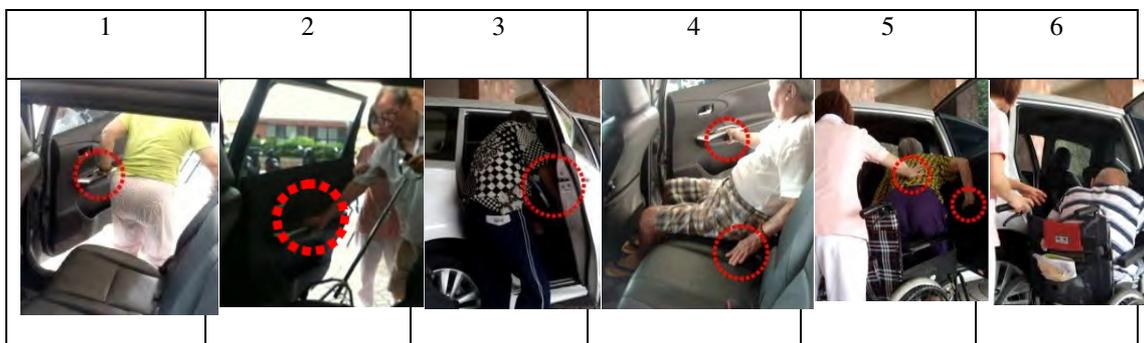
Study results

Key frames of the video were taken for analysis. There are six types of problems frequently seen in the experiment. The elderly handicap subjects had many difficulties in getting on and off the car.

Problem 1: Subjects need to hold the side handle bar to get in and off the car

From pictures in Table 4, all six subjects needed to hold the side handle bar to get in and off the car. In getting on the car, the side handle is the only support for them. In getting off the car, they had difficulties in standing. Therefore, they would hold the side handle bar to leave the car.

Table 4 Subjects hold the side handle bar to get in and off the car



Problem 2: Subjects need to hold the front seat to get in and off the car

From the pictures in Table 5, five subjects held the front seat to help them get in and off the car. It is clear that the front seat is the biggest support for the people seated in the back seat. When there is no assistant device in the car, the front seat is the major choice for the subjects to hold on for getting on and off the car.

Table 5 Subjects hold the front seat to get in and off the car



Problem 3: Subjects need to hold the seat back to move in the car

From the experiment, 6 subjects needed to hold the seat to move in the car. In getting on the car, there is no hand grip to the left. Therefore, they will hold the seat to move inside. When they prepare to get off the car, they will hold the seat with one hand to step out of the car because they don't have strong legs and stability.

Table 6 Subjects hold the seat back to move in the car



To solve these three problems, Japanese car manufacturers adopt hand bars on the back of the front seat (Table 7) for the elderly disabled passengers to hold or support their body to get on and off the car.

Table 7 Current solutions of Japanese car manufacturers

Nissan Serena	Nissan NV200	Daihatsu Tanto	Toyota Raum	Toyota Sienta
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(Source: Nissan, Toyota, and Daihatsu websites)

In Table 7, Nissan Serena is a 7-passenger vehicle, in which there is a reversed L-shaped handle bar on the back of the first row of seats and a regular size of hand grip on the door side. And on the back of the second row of seats, smaller hand bars are provided. Because of the bigger space, Nissan NV200 uses bigger horizontal hand bars and hand grips to help passengers get on and off the car. Toyota Sienta is a small-sized car and has no space for the bigger hand bars, so the hand bar is integrated with the seat. Daihatsu Tanto and Toyota Raum are also small-sized cars. Though they have big hand bars, they don't occupy the passenger space.

Problem 4: It is not easy for subjects to open the door

In six subjects, four had difficulties in opening the door because they are weak in the hands. Because of the degeneration of muscle force in fingers or arms, it is not easy for them to open the door.

Table 8 It is not easy for subjects to open the door

1	2	3	4
			

Problem 5: It is not easy to push open the door because of the feedback force

From Table 5, four subjects had difficulties to push open the door due to the feedback force of the door. They are weak in muscle of their arms, it is not easy for them to push the door in one trial.

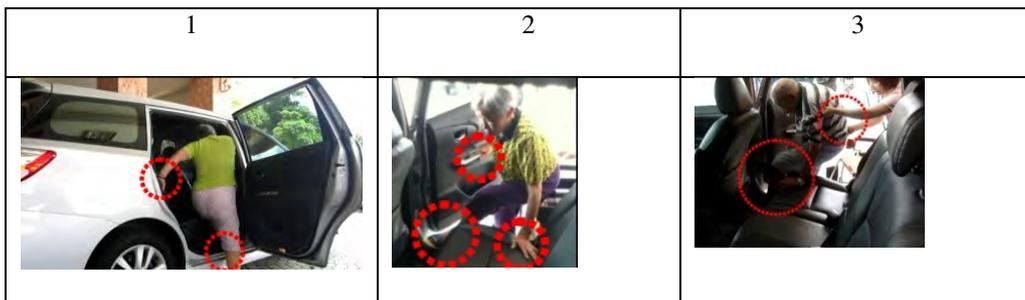
Table 9 It is not easy to push open the door because of the feedback force

1	2	3	4
			

Problem 6: It is not easy to get on the car because the car and lower part of the door is too tall

From pictures of Table 10, three subjects had difficulties in getting on the car because the car and lower part of the door is too tall. The reason is that the elderly subjects are weak on the knee and joints, so they don't work well in extension and supporting functions, leading a problem in getting on the car. Japanese car manufacturers have solutions to problems 4 to 6 listed in Table 13.

Table 10 It is not easy to get on the car because the car and lower part of the door is too tall



To cope with the problem in opening the car door, Japan car manufacturers enlarge the hand bar, add the width or thickness to reduce the pushing force so that it will be easy for the elderly passengers to open the door. For the problem of feedback force, a sliding style is used to replace the regular door opening way. For problem 6, car manufacturers lower the car height or car floor to 330mm~370mm.

Table 11 Solutions in current Japanese car manufacturers

Honda Freed	Mitsubishi ek	Back seat can move back and forth	Lower the height of the car floor
			

(Source: Honda, Mitsubishi, Daihatsu, and Suzuki websites)

Discussions

From the experiment, six kinds of problems were identified from the elderly subjects and their redesign and solutions are listed in Table 12.

Table 12 Problems elderly subjects have in taking the car and their redesign and solutions

Problems in taking the car	Solutions and redesign
----------------------------	------------------------

1	Elderly disabled subjects need to hold the side handle bar to get in and off the car.	Improve or add the hand bar to help get on and off the car; the hand bar can be stored or hidden.
2	Elderly disabled subjects need to hold the front seat to get in and off the car.	
3	Elderly disabled subjects need to hold the seat back to move in the car.	Add a hidden hand bar on the ceiling to help elderly disabled people move their bodies.
4	It is not easy for elderly subjects to open the door.	Adopt the sliding way to open the door (available in many current cars).
5	It is not easy for elderly disabled subjects to push open the door because of the feedback force.	
6	It is not easy for elderly disabled subjects to get on the car because the car and lower part of the door is too tall.	Reduce the height of the lower part of the car door (available in many current cars).

Problems 1 and 2 happen in getting on and off the car. Currently, Japanese car manufacturers have offered hand bars for the elderly passengers to hold and get on and off the car. A hidden hand bar is proposed in this study on the door side and upper part of the door. They will lower or arise when the car door is opened and will be hidden when car door is closed.



Figure 2 The holding bar on the door and hand bar on the ceiling

(Source: Daihatsu website)

Problem 3 frequently occurs when the elderly disabled subjects move in the car. It is often the case that the elderly passengers are unable to move to a proper place in the car, causing inconvenience in the action. Because of no assistant device, the elderly passengers need to rely on the front seat to move their body in the car. It is suggested to have a hidden hand bar on the ceiling above the rear seat. The hand bar will make it possible for the elderly passengers to support their body by directly holding the hand bar above. In addition, problems 4 and 5 are related to the door open problem. Currently, the best solution to this problem is the sliding style door opening system. It not only solves these two problems but also adds space in getting on and off the car. At last, problem 6 happens when the car or car door is too high, making it

difficult for the elderly passengers to get on and off the car. Doubtlessly, the decrease of the car height and the car door is the way current Japanese car manufacturers adopt to solve the problem. It will make it more convenient for the elderly passengers to get on and off the car.

Conclusions and suggestions

Physically disabled aging passengers have most difficulties in getting on and off the compact city vehicle. Another problem lies in the fact that they don't have enough muscle force in opening or closing the door. The high car door is still another problem. Currently, car manufacturers adopt hand bars in the rear seat and hand grips on the door side, sliding car door opening system, and reduce the lower part of the car door to help elderly passengers get on and off the car. A hidden hand bar in a proper place that can be stored when it is not used is proposed in this study to directly support the elderly passengers and make it easier for them to move inside the car and get on and off the car. Though we also conducted a questionnaire survey in the observation, the subjects are aged and have difficulties in expressing their ideas, causing an improper validity. In the future, a concise questionnaire survey should be designed so that it will be easy for the elderly subjects to answer the questions. In the study, only six subjects were recruited. More subjects may be invited to improve the validity in the future.

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KEYNOTE PRESENTATION

INcredibles: An artistic Perspective on CorporEal Design

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KEYNOTE PRESENTATION

ABSTRACT

In the collective search for self-realisation and improvement, societies around the globe engage in experimenting with medical technologies and procedures, supported by expanding industries. With the help of scientists, surgeons, psychologists and personal trainers the human body has become the subject of design, a luxury item and a commodity to be optimised and aestheticised. The paper critically reflects on the phenomena of body customisation and poses questions around how these developments may affect people's perceptions of identity and in which way the experience of the sensible world may be altered or extended. The paper reports on an ongoing artistic enquiry, and particularly focuses in the works of three recent exhibitions. There, artistic strategies with an affinity to Critical Design have been combined with surgical techniques in order to create discursive objects. The investigation suggests a possible "Corporal Design"-practice and sees the emerging field as the ultimate 'embodiment' of material culture. Through the making of critical, artistic objects and fictional products it assesses relevant cultural, social and political metamorphosis happening skin deep.

Starting from the theses that the human body is unspecialised, not particularly well-adapted to any ecological niche and for this reason rather vulnerable, the philosopher Arnold Gehlen defined the human being as a *Mangelwesen* (lacking being) (Gehlen 1940). In order to survive, humans transformed themselves into 'prosthetic beings: They developed artificial environments, using tools to increase their physical and mental abilities and invented innumerable artefacts to define, communicate and sharpen their identities. Yesterday, humans, invented wheels and metal wings, in order to increase their mobility. Today, thanks to medical advancements and plastic surgery, people enlarge their breasts or genitals to increase their attractiveness and pleasure or they modify their facial features and body contours to compete, for example, with members of the same species for jobs in a competitive environment. The increase in body modification for aesthetic reasons using invasive medical procedures is a fascinating as well as deeply disquieting reality. Without doubt, plastic surgery is a form of empowerment and affects people's perceptions of identity: their own, and that of others. What started out with a medical necessity, the re-construction of body parts after World War 1, (Fig.1) has a century later moved into a flourishing industry on an inter-cultural scale.



Figure 1. Soldier Walter Yeo after the re-construction of his face in form of a mask in 1916

The discussion on how the body can be tuned, pimped up and modified is in full race. Accessibility and the right to choose from what is available on the globalised markets seem to have become an overriding value in all liberal-democratic consumer societies. The field of cosmetic surgery is not an exception, and prices for the use of state of the art medical technologies are dropping. The freedom of choice has captured peoples' imagination also when it comes to thinking about their own bodies. It seems as if what is medically possible, aesthetically desirable and ethically 'just' acceptable gets realised. The scope of these practices create controversy about what is 'natural' or normal. What is norm, is a social construct, what is healthy, beautiful, just harmful or truly irresponsible is to be discussed.

For the past 18 years I have been exploring these phenomena, since they are inextricably connected to normative aspects of aesthetising the body, which traditionally touches the field of jewellery and body adornment. My research enquiry has been looking at jewellery as a cultural prostheses aiming to extend or update the definition of body adornment. Through the making of critical, artistic objects or the design of

fictional products I contemplate and reflect on these wider cultural, social and political metamorphosis happening skin deep. Currently, I have appropriated surgical skills and medical technologies in order to further explore the many factors that are challenging contemporary living and which have or will affect human's perceptions about themselves.

About two years ago I reached a point where sighting specialised literature and following the debate within academic communities as much as within the public opinion, was not satisfactory anymore in order to understand the complex phenomena of plastic aesthetic surgery. The more I knew, the less I trusted second hand sources. After working at the periphery of the topic for so long, it became necessary for me to get closer to the main stakeholders, patients and surgeons, and gain direct access to what is NOT discussed and maybe hardly ever talked about: With this I mean, I decided to "go in", to enter operation theatres and spend time alongside surgeons to see and learn. After some time, I found an experienced female plastic surgeon from the French-part of Switzerland who was interested in a dialogue and invited me to watch her operate in a PRIVATE Clinic. Interested in art herself and in interdisciplinary research, we identified common ground and talking to her and ultimately also to her colleagues, assistants and clients opened further doors, so that perceptions shifted and new questions evolved through watching and listening.

One of the first acknowledgements was that distancing and depersonalisation become unavoidable imperatives, when the body appears to be first of all 'material' in the surgeon's hands. Under narcosis, the 'individual' and 'character attached to the body has to move out of sight', states the surgeon I work with. She has to deal with the physical body safely, effectively, professionally and without delay. During the operation there is little time for doubts but still enough time for the unexpected. According to the philosopher Donald Schön, 'complexity, uncertainty, instability, uniqueness and value conflict arise at the meeting point between traditional patterns of practice and the reality of a practice' (Schön 1983:18). From the perspective of a reflective practitioner, there is hardly any other place, where the discussion about tacit knowledge becomes so crucial, as at the intersection between body and surgery. Each body is unique and the risk patients accept to take, felt much more real after having attended several operations, where the body was submitted to 're-construction'. As a trained craftsman and designer-maker I could appreciate the manual skills of the surgeon, aiming to do a good and possibly perfect job, in the same way that the craftsman defined by sociologist Richard Sennett would. I could also sense her ambition to design the body towards the ideal agreed with the patient, in pursuit of a particular aesthetic vision. Through observing the surgeon and interviewing her and her colleagues it became clear to me, that surgery means 'designing' and 're-designing' body parts, creating body images and participating in subject constructions, which are also the territories of art and design. I also realised that body parts can become artefacts, commodities, even luxury items, moving from nature to material culture and becoming uncanny "incarnated objects". Their

fragmentation and disconnection from a unique 'entity' called 'human being' is problematic and rushes society to address philosophical issues and enter a new existential landscape.

In this quest of enhancing, improving and optimising the body, it appears that people choose to take considerable risks and expectations seem to out-rule fear. After witnessing surgical interventions, I became aware of the body's fragility and vulnerability but more so, of its tremendous malleability, its plasticity and capability to recover from the often heavy physical incisions and interventions. There must be another kind of 'return' beyond improvement and aesthetics, and also beyond the overcoming of often considerable pain and psychological assistance. The body is all we have, and precisely because of this, it has become a precious reservoir of empowerment and territory for self-realisation, where individuals are fully in charge. The Australian artist Stelarc (currently Professor at Brunel University, London), has dealt with such issues in a pioneering way. Since the mid-80's he experimented with his own body and declared the human body as obsolete. Nowadays he further radicalises his position and states: '*We inhabit an age of Circulating Flesh. Organs are extracted from one body and implanted into another body. (...) Engineering organs through stem-cell growing (them) or Organ printing (them) will result in an abundance of organs. An excess of organs. Of organs awaiting bodies. OF ORGANS WITHOUT BODIES.*' (Stelarc). Influential art and design exhibitions, like *Posthuman* (London, 1992), or the more recent *Entry Paradise* (Essen, 2006) or the 3rd triennial for contemporary art, fashion and design, symptomatically entitled *Superbodies* (Hasselt, 2012) have also contributed to the current interdisciplinary debate. But, while these scientific, artistic, philosophic or media-driven debates take place, peoples' fantasies are already ahead and find their way into popular culture.

The internet-phenomena of caricaturising celebrities, by photoshop-ing their look, has become an extended hobby. A remarkable creativity is out on the net, where users deal with emotional responses to the body images distributed by the media. Other communities entangle in actual surgical interventions at the edge of legality in order to reassemble their idols, for example, enlarging their ears, in order to look like elves. People also dream of extended functions to improve and design their bodies, for example opening doors with a security chip-implant. Not less controversial is the sex-appeal of cyborg-like attributes, like the success of Aimee Mullens, an athlete with artificial legs, as a fashion catwalk model for Alexander McQueen in 1999. Aestheticised high-end products do certainly function as talking points and transform what was before a handicap into a potentially desirable asset. Body modification as a life-style trend belongs to the current panorama of 'total design', described by the art critic Hal Foster, where everything 'from jeans to genes' (Foster 2000:17) seems to have become a matter of design, with all the ethical dilemmas it involves. How relevant is it still nowadays to point out at the blurring line between the natural and the cultured body? Hasn't the body always been „cultured“? Is the human anatomy, just an anecdotic starting point? The philosopher Boris Groys states:

'Once people had an interest in how their souls appeared to God; today they have an interest in how their bodies appear to their political surroundings. (...) In his day, Beuys said that everyone had the right to see him-or herself as an artist. What was then understood as a right has now become an obligation. In the meantime, we have been condemned to being the designers of ourselves.' (Groys 2010: 36)

In the contemporary quest of self-design, the pertinence of placing objects ONTO the body, in order to enhance people's identity and to reflect their social and cultural standing, their life-style and individuality, has shifted under the skin. Despite the radical move INTO the body itself, the function, language and procedures in self-design follow very closely the tradition of body adornment and jewellery. But if design history could trace the lineage of designers for the body, today the question about who are the actual professionals engaged in designing 'the' body becomes tricky. Are they Medical Researchers and Surgeons? Is it the film industry or life-style journalists? Gym personal-trainers? Or Therapists and Psychologists? The objectification and customisation of the body implies design and engineering activities. Medical advancements have made it possible to fine-tune and shape the body in such ways, that we are not far from having to think about 'Corporeal Design' as an emerging field. I like to propose a possible "Corporeal Design"-practice in an interdisciplinary forum (bringing Art and Design practices together with Medical and Social Sciences, Engineering among others) to constitute a ground for debate and research, in order to provide a much needed CRITICAL voice BEYOND market driven goals.

My current artistic research tests the scope of such Corporeal Design hypothesis through actual making, through playing with physical plausibilities and to a certain degree ridiculing or exaggerating what may be possible from a pure medical-scientific perspective. In three exhibitions, all shown in 2010, I presented objects and installations, responding to factual, fictional and ethical dimensions of the subject.

The first show, the group exhibition *Des Seins a Dessein* (Breasts to Design) at the Museum ESPACE ARLAUD in Lausanne (CH), was initiated and set up by two engaged women, a Curator and Art Historian and a Plastic Surgeon, for the benefit of a Swiss Breast Cancer Foundation. For this show I developed a floor-based installation, consisting of three pieces in tubular chrome-plated structures, and leather surfaces with superimposed wax elements (Fig.2). A stretcher, a chair and a coat-rack, all placed in the centre of the room were referring to public as well as domestic furniture, offering various readings, including a comment on the obsessive and fashionable gaze on the medical body (Fig.3)



Figure 2. exhibition view; Espace Arlaud, Lausanne Fig.3. detail

The works belong to the ongoing 'FROM THE INCREDIBLES- SERIES', where I make use of exaggeration as critical strategy, in order to explore the spectacular side of medical body modification and its psychological implications. The series builds on the conceptual ground of FOREIGN BODIES, a former work in BIO-COMPATIBLE medical-grade steel (implantable) and OSSARIUM ROSE, a series of bone-like work, flocked in a pinkish colour, which set out to seduce as well as irritate also through its furry surfaces.

The second exhibition at Gallery Marsden Woo, London, entitled BIGGER THAN THE REAL THING, was set up as a joined show with artist Emma Woffenden. Our aim was to create a discourse around bodily expression as a contemporary as well as ancient neurosis that overwhelms imagination and which language may sometimes struggle to express. While Emma's work in glass and white plaster was all placed as sculpture in the centre of the space, most objects I showed 'FROM THE INCREDIBLES- SERIES' were wall-mounted, referring to domestic coat hangers, suggesting usability and function (Fig.4, 5)



Figure 4. wall-piece, from the Incredibles-series



Figure5. surface detail

Coated with a matt and soft layer of black rubber, these works optically resisted easy identification of contours and structural details. The ambiguous surface demanded closer inspection. In one piece the modular construction of the work commented on limb-lengthening another on the 'fetishisation of choice' (various differently shaped nipple-like elements) when it comes to body contouring. (Figs 6, 7). Some pieces allowed for interaction.



Figure 6. exhibition view; Marsden-Woo Gallery, London, wall-piece, and Figure 7.. detail

The third exhibition at ANNEX, an independent Art Space connected to Gallery ViceVersa in the City of Lausanne, also run for two months in parallel to the group-exhibition at the Museum ESPACE ARLAUD. This show offered me the opportunity to create a more complex environment in a single room with an oversized bay window, which amplified the impression of exposure and echoed a sense of clinical vulnerability inherent in some of my works. (Fig.8)



Figure 8. exhibition view; Annex independent Art Space, Lausanne

Stainless-steel catering-trolleys and industrial kitchen furniture were used as display structures, establishing a strong contrast with the works in Madame Tussaud's wax presented on their smooth cold surfaces. The

choice of this particular wax (skin coloured, hard and stable) allowed me both to explore form, (exaggeration in a cartoon like manner) but also 'formlessness' through bodily warmth. (Fig.9, 10)

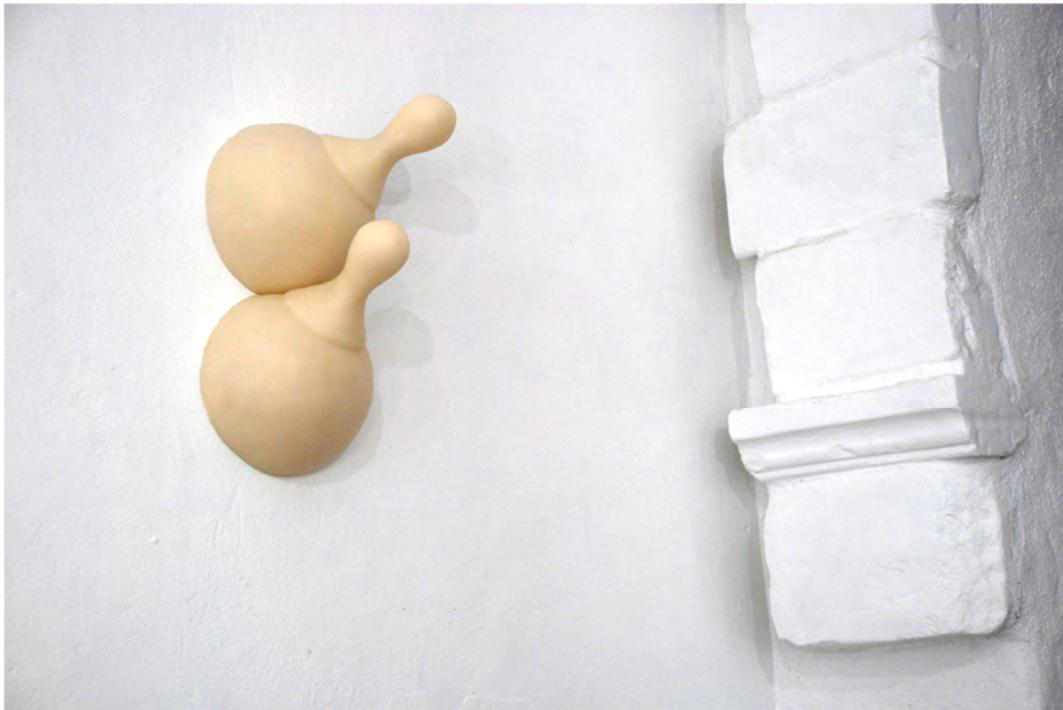


Figure 9. *Boobs*, wax



Figure 10. *Excess-pieces*, wax

By contrast to the works in wax, other works showed naturalistic body parts with detailed finishings in a cool white porcelain, like the over-sized arms with just two, respectively three fingers, capturing precise movements connected to routine postures, like scrolling on a touch-pad. Entitled *Plug-ins* and *Add-ons* these works referred to fictive implants and wearable computing. (Fig.11, 12, 13)



Figure11. *add-ons*, from the *plug-ins* and *add-ons-series*, porcelaine, rubber



Figure12. *add-ons*, porcelain



Figure13. *add-ons*, porcelaine

Finally, *26 Stitches* was the title of a wall-piece constructed in leather in the shape of an oversized medallion or an oval mirror frame. It showed a nipple-areola re-construction, using the technique surgeons craft them by cutting, forming and stitching the human skin in such a way, that the previously amputated body part will again appear as 'natural' as possible. (Fig.14)



Figure 14. *26 stitches*, leather

The three exhibitions reported in this paper summarise the interdisciplinary nature of my ongoing research and artistic practice. Customising and enhancing the body is an emerging and complex field for critical debate: 'Corporeal Design' does not only changes the body, it changes people, it changes peoples outlook on life, their body language, their desires and mental set up. The real questions around how these developments may affect people's perceptions of identity, the existential and spiritual dimension of the individual and in which way the experience of the sensible world will be altered, limited or even extended, will keep us busy in years to come.

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