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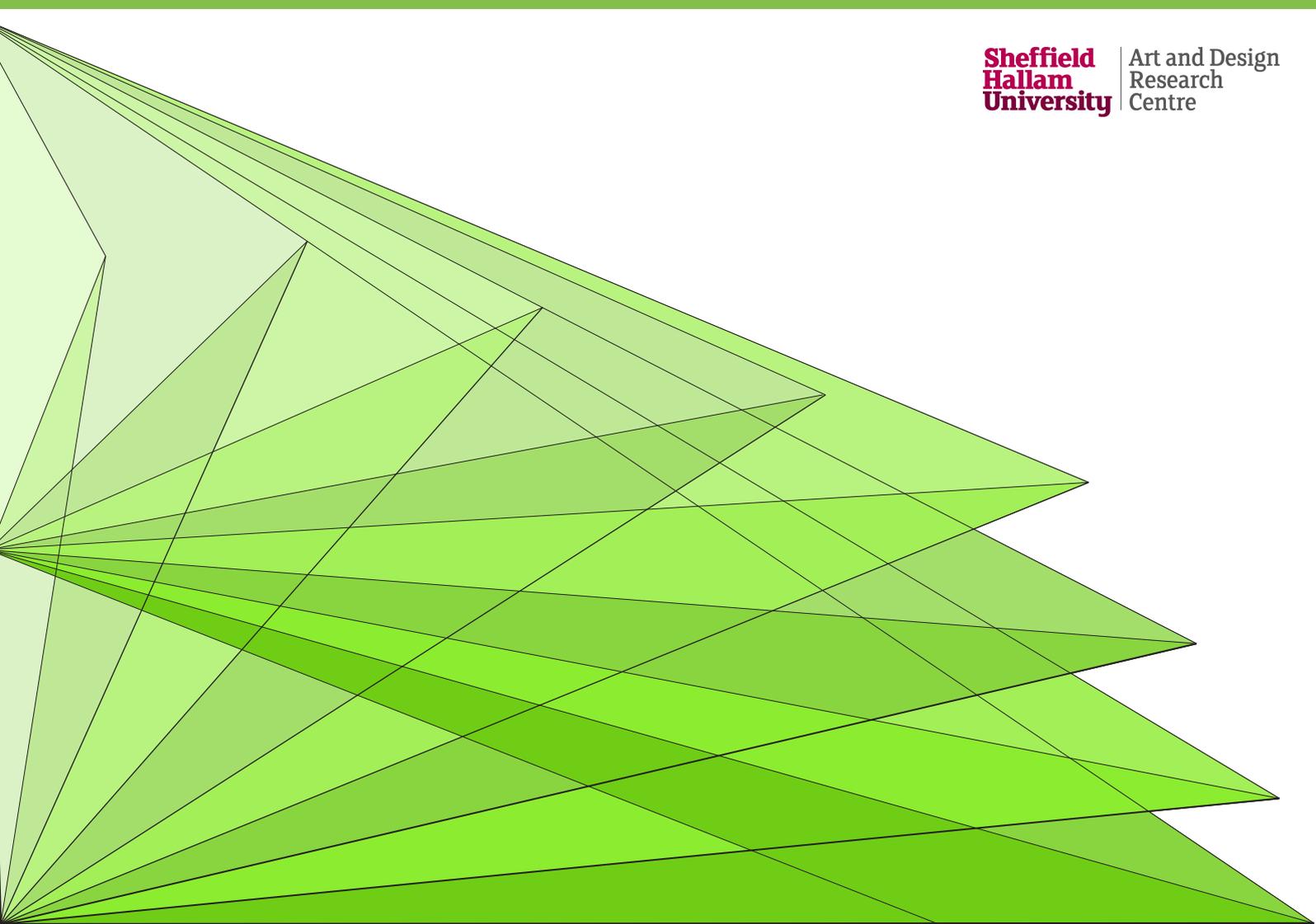
# Design 4 Health

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

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

Volume 2

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## **Dignified Spaces: participatory work de-institutionalises rooms in the heart of the clinical environment**

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### *Abstract*

*There is increasing recognition of the need to treat not only patients but also families and carers with dignity, particularly at times of stress. New hospital design includes rooms variously labelled 'Quiet', 'Family' or 'Interview' for these purposes. This paper reports on the design process used during the development of the New South Glasgow Hospitals to meet user and service owner needs. The artist leading the project utilised a biophilic design approach and a participatory process of working to both understand users' issues and also to involve users in the design of elements of the scheme.*

Keywords: dignity, art and design, families and carers, conversations,

## Background

The on-going work that this paper reports on is underpinned by the question, 'What does dignity mean to users and how can an understanding of dignity inform the design process?'

"The hospitals should be an iconic development portraying a positive image of the NHS, reflecting their importance and communicating respect and concern for the needs of patients, families and carers."

Patient dignity has become an increasingly important aspect of healthcare, as evidenced by the above statement from NHS Greater Glasgow and Clyde (NHSGGC) Community Engagement Team report (2009) underpinning design of the new 160,000sqm adult and children's acute hospitals being built on the site of the Southern General Hospital in Govan, Glasgow.

The *Working Well People and Spaces: Therapeutic Design and Art Strategy* (2011) for NHS Greater Glasgow and Clyde's (NHSGGC) New South Glasgow Hospitals (NSGH) has a key focus on patient dignity and participation. The Strategy for the New South Glasgow Hospitals has been developed by Brookfield Multiplex's public art and design consultants, Ginkgo Projects.

This paper provides a reflection exploring the process of creative practice and innovation in the ongoing Dignified Spaces project which forms part of the *Working Well People and Spaces* strategy.<sup>1</sup> Whilst the priorities for hospital design were developed by NHSGGC Community Engagement through public consultation, co-creative and participatory processes used by artists and designers are different (and also distinctive from user-centred design if it involves the participants directly in producing the work rather than just informing it). One aims to be democratic, seeking to synthesise the views of a wide range of people including specific groups with particular needs. The other works with a small group through a creative process to produce a 'work of art' whether that be a performance or installation or, as in this case, designs for rooms in a hospital. For a more detailed reading of this issue see Fremantle and Harris (2013).

The Dignified Spaces project addresses some 80 rooms variously labelled Quiet, Interview, Relatives or Family Rooms on the plans for the new hospital buildings. We will call them Quiet Rooms for the purposes of this paper. Of the 80 rooms in NSGH, 21 were prioritised and of these five were identified as the most important. The prioritisation was undertaken by the NHSGGC Capital Planning Team. Highest priority was given to rooms in areas where staff most regularly deal with very stressed families, relatives and carers including the Emergency Department, Critical Care Unit, Child Protection Unit and Body Viewing Rooms.

The Dignified Spaces project was approved as one of eight core elements in the Therapeutic Design and Art Strategy for NSGH. An Open Call was held and the artist Alexander Hamilton with a team including Catalog Interiors and Grazyna Fremi, Curator were selected. The team has expanded to include other designers and experts, as noted below.

The Brief for the project asked the appointed team to work with the lead architects to develop wall colour and flooring designs for all 80 rooms, and contribute wall coverings, artworks, lighting and furniture for the 21 prioritised rooms. Lighting in all the rooms will be 3500 Kv rather than the

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1 The project will be completed prior to handover in early 2015.

normal hospital 4000 Kv creating a sense of warmth in comparison to the clinical environments. Furnishings for the remaining 59 rooms will be supplied by NHSGGC.

## Context

The need for Quiet Rooms has emerged within hospital design and in NHS Greater Glasgow and Clyde (NHSGGC); this is the first generation of buildings in which these spaces are included as part of the Employer's Requirements. These spaces are used for a range of purposes of which the most important are conversations between clinical, nursing or spiritual care staff and patients' relatives and carers.



Figure 1: Existing Quiet Room in Emergency Department (2014). Photo: Chris Fremantle

Previously these types of spaces have been created in older buildings as part of refurbishment programmes. For instance they exist in the Emergency Department and Critical Care Unit at Yorkhill Children's Hospital, Glasgow. Although located in clinical areas, these spaces are used for a range of non-clinical purposes of which the most important are the 'difficult' or 'challenging' conversations. They are also used by relatives and carers waiting to have conversations with healthcare professionals. Waiting can be for significant lengths of time and is frequently a stressful experience. Whilst these rooms can be used for other purposes, e.g. staff meetings, their primary function is not best described as a 'meeting' room because of the emotional nature of the conversations that take place. It is also important to understand that the function goes beyond that of a waiting room, which is a holding space for something important that happens elsewhere.

These spaces are places in themselves, distinct from wards, treatment rooms and theatres. They indicate that the experience of families, relatives and carers is also considered.

The existing precedents for these spaces are developments such as Maggie's Centres and initiatives within the King's Fund *Enhancing the Healing Environment* Programme.

There are two requirements for these rooms. On a practical level the rooms need to be comfortable, safe and quiet. They also need to convey that users of the rooms are being treated with dignity. We understand dignity to mean that the user is treated as an individual. To convey this quality of being treated as an individual we have sought to achieve a level of de-institutionalisation, by which we mean distinctiveness from the surrounding (institutional) environment. The potential for creating de-institutionalised spaces is constrained within an acute hospital setting. Particular factors are infection control, maintenance and renewal. All of these rooms are located in clinical settings. Staff will be moving from clinical areas into these rooms and back again, creating a risk for infection control. The rooms, their fixtures, fittings and furnishings must therefore meet the same cleaning standards as other areas of the hospital. In terms of maintenance and renewal, NHS budgets are constrained and focused on clinical need. This gives rise to a possible dichotomy between distinctiveness and clinical imperatives which the team (with staff input) must negotiate.

## Biophilia Informed Design Approach

The approach by Alexander Hamilton and his team in preparing design ideas for these rooms has been to use biophilic design to bring nature into these rooms.

The term biophilia first came to prominence in the eponymously named book by the biologist E. O. Wilson. Wilson says of biophilia,

"...which I will be so bold as to define as the innate tendency to focus on life and lifelike processes."

Biophilia, whilst remaining a hypothesis, has become increasingly influential in design. Hamilton draws on the aesthetics of John Ruskin, the Victorian artist and critic, to inform his understanding. Alan Davis says in his introduction to the exhibition *Ruskin's Organic Vision: Nature, Life and Art* (2005),

"...his 'organic vision': a way of seeing the natural world as an integrated whole, resembling a living organism in which the component parts undergo individual variation and growth, subject to certain fundamental laws of life."

Robert Ulrich makes a specific case for biophilic design in healthcare to address the challenge of stress (Ulrich, 2008, p.88-89) saying,

"Stress is central to understanding how biophilic design, and healthcare physical environments more generally, can influence outcomes (Ulrich, 1991, 1999, 2006). ... In addition to afflicting patients, stress is also a burden for families of patients and visitors, and a pervasive problem amongst healthcare staff. "

As noted the Quiet Rooms were identified as locations where stress was a particular factor, and they were also prioritised based on the perceived levels of stress likely to be experienced in them. The stress obviously applies both to the families and carers as well as the healthcare staff.

Another related area which helps to understand the value of biophilic design is Kaplan's Attention Restoration Theory. 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. Attention is a key factor specifically in relation to conversations with healthcare staff. For a more detailed reading see Fremantle (2011).

A number of visual artists currently working in Scotland on projects in healthcare contexts (in addition to Alexander Hamilton), including Dalziel and Scullion, Donald Urquhart, and Emma Varley as well as the poet Thomas A Clark all articulate versions of biophilia as fundamental to their design processes. See Fremantle (2014) for examples of some of this work.

Hamilton and his team used the analogy of walled gardens to give a practical dimension to the broad idea of biophilic design. This was further reinforced by the use of an actual walled garden as a site for creative engagement (see below), informing the development of the designs. Hamilton highlighted certain key aspects of walled gardens including the aspects of care, the functional and reflective quality of the space, the greater warmth of the spaces (making them suitable for vulnerable plants) were also relevant characteristics for the designated rooms.

The Walled Garden concept fitted within the overall *Working Well People and Spaces* strategy theme 'layers within the landscape', and helped to underpin the wayfinding strategy for the hospitals. It also acknowledged the control and management of a space, translating from gardening to healthcare and the requirement to meet levels of infection control and to provide appropriate hygienic regimes required in the acute hospital context.

## Engaged Design Process and Partnerships

To drive the biophilic design, a process of creative engagement was undertaken. This was supported by a New Sponsor Award from Arts & Business (Scotland),<sup>2</sup> in a partnership with Ginkgo Projects, Public Art and Design Agency,<sup>3</sup> and Teal Ltd,<sup>4</sup> a leading UK furniture manufacturer. The aim was to deliver an enhanced program of creative engagement focused on the meaning of dignity. The benefits to the commercial sponsor are to develop a clear understanding of dignity in this context and to inform their design approach to healthcare furniture. It was agreed that the process would be publicly accessible through a website <http://designingfordignity.co.uk/>, an exhibition at The Hidden Gardens<sup>5</sup> and a publication. This paper forms part of the process of making the creative engagement publicly accessible.

There were two strands to the engagement process.

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2 <http://www.aandbscotland.org.uk/> accessed 03 January 2014

3 <http://www.ginkgoprojects.co.uk/> accessed 03 January 2014

4 <http://www.teal.co.uk/> accessed 03 January 2014

5 The Hidden Gardens is a public greenspace and community development organisation located in Glasgow. <http://thehiddengardens.org.uk/> accessed 03 January 2014.

- Workshops at The Hidden Gardens with volunteers drawn from both The Hidden Gardens' own programme and also from the Community Engagement Team's volunteers.
- 'Clinical conversations,' meetings between the Lead Artist and key Service Owners. These emerged because of the difficulty in securing the participation of clinical staff in the workshops at The Hidden Gardens.

Ideally both strands would have included creative activity, but the clinical conversations took a more pragmatic form, focusing on the practical aspects of the uses of the Quiet Rooms.

## Pattern of activity: Workshops

Table 1: Workshops

Date	Location	Participants	Focus
15/05/13	The Hidden Gardens	NHSGGC Staff and Volunteers from The Hidden Gardens	Perceptions of Hospitals
29/05/13	The Hidden Gardens	NHSGGC Staff	Infection control and cleaning regimes
08/06/13	Elder Park Farm	Volunteers from EPF	Community Farm
09/06/13	Forth and Union Canal	Volunteers/ Hidden Gardens team	Healing and Edible Plants
11/06/13	Battlefield Primary School	Children and class teachers	Uses of plants
19/06/13	The Hidden Gardens Workshop led by medical herbalist	Volunteers and staff Hidden Gardens	Healing and Edible Plants
22/06/13	The Hidden Gardens	Open Day at The Hidden Gardens	Storytelling and plants

Participants had been selected by the NSGH Capital Planning Team and Community Engagement Manager. Non-clinical participants were active volunteers within local hospitals. Some were also representatives on NHSGGC Panels (e.g. Better Access to Health), or volunteers with The Hidden Gardens. Some of the NHSGGC nominated participants had helped to advise on the selection of

furniture for other hospitals. Clinical participants were nominated for their relevance to contribute ensuring the design met clinical and users' needs.

A typical workshop began with the participants walking with the Lead artist around the garden. This set the stage for the workshop, where the garden became for the day 'a laboratory,' a place to listen to nature, to discuss ideas on dignity within clinical spaces and to make an image from nature.

The garden was also a place to rebalance the participant's engagement, so that the presence of nature would help to guide the participant's responses. The morning session (held within a Yurt within The Hidden Gardens) was devoted to considering the design elements within the room; the furniture, lighting, wall colours etc. Participants were encouraged to express preferences, based on their own experiences of working or receiving support from the Health Service. Images of typical types of clinical chairs, or light units, and visual examples of art were presented. Individual expressed whether for example if they preferred abstract or realistic art. Natural scenes, painted or photography.

The characteristics of the institutional environment were discussed including the conservative and utilitarian character of furniture as well as the character of lighting: Strip lights were unanimously agreed to be too harsh and people felt wall lights should be used instead. Natural light was seen as essential, but where that wasn't available the idea of lightboxes with nature based imagery was supported. Participants commented that rooms should have a sofa as well as chairs. A sofa allows to people to sit together and someone can be comforted. It was also commented that in a difficult relationship it is important that everyone is at an equal height, so everyone is included. Another comment was that seating needed to accommodate the needs of different users and different levels of mobility. The tactile qualities of furniture were commented on.



Figure 2: Workshop at The Hidden Gardens 2013 selecting plant material. Photo: Alexander Hamilton.

The afternoon session was devoted to a direct engagement with nature. In some workshops, a creative writer or a plant specialist were involved. The final approach was however similar, in which the workshop participants, walked around the garden and freely chose the leaf types and flower petals that spoke to them. Their selection of plant material was then taken back to the Yurt. The participants freely choose how the various leaf and petals should be arranged on a sheet of paper. The guidance, offered by the Lead Artist, was to let Nature Speak. Some participants, found the request difficult, a concern expressed was, "I am not an artist, I can't make art." The reassurance

that they are not required to be artists, only to enjoy connecting to nature, helped free up the creative responses.

Individuals chose plants for a range of reasons. One individual chose the fern as he said it reminded him of Christmas with his family. It also spoke to him because he saw it as ancient and powerful, growing on the planet whilst dinosaurs walked the earth. Another chose wild garlic. She is a passionate cook and is interested in both the healing and edible properties of herbs and plants.



Figure 3: Workshop at The Hidden Gardens 2013 arranging plant material. Photo: Alexander Hamilton



Figure 4: Workshop at Battlefield Primary School 2013 arranging plant material. Photo: Alexander Hamilton

The participants then transferred the plant leaves and petals to paper prepared for making cyanotype images and placing them under glass; the pressed plant forms were exposed to sunlight. In the garden shed, within the grounds of The Hidden Gardens, a temporary photographic studio had been set up and the cyanotypes, or 'sun pictures,' were then developed and hung to dry. At each stage, the workshop participants saw the process unfolding. From the

selection of leaves, to making a picture, to creating a photogram and finally to seeing the result



(web site for video clips of this process- [www.designingfordignity.co.uk](http://www.designingfordignity.co.uk)).

Figure 5: Workshop at The Hidden Gardens 2013 selected plant material under glass. Photo: Alexander Hamilton.

At the end of day workshop all the cyanotypes were viewed by participants and further discussion was held on the how the images would be used, in the furniture and other design requirements. The Lead Artist explained that the cyanotypes would drive the design process and be used to bring nature back into the clinical environment. The platform for these images would be fabric to be used on the furniture and wallpapers to be used within the clinical rooms. The challenge was to engage and direct these visual outcomes towards the complex arrangements that control the delivery of design within clinical spaces.



Figure 6: Workshop at The Hidden Gardens 2013 completed cyanotypes. Photo: Alexander Hamilton.

In return for their engagement the commitment was made to keep participants informed and return regularly to The Hidden Gardens to present the results of the design development process.

A travelling exhibition of the key results from the community engagement process was also prepared. The exhibition was launched at The Hidden Gardens January 2014 and then to be toured to all the hospitals who were involved in the clinical conversations. Yorkhill, Western Infirmary and Southern General Hospitals.

## Pattern of Activity: Clinical Conversations

Table 2. 'Clinical Conversations'

Date	Participants	NHSGGC Facility	Focus
11/06/13	Occupational Therapist	Royal Alexandra Hospital	Current use of Quiet Room - scope for improvements
02/07/13	Manager Infection Control	Royal Hospital for Sick Children (Yorkhill)	Introduction of design elements (type of fabric used etc) into clinical rooms.
02/07/13	Lead Nurse in Emergency Department	Southern General & Western Infirmary	The use of quiet rooms and design preferences
02/07/10	Lead Nurse Coronary Care	Western Infirmary	The use of quiet room and design preferences
31/07/13	Staff Nurse	Victoria Hospital	The use of quiet room and design preferences
16/08/13	Consultant and Nurse, Paediatric Emergency Department	Royal Hospital for Sick Children (Yorkhill)	The use of quiet room and design preferences
3/09/13	Clinical Director, Child Protection Unit	Royal Hospital for Sick Children (Yorkhill)	The use of quiet room and design preferences

In the conversation with clinical staff, a similar process of looking at the requirements of the rooms was undertaken. Clinical staff were happy to engage in discussion, but only in formal meetings in their offices. Each discussion would last usually for one hour.

A common concern was that they felt that the consultation process in designing the new hospital was challenging. Usually they were expected to offer an opinion on key design requirements in one brief 15 minute meeting. The focus of these consultations was on technical requirements. Methods to successfully engage creatively with clinical staff clearly need to be better considered. The conversations held by the Lead Artist in gaining their perspective on the importance of design and art did create a positive pathway. The introduction of ideas on rethinking the designs for furniture, lighting and art within clinical rooms received a very positive response. A frustration was evident in comments concerning the sterile nature of new hospitals, the removal of flowers and other items now considered unacceptable because of infection control. Anything to bring nature back in clinical spaces was welcomed.

The primary focus of discussion was on the practical aspects of the rooms including cleaning, dealing with people waiting for extended periods, security, access to refreshments, appropriate distractions as well as simple things like coat hooks. Staff noted that there was an increased expectation of access to plugs to charge mobile phones, as well as wifi. Staff made specific references to the needs in the case of bereavement, particularly in the Children's Hospital context.

Throughout the process the use of imagery drawn from nature in the design and art was welcomed by participants in the workshops and clinical conversations.

The key design characteristics identified by participants across this process can be summarised as:

- Natural lighting, or design features which provide the quality and impression of windows and daylight
- Controllable artificial lighting
- Availability of comfortable seating and furniture
- Wayfinding (clarity and distinctiveness of the room within the Department and Hospital)
- Reduction in noise level
- Movement of fresh air
- Distinctive surface treatment of walls and floors
- Provision of nature-inspired art

A number of supportive elements were also identified:

- Provision of wifi for communication
- Provision of mobile phone charging points
- Provision of tea making facilities
- Security cupboard for bags, laptops

## Design Development

As noted above the cyanotypes created through the workshops at The Hidden Gardens and other locations were developed into designs for wallpapers and fabrics. The Lead Artist worked with the designer Nicola Murray, again supported by Teal Furniture, to produce designs. Alexander Hamilton, the Lead Artist, emphasises the importance of the story of participants from the wider hospital community making cyanotypes at workshops in The Hidden Gardens clearly linking to the evolution of the designs for fabrics and wallcoverings to be installed into the new Hospitals.

The following sequence of images best articulates the development of designs from artwork to fabric and also wallcoverings.



Figure 7: Initial development from cyanotype to design for fabric and wallpaper 2014.



Figure 8: Fully developed fabric design alternatives 2014.



Figure 9: Visualisations of fabrics applied to furniture for Quiet Rooms 2014.



Figure 10: Wallcovering design alternatives 2014.

## Conclusions

The extended creative engagement process, supported by NHSGGC, Teal Furniture Ltd, The Hidden Gardens and Ginkgo Projects, has resulted in an understanding of the practical requirements of users of Quiet Rooms in acute settings as described above. There is agreement on the importance of comfort, privacy, peace, safety and security in the design of Quiet Rooms, but dignity is about the fundamental need and right for each user to feel that they can be recognised as an individual within the necessary constraints of a large institutional space. Challenges remain in securing participation in creative engagement processes beyond traditional 'consultation by meeting' with clinical and nursing staff.

Whilst there is substantial evidence of the value of biophilic design, bringing nature into buildings, this process also utilises aspects of participatory art and design to both engage individuals associated with NHS Greater Glasgow and Clyde's capital programme directly in the creative process, not as 'consultees' but as contributors.

Alexander Hamilton emphasises the importance of the story of the wider hospital community engaging in creating artworks which have been developed through a design process to be used on fabrics and wall coverings.

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# **A Participatory Journey Towards Building Competency For People With Autism Through Technology**

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*(Contribution from the "Speak up for Autism" group members)*

## **Abstract**

*Participatory research methodologies assume a level of cognition and understanding of social and political processes and embrace an explicit political agenda. This study aims to utilise participatory research methodologies to enable a group of people (adults) with Autism Spectrum Conditions (ASC) how to recognise a level of 'consciousness' in the development of themselves and in relation to the group processes. Participatory research aims to develop critical consciousness, to improve the lives of those involved in the research process, and to transform fundamental social structures and their relationship. This research seeks to enable greater accessibility of participatory research methodologies by utilising more functional and behavioural models, like Training in Systematic Instruction (TSI) and to use computer assisted learning as a method of engagement to help individuals and groups participate in a wider political and social dialogue about 'autism' as a defined condition. This study follows a conceptual understanding of autism through the lens of the social model.*

Keywords: participatory research, Autism/autism spectrum condition, technology, social model, critical consciousness, development.

## Introduction

The aim of this study is to utilise participatory research methodologies to enable a group of people (adults) with Autism Spectrum Conditions (ASC), who are concrete thinkers and sometimes unable to understand abstract concepts, to recognise a level of 'consciousness' (Freire, 1970) in the development of themselves and in relation to the group processes. Participatory research methodologies assume a level of cognition and understanding of social and political processes and embrace an explicit political agenda (Gouin, Cocq and McGavin 2011). Maguire (1987, p3) states that "participatory research aims to develop critical consciousness, to improve the lives of those involved in the research process, and to transform fundamental social structures and their relationships". Adults "are capable of learning, of changing, of acting, and of transforming the world" (Tandon, 1988, p5) is a cornerstone of participatory research.

This research seeks to enable greater accessibility of participatory research methodologies by utilising more functional and behavioural models, like Training in Systematic Instruction (TSI), (originally devised by Dr Marc Gold, an American psychologist in the mid 1970s) and to use computer assisted learning as a method of engagement to help individuals and groups participate in a wider political and social dialogue about 'autism' as a defined condition. This approach seeks to break down barriers of inclusion in social and political process and enable individual and group empowerment.

This study follows a conceptual understanding of autism through the lens of the social model (Oliver, 1983). The social model requires a level of analysis of the disabling barriers that result in exclusion from aspects of social and political life (Oliver, 2013). Being able to engage with research through participatory research methodologies requires facilitation and enablement to challenge the barriers of engagement. For people with autism, this is about challenging the abstract language of the development of types of 'critical consciousness' (Freire, 1973). Levels of analysis will involve examples of the 'translation' of political and social processes and explain how individual and group decision making processes, the skills of reflection and the feelings of empowerment are explained by individuals and the group, as a way to determine their own destiny. The focus is to examine how a newly formed self-selected advocacy group can explain the experience of 'critical consciousness' and how this in turn enables them to participate as self/peer-advocates.

While this article will focus on the development of 'inclusivity' of the theories of participatory methodology (Cargo and Mercer, 2008), (through the use of teaching methods and via a technological platform 'PebblePad'); the study will also report on the outcomes for individuals and the groups (e.g. conference presentations; published papers; influencing policy and practice, such as recruitment for employment).

There is a paucity of literature about 'assistive technology and people with autism spectrum condition' with no study entirely devoted to examine how technology can help their participation and help recognise social and political consciousness in people with autism through a process of self-development. There is an absence of literatures that explains how state of "critical consciousness" can be accessed and understood by people who are more concrete thinkers (Frith

and Happe, 1999). There is no theoretical model to explain the accessibility of participatory methodologies and the translation of key concepts such as 'critical consciousness'.

To explore the possibility of the development of social and political awareness of people with autism, I have been working with a group over the last year, called "Speak up for Autism". The Group (Speak up for Autism) is set-up by a group of self-selected people with autism within the organisation 'Speakup Self Advocacy' in Rotherham ([www.speakup.org.uk](http://www.speakup.org.uk)). 'Speakup Self Advocacy' is an organisation run by and for people with learning disabilities and/or autism with an aim to ensure that people with learning disabilities and/or autism are valued and included within society. Speakup are experts in developing and delivering accessible information, training and resources that improve the lives of people with learning disabilities and/or autism. They have a level of expertise but lack social and political consciousness. 'Speak up for Autism' have devised terms of reference for the group and have agreed to participate with co-opted research collaborators from Sheffield Hallam University.

The group has gone through a journey in the last year. The group participated in a research project as co-researchers to pilot a stress sensor device (worn as a watch) in September 2012 (the sensor seeks to measure stress level of an individual through contact between the device and the skin) in Sheffield Hallam University's ACES (Faculty of Arts, Computing, Engineering and sciences) faculty. The aim was to develop confidence and competency, build organisational skills, develop knowledge and understanding about ethical issues on conducting and participating in research, examine if a level of engagement with the stress sensor project will enable the development of knowledge and understanding of stress, measure what difference engagement with the project has made to them in terms of contributing to the self-monitoring of stress for self-management.



Figure 1: The Stress Sensor

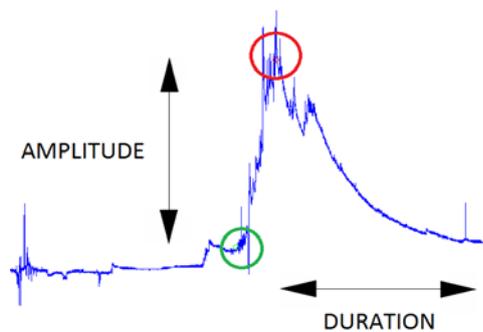


Figure 2: Mood Diary Record Sheet

The stress sensor (figure 1) with electro-dermal reads stresses level when people with autism are stressed and relaxed. The study was to investigate if the device was able to record stress experienced by physical symptoms of activity and temperature. The group members maintained a mood diary (figure 2) recording events including how stressed they felt at that particular time. The data collected by sensor were then analysed by matching them with the diary sheet to determine whether the stress sensor can identify periods when the individual was highly stressed.

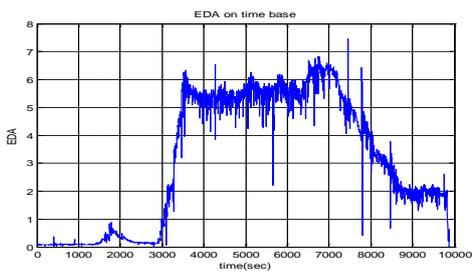


Figure 3: EDA on Time Base

activity experience and mood diary Researcher name: [redacted]

Date	Time activity happened	What were you when this happened?	What happened and how did this make you feel?	Who/when did you complete this form?	How did you cope?
8/11/12	9:00	Stood at a Bus Stop	A member of the public shouted at me for something I haven't done.	Dinnerhouse Thursday	I got a bit stressed
8/11/12	17:00ish	At home	I got home and got angry with a member of staff for not fixing my headset.	10:30 Friday	I used my Coping techniques and went for a walk.
8/11/12	Dinner time	Speechup	I got stressed when the little woman in town	10:30 Friday	I found the park and fed it.

Figure 4: Signal Characteristics

Figures 3 and 4 illustrates different level of stress at different time.

At present, the group is working on PebblePad, an online portfolio with two main components: Pebble+ and ATLAS. Pebble+ is the personal learning space where personal resources like achievements and accomplishments, CV and records of personal learning can be kept. On the other hand, ATLAS is the community space where the group can communicate with each other; share their ideas with others through blogs.

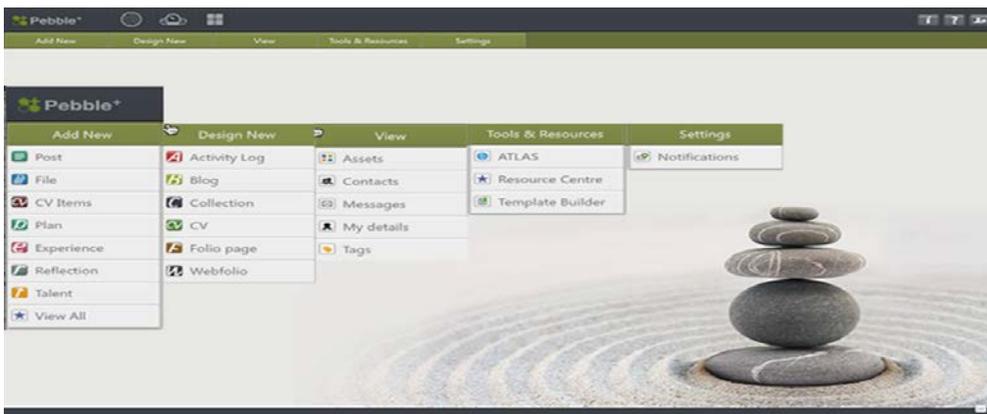


Figure 5: PebblePad

In this study, it will not be the stress sensor or PebblePad that helps them to raise critical consciousness, but will be the facilitated group processes using the tools of PebblePad and computer assisted learning.

## What is Autism?

Autism is a condition that creates barriers to understand political and social process (Swain et al. 2013). Autism affects people in different ways. Some are able to live relatively 'everyday' lives; others need a lifetime of specialist support. Yet, the right support at the right time can make an enormous difference to people's lives and help them to lead the life they choose (Bancroft *et al*, 2013). The National Autistic Society (NAS) defines autism as a lifelong developmental disability that affects how a person communicates with, and relates to other people. It also affects how they make sense of the world around them. Aylott (2003) highlighted that an understanding of autism from a social model perspective helps to explain how some individuals can be disabled in one environment, but enabled in another.

### Medical and Social Model of Autism

The medical model is presented as viewing disability as a problem of the person, directly caused by disease, trauma, or other health condition which therefore requires sustained medical care provided in the form of individual treatment by professionals. The medical model informs the definitions of the International Classification of Impairment, Disability and Handicaps proposed by the World Health Organisation (WHO) and defines disability as referred to the restriction in the ability to perform tasks (WHO 1980).

In contrast, the social model of disability (Oliver, 1983) helps to understand autism as it shifts the focus from reshaping the individual to reshaping society in terms of society's response, attitudes and accommodation of those individuals (Autism and Oughtisms, 2011). Dewsbury *et al.* (2004) coded (Oliver, 1996, p32):

It does not deny the problem of disability but locates it squarely within society. It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation.

The social model of disability has furnished a significant and empowering political agenda (Oliver 1984, 1996) and allowed the contested notion of disability to become a significant and powerful force influencing social policy (Backett and Wrighton, 2000). Social model defines a person with autism in reference to how much the society is accommodating the individual, rather than as something defined by the condition the person has. It does not seek to deny the impairments but instead focus energy and effort on 'enablers' in the environment to enhance the life chances of people with autism and tend to agree that there are sensory and communication differences, just that these are an equally valid way to operate, not a disability (Autism and Oughtisms, 2011). Shakespeare (2014) highlighted that distinction between impairment and disability lies at the heart of the social model of disability and disability is what makes impairment a problem.

But the emergence of social model of disability (UPIAS, 1976 and Oliver, 1983) talks about physical disability and did not mention people with autism (Aylott, 2003).

## Barriers Faced by People with Autism

Disabling barriers is a concept that has emerged from social model (Zarb, 1997, Swain *et al*, 2013). Fundamental barriers exist for people with autism in engaging with the world around them. Taylor and Marrable (2011) has pointed out that for many people with autism and their carers, it is a wearing battle to get the social care they need.

Cargo and Mercer (2008) pointed out that participatory research approaches address potentials for bridging gaps between research and practice, help remove social and environmental injustice and enables people to gain control over determinants of their health. It also helps to determine one's own destiny and transform individual via consciousness raising (Henderson, 1995).

A lack of awareness about autism among social care staff, other professionals and society as a whole poses the biggest barriers for people with autism and this condition needs to be understood differently from the more clinical model and practitioner need to understand autism through social model (Aylott, 2011). The Equality Act 2010 replaced most of the Disability Discrimination Act 1995 and highlights a 'reasonable adjustments' to the way things are done in public service by changing a policy, changing the structure of the building or providing information in an accessible format. The learning and outcome of this study could inform the evidence base and rationale for the advocating of specific 'reasonable adjustments'.

One of the areas thus requiring further investment is the role that cognitive processes work with this group of people with autism in the way they understand social and political processes. Research suggests that people with autism have an impairment that is defined as a different cognitive learning style (Prior, 1979). They lack the ability to abstract, have weak central coherence and uses a rote or chunk learning style (Scott, Clark and Brody, 2000). People with ASC often have difficulty using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice and they process information better visually instead of linguistically (Cashin, 2005) and prefer to use communication methods suitable to them.

This is why the participatory paradigm of research is so important to re-define and position the power relationship between the researcher and the participants. There must be no ego, no position of control from the researcher, more a facilitative, enabling and supportive role to help participants develop an awareness of self in relation to the wider group.

## Technology and Autism

The facilitative relation can be best practiced through technology. Putnam and Chong (2008) highlighted that there are examples of ostensibly successful technology-based products and prototypes, but very little is known and evidenced about how these are helpful and integrated into lives of people with autism. Findings from their study indicated that people with autism and their families desire technology that is designed to help people with autism to improve social skills, academic skills and organisation skills.

Barriers faced by individuals with autism spectrum conditions can be challenged by technological innovations. Carothers and Taylor (2003) state that portfolios are a useful tool and are being used in educational settings increasingly as it provide benefits to all in the educational process. These portfolios are especially useful for students with autism spectrum conditions because they allow for the collection and communication of authentic data across a variety of skills areas and setting.

Professor Simon Baron-Cohen in a conference in London in 2011 highlighted that the potential of computers to help a group that struggles to communicate and form relationship in real life is obvious. They can observe interactions, choose when to be sociable and make contact with other people who have autism. However no mention is made of computer assisted learning helping individuals to reflect on self, to consider self in relation to others with the condition and to understand the condition from a social and political perspective.

Portfolios have been classified in a variety of ways by different authors. Salend (1998) defined showcase, reflective, cumulative and goal-based portfolios and Carothers and Taylor (2003) suggested that for learners with autism, a portfolio that combines the features of both reflective and cumulative portfolios is the best. Reflective portfolios are used to help learners, parents and teacher and other professionals think about dimensions of learners learning, such as effort and use of strategies. Cumulative portfolios, on the other hand, contain items collected over an extended period of time that are analysed to verify changes in students' learning. These portfolios have the advantage of illustrating developmental stages in the learner's acquisition of new skills and/or knowledge. They have the potential to store reflections on learning. Pebblepad is a combination of both reflective and cumulative nature and facilitates the group to comment on each-other's reflections and this facility of feedback, can help develop self and enhance learning.

It is intended in this study that use of PebblePad would provide group members with opportunities to develop self-regulating in learning and to make participatory research methodologies accessible and to help translate the abstract concept of 'critical consciousness'.

### Critical Consciousness, Critical Literacy and Autism

Critical Consciousness is a dialectical process; changes in an individual's internal world can only come about when there are changes in an individual's external world. At the same time, changes in one's external world can only come about following changes in one's internal world. Hence, critical understanding of situations leads to critical action (Freire, 1970, 1972 and 1973). Critical consciousness is a process that involves helping individuals names the multiple conditions of their lives; identify the limits imposed by their situation, and take action to transform the conditions. Diemer *et al* (2014) pointed out that critical consciousness helps oppressed and marginalised people to critically analyse their social and political conditions and take individual or collective action to change perceived inequalities. Consciousness allows people to question the nature of their historical and social situation, to read the world, with the goal of transforming the object experience into a subject experience (Freire and Macedo, 2013).

Interfaces of this study emerge from within Paulo Freire's radical, critical and liberating pedagogical theoretical discourse. The group has explored consent, particularly 'evolving consent' to enable them to have more meaningful participation, but this is also compliance to good practice in Participatory Action Research (PAR) (Baum, MacDougall and Smith, 2006). Participatory

Research (PR) processes and re-concept of co-production has led to the group devising “easy read” and a “person centred ethics protocol” which has resulted in engagement in innovative learning process.

Functional brain imaging studies of autism have found systematic differences in neural functioning that could probably underpin differences in the learning process (Schipul *et al.*, 2012). Moreover, the under-connectivity theory of autism suggests a reduced communication bandwidth (rate of information transfer) between frontal and posterior cortical areas, may also be account for learning differences in autism (Just *et al.*, 2012).

Paulo Freire, in working with marginalised, indigenous and peasant communities in Brazil coined 'critical literacy'. In his work, *Pedagogy of the Oppressed* (1970), Freire criticised the "banking model" of education which he levels 'bourgeois' and it does not take learners' lives and cultures into account. Luke (2012, p5) pointed out that, since Freire's (1970) educational projects in Brazil, approaches to critical literacy have been developed through feminist, postcolonial, poststructuralist and critical race theory; critical linguistic and cultural studies; and, indeed, rhetorical and cognitive models. Critical literacy is an overtly political orientation to teaching and learning and to the cultural, ideological and sociolinguistic content of the curriculum.

Radical approaches to literacy are about 'critical reflection' (Mezirow, 1998). Under radical adult education approaches, literacy is often claimed to be a tool for empowerment and social change. But the development of literacy skills does not necessarily, on their own, lead to empowerment and social change, though it can be a tool for working towards transformation at both the individual and societal level (Foley 2001). It engages people in actively constructing literacy as a tool for change. Freire believed that critical consciousness is demonstrated by a number of qualities:

**Power Awareness:** Knowing that society and history can be made and remade by human action and by organized groups.

**Critical Literacy:** Analysis of discourse that goes beyond surface impressions and traditional myths.

**Desocialization:** Recognizing and challenging the myths, values and behaviours learned in mass culture.

**Self-Organization / Self-Education:** Taking the initiative to transform relationships and society away from authoritarian relations and the undemocratic, unequal distribution of power.

Although Freire's models provide a pedagogical approach and a political stance, they do not specify how teachers and students can engage with the complex structure of texts, both traditional and multi-modal (Luke, 2012). It does not indicate complexity of involving people with autism and their cognitive abilities to critically reflect and any alternative to raise critical consciousness for people with autism. In this study, it will not be PebblePad that helps them to raise critical consciousness, but will be the facilitated group processes using the tools of PebblePad and computer assisted learning. The above four elements (power awareness, critical literacy, desocialization and self-organisation/self-education) will frame my enquiry which will be channelled into qualitative open ended interview/facilitative interview with computer and

PebblePad as media to understand social and political consciousness. To frame the interview, TSI best meet the cognitive style of autism. Training in systematic Instruction (TSI) is an approach intended for those directly working with people with learning disabilities and autism spectrum condition to teach them how to enable those people to learn the skills associated with any given tasks. The 'task analysis', which Alberto and Troutman (2003) says is the process of breaking down a complex task into its smaller steps or components will help me to facilitate the group to enable them of learning.

## Employment and People with Autism

This study intends to enable to develop computer literacy through the use of PebblePad. This would, in turn help them to get into employment. The National Autistic Society (NAS) statistics shows that only 15% of people with autism are in fulltime employment while 9% work part-time. The figures compare unfavourably with the 31% of people with disability in full-time work in the UK. More than a quarter graduates with autism are unemployed, the height rate of any disability group.

A level of critical consciousness in relation to self and others will help teach the individual levels of insight into their own strengths and limitations. This will hopefully help individuals to negotiate more successful placement in positions of work. Nevertheless, employers are increasingly coming around to the arguments from disability advocates that employing those on the spectrum are not about charity and social responsibility, but the empirical benefit of taking on people with unique skills.

Regular employment can bring psychological and social benefits to people with autism, including increased self-esteem and better social integration, as well as potentially generating financial and economic benefits through increased productivity and reduced benefit payments. One of the ways for people with autism to achieve their potentials is to develop their skills through educating them.

## Conclusion

The group has participated and presented papers in various seminars including in the University of York, RDaSH conference, partners in learning conferences and in Design4Health, a European conference held in Sheffield. While the group is functional and operational, they do not have a frame of references of social and political awareness.

The evidence to date is that the group are using reflection to help to make conscious decisions. The next stage of the study seeks to explore how a model of teaching critical consciousness can enable the group to develop self-awareness and the extent of development of critical literacy. The participatory research paradigm seeks to support and enable this group to develop as adult learners and to seek sustainable employment.

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# Multisensory Environments (MSEs) in dementia care: the role of design - An interdisciplinary research collaboration between design and health care

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## Abstract

*An interdisciplinary research project has evolved from a broad consideration in respect to the rising number of people with dementia, rapid growth of an ageing population, over-prescribed use of antipsychotic medication and the need for cost-effective interventions supporting dementia care. Within this context, this research aims to explore the quality of multisensory stimulation offered in homes for residents living with dementia, focusing on Multisensory Environments (MSEs) in particular, and whether design can improve such experiences and maximise therapeutic benefits. MSEs are widely used in dementia care as a meaningful leisure activity and a therapeutic intervention. However, evidence suggests that they often fail to address the specific needs of people with dementia due to inadequate design and poor facilitation. Also, little research has considered the impact of MSE design on engagement and wellbeing. Hence, this research investigates the aesthetic and functional qualities of MSEs currently provided, such as material, colour, imagery, spatial set-up, usability, and accessibility, with the aim of establishing reasons for success and failure. The research includes learning about the approach and challenges care home staff face in their daily work and exploring how they can be supported in providing improved care. Care homes have been visited to examine and record how they facilitate MSEs, applying ethnographic methods that incorporate structured interviews with care staff and managers, observations of sensory sessions and a focus group workshop with care home staff. The results of this study will inform the development of design recommendations for MSEs for people with dementia, potentially maximising the benefits for residents through improved design providing a person-centred experience.*

*At the time of the conference the project was in its early stage and only preliminary results were available. The paper therefore focuses on the research context and discusses the process of identifying and setting the problem and research question. This research, a collaboration between researchers from design and occupational therapy, is funded by the Arts and Humanity Research Council (AHRC) and supported by Care UK.*

*(More information under [fada.kingston.ac.uk/de/MSE\\_design\\_in\\_dementia\\_care](http://fada.kingston.ac.uk/de/MSE_design_in_dementia_care))*

Keywords: dementia, wellbeing of older people, Multisensory Environment (MSE), multisensory stimulation, care home environment, inclusive design, evidenced-based

## Introduction

This paper presented at the *Design4Health2013 conference* emerges from an ongoing research project that critically investigates the success and failure of multisensory facilities within a residential care home context for people with dementia, with a particular focus on the role of design. Against the sharp rise of the population affected by dementia, this interdisciplinary research evolved from a broad consideration in respect to the quality of dementia care and the need for cost-effective interventions in this sector. So far, very little research has considered the impact of design on engagement and wellbeing or has addressed the functionality and aesthetic quality of Multisensory Environments (MSEs) for people with dementia and older people in general. As a result, it has rather been left at the discretion of the industry (Anderson *et al*, 2011; Collier *et al*, 2010).

At the time of the conference the research project was in its early stage and only preliminary results were available. Therefore, the first part of this paper focuses on the contextual conditions regarding the MSE and dementia care with reference to publications by the Department of Health and current academic research. In the second part the process of identifying and setting the problem within a design context is discussed. The paper explains preliminary investigations and results leading to the detailed articulation of the research question. This includes observations from initial visits to residential and nursing homes caring for people living with dementia in and around London and conversations with care staff and home managers.

## Project background

The project was developed on the basis of prior research by both authors culminating in a unique collaboration between design and occupational therapy. Although coming from different professional backgrounds, the authors identified similar questions, both recognising the need for evidence-based research into the functionality and aesthetics of MSEs for people with dementia and the role of design in this.

Anke Jakob is a design researcher and practitioner with a background in textile design and digital media. Jakob's research focuses on the design of multisensory experiences defined through the experimental use of digital media, projection, light and textiles, and its potential application within therapeutic environments and the health and wellbeing sector (Figure 1; Jakob, 2008). An occupational therapist by profession, Lesley Collier's research explores sensory processing in people with moderate to severe dementia, in particular the efficacy of multisensory stimulation in improving occupational performance as well as mood and behaviour. Her work includes designing treatment protocols to assist with the delivery of multisensory stimulation (Pool, 2012).

Collaborative partnerships were formed involving experts and professionals from design and health care including Care UK, a leading independent provider of health and social care services. The project is funded by the Arts and Humanities Research Council UK (AHRC). A project summary can be found under: [fada.kingston.ac.uk/de/MSE\\_design\\_in\\_dementia\\_care](http://fada.kingston.ac.uk/de/MSE_design_in_dementia_care).



Figure 1: Examples of Jakob's research investigating sensory experiences through the experimental use of light and colour, projected imagery, textiles and space. (Images © A Jakob)

## Dementia and the Multi Sensory Environment (MSE)

### The need for non-pharmacological interventions in dementia care

Over 800,000 people in the UK are living with dementia - a figure expected to double in the next 40 years. As there is no cure for dementia currently, treatment focuses on care strategies alleviating the signs and symptoms of the disease. Cost-efficient interventions optimising dementia care are therefore urgently required. *Living well with dementia - a National Dementia Strategy*, published by the Department of Health (DoH) in February 2009, emphasises the importance of providing good-quality care for all with dementia (DoH, 2009). In November 2009, the subsequent publication of a follow-up report made reference to the over-prescription of antipsychotic medication in treating behavioural and psychological symptoms of dementia. The report stated that out of 180,000 people receiving this form of drug therapy, two thirds of prescriptions were deemed unnecessary (DoH, 2009). The Alzheimer's Society argued that behavioural and psychological symptoms can be managed without resorting to antipsychotic drugs: "The person (with dementia) should also be helped to lead an active life, with interesting and stimulating daily activities. In this way it is often possible to avoid the use of drugs altogether" (Alzheimer's Society, 2012). The principles of good person-centred care are posited as crucial in achieving increased wellbeing and happiness in people with dementia. Further, the NICE clinical guidelines, providing recommendations for treatment and care for people with dementia, suggest a number of approaches for non-pharmacological interventions, including multisensory stimulation (NICE, 2009/2012).

### MSEs for people with dementia

As an alternative to drug therapy, the use of MSEs – sometimes also referred to as 'Sensory Room' or 'Snoezelen' - represents a potentially valid intervention. Multisensory stimulation aims to actively stimulate the senses of vision, touch, hearing, smell, taste, and movement with limited need for higher cognitive processing. An MSE is a designated space where this stimulation takes place. It can be described as a 'toolbox' that contains a number of different sensory tools to provide different intensity of stimulation. Structured use of multisensory stimulation aims to enhance feelings of comfort and wellbeing supporting positive emotions, relieve stress and pain,

maximise a person's potential to focus, and support communication and memory performance. (Figure 2)

The MSE concept originated in 1966, when American psychologists Cleland and Clark set up several Sensory Rooms they referred to collectively as a 'Sensory Cafeteria' (Cleland, Clark, 1966). Following on from this the first 'Snoezelen' (the term derived from the two Dutch words 'snuffelen' and 'soezen' - the equivalents for English 'sniffing' and 'dozing') was subsequently developed by Dutch therapists Jan Hulsegge and Ad Verheul in the 1970s for adults with severe learning disabilities (Hulsegge, Verheul, 1987). The MSE concept has since been adopted worldwide coming to the UK approximately 30 years ago where it was embraced as a leisure driven activity with a focus on enablement (Hulsegge, Verheul, 1987).



Figure 2: MSE examples: Snoezelen room for people with severe cognitive disabilities in De Hartenberg Centre, Netherlands (© A Verheul); Multisensory Room by ROMPA, one of the leading suppliers of MSE equipment (Source: online, last accessed 12/12/2013, <http://www.rompa.com/multisensory-environments-rooms>); MSE for older people in The Mount Hospital Leeds (Source: online, last accessed 12/12/2013, <http://www.communitycare.co.uk/blogs/mental-health/2010/02/multisensory-snoezelen-room-fo/>)

As an enabling environment, the MSE is particularly effective for individuals with limited cognitive functioning (Collier *et al*, 2010). It offers an alternative way to communicate with such individuals, as communication does not have to take place on an intellectual level through language but on an emotion-orientated level through the senses (Pagliano, 2008). Subsequently, the approach had been broadened, offering a range of activities for diverse populations including people with dementia. A number of studies have shown that the use of the MSE in dementia care has beneficial effects as a resource for meaningful engagement and is a powerful tool in improving function, alleviating psychological and behavioural symptoms e.g. challenging behaviour and depression, increasing appropriate communication, and improving staff morale (Sanchez *et al*, 2013; Collier *et al*, 2010; Staal, 2007). Research suggests that with a carefully constructed assessment and intervention plan this approach can be used both in care homes as well as the community. Van Weert's work illustrated the positive effect on staff /resident behaviour as a result of a multisensory environment approach (Van Weert *et al*, 2011).

However, little research has been published considering the actual design including functionality and aesthetics of MSEs and its impact on engagement and wellbeing. A recent literature review produced only two publications concerned with this issue. The research and practice of British designer Katie Gaudion and Finnish artist and care practitioner Sari Hedman illustrate design thinking and highlight the need for design interventions in relation to currently existing MSEs. Gaudion criticises the lack of multisensory stimulation, the emphasis on sight neglecting other

senses and the predominance of high-tech equipment often to be found in current MSEs (Gaudion, 2011). Hence her research project *Textile props for multisensory environment* focuses on the development of 'Occupational Textiles' (textiles to engage with) and textile props to be used within MSEs (Gaudion, 2011). The props aim to encourage touch, movement and the occupation of play. Hedman identified that the aesthetics of traditional MSEs are not appropriate for older people with dementia, referring to them as childish. Furthermore, items aimed at tactile stimulation such as horsehair were used out of context which was not helpful for this user group (Hedman, 2008). Consequently she started to explore what older people with dementia might want to experience and implemented the results of her research within her design of six multisensory spaces for older people in Helsinki.

## The MSE in care homes: what is currently on offer?

As a consequence of reported benefits, MSEs have been established within a number of dementia care settings to be used as a meaningful leisure activity and a therapeutic intervention. However, evidence suggests that such facilities are often underused and sensory sessions are not performed. Also, the MSE fails to address the specific needs of people with dementia due to inadequate design and poor facilitation. A report by Dalke and Corso *Living with dementia: can design make a difference?* states that "Reports on various kinds of sensory rooms have not been positive; poor design, non-independent use by residents, fear of the spaces by both staff and visitors leave them locked up." (Dalke, Corso, 2010).

This gave reason to investigate further into the problem, and 40 care homes in and around London were contacted to find out if they had either a Sensory Room or mobile sensory equipment. The care homes were selected from a list already available through previous research projects at Kingston University (Dalke, Corso 2010). Approximately two thirds of contacted homes did not provide such facilities for various reasons such as: no space for an extra room; no funding; management was not convinced it would make a difference if offered to their residents. One care home stated that MSEs were not required by residents.

Subsequently, initial visits were arranged with six care homes who confirmed having a Sensory Room, to view their facilities and interview staff about their use. Only two of the care homes visited made regular use of the Sensory Room with the activity co-ordinator playing an active role in providing multisensory stimulation. In the other homes the facilities were rather neglected, not used very often, and installed equipment was not accessible to users. Overall, from a design perspective, none of the rooms were suitable for people with dementia in terms of aesthetics and functionality. (Figure 3).

In particular, the aesthetics were often not age-appropriate. Imagery applied was sometimes juvenile and appeared patronizing. One member of staff commented that the Sensory Room was not used very often as "the flashing lights might not be appropriate for this age group, who are not familiar with disco lights as we are". Often the spaces were cluttered with distracting and unnecessary accessories or furniture; in some cases the room was used as a storage space. In all homes there was insufficient range of multisensory equipment, in particular for tactile stimulation. In most cases the rooms' appearance in respect to seating, curtains, and carpet did not differ significantly from the rest of the home, missing the chance of offering a different spatial

experience. The furniture did not offer an alternative seating position; the vestibular sense was neglected completely.



Figure 3: Existing MSE facilities / Sensory Rooms in some of the care homes visited

Furthermore, interviews with staff revealed that few had been trained in how a sensory approach should be applied. Almost all of staff interviewed were not satisfied with the MSE equipment or MSE items available through suppliers. Staff felt overwhelmed and uninspired by the suppliers' catalogue and the researchers experienced a sense of helplessness amongst some of the staff.

## Research question and problem

These preliminary visits were extremely informative, revealing a number of issues. It is apparent that there is a large gap between research regarding the benefits of a MSE in dementia care and how it might be implemented in practice. Often simple practicalities prevent the frequent use of the Sensory Room such as that it is located too remotely from the daily action of the care home, or there is not enough staff to take residents there. It is also evident that there is often a significant lack of guidance and training about how to use a MSE as well as lack of inspiration and ideas amongst staff.

In conclusion it would appear that MSEs / Sensory Rooms have been installed with little thought to their design or how they are to be used. Often care homes rely on the supplier to design and set up the room with little or no involvement of care home staff. Subsequently, the MSE does not always achieve the beneficial effect for the person with dementia and staff become despondent as

a result. The consequence is an unused space that is perceived as being of little value. Identifying the design features that potentially can improve accessibility for older people with dementia will help care homes to create an environment that is appropriate for residents and their families as well as staff.

## Ongoing Research

Following this first investigation, a more in-depth study has been undertaken involving 16 care homes with MSEs in Greater London and the Southampton area with the aim of examining and recording the current use of MSEs, the design features and the opinions of staff using these facilities. Ethnographic methods have been applied to collect data including structured interviews, observations of sensory sessions from the point of view of the person with dementia, and a focus group workshop with staff. The research does not directly include people with dementia and/or their immediate relatives, as this is beyond the remit of this research project. The study focuses primarily on care staff and home managers aiming to learn from their experience and approach, to develop understanding and insight of the daily tasks and challenges care homes and their staff face, and how they can be supported in their work. The outcomes of the study will be published in a subsequent paper.

Based on the results of this study, preliminary design recommendations tailored towards the needs of care homes and their residents will be developed, to potentially support and improve age appropriate multisensory stimulation. The design outcomes of this research, which will be accessible online, aim to contribute towards improved care services positively enhancing the lives and wellbeing of people living with dementia.

On the basis of the results of this project, subsequent research will be undertaken to establish a 'proof of concept' study involving residents with dementia, family members and staff.

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## **Applying inclusive design principles to improve self-management in Spinal Cord Injury**

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### *Abstract*

*This paper describes an exploratory study undertaken in Sheffield which examined the potential role of design in enabling individuals with spinal cord injury to manage their condition. An inter-disciplinary team of researchers and designers facilitated a series of five workshops on a spinal injuries unit in Sheffield with the aim of exploring concepts of design thinking and looking at how these might be applied to the everyday challenges that living with a spinal cord injury brings. This was part of a national piece of work instigated by the Royal Society of Art (RSA) and has formed the basis of an ongoing research study exploring the potential of design and health.*

Keywords: Design thinking, spinal cord injury, rehabilitation

## Introduction

Spinal cord injury (SCI) is defined as damage or trauma to the spinal cord that results in loss or impaired function or feeling. It is estimated that at present there are 40,000 people living with a spinal cord injury in the United Kingdom. Initial treatment focuses on medical stabilisation followed by inpatient rehabilitation. This can be lengthy and focuses on the one hand on helping individuals to maximise function and on the other to develop compensatory techniques to manage on-going disabilities caused by the injury.

In 2011 the Royal Society of Art instigated a study that sought to explore the potential of design for people who are spinal cord injured (RSA, 2012). Initial work focused on people who were living in the community and used design to reframe the injury and enable individuals to adopt a positive problem-solving approach to everyday challenges. Further funding was made available for work to be undertaken between designers and design researchers with identified spinal injuries units across the country. The final sites chosen included Sheffield, Glasgow and Cambridge.

The focus of the Sheffield study was based around individuals who had recently experienced a spinal cord injury and who were inpatients in the Sheffield Princess Royal Spinal Injuries Centre. The study, which was the basis of a service evaluation, sought to answer the following questions:

1. Would people who had recently had a spinal cord injury be interested in attending workshops that taught them design thinking?
2. What form would these workshops take and what considerations might there need to be in relation to practicalities?
3. How could impact (including potential gains) be measured and evaluated?

## Literature Review

Spinal cord injury (SCI) is defined as damage or trauma to the spinal cord that results in loss or impaired function or feeling. Every eight hours, someone's life will change forever in the UK as they incur a spinal cord injury. It is estimated that there are 40,000 people living with a spinal cord injury in the UK, with around 800-1200 new injuries each year, three quarters of them male. These statistics only refer to the people who have been through a spinal cord injury centre, and do not include those who have suffered paralysis and been treated in a general hospital. The majority of this population are aged 16 to 35, although the proportion over 50 is increasing. The most common causes are falls and road traffic accidents, but there are also many casualties from sporting accidents, such as through horse riding, diving and rugby (The Back Up Trust).

The spinal cord communicates two-way messages to and from the brain and skin, muscle and organs of your body. When your spinal cord is damaged it interrupts the flow of messages, leading to the loss of movement and/or sensation in different parts of the body. The extent of this depends on where the spinal cord has been damaged in relation to the vertebrae of the back and to the level of injury, known as complete or incomplete. A complete injury means that there is no function below the level of the injury; no sensation and no voluntary movement, with both sides of the body equally affected. An incomplete injury means that there is some functioning below

the primary level of the injury. (The Back Up Trust) A person with an incomplete injury may be able to move one limb more than another, may be able to feel parts of the body that cannot be moved, or may have more functioning on one side of the body than the other. With the advances in acute treatment of SCI, incomplete injuries are becoming more common. SCI injuries are split into four regions depending on which vertebra they affect; cervical, thoracic, lumbar and Sacral. Each will affect different areas of the body (See figure 1) For the individual, SCI can affect bladder, bowels, temperature, sleeping, diet, balance, trunk stability, sexual function, regulation of blood pressure, the ability to sweat and can cause pressure sores. Thanks to modern medicine, life expectancy for people with SCI is near normal. This is positive news, but the long-term demands on medical and support resources are huge.

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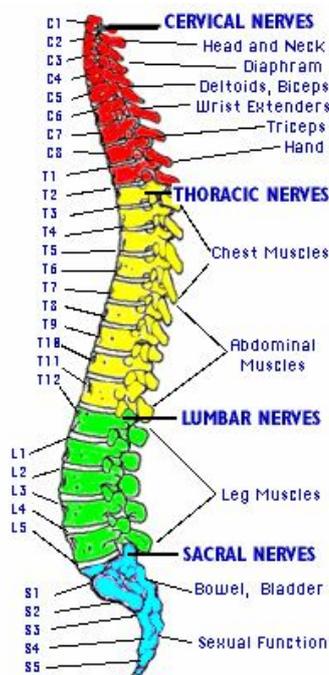


Figure 1: Diagram of SCI and the affected body parts.

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Once medically stable, inpatient rehabilitation for people with SCI is predominately Physiotherapy (focussing on muscles and movement) and can involve splinting, stretching, standing frames, improving circulation for example) and Occupational Therapy (that focuses on meaningful activity) and can involve practising daily life activities such as car transfers, toileting, computer work, brushing or shaving). However, inpatient SCI patients can struggle with boredom and monotony, which can reinforce depression (Campbell, 2011).

Subjective well-being (SWB) as an indicator of adjustment to disability has recently attracted more attention from researchers in the rehabilitation field (Bracke, 2001; Chase, Cornille & English, 2000; Cummins, 2002). Researchers tend to agree that SWB should be one of the major goals of rehabilitation (Boswell, Dawson, & Heininger, 1998; Bracke, 2001). In the literature, SWB has been defined as an individual's evaluative reaction to his or her life (Boswell *et al*, 1998; Fuhrer, 1996; Krause, 1998a). SWB is a hierarchical and multidimensional concept and can be separated into

cognitive or affective aspects (Fuhrer, 1996; Krause, 1998a). The cognitive aspect includes general life satisfaction and life domain satisfaction (Fuhrer, 1996). The affective aspect contains positive emotions (e.g., joy, pleasure) and negative emotions (e.g., anxiety, sadness; Fuhrer, 1996)

Post-discharge, people with SCI are relatively well-served with opportunities to engage in sport and physical activity (through charities such as the Back Up Trust) but programmes that bring them together to share knowledge and experience of technical or professional issues are scarce. There are outreach programmes in ICT and assistive technology, general work skills courses covering interview techniques, employment rights and CV writing; and courses in drama for personal skills development; but nowhere has design been identified as a key component of autonomy worthy of specific training.

**Comment [RP5]:** reference the course by places such as back up trust

Other creative disciplines have a longer standing place in rehabilitation with art and music therapy being at the forefront. Art therapy involves the discovery of new connections, relationships and meanings, which in turn can provide alternative perspectives on life and relationships with others. Art therapy can work in multifaceted ways involving the sensory-motor, perceptual, cognitive, emotional, physical, social and spiritual. Art therapy is used as a form of rehabilitation that seeks to fulfil the innate desire to be productive, seek creative autonomy, and provide an outlet for expression. The recreational nature of art therapy also serves to reduce boredom, ease mood, as well as build relationships (Van LITH *et al*, 2010).

The underpinning premise behind the introduction of design as a therapy is less about occupying the mind or the therapeutic benefits of the creative process, although these could well be beneficial secondary outcomes. The primary driver is to equip people who have a greater need to be resourceful with the necessary tools to be more resourceful. The project was based on Campbell's premise that if people in general (not just designers) have tools available (cognitive and physical) to be more resourceful, then changes may be seen in their self-management ability (Campbell, 2009). Campbell defined resourcefulness as *'the confidence that comes with knowledge: having a skill or a range of skills at your disposal; knowing enough to make a wise choice; having analogous experience; having connections to draw on and knowing how to collaborate'* (Campbell, 2009 page 2). The workshops anticipated that design thinking, that is thinking like a designer and applying design skills to problems, would foster independence by addressing the loss of confidence and motivation that often results from a sudden physical impairment, by developing methodological and practical skills for problem solving (Campbell, 2011). However, there has been little documented use of the use of design thinking in the UK or internationally that specifically applies design thinking in the context of teaching SCI patients and the skills involved in design thinking, besides the work that was conducted by the RSA and partners mentioned above (Craig *et al*, 2013). Currently, published National Institute for Health and Care Excellence (NICE) guidelines do not exist for the rehabilitation of SCI patients. However, the National Spinal Cord Injury Strategy Board, led by Dr Fiona Barr, is working towards developing SCI care pathways, consequently it is a pertinent time to be evaluating the design thinking workshop and its impact on SCI patients (Craig *et al*, 2013).

## Methodology

The initial work conducted by the RSA and the Back-up Trust, the national spinal cord injury (SCI) charity, delivered design workshops to people living with SCI to test the concept that this might be of value, improving self-esteem, self-reliance and resourcefulness. Whilst the feedback from this initial work was positive, the optimum approach to transferring design thinking and practices to people living with SCI remained open to definition. The RSA invited three universities to build upon their work; to develop, test and evaluate methods of delivering design workshops for people with spinal cord injury (SCI). Each university worked closely with one of the UK's eleven specialist units for SCI. The partnerships were:

- Buckinghamshire New University and the National Spinal Injuries Centre at Stoke Mandeville
- The Glasgow School of Art/University of Strathclyde with Glasgow Queen Elizabeth National Spinal Injuries Unit
- Sheffield Hallam University and Sheffield Princess Royal Spinal Injuries Centre

The challenge to these three partnerships was to provide alternative views to the initial work by the RSA. Whilst the methodology remained open to definition, the common element across these three partnerships was the introduction of design related activities through a participatory workshop format. Many questions remained amongst which were who the workshops were delivered to, where they were delivered, the nature of the activities and who was facilitating the workshops.

Representing Sheffield Hallam University was a team of designers/researchers from Lab4Living, a creative partnership bringing together research expertise spanning the fields of health, rehabilitation, design, engineering, ergonomics and user led design. They were accompanied by several students from the MDes and MA design courses from the University.

The Sheffield project took an exploratory, responsive, and creative approach that recognised and accepted a 'zero' start point with limited knowledge of how the intervention would work and used little in the way of pre-defined concepts, instead privileging emergent ideas and activities as the workshops unfolded. Unlike the RSA approach, Sheffield worked with in-patients; people who had recently sustained some form of SCI, had moved out of the acute wards and were situated in the rehabilitation wards on the Princess Royal Spinal Injury Unit. The duration of stay on the rehabilitation ward varied from 6 to 18 months. Part of the rationale for the decision to select this point in the patient pathway for the intervention was simplicity, to facilitate recruitment and evaluation. Additionally, this approach posed a different intervention time in the patient pathway, compared to the previous RSA work which could potentially yield additional learning about the appropriateness of this intervention relative to its timing and patient's readiness.

Due to a compressed time frame and a desire to sustain attendances to the course throughout the entire duration of the workshop, a programme of six workshops at a rate of one per week was scheduled with the rehabilitation unit. The workshops were typically three hours in duration with drinks and comfort breaks. This duration was perceived to be optimal given the mixed activity

approach. To open inclusion to the widest possible number of participants, these workshops were scheduled on a Wednesday afternoon, a time that is typically kept less intensive with regards to other rehabilitation activities.

The inclusion criteria were sufficient cognitive ability (the project team relied on routine cognitive assessments by the ward teams) and a desire to be involved in the programme for as many workshops as possible, with a maximum attendance at each workshop of 12 participants on a first come first serve basis.

Exclusion criteria were insufficient cognitive ability, unwillingness to engage, physical health instability or maximum workshop participant threshold achieved.

Participants were recruited to the workshops via adverts placed on the relevant ward notice boards, information passed on by ward staff to those that met the cognitive and physical inclusion criteria and by staff 'touring' the wards prior to each workshop to remind potential participants, answer further questions, give participant information and take informed consent. These tours also acted as a means of assisting willing participants to mobilise to the workshop venue if required including moving one participant in a bed.

The team approach was to establish shared ownership of the project and specifically the workshops with the SCI participants and healthcare staff involved. It was made explicit to these other stakeholders in the very first workshop that this was a joint enquiry and an opportunity for shared learning, the primary driver behind this approach being to disarm the role of the designer as the 'expert' who will 'solve' the 'problem' and to steer away from individual challenges or issues any of the participants might face as this might compromise the overall goal of transferring generalisable problem solving skills as opposed to solving individual problems. In an attempt to fulfil the shared ownership ambitions, the structure of the six workshops was loosely defined as a framework or menu of possible topics and activities under some pre-defined themes. The nature of the activities was left flexible to accommodate variation in the physical abilities of the participants. More detail was applied to the first workshop while setting a structure that allowed participant feedback at the end of each session to inform content for the following workshop.

The loose content structure of the six workshops was defined as:

1. What is Design? - case studies, which potato peeler is best?
2. Prototyping - iterative trial and error - making towers out of spaghetti and marshmallows
3. Design Encounters - sensing the world differently; sounds, textures, barriers, light, order and nature (See figure 2)



Figure 2: A participant exploring the unit thinking about its sounds, textures, barriers etc

4. Mapping and Contextualising - mapping the design encounters onto hospital plans
5. Design Questions and Lateral Thinking - what is a problem?
6. Design Activity (See figure 3)



Figure 3: Design Activity

Each workshop session followed a format similar to that outline below:

- Introduction and recap of previous weeks activity
- Review of stage relative to over trajectory of the six week programme
- Set out draft agenda for the current workshop from previous week and amend or modify with input from the participants
- Introduce main topics and activities for the day
- A discussion of the day's activities and the proposed themes, topics and activities for the following weeks workshop with some consideration for which activities might be most appropriate and engaging

The mode of delivery included presentations, video clips, exemplars, discussions, scene-setting exercises, observational and recording exercises around the units grounds and facilities, design thinking and making exercises. The content of the activities and exercises comprised of 'ice-breaker activities based on problem solving, practical 'prototyping' activities, observational activities using all senses, lateral thinking exercises, grouping and classifying exercises.

The students accompanying the project team became an invaluable resource acting with, on-behalf of and under instruction from the participants as and when required and hence enabling participants of all functional capability to engage with all activities in some way (see figure 4).



Figure 4: A team of students and participants on the marshmallow challenge.

The methods of evaluation followed real-time feedback from participants, a review at the end of each workshop with the participants, a post workshop debrief with the project team and students following each workshop and a more in-depth participant questionnaire at the end of the final workshop.

## Findings and Conclusions

This was a brief exploratory study. People on the unit who had experienced a spinal cord injury did engage in the workshops and anecdotally reported their enjoyment of the sessions.

The study did identify some of the complexities of undertaking work of this nature in this setting - part of the difficulty was in relation to the fixed routines, primacy of existing therapeutic interventions which took priority, difficulties in fitting the intervention around individuals' lives. Our learning in terms of the shape an intervention might take and ways to evaluate this.

This study set out to explore the potential role of design in enabling individuals with spinal cord injury to manage their condition. Key aspects of this that the study attempted to shed some light on were:

1. the receptiveness of both clinical staff and patients to such design training
2. the methodology of imparting design thinking and design skills to patients with SCI
3. any indication of potential benefits of such training
4. the logistical and operational considerations to delivering this training to people with SCI

The work demonstrated that on a small sample of SCI inpatients there was receptiveness to the form of design training delivered. However, the receptiveness amongst clinical staff was mixed, with some being enthusiastic whilst others appeared more restrained in the response to this as a therapeutic intervention.

The methodology in the workshop approach appeared to be an acceptable model in general but further piloting and evaluation would be required to develop and refine this type of activity. The content of the workshops and mode of delivery was also broadly acceptable to the participants. Anecdotally there was the need for some ability to personalise the activities used to more broadly communicate some of the concepts and skills that were being transferred. This was to account for variation in physical ability (and therefore what activities might be within an individual's ability) and for variation in individuals' preferences for levels of engagement.

Of both methodological and logistical relevance was the group format of the workshops. Fitting these workshops into and around other rehabilitation activities was complex and resulted in some participants having to leave early, arrive late or miss all or part of a session, often to their frustration and creating some minimal disturbance to the other workshop participants. This study did not give any conclusive findings about an appropriate format for delivery but raised questions as to whether smaller numbers or one-to-one sessions might be a more effective model.

Feedback from the participants was positive and alluded to potential benefits without being conclusive.

The project has since secured funding from The Health Foundation SHINE programme to implement a revised workshop format into the rehabilitation schedule for a 12 month period and, in collaboration with the hospitals Service Improvement Team, use a time series analysis of routine data along with specifically applied patient feedback tools (in-depth interviews and questionnaires) before, during and after the workshops with 3 and 6 month follow-up. It is hoped that this data will demonstrate evidence of sustained retention and meaningful use of design knowledge.

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## Exploring design's potential agency in changing roles and responsibilities in SCI rehabilitation

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### *Abstract*

*Design research has recently been exploring the application of design approaches and methods in new fields such as service design, and in healthcare. There is a small but growing body of robust literature on the application of design approaches used in these types of contexts. Healthcare service delivery is facing complex challenges in developing patient-centred 'social model' approaches which can complement or enhance prevailing clinical 'medical model' approaches and which allow patients to take more ownership of their recovery. The work described here opens up the discussion of potential opportunities to enhance the rehabilitation pathway and to improve self-management for Spinal Cord Injury (SCI) survivors, of how management is conceived, and of how this affects the relationships between and responsibilities of all concerned. It does so by asking if 'design approaches' can be used to help increase the resourcefulness and resilience of, and reduce dependency in SCI survivors during their rehabilitation and on their return to the community. Literature reviews were conducted of: 1) prior work; 2) patient-voiced issues; 3) SCI patient pathways and rehabilitation management models; 4) design literature discussing structured design thinking, skills, methods, and approaches. From these a framework for the analysis of tacit skills in SCI patients was derived for a workshop designed to observe and record tacit skills used by SCI survivors in addressing a daily living challenge. Although this research revealed that SCI survivors are able to demonstrate the use of innate 'design' skills, the question remains about the conditions required for these to be practiced, autonomously, in everyday situations.*

Keywords: Design approaches, spinal cord injury, rehabilitation, self-management

## Introduction

The idea that everyone is an inherent designer is hardly new. The concept of participative design (Bjögvinssen *et al*, 2012) is predicated on the idea that non-designers can exercise tacit design skills and become involved in the co-design of, e.g., products, experiences and services. This approach has increasingly been used within the healthcare setting to improve, e.g., healthcare services delivery and the patient experience (Cottom & Leadbeater, 2004; Bate & Robert, 2007; Pickles *et al*, 2008; Hampson *et al*, 2013; Design Council, 2014a, 2014b; Donetto *et al*, 2014).

However, the idea that this approach might have an application within rehabilitation, and specifically for spinal cord injury (SCI) is more recent. Campbell (2009), previous Director of Design at the Royal Society of Arts (RSA) proposed, within the context of training for people with SCI, that *'design as a discipline, or structured thought process, can address the dramatic loss of confidence and diminished motivation that may result from a sudden physical impairment, and [design] can contribute to independence'*. In 2010, Campbell ran a 3-day pilot workshop at the RSA for a group of SCI survivors (hereafter referred to as survivors) working with a team of three designers to explore this idea (Campbell, 2011). Following this RSA pilot, Campbell then selected three spinal injuries units across the UK to work with individuals in the 'best local universities teaching design' to explore this idea further, each in their own preferred way. The Queen Elizabeth National Spinal Injuries Unit (QENSIU) at the Glasgow Southern General Hospital, and the School of Design at The Glasgow School of Art (GSA) were selected to work together in one of these three partnerships whose work is summarised in the RSA's report (Campbell, 2012).

## Questions arising

Many questions, typified by the following, arose for this author from this pilot RSA work. In the RSA work survivors were able to engage in 'designerly' activities and demonstrate certain designerly skills during the RSA workshop, however, were they only able to do so facilitated by designers? Would survivors be able to demonstrate these skills autonomously following such an encounter with designers, and if so, for how long? Would survivors be able to 'see' and define problems sufficiently well to be able to apply these skills and approaches autonomously? What conditions would need to exist for any 'designerly' skills to be exercised?

Given the premise implicit in the idea of individuals possessing tacit design skills, the author defined the following set of working propositions to test in the context of this pilot QENSIU/GSA study: i) designers have a describable set of skills they use to tackle problems and develop solutions; ii) non-design individuals might have this set of skills but not be aware of these; iii) these skills can be revealed and made explicit; and iv) they can be used in a structured way. From these arose a set of research questions: i) what is the skills set of designers? ii) do survivors possess innate design skills and if so, what kinds of skills are these? iii) what is the match between designers' and survivors' skills? iv) if such a match existed could survivors' skills be developed by training or facilitated, through, e.g., a toolkit, to enhance their resourcefulness in tackling the daily life challenges of SCI? and v) if so, when, where and how?

However, there is a certain presumption in the questions above. Before any thoughts of designerly interventions were to be entertained, this author required to know much more about the

individuals at the centre of this study, i.e. the survivors. As the above questions suggested a much larger and longer programme of research than the funding provided for the GSA/QENSIU pilot described here would allow, only two principal questions were explored. The first question was: what is the survivor’s rehabilitation journey and their experience of this journey? The second was: do survivors possess innate design skills and if so, what kinds of skills are these?

## The SCI survivor’s journey

What is survivor’s rehabilitation journey, how is this described and who describes this? If one examines the way the patient ‘pathway’ through rehabilitation is currently described, this is largely from the clinical perspective of functional rehabilitation. Figure 1 provides a simplified version of the model of the ‘Patient Pathway’ used by QENSIU. The total extent to which SCI is understood as a life-changing event begins to sink home when one also views the ‘Goal Planning Checklist’ used by QENSIU which helps the SCI survivor, working with their Key Worker, to ‘assess and identify what you need to know, what you are able to do, and what you still have to learn or achieve’. This 18-page checklist is used to discuss, assess and record progress in relearning the management of such areas as: e.g., eating, dressing and undressing, grooming, and personal hygiene; skin, bladder, physical and psychological sexual issues; bowel and chest; joints - to prevent contractures; management of autonomic dysreflexia; issues surrounding mobility such as bed, transfers, wheelchair, ambulation, and driving; new equipment and assistive aids - wheelchair, cushion, standing frame, upper limb splints, and orthosis; one’s accommodation - house, placements; social issues - social work, social activity, personal assistants, district nursing services; schooling; and employment. The checklist reveals just how complex the problem of simultaneous functional management of the many aspects of SCI is.

Patient Pathway						
	week 1	week 2	week 3	....	discharge	follow-up
medical						
nursing						
physio						
OT						
psychology						
social worker						
key worker						

Figure 1: A simplified version of the ‘Patient Pathway’ used by QENSIU.

However, the survivor’s *experience* of this journey is essential to understand as a context for this research. The SCI patient’s ‘voice’ is noticeably absent from the literature, revealed in only a small number of studies, such as in Dickson *et al* (2011, 2012) who discuss survivors’ and their carers’ lived experiences of SCI, and survivors’ difficulties in adjusting to home and community life following discharge. In contrast to the busy, supportive community of individuals in QENSIU with

broadly similar SCI conditions, survivors experience, on return to the community, e.g., a 'loss of camaraderie', 'lack of post-discharge care', and 'other people's [negative] reactions to SCI' (Dickson *et al*, 2011). They can also have 'difficulties in accepting the new, disabled self' and it can take from five to seven years to adapt and reach 'stability'. Adaptation is required at three levels, at the: i) individual ('a strong desire for independence for successful adjustment'); ii) social ('reintegration as active member of community enhancing self worth and esteem'); and iii) environmental ('accessibility and the public's attunement in interactions with disabled individuals') levels (Dickson *et al*, 2011). Derived from the reading of Dickson *et al* (2011, 2012) and also from Lawton (2009), this author developed a speculative working view of this experience (Figure 2) which contrasted two key 'transitions' linked with some of the potential associated emotional issues described in this literature. The first transition is that from one's

Past Life				Future Life
Previous Life	Incident	Acute	Rehab Unit	Community / Home
Adaptation / adjustment to life in the unit				Adaptation / adjustment to life at home (perhaps via nursing home)
Growing camaraderie with others in the unit (sense of belonging)				Sense of Isolation
Increasing sense of being 'normal' within a disabled community				'Abnormal' within an able-bodied community: stigmatising reactions
Support for improving physical condition				(Lack of) support / physical de-conditioning
Growing feeling of safety and security				Feeling of being exposed / isolated
Busy environment				Quiet environment
<b>Transition / biographical disruption 1: previous life to rehabilitation unit</b>  Grieving for one's past life and trepidation about one's future. Reinventing and renegotiating one's self and identity. Learning to become a member of the QENSIU community.				
				<b>Transition / biographical disruption 2: rehabilitation unit to community and home life</b>  Having coped with and adapted to the community and life within QENSIU, SCI survivors are faced with another stage of adjustment without the peer and professional support found in QENSIU

Figure 2: A speculative working model constructed by the author from Dickson *et al* (2011, 2012) and Lawton (2009) to reveal the contrast between the two key 'biographical disruptions' and some of the potential emotional issues arising.

'pre-SCI' life, through the 'life-changing' event, where having experienced the trauma of SCI, one enters into the distinctive life, routine and culture of the rehab unit, a sympathetic and supportive environment. The second transition occurs post-discharge when coping with life back in the community, without the peer and same extent of immediately accessible healthcare professional support of the rehab unit. QENSIU indicated there is also a critical point about one-year post-discharge when survivors can be at a very low psychological ebb. Before any thoughts of design interventions were to be entertained, this aspect, of developing an understanding of the survivor

journey as experienced by the survivor, was felt to be crucial as this might assist in identifying the point(s) at which the introduction of any intervention might have specific and useful applications.

## The designer's skills set?

How does one define the skills set of a designer, skills that might be useful in this context and that we might want to detect in non-designers? Useful for exploring this question, for structuring activities and evaluating results, a framework devised by Kimbell and Miller (1999) was identified from a review of potential models. Their terminology was straightforward, judged to be accessible for non-designers and reflected many types of skills necessary for everyday life. Kimbell and Miller's framework enabled a simple matrix to be derived, listing each of these skills, which was to be used to evaluate, which of these skills, or combinations of these skills, were used during each of the three following workshop activities. Kimbell and Miller separated these skills into three categories: i) higher order skills (*intentions / purposes*), useful to plan / order, generate / create, investigate / find out, evaluate / judge and communicate / present; ii) operational strategies (*making thinking explicit*), useful for unpacking wicked tasks, iterative thinking, playing with reality, optimising values, modelling futures, managing complexity and uncertainty, optimised decision-making, collaborating (creative brainstorming), collaborating (evaluating / planning) and researching (seeking knowledge); and iii) functional skills, useful for talking, writing, calculating, drawing and making.

## Workshop design

Because of the limited time that SCI survivors, both in-patients and out-patients, were available due to, e.g., treatment, stamina and travel (barely a three-hour slot), a set of three short, sequential structured workshop activities with an additional evaluation and feedback session, was devised for survivors, to be held in an activity space within QENSIU. The intention was to identify if any, some or all of the above skills were being exercised, identifying specific sets of skills used for different kinds of activities. The workshop was structured around the theme of the 'shopping journey', as this encompassed a number of problems and a degree of complexity, reflecting many daily life situations, to explore i) the range of inter-related issues for survivors and ii) the skills they utilised in tackling various problems and issues arising from this. Careful pre-preparation of the workshop and workshop materials was essential to optimise the limited time available. The participants were: three outpatients in wheelchairs; one in-bed inpatient; a further wheelchair outpatient joining later for activity 3. A number of QENSIU clinical, ward staff and therapists joined after activity 3 to witness the results and to participate in feedback occurring at the conclusion of the activities described below. As it was important to understand the SCI participants' own innate skills, the facilitators were instructed not to 'lead' with their own ideas but only to 'enable' the participants to contribute theirs by scribing responses or sketching their ideas if this proved difficult for survivors themselves (thereby clearly distinguishing this from co-design at this stage). SCI participants were paired and two facilitators were assigned to each SCI pair both to capture comments (on sticky notes) and issues and ideas (through sketch visualisation). The rationale for the type and content of each activity and observations arising from each has been previously described in detail in Macdonald (2013). They are described in summary below.

## Activity 1: role-playing the personal shopper

One key ability, not unique to - but certainly well-exercised within - user-centred design, is the ability to think of another's needs. The first activity required role-playing 'the personal shopper' for their workshop partner. The brief was to identify clothing for a special occasion, when looking good and a projection of their partner's individual preferences and personality were important. Here, in contrast to the 'auto-biographical' mode used by survivors when discussing their own personal experiences and difficulties in a seminar prior to this workshop, the intention was to identify if survivors could begin to think and speak from the perspective of another's needs. This 'ice-breaker' activity lasted 20 minutes.

## Activity 2: the shopping 'status quo'

The second activity, a 45 minute session, explored the 'shopping journey' scenario to understand how well survivors were able to identify and define problems with the status quo. For the purposes of the workshop, the shopping journey was deconstructed into a series of distinct stages and, after being prompted by visual cues for each stage, survivors would be asked to think about and rapidly describe their own shopping experiences and to identify problems and issues they had with current store-based expeditions. This was to reveal a range of tangible interaction and service 'touch-points' issues, as well as more intangible (de)motivating, and emotionally frustrating issues.

## Activity 3: What if...?

Having identified a number of key issues and problems, survivors were given the opportunity to imagine and design improved 'store-based' shopping experiences using the problematic issues they had identified in Activity 2 as their starting point. Activity 3, again 45 minutes long, used the kinds of 'what if...?' approaches familiar to designers during workshop-type brainstorming activities. Here, many ideas were generated by survivors, such as a shopping centre collection service for wheelchair shoppers, centralising and storing all bags bought in different shops until they were ready to leave for the car park.

## Evaluation and feedback

Using the matrix based on Kimbell and Miller's model described above, the workshop participants retrospectively self-reported which combinations of separate skills they had used in each of the three activities. This and other feedback was provided in a post-lunch session with the therapists and doctors listening in.

## Findings

Not surprisingly, survivors appeared to have many of the skills we would recognise as design skills. Of interest too, to the therapists, were the kinds of issues which had been revealed and which survivors had not articulated to them previously (Figure 3). Although the idea that everyone possesses a latent resourcefulness is not new to designers, demonstrating these as distinct and differentiated skills to the healthcare professionals in the unit, through the kinds of methods described above, was a revelation and inspiration for further collaborative work.



Figure 3: Healthcare staff at QENSIU viewing SCI survivors' critiques of the shopping experience status quo. Still from film, 'Design and Rehabilitation', Dir. Claire Levy © 2012.

## Discussion

In the three activities in this workshop the survivors demonstrated that, to a greater or lesser extent, they could clearly: i) think of others' needs; ii) identify and detail problems with current service provision (i.e. the shopping experience); and iii) imagine improved scenarios/designs, all skills locatable within Kimbell and Miller's (1999) framework, thereby revealing that survivors possess at least some of the same skills as designers, although perhaps not used so intuitively, consciously or as in as practiced or structured a manner as designers.

The pilot research described here clearly has its limitations. For all workshop activities, there remains the question of whether the survivors would have tended to do any of these spontaneously without being facilitated. However, Activity 1 changed the mode of survivor narrative from 'self' to 'other', perhaps of value in its own right for use within rehabilitation healthcare. For Activity 2 the shopping journey had to be preconceived and deconstructed by the researcher, not only into the distinct phases, but also structured to allow for the capture of the more emotive issues as well as practical difficulties. The envisioning of the participants' comments and issues by the workshop facilitators no doubt helped participants begin to 'see' and specify the issues in ways that they would not have done before. So although these problem-identification skills are apparent in the survivors, it could be argued that the approach to unpacking the problems and separating out the issues was facilitated in a designerly way. Activity 3 was, initially, the most difficult of the three activities for the survivors to engage with. One possible interpretation of this might be that the status quo was so problematic that they had become habituated to this to the extent that it was difficult for them to imagine how the experience could be improved and also perhaps because the idea of exploring improved or future 'ideal' scenarios was not one familiar to them. However, with appropriate encouragement, assisted through the use of scribing and visualisation techniques by the facilitators, some interesting ideas began to

emerge demonstrating that, once enabled, the survivors demonstrated an innate ability in some of the kinds of speculative and imaginative skills which designers are fond of citing as part of their own skills-set. Activity 3 created a bank of ideas that could potentially and subsequently be prototyped, tested and refined.

The use, by the participants, of the matrix to retrospectively self-report the different combinations of design skills they thought they had used in each of the three activities proved not to be useful: the tendency was for most of these separate skills in the matrix to be ticked for all of the activities (was this to please or impress the researcher?). This form of evaluation was initially decided as a feedback method achievable within the very compressed timeframe of the workshop, Instead, follow-up interviews would have been a better method for eliciting this information, although much more time-consuming.

In workshops such as these, although one can demonstrate that 'designing' occurs using recognisable and categorisable sets of designerly skills and approaches, it is not only a matter of survivors developing or acquiring the designer's particular set of skills. Throughout this enquiry, questions emerged such as: i) How much exposure or training might survivors require through design activities for them to begin to develop sufficiently autonomous skills without having to undertake the normal kind of training a designer would undertake (if indeed that could happen at all)? ii) How enduring would these learnt skills be, i.e. once the immediacy and novelty of workshop-type experiences had diminished, for how long could they continue to apply these (i.e. would any positive effect be time-limited)? iii) Could – and if so, at what point - survivors begin to autonomously address some of the 'wicked problems' of daily living they face, through the practice and application of these design skills and approaches? One of the challenges of this kind of project is not only understanding if non-designers can 'design' as such and to what extent, but under what conditions can 'designerly' activities be best fostered and flourish. We have no data to answer these questions; a longitudinal study of the durable impact of the initial RSA pilot has not been made. Indeed the author's study was only intended as an exploratory experiment and is more fully described in Macdonald (2013).

## Conclusion

This pilot work described here was important for the author to understand a little about SCI survivors, their pathway, experience and latent abilities, albeit within the time and resource constraints of this limited pilot, before any thoughts of participative co-design processes and stages could be entertained. If self-reliance and resourcefulness are to be assisted and developed by survivors through designerly approaches either whilst within a SCI unit such as QENSIU or post-discharge, the challenge would be not only to develop designerly skills and methods within the individual *per se*, but also how the requisite conditions or environments for designing as such could be created for - or by - the survivors. There are two very different kinds of environments within which these be developed and applied: either within the rehabilitation unit (in this case QENSIU) which has (understandably) a predominantly medical/clinical ethos with a certain kind of professional-survivor hierarchy, or in the relatively more isolated and less well supported environment of the community or home.

From QENSIU's perspective, as SCI poses unique challenges for its survivors, as a result of this short workshop and subsequent reflection, there was an interest in how 'design' approaches and methods might be able to help: i) staff and carers in the personalisation of survivors' treatment and access to rehabilitation; ii) survivors and their carers in the 1-year post-discharge phase which has been identified as particularly problematic; iii) assist in the socialising, engagement and integration of survivors into the wider community; iv) staff improve the process of rehabilitation and how this is delivered; and v) develop skills in survivors to promote resourcefulness and self-reliance and decrease the need for dependency on carers and healthcare professionals, i.e. alter the patient-to-healthcare professional relationship. Subsequently a GSA/QENSIU proposal for three-year PhD study to continue this early pilot work has been funded by the Arts and Humanities Research Council through a Collaborative Doctoral Award and commenced in 2013 to explore design's potential agency in changing roles and responsibilities in SCI rehabilitation.

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# When a patient goes home: Meaningful lessons in designing for the patient experience of Cervical Radiculopathy and Stroke paralysis

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## Abstract

*Learning outcomes from two researchers in two separate studies have been combined in this paper; the first explored the lived experience of patients suffering paralysis from stroke or brain haemorrhage and the second focused on out-patients with Cervical Radiculopathy. Both studies originated in Denmark and are linked to recent Danish initiatives aimed at increasing the future performance of home rehabilitation for patients who (it is intended) will be strongly supported by new technological innovation (P@H, 2013). Many of the technologies presently being developed are intended to offer solutions that (in a clinical setting at least) would provide a best-practice level of therapeutic outcome. In some cases these technologies (products, services, systems and environments) have been developed using 'user-research' or various participatory methods. In this paper we propose that 'User' oriented approaches do not go far enough in exploring the life-world of the people they are intended to serve and designs based on these approaches run the risk of failing under uncontrolled, non-clinical contexts of use (Grönvall and Kyng 2013; Redstrom, 2006). We further propose that useful and applicable methodological and health related insights can be gained by applying a human science approach to this type of project. Our goal in this project has been to burrow deeper into the life-worlds of our patient participants so as to investigate the role that a more patient-centric basis for future design interventions might play ahead of their development.*

*The framing for each of the two projects was broadly similar; to develop an open exploration of the contextual complexity that is the first-person, at-home, 'lived experience' of patients recently released from hospital with (mostly) lower limb paralysis from stroke or brain haemorrhage and those with Cervical Radiculopathy. We applied a hermeneutic phenomenological methodology (van Manen, 1997) using open-ended 'conversations', deep textual analysis, patient feedback sessions on synthesised insights and experiential presentation of final results. We present the insights gained in these two projects as examples of this methodology and its value for patient-centred research and design.*

Keywords: Experience-based Designing, lived experience, Experience of understanding, SEEing method, Home-rehabilitation, Patient perspective, Embodiment, Experience of researching

## Introduction and background

Separate learning outcomes from two researchers in two separate studies have been synthesised in this paper – the first explored the lived experience of patients suffering paralysis from stroke or brain haemorrhage and the second focused on out-patients with Cervical Radiculopathy. The main focus in both cases is on the lived experience of 'going home' i.e. what was it like to re-learn to live in a world that was once so familiar but now is forever changed – their own home.

Both studies originated in Denmark and were linked to recent Danish initiatives aimed at increasing the future performance of home rehabilitation for patients who (it is intended) will be strongly supported by new technological innovation (P@H, 2013). Many of the technologies presently being developed are intended to offer solutions that (in a clinical setting at least) would provide a best-practice level of therapeutic outcome. In some cases these technologies (products, services, systems or environments) have been developed using 'user-research' or various participatory methods. In this paper we propose that 'User' oriented approaches do not go far enough in exploring the life-world of the people they are intended to serve and designs based on these approaches run the risk of failing under uncontrolled, non-clinical contexts of use (Grönvall and Kyng 2013; Redstrom, 2006).

The framing for each of the two projects was broadly similar; to develop an open exploration of the contextual complexity and primary concerns evidenced in the first-person, at-home, 'lived experience' of patients recently released from hospital with (mostly) lower limb paralysis from stroke or brain haemorrhage and those with Cervical Radiculopathy. We applied a hermeneutic phenomenological methodology (van Manen, 1997) using open-ended 'conversations', deep textual analysis, patient feedback sessions on synthesised insights and experiential presentation of final results. The primary objective in these projects has been to burrow deep enough into the life-worlds of our out-patient participants so as to provide a sound evidence base for patient-centric design interventions.

The principle role of this paper is to showcase and share the lessons that arose during the two research projects mentioned above, with the intention of assisting others conducting similar research or working with patients in not too dissimilar circumstances. In many ways the insights discussed in this paper might appear to be common sense or 'low hanging fruit'. However, we would also contend that these are the same fundamental aspects of patient experience that are often overlooked or undervalued by design researchers following a problem/solution approach (Grant *et al* 2013; Jones, 2013).

## Methodological approach

Broadly speaking, a hermeneutic phenomenological approach (van Manen, 1997) was adopted in both projects but with variations to suit the differing contextual circumstances. Both incorporated methods such as researcher embodiment (experience prototyping) (Buchenau and Fulton Suri, 2000), immersive field data gathering (utilising new digital technologies) (Taylor *et al*, 2002), and unstructured in-situ conversations (Moustakas, 1994; van Manen, 1997) as well as direct observations during treatment processes (Bate and Robert, 2007). Data analysis was conducted using a detailed nine-step process (Coxon, 2013). All of these processes or methods were used to

enhance the depth achieved in interpreting patients' experiences, particularly the explication of deep meaning structures hidden within their various communications.

*"To be really useful to design, observation is not enough. We cannot observe people's thoughts and feelings - their motivations, emotions, mental models, values, priorities, preferences and inner conflicts. Yet these subjective phenomena are so important for designers to grasp, for it is these that make up peoples experience" (Fulton Suri, 2003, p.53)*

## Embodiment (Experience Prototyping, empathy building and subjectivity priming))

A vital part of the research approach, the embodiment, can be seen as a kind of experience prototyping, where "the designer steps into parts of the persons experience by simulating the 'users' condition" (Rijn *et al*, 2011, p.66). After preliminary research into the different types of disabilities and impairments with various professional therapists and a meeting with two of the patients participating in the study, the goal for our embodiments was to try to recreate their conditions as faithfully and powerfully as possible. Of course the use of embodiment exercises is not new and MIT provides an example of embodiment to raise empathy in their AGELAB where they constructed the AGNES (Age Gain Now Empathy System) suit, to better understand the physical challenges associated with aging (MIT, 2012). One of the key intentions of an embodiment is to enable a closer understanding to develop when conducting subsequent conversations with the patients, Embodiment exercises help in forming an empathic bond, enabling deeper conversations with participants to be explored (Patnaik, Dev. 2009).

*"Direct contact brings empathy with users to design teams and positively influences the quality of the product concepts they produce. Willingness and motivation of designers are key factors in empathic design" (van Rijn *et al*, 2011 p.65)*

## An example from the field research

During a conversation with a patient, I told her about the experiences I had undergoing the embodiment. As I was telling about my experience of feeling irritated with my difficulty and struggle to close my pants, the patient (who had similar difficulties) contributed with her view and feelings of her experience adding that she also felt frustrated and angry with her inability to undertake such a 'simple' task- in that way, the embodiment facilitated a deeper level in the conversation. Again in this case the patient opened up to reveal that she often cried when the whole situation became too unmanageable. Of course this is only a single example but it showcases how the embodiment proved to be a useful tool - facilitating deeper conversations about feelings and managing daily difficulties.

## In-situ *conversations* and data gathering

The primary method for gathering data from participants in this research was through in-situ conversations. Using conversations in the home enabled us to obtain more detailed person-to-person information directly from the participants about their experiences, thoughts and emotions. We intentionally avoid the term 'interview' as it can have a sense of formality about it, which can also make participants reluctant to participate when approached. Our main intention was to

facilitate an informal atmosphere and open flow of information in the exchange. We encourage participants to talk about their experience in their own words and at their own pace; from their first symptoms until the present; letting the conversation flow as freely as possible. This unstructured conversational style opens up opportunities to probe deeper levels of personal reflection and the chance of uncovering unexpected findings. This process also tends to preclude the use of overtly visible recording equipment for documenting the conversation. In order to preserve our conversations and other observations in the least intrusive way, we utilized 'spy-equipment' in the form of HD camera glasses, camera pens and micro cameras that were barely noticeable. The use of these devices was discussed with all participants well in advance of the conversation sessions and their permission was always sought and granted before use.

## Qualitative data analysis

While the embodiment and participant conversations are a vital aspect of the entire research approach, it is then vital that the material gathered during these processes is analysed and synthesised in a rigorous and meticulous way. The *SEEing* method is a set of nine detailed sequential steps, through which the gathered qualitative field data is opened up (inductively), distilled and then categorised into essences (patient stories). The intention through this process is to make the strongest and deepest meanings in the experience more visible (Coxon, 2013).

Following these data processing steps we conducted a series of participant feedback sessions with the patients we had talked with in order to validate, confirm and/or disconfirm our findings. The feedback we received from participants was very encouraging. In most cases they agreed that we had captured the essential elements of what they had discussed with us and were able to add aspects that they felt we had missed or misinterpreted. This made the whole process much more robust and valid.

"As we ended the conversation, he thanked me for the talks we had had and just for being there and listening. Essentially, it made me realise the importance of what we had done by simply offering some understanding of them" (Field notes: Sven Doefler)

## Reflections on the methods used

### Bringing the work home with you

The difficult part in having conversations with people dealing with a life changing condition is to refrain from bringing it home. Having a conversation with a person who is obviously struggling and where you can sense the underlying emotional turmoil is a tough emotional space to share, especially if the person is someone you can closely relate to. Of course, it is not an entirely negative thing to gain empathy for a participant but it is the level of drain on your own personal energy that can be surprising. We found that we coped with this situation better by talking to each other within the research-group, which not only helped us process our own thoughts and emotions, but also made us realise some general similarities in the projects and patient experiences. This kind of 'emotional debriefing' also helped us understand how relatives and friends of patients might feel when trying to support a loved one struggling with these conditions.

" She then looked me in the eyes and said: "I really hope, that what you do with this can help others, if not myself" (Field notes: Lasse Nielsen)

## A deeper insight

The embodiment brought a sharper focus a greater empathic understanding to subsequent conversations with the patients. Secondly, participants deeply appreciated the level of dedication and effort we had put into understanding them and were surprised that our experiences in the embodiment stage were so close to how they experienced similar situations themselves.

"Those are some cool pictures – you really went all in!" (Field notes: Patient comments - Lasse Nielsen)

## Breaking down intimacy barriers

When communicating with patients, we also found that pictures and stories from our embodiment were useful for sparking conversation that helped us break down barriers to sensitive topics, enabling deeper conversations to take place. On several occasions we were presented with information that the participants had not mentioned previously to their closest relatives.

## Key insights arising from the research and patients primary concerns

### Professional blind-spots

Another concern highlighted in the research relates to how some clinicians perceive or understand the sometimes irrational personal hurdles that patients face. An example of this lies in the use of terms such as 'compliance rate' and 'goal setting' (Rosewilliam, 2011). In our research these expressions were often referred to by patients as terms that their therapists used to measure 'performance' in relation to their scheduled exercises, but they were concepts that they did not relate well to. Patients felt that terms such as these do not take into account the way they felt about themselves or were coping with their experience of rehabilitation. Patients struggling to cope with all that is going on around them in the many aspects of their 'new' lives can be left feeling unimportant, not taken seriously and ultimately might fail to 'comply' with the treatment plan.

### A focus on the physical side of treatment

During the research it became increasingly evident that clinical treatment is strongly focussed on physical impairment or disability and that the psychological impacts of treatment or rehabilitation appear to be less addressed. Care providers and health equipment developers are naturally focused on the efficacy of physical treatment options but the emotional needs of patients are also important to the healing outcomes achieved (Myss and Shealy, 1988). Unaddressed emotional issues can lead to frustration and discouragement in patients, as they find themselves struggling to comply with both their own and their therapists' rehabilitation expectations.

## Perhaps a pill will solve the problem

Frustration and uncertainty tend to build up over time, causing some patients to isolate themselves, trying to deal with their problems by themselves or trying to avoid being a burden on their family support system. Some patients eventually become depressed, and are then treated with antidepressant medication, while the actual cause of their problems remains unchanged. This suggests that current therapy options may need to include a closer consideration of the psychological impacts of a patient's physical condition on their emotional state.

## Conclusion

The most important take-away from our experiences in these two projects is the critical need to better appreciate and provide for the context and individuality of patient experiences, rather than an expectation that new technologies will be efficacious enough on their own merits across the broadest spectrum of patient conditions. Compounding this view is one where, if a health intervention (therapy, program or equipment) fails, then it is the patient that is at fault for not adequately 'complying'.

We found the methods utilised in this research to be helpful in getting a much deeper understanding the experience of participants with paralysis and cervical radiculopathy in their 'new' life. From this rich research material we were able to identify key elements of their experience which we might further consider in designing interventions with a better emotional 'fit' for patients with the added expectation that they will also offer better healing potential.

We have a long way to go to be able to design mediations that can better assist in the treatment and welfare of stroke and cervical radiculopathy patients but through this type of research we hope to provide some ways in which patients' non-medical symptoms and behaviours might be better understood so that better home-care can be enabled as a result.

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# Evidence-Based Design: The Effect of Hospital Layouts on the Caregiver-Patient Interfaces

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## *Abstract*

*Evidence-based design (EBD) takes information from credible research and case evaluations into account for design-related decision-making. Despite a wealth of studies in healthcare buildings, EBD has so far considered hospital layouts and their effects only marginally. Therefore, this study contributes to the EBD of hospitals by studying configurational issues. It focuses on how a building layout can affect communication between people that is crucial for good healthcare provision. Two types of interface created between users in outpatient clinics are analysed: caregivers-patients and caregivers-caregivers by comparing spatial layouts across two very differently organised hospitals. The two settings are compared using 'Space Syntax' as a methodology; this is brought together with findings from a staff survey identifying communication networks and direct observations on everyday activities of caregivers.*

*Results suggest that by providing shared facilities and bringing caregivers together, communication is more frequent. Creating a clear spatial separation of staff and patient areas facilitates good communication, both among caregivers and between caregivers and patients. However, space is not the only factor affecting communication, since other aspects such as workflow or culture also have an effect on interaction patterns between users. In summary, configurational issues matter and should be studied further by researchers in the field. The paper adds to the existing body of evidence in the field of healthcare and thus enhances the current understanding and knowledge of practitioners on the influence of the built environment on people. Implications for architects and designers in healthcare are discussed briefly.*

Keywords: evidence-based design, hospital layout, communication patterns, Space Syntax

## Evidence Based Design: Application Problems and Gaps

Evidence-based design (EBD) enables designers and architects to base design decisions on the best available information from credible research and evaluation of existing projects (Hamilton, 2006). It is suggested that using EBD professionals can ensure well designed physical environments that may help patient safety and improve patients and staff outcomes (Ulrich *et al*, 2004). EBD stems from evidence-based medicine (EBM), which is defined as 'the use of mathematical estimates ... derived from high-quality research on population sample to inform clinical decision-making in the diagnosis, investigation or management of individual patients' (Greenhalgh, 2010). EBM is built upon a very well established scientific and theoretical basis and uses well-constructed methodologies. EBD is relatively new and clearly seeks to create an evidential foundation that goes beyond anecdotal evidence.

In a systematic review of the research literature on evidence-based healthcare design Ulrich *et al* (2004) identified more than 600 'rigorous' studies. However, if the appendix to their paper is looked at closely, the authors included studies with low methodological rigor in their review (Sailer *et al*, 2008). Four years later, the research team conducted a new and more extensive search for empirical studies and found a growing body of research (Ulrich *et al*, 2008). In this second report, the authors have substantially revised and expanded the scale of most sections. This time they addressed the limitations of the quality of existing evidence themselves, stating they have included 'many studies [which were] not well controlled'. It is hard though to produce 'controlled trials', as most changes of the physical environment could alter several factors simultaneously making it hard to identify the independent effect of the change of interest (Ulrich *et al*, 2008).

Ulrich *et al* (2004; 2008) mainly identified studies with a focus on environmental issues such as noise, light and air quality. In cases where the layout of the building was of interest various aspects were studied including (among others) single versus multi-bed rooms and their effects on reducing falls, preventing infections, providing better privacy, less noise and facilitating communication. However in these studies the layout was either rather generally defined (radial, single or double corridor ward) or not taken into account at all (Sailer *et al*, 2008). Therefore, a major gap in the practice of EBD is the lack of research that studies buildings' configuration and its influence on patients and staff.

To compensate for this lack of studies, this paper builds on the tradition of Space Syntax research as a theory and method that is designed to allow a rigorous and systematic way of studying the built environment and its influence on people. In this approach every building defines an interface that is the spatial relation between or amongst two broad categories of persons: inhabitants, those who have some degree of control of space and visitors who lack control (Hillier and Penn, 1991, Hanson and Hillier, 1984). Space generates and controls encounter between these two groups and thus influences communication patterns (Allen and Fustfeld, 1975; Penn *et al*, 1999; Rashid *et al*, 2006; Sailer and Penn, 2007; Sailer and Penn, 2009).

Traditionally activities in hospitals were considered to be rather programmed than configurational and thus not affected that much by the building layout (Hanson and Hillier, 1984). However in recent studies it was argued that the configuration of healthcare buildings could influence people's movement and interaction (Lu *et al*, 2009, Heo *et al*, 2009, Cai and Zimring, 2012, Koch

and Steen, 2012b, Koch and Steen, 2012a). It was also shown that levels of programming in hospital settings can vary significantly (Sailer *et al*, 2013).

Therefore this study focuses on configurational issues to contribute to the relatively small but growing body of recent literature that studies the relationship between healthcare buildings and people's behaviour. A well-constructed multi-layered methodology, aligned with Sailer's framework for EBD (Sailer *et al*, 2008), is applied to the two types of interface created between hospital users in outpatient clinics: caregivers-caregivers and caregivers-patients. Communication patterns are of interest in this study because through communication people exchange knowledge and information and consequently this has an impact on the quality of the provided healthcare (Donchin *et al*, 1995).

The research questions addressed in this study are: 1) How are the different interfaces in hospitals constructed spatially? 2) How does the spatially constructed interface affect communication patterns and thus care provision?

The argument will proceed in the following steps: section 2 presents the case studies; section 3 introduces the methodology used; section 4 highlights the main results of the study and a final section 5 discusses the findings and reflects on the practice of evidence-based design.

## Case Studies

Communication patterns in two different hospitals were compared. Five corresponding outpatient clinics in each hospital were selected for comparison. The two hospitals were specifically selected to contrast in their setup and spatial organisation. While Hospital A stands for a new and innovative model of healthcare provision, Hospital B is more traditionally organised.

Hospital A is a new and large stand-alone building located at the outskirts of a small town in the Netherlands. The main entrance of the building leads to a large atrium where receptions and waiting areas are situated (fig.1). The clinics are located on the first two floors on both sides of the atrium. Figure 3a shows the layout of one of the clinics. Clinics are co-located and have a clearly defined large and shared area for professionals called the 'Knowledge Centre' (fig.1). This area is located on a half level in-between the two outpatient clinic floors and accommodates open-plan workplaces with shared desks and facilities such as meeting rooms, quiet rooms, tea points and printing areas.

In contrast, Hospital B is structured as a campus of several buildings, located in the centre of a big city on the West Coast of Canada. It was first opened in 1912 and refurbished in several stages. The complex has two main buildings with links connecting the buildings on the first four floors. The five studied clinics are located on the fourth, fifth and eighth floor of the building. Figure 3b shows the floor plan of one of the clinics as an example of a traditionally structured corridor based layout. Physicians in Hospital B have either single or shared offices for two to three people. In some of the clinics there are also clinic-internal teamwork areas.

There are two major differences between the layouts of the clinics that reflect on the interface between staff and patients and amongst staff. The first one is that in Hospital A the back- and front-of-house areas are strictly separated while Hospital B is more traditionally structured with a

system of corridors that connects waiting areas with exam and consultation rooms (fig.2). The second difference is that in Hospital A the clinics are co-located and have a shared work area – the ‘Knowledge Centre’ while in Hospital B clinics are separated and do not have shared facilities. Therefore, in Hospital A caregivers are brought together with each other and are separated from patients while in Hospital B caregivers are separated from each other but brought together with patients.



Figure 1: Hospital A – patients waiting area and reception; the Knowledge Centre;



Figure 2: Hospital B – patients waiting area and reception; a corridor;

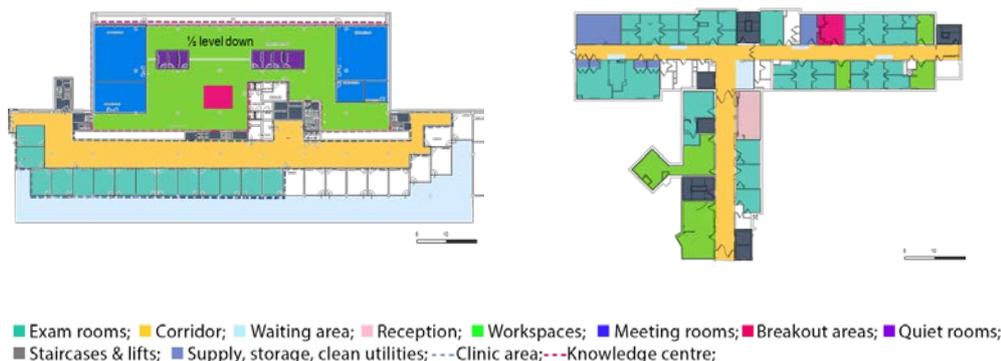


Figure 3a and b: Floor plan of Surgery in Hospital A and B

## Methodology and Metrics Used

Three distinct methods were combined in this paper. Space Syntax was used to analyse the spatial configuration of the buildings. Social Network Analysis was employed to study results from an online survey of communication patterns. Direct observations of activities were conducted to gather quantitative data on social life in the two hospitals.

Space Syntax represents the continuous flow of space as a series of linked elements, for instance rooms and corridors in a building are connected by doorways or staircases. Axial models of the clinics were constructed using Depthmap software (Turner, 2010, Varoudis, 2012). Axial line maps can be defined as the least set of straight lines covering all parts of the building, thus all routes of movement and making all links necessary to represent the relationship between people through space (fig. 4). The metric axial step depth was used to measure the distance between two axial lines as the number of axial steps that one needs to take to get from one space to another.

A staff survey including a Social Network Analysis was conducted in both hospitals to quantitatively assess communication patterns amongst caregivers. 177 and 206 physicians, nurses, clerks, residents and allied professionals from Hospital A and Hospital B respectively were invited to participate. The return rate for Hospital A was 31% and for Hospital B 43%. In the first part of the survey participants were asked to rate the importance of required work activities on a scale from 1 to 7 and to rate how much the spatial layout of the hospital supported these activities. In the second part of the survey they were asked to select up to 25 colleagues and to indicate on a scale from 1 to 7 how often they communicated face-to-face planned, face-to-face unplanned and electronically. Results were analysed with UCINET (Borgatti *et al*, 2002).

Observations were conducted by following six different caregivers each day for ten working days in each hospital (two days dedicated to each clinic). In total 128 members of staff were observed (64 physicians, 33 nurses and 31 clerks), each for a period of 1.5-2 hours during examination hours. Sequences of activities and locations, durations and types of activities were digitally recorded. Pre-programmed PDAs (Personal Digital Assistants) were used for the data collection. Differences in time spent in certain activities and locations between the two hospitals were analysed.



Figure 4a and b: Axial maps of Surgery in Hospital A and B

## Communication and Encounter Patterns

This section will investigate communication and encounter patterns for both interfaces mentioned: firstly the interface caregiver-caregiver will be analysed, and secondly the interface caregiver-patient.

In Hospital A caregivers are co-located and physically brought together in the open-plan area of the Knowledge Centres. During exam hours, caregivers spend 69% of their time in the charting galley, adjacent corridor and knowledge centre (with 21% of their time spend in the exam rooms). This means during the majority of their working day, caregivers are available and accessible to interact and communicate with each other. Moreover the separation of back and front-of-house allows caregivers to consult other staff members freely without worrying of being overheard by patients. Indeed, one of the best features mentioned in an open question by 14% of participants in Hospital A was the back-of-house, where they can easily interact with other caregivers. 19% of time during exam hours is spent talking to colleagues internally and another 3% to external ones. An average conversation between caregivers within a clinic lasts only 44 seconds, which means communication is short, frequent and ubiquitous.

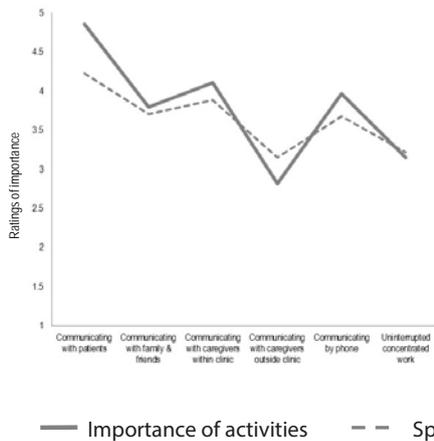
In the survey, communication to other staff inside the same clinic was considered as an important or very important activity by 79% of caregivers; communication to colleagues in other clinics was valued by 26% of staff. The building was rated as an enabling factor for the caregiver-caregiver interface (see figure 5a), since an average rating of 4.1 (on a scale from 1-5) was given to the spatial suitability for intra-clinic communication and 3.4 for inter-clinic communication. A potential area of dissatisfaction was concentrated work, since 29% of staff suggested that more private spaces were required. Still in this hospital, the importance given to an activity and the rating of the spatial layout match to a high degree.

The compact spatial structure of Hospital A results in high levels of proximity between the clinics so that distances between clinics are rather small and range from one to eight axial steps. This has an effect on communication intensity (as argued in more detail by Sailer *et al*, 2013): with the increase of distance between clinics, communication decreases logarithmically. Workflows and speciality of clinics were identified as confounding factors.

The integrative nature of the flexible and open work environment of Hospital A is also reflected in the workflow patterns of staff. As shown in figure 6a, physicians and nurses have a very similar activity pattern and spend comparable amounts of time in the same locations. Only clerks show a completely different pattern of occupation. This means the spatial layout acts integratively and brings caregivers together, resulting in ample opportunities for communication across the professions.

In summary, the caregiver-caregiver interface in Hospital A allows for frequent and intense communication between staff within as well as across the different clinics. Close proximity and an open-plan layout are facilitating factors.

Hospital A



Hospital B

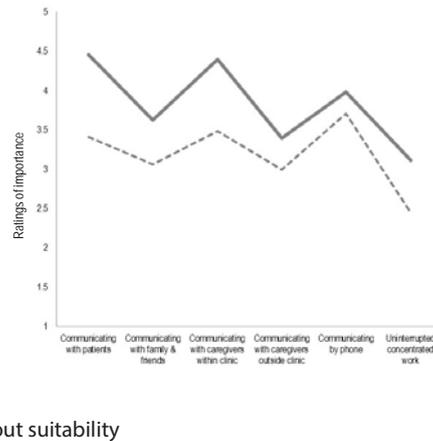


Figure 5a and b: Importance of different activities and suitability of the spatial layout for Hospital A and B.

In Hospital B caregivers are much more segregated by the partitioning of the traditional corridor-offices layout. During exam hours, caregivers spend only 46% of their time in teamwork areas and corridors (with a comparable 24% spent in examinations), so that in effect caregivers are not as openly available for communication and interaction as in Hospital A. While a similar amount of time of the working day (during exam hours) is dedicated to communication with 22% of time spent talking to caregivers in the same clinic and 0.2% to external caregivers, average conversation length is 1 minute and 21 seconds, i.e. twice as long as in Hospital A. This means each instance of communication lasts longer and is therefore in all likelihood more planned and less spontaneous.

Survey results in Hospital B are similar to Hospital A, as communication between staff is regarded highly: 85% think communication within clinics is an important or very important activity and 44% think the same for communication across clinics. However, the building seems less suitable: ratings of 3.5 out of 5.0 (intra-clinic communication) and 3.0 out of 5.0 (inter-clinic communication) were made regarding the question to which degree the spatial layout supports necessary workflows. Again, the ability to concentrate seems compromised and 16% of staff mentioned the need for more private spaces. The gap between importance of activity and suitability of the building is much wider for all activities, as shown in figure 5b.

The traditional spatial structure of Hospital B creates much greater distances between caregivers than in Hospital A. Axial step depths range from one to sixteen steps separating the different clinics from each other. The relationship found between distances and communication intensity in Hospital A does not hold in this case: it seems that other factors such as working cultures, workflows and specialism of disciplines are much more important in the face of a partitioned layout and particularly high vertical distances.

The segregating nature of the building also becomes apparent in workflow patterns (see figure 6b): in Hospital B physicians and nurses show more deviating patterns of occupation than in

Hospital A – the different professions tend to spend time in different places. This results in lower chances for communication and means a more disrupted interface.

To summarise, the caregiver-caregiver interface in Hospital B is characterised by longer and more programmed conversations focusing on relationships within rather than across clinics, and within rather than across professions. Higher spatial distances and the overall configuration contribute to lower ratings of satisfaction with the building.

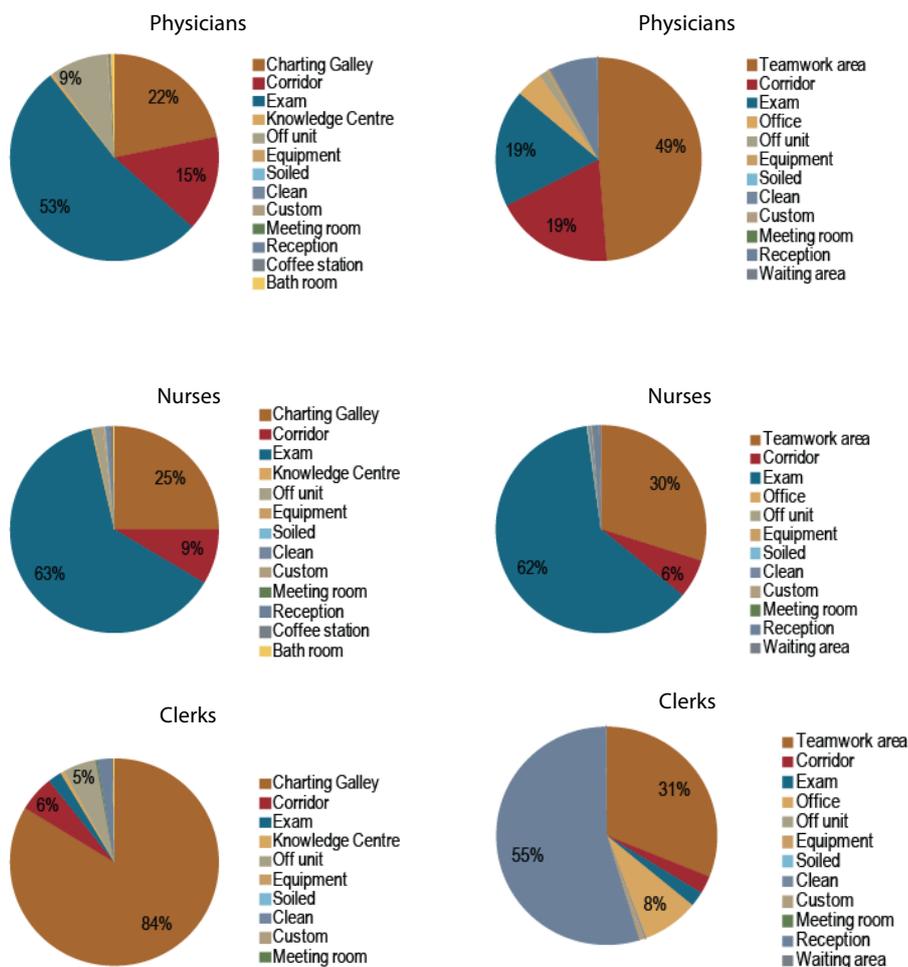


Figure 6a and b: Percentage of time spent in various locations by physicians, nurses and clerks in Hospital A and B;

Similarly to the differences in the caregiver-caregiver interface, the interface between caregivers and patients also varies between the two hospitals.

In Hospital A communication with patients is considered as the single most important activity in the work of caregivers with a rating of 4.9 (on a 1-5 scale). Even though the interface is highly

regulated spatially since all areas of the Knowledge Centre are inaccessible to patients, caregivers spend a lot of time with their patients (15% of time talking to and 5% caring for patients plus another 1% talking to family).

On the contrary, communication with patients is not quite as high on the agenda in Hospital B. Caregivers give it a rating of 4.4 and see it as equally important to communication with colleagues. Time spent with patients is a lot shorter than in Hospital A with caregivers spending only 4% of their time talking to and 7% caring for patients plus another 0.3% talking to family. However, another 5% of caregiver time is spent in phone calls with patients and again the need for more private spaces becomes obvious as the following quote exemplifies: *"I have gone into the bathroom and shut the door to take more than one difficult phone call in order to have some safe, quiet space for the patient calling"* (Allied Professional, Pacific Lung Clinic, Hospital B).

In summary, the interface between caregivers and patients is structured very differently in both hospitals. The secluded area of the Knowledge Centre in Hospital A, which is inaccessible to patients, creates a rather programmed spatial interface – patients and caregivers mostly meet in the exam rooms only and nowhere else. Still a lot of time is committed to patient communication and care. Hospital B in contrast allows for more random encounters between caregivers and patients on the jointly used circulation spaces, yet less time is spent with patients face-to-face.

## Conclusion

This paper gives insights into the effect of the design of hospital buildings on people's behaviour. Two different hospital layouts were analysed and their implications on communication patterns of caregivers were discussed. It was shown how configurational choices and simple design principles (access, co-location, openness, proximity) have an impact on the creation of the caregiver-caregiver and the caregiver-patient interfaces and how this in turn affects communication and occupation patterns, which are an important factor in good care.

Integrating caregivers in an open area and segregating patients at the same time, as realised in the spatial layout of Hospital A, seems an innovative design choice resulting in intensive and frequent communication patterns all around.

Although very rich data was gathered for the present study some limitations should be noted. First, observations were done during exam hours in outpatient clinics only. Therefore the social behaviour in areas such as the Knowledge Centre or the public areas was not fully captured. Second, the return rates from the online survey were relatively low, which weakens our multi-layered data.

Still the rigorous methodological framework of this paper combining quantitative as well as qualitative data on spatial and social aspects allows new insights. This knowledge is important for architects and designers of healthcare buildings. Adopting an evidence-based approach and using insights from rigorous research can advance the provision of good healthcare by designing hospitals that ease communication among staff and allow staff to focus their attention on patient care. The spatial organisation of buildings influences communication patterns and as such configuration matters.

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# Architecture and Psychiatric Disease - Rethinking places of care

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## Abstract

*The interaction between patient and healthcare environment influences well-being and course of treatment. This influence is even stronger for users as sensitive as psychiatric patients and leads to research specific issues and approaches to support the facilities' design.*

*The presented work aims to investigate the relationship between psychiatric patients and places of care and the environmental aspects that can improve patient experiences and enhance the healing process.*

*At an exploratory phase, the multidisciplinary research team (psychology, architecture, ergonomics, design) has built a common base of knowledge through informal discussions, sharing of data, focus groups with patients and medical staff. Then the research was focused on "non-hospital residential services" and carried out through a field study, in three phases: 1. exploratory visits and informal interviews with staff and patients of three residences, matched with issues from literature, to identify key issues to be investigated (e.g. privacy, safety); 2. semi-structured interviews with patients; 3. direct observation of the usage of the environment by patients and staff. With the help of the Experimental Center of Cinematography, the work availed itself of an additional tool: three short films (Fig.2) that explore, from different points of view, the relationship between patients and spaces.*

*The findings were formulated in three principles (e.g. "awareness about the importance of space by staff and users") and ten criteria (e.g. "non-medical environments, with no memories of hospital", "integration and openness to the inhabited territory") aimed at inspiring the design of psychiatric healing environments.*

*The field study and the multidisciplinary composition of the team were essential for understanding patient's needs. The adoption of an interdisciplinary and collaborative approach has allowed the team to develop shared criteria. These criteria will be the starting point for further processing of technical design requirements.*

Keywords: psychiatric facilities, supportive healing environment, interdisciplinary working

## Context of the research

This research on mental care's services focuses on the influence of the physical environment that surrounds the patient and the benefit we can obtain from this interaction. The work is inspired by international results of supportive healing environments' research, increasingly showing how the interaction between patient and healthcare environment influences the well-being and the course of treatment (Codinhoto, 2009). This influence is even stronger for users as sensitive as psychiatric patients (Thiels, 1993; Karlin, 2006). It might therefore be interesting to explore the application of a salutogenic model to architectural design for psychiatric care (Golembiewski, 2010). The WHO (2010) also acknowledges this relationship and promotes the design of environments that support mental health by allowing people to adopt and maintain a healthy lifestyle.

Until the mid-twentieth century, asylums were the elective sites of mental care. They were designed according to the ideology of their time and responded perfectly to the concept of total institution approved by medical staff, family members and public administration (and sometimes perhaps even by the patients themselves). Their key points were removal, segregation and control (Goffman, 1961). The first wave of deinstitutionalization took place from the end of the Second World War to the 1970s (Shorter, 2007). This new trend was fostered by the spread of "Normalization theory" whose purpose was to making available patterns and conditions of everyday life, as close as possible to those of the mainstream of society, such as: normal rhythm of day, facilities integrated in a normal context, etc. (Nirje, 1969). This theory still influences the mental care model, inspite of the debate on risk to "normalise" individual's differences, requiring people to conform in order to gain acceptance (Landesman & Butterfield, 1987; Culham & Nind, 2003). Nowadays, most western European countries "have taken to their hearts the vision and evidence supporting deinstitutionalization and establishing services close to where people live" (WHO, 2008). Strengthened by dynamic vision of recovery (Gilburt *et al*, 2013), this trend is moving towards the replacement of psychiatric hospitals with a network of community based facilities, integrated in the context and with an image as close as possible to the domestic environment (Gabel *et al*, 2012).

Despite this shared vision, a design model that fully reflects the current thinking on psychiatric care is not yet developed. The wide variety of options that replaced hospitals combined with the lack of design research and knowledge of the actual needs of users, is leading to the proliferation of "non-thoroughly researched options for the design of environmental settings" (Chryssikou, 2012). In Italy, the only European country where, thanks to a 1978 law, mental hospital were totally banned (De Girolamo, Cozza, 2000), there was no real effort to develop an architectural typology that takes into account the specificity of a mental health care model based entirely on territorial services (De Vito, 2010). Places dedicated to the care of mental disorders reproduce in part the mental hospital setting and culture of separateness - long corridors with rooms all the same, locked rooms, etc. - in part the spaces and furnishings designed for a "standard hospital patient" - spaces and finishes aseptic, hospital beds, neon lights, etc. (Savuto, 1999; Dell'Acqua, 2009).

Literature shows several studies addressing issues related to new places for mental health care. Some of those present a comprehensive analysis of the problem from a psychological or sociological perspective (Mahoney, 2009; Curtis, 2009) but their humanistic approach makes their

use in the design phase less straightforward. Other studies address some specific issues in depth, such as the issue of safety and security (Ulrich, 2012), reaching even to the definition of design guidelines (Department of Veterans Affairs, 2010). Sometimes, however, the reported results of these studies do not leave out completely the perspective of the patient, his needs, his desires. In this context, there is still a need for studies carried out by interdisciplinary research teams and with the direct involvement of patients, in order to define patient and care centred criteria for the design of psychiatric facilities.

## Questions addressed

This research was intended to meet the demand of a group of users of psychiatric services (Lighea community: three residential therapeutic communities, one day care centre and some independent housing)<sup>6</sup> in the town of Milan (Italy). These users, both patients and caregivers, complained about a lack of correspondence between their actual needs and the current architecture of psychiatric facilities. They sought to rethink the design of mental care environments in order to improve the patient's experiences and enhancing the healing process.

To respond to these issues, the study focused on the identification of users' needs, problems and expectations about the physical environment of care. The study intended to use the findings as a basis for the definition of criteria to guide the design of psychiatric supportive healing environments.

## Methods

The study was carried out assembling a small multidisciplinary research group (Social Architecture, Technological Design, Interior Design, with the aid of Psychiatry and Art). The users involved were psychiatric patients in non-acute phase, suffering from severe psychiatric disorders, aged between 18 and 50 years old, living in three non-hospital residential facilities of eight to ten beds (a total of 26 patients). The patients didn't experience the role of "object of study"; they themselves participated in defining the research objectives, carrying out the research and sharing the results.

The work was started with a preliminary phase of analysis of the issues and setting of the research. Then the work was focused on "non-hospital residential services" and carried out through a field study, in three phases: 1. Exploratory visits; 2. Interviews; 3. Direct observation. The analysis tasks were carried out through qualitative methods.

With the help of the Experimental Centre of Cinematography, the work availed itself of an additional tool: three short films exploring, from different viewpoints, the relationship between patients and spaces.

At the end, the research team analysed the resulting material and highlighted the critical issues and the deepest needs of the patients and the staff. The findings were formalised in principles and criteria which were shared with patients and staff.

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<sup>6</sup> Facilities of Lighea Foundation, Milan, Italy.

## Preliminary phase

The work started with the analysis of documents provided by the patient themselves: a written story of life experience in psychiatric facilities, a list of critical points of the environments, a report with design ideas. The team started sharing information, taking into consideration elements like user-responsive design, mental care facilities' issues, suggestions contained in literature. The team also organised a discussion group, chaired by the head of the residential community<sup>7</sup>, which was attended by 15 patients, two staff operators and the three involved researchers, on the topic of the relationship between physical space, mental distress and the path to recovery. One of the goals of these preliminary activities was to build a common ground of language among team members, as needed for an interdisciplinary work.

At the end, based on the cooperation of staff and patients of the concerned community, it was decided to limit the analysis to the non-hospital residential facilities, housing for patients in non acute phase but requiring an internal support of caregivers to help those living there safely and as much as possible in autonomy.

## Field study

A direct investigation was conducted, in three steps, in the non-hospital residential facilities of Lighea community: 1. exploratory visits; 2. interviews; 3. direct observation.

### 1. Exploratory visits

At first we looked for key elements to consider and develop. We informally visited the locations (Fig. 1) and spoke with the working staff and with some patients about their experience and the condition of the environment. The first results allowed us to identify key issues to be investigated (e.g. privacy, safety, territoriality, etc.). The three residences are located in the centre of the city, in valuable and lively areas, two in buildings of mixed use (residential / office), one in an independent but not insulated building. The Lighea patients form an interacting community for the many activities carried out jointly (i.e. the laboratories of the day care centre). The community is dynamic, the same patients can move between the three residences depending on the stage of the care pathway or according to specific needs or challenges.

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<sup>7</sup> Giampietro Savuto, psychotherapist, director of Fondazione Lighea Onlus, Milan (It).



Fig. 1: The analysed facilities: three Lighea non-hospital residential facilities

## 2. Interviews

Then, with the guide of the identified key elements, the research team drew up and carried out semi-structured interviews with patients. At first, structured interviews were programmed in order to obtain elements easy to translate into requirements but the pilot interview showed that this was not the right tool to relate to the people involved in this experience. Then it was opted for semi-structured interviews, with elements of the key subjects to discuss, leaving wide range towards time and modality of interaction of each interviewed person. Despite the interest shown by patients to the issue in question and their broad participation during the informal talks, many of them did not feel up to face to face individual interviews. So the researchers collected fewer interviews than hoped (only five), but on the other hand, the highest cooperation from the patients who participated was obtained.

## 3. Direct observation

Two observers<sup>8</sup> directly collected data in one of the three residential facilities, giving us information about the way patients use the spaces. The apartment chosen for the observation is located in a building in a central location, in close contact with other "normal apartments" and work activities. The interior is similar to those of an ordinary home. The place is designed to allow the carrying out of simple everyday gestures (getting up early in the morning, going out for shopping, cooking, eating together, tidying up etc.), "doses of daily engagement," leading to the path towards autonomy, the main goal of their community.

During the first day of observation, in the apartment there were between five and seven patients (depending on the time in the day), two visitors (for lunch), an operator and a trainee. During the second day, there were two to seven patients, four visitors (two lunch, one for one hour, one for a few minutes) and an operator. Different techniques were used for investigating use of the spaces, critical issues and expectations of patients: structured observations - using preset grids - and unstructured - annotations, dialogues. In the first part of the observation, the physical characteristics of the apartment were analysed. Photographs were taken of the different rooms and the details that attracted the attention of observers. The characteristics of the spaces

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(dimensions, materials, colors, furniture, etc.) were shown on a floor plan. Then, the use of the spaces was analysed in detail: how and where patients were most likely to spend their time in relation to their different needs, the interaction between patients, staff and spaces. After the collection of information, drawings were made on the plan marking the positions of the people at intervals of 15/30 minutes, by distinguishing between staff and patients and posture that they had adopted, such as standing, sitting or lying down (Fig. 2). To respect the privacy of patients, it was not always possible to get in all the rooms.



Figure 2: Use of the spaces: - time and manner - people interaction

## Short films

Thanks to the help of “Centro Sperimentale di Cinematografia” of Milan, the researcher had three graduating students creating three short films (Fig. 3) about patients’ life and the interaction among themselves and the environment they live in. In the first short film, the director has inverted the rules of the “institutional documentary” asking a patient to interview the researchers (Tadiello, 2011). In the second, the director has led six of the involved patients to a theatre to rebuild their “inner spaces” within the empty space of the stage (Maralla, 2011). In the third, the director has used the three residences of Lighea as a set, with the involvement of nine patients, with the aim of shooting scenes of real life, the everyday experience of rehabilitation (Donzella, 2011).



Susanna Tadiello

Rita Maralla

Mauro Donzella



Figure 3: Images from the short films, CSC, 2011

## Findings

The findings about the needs, problems and expectations of patients were collected, starting from their direct statements (their preliminary documents, informal talks during the various stages of research, interviews, etc.).

Many of the patients involved in this study had previous experience of in-patient psychiatric facilities (general hospital wards, private psychiatric inpatient facilities, non-hospital residential facilities) and they reported how those facilities were far away from the concept of recovery communities. The patients highlighted the active role they can play within the Lighea residences: the domestic setting of these communities requires them to take charge of daily activities related to the concept of "care of the place," so deeply connected to the concept of "care of themselves and of human relationships." They expressed the critical relationship between the need for "domesticity" and the requirements of the building regulations that follow too much those of the hospital spaces. Patients expressed the need to avoid creating too close links with these houses, remembering that the experience in the residential structure must be temporary (flowing vs. timeless spaces). A particular emphasis was given to the possibility of having time and space for privacy. At the same time, patients highlighted the need for situations and spaces that facilitate, almost demand socialization. Patients are aware of their tendency towards isolating, typical of many mental disorders, and of the importance of socialization for their well-being and recovery process. For example, although patients appreciate the single room that allows privacy and personalization, they prefer multibed rooms because it prevents them from indulging and isolating themselves excessively.

Issues reported by patients were shared with the caregivers. The psychotherapist in charge of the community has highlighted other aspects of space that, in his experience, can have a positive impact on the process of care. For example, not only decorating the rooms with new elements but also with furniture and fancy goods with a past, a previous history, can help the patient to perceive the flow of time and build the development of a personal history, as opposed to fixity dictated by mental illness.

The direct observation of the environment in use has allowed to further highlight the strengths and weaknesses of spaces, not collected through other methods of investigation. For example, it has been observed that the patients considered very comfortable the only balcony in the house because it allows them to stay on their own and feel a sense of privacy. It was also observed an over-use of the staff room, with the internet point, with negative effects on the interaction between patients and staff.

The short films have provided an introspective point of view that allows to expand the knowledge on the patient's experience and their deep and intimate relationship with the places.

The findings were discussed among researchers and practitioners. The results were formulated by the researchers in shared principles and criteria aimed at inspiring the design of mental care supportive healing environment.

## Principles

Here are three principles, premise for every other action:

A - Consciousness of the importance of the space by the organization and the residents - an essential component of the community model and intervention.

B - Continuous caring of the aesthetic - the well cured environment communicates to the resident "you are valuable", on a daily basis.

C - Importance of the affective and creative dimension - building a creative and emotional environment in the home

## Physical environment criteria

Here are ten criteria about the environments, based on the needs and expectations of patients found through the field study and the information taken from the short films:

1. Integration and openness within the inhabited territory – to facilitate the relationship with the surrounding environment (Fig. 4);



Fig. 4: Accordance with "Integration to the inhabited territory" .

2. Non-labelling environment – avoiding the risk of stigmatization and isolation

3. Non-medical spaces, with no reminiscence with hospital environment – to recognize the specifics of the psychiatric patient and to avoid the stereotype of the “standard patient”
4. Spaces and equipment activities’ friendly– designed according to the requirements of security and usability, in order to allow patients to experience and increase their autonomy (Fig. 5);



Fig. 5: Accordance with “Activities’ friendly”.

5. Flexible spaces – to support relations and exchanges leading to the creation of a true community
6. Customizable spaces – to have a feeling of a personal space
7. Environment with background elements – to allow the perception of time (Fig.6)



Fig. 6: Accordance with “Environment with background elements”.

8. Friendly and rich of stimulus – to promote daily tasks and leisure activity
9. Articulated spaces – to follow the guest through the different steps of care
10. Non-binding environment – to allow the transition from these protected spaces towards more free environments

## Conclusions

The present work has analysed the interaction between psychiatric patients and healthcare environments, with specific reference to non hospital residential facilities. The study has highlighted the needs, problems and expectations of patients, together with the staff's and treatment's demands. Many aspects have emerged, such as the need for a 'domestic' environment but at the same time a non-binding one, a place that allows customization of space and privacy

but at the same time promotes socialization. The study has led to the definition principles and criteria aimed at inspiring the design of mental care supportive healing environment.

The contextual research and the multidisciplinary composition of the team were essential for deep understanding of the patient's needs. The adoption of a collaborative approach has allowed the development of truly shared criteria. These criteria are not technical design requirements, but they can be the starting point for their further.

In conclusion, this study highlights the importance of providing a space that succeeds in being a home without the emotional ties of the family's home and that allows the individual to rebuild an everyday life and relationships.

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# Biophilic Design as a Medium Towards the Psychosocially-Supportive Design of Outpatient clinics Settings

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## Abstract

*Outpatient-clinics provide primary-care services through the extensive work of their staff members. As, all outpatient-clinics are alike in having no overnight patients (Haron et al., 2012), the caregivers are the users most affected by the physical environment. Most environmental-psychology research and theories are concerned with the adaptation and comfort of people within their working environment. A healthcare setting is viewed as one of the most stressful working environments; the increasing complications of the system impact staff as much as they affect patients (Berwick, 2002). Significantly, the history of healthcare reveals that Ancient Cultures considered healthcare settings for their therapeutic value, not merely their purely functional designation (Verderber, 2010). Biophilic design attempts to reflect the congenital human affinity towards nature (known as Biophilia) into built-environment design. Whereas, the psychosocially-supportive design model augments users' wellness by reducing their anxieties by challenging their minds to construct stimulation, creativity, satisfaction and admiration (Dilani, 2001). Therefore, this paper argues that the two theories are congruent and that there is a great opportunity to use Biophilic Design research to inform the Psychosocially-Supportive Design model.*

*The paper reports on literature-review analysis, aims to enhance the psychosocially-supportive design of the outpatients' clinics by exploring the areas of connexions in the biophilic design connotation. The paper's first objective is to delineate the areas of association of the two design trends [psychosocially-supportive and biophilic designs] to extract design parameters that could be employed within the outpatient clinics' settings. The second objective is to contrast the extracted biophilic design attributes against NHS design requirements and standards for outpatient premises. The paper's final outputs are biophilic design recommendations that can be employed as part of the psychosocially-design model of outpatient clinics, in order to enhance primary care design outcomes and to strengthen caregivers' wellness and wellbeing.*

**Keywords:** Outpatient clinics design, Biophilic Design, Psychologically-Supportive Design, Staff Wellbeing

## Introduction

During recent history, technical accomplishments have guided the scientific community towards a purely pragmatic approach that has dominated academic research. This trend has been realised in architectural design and studies, through raising the functional value of design, standardisation, lack of aesthetic considerations, etc. As such, less consideration has been given to the philanthropic side of a building's design, especially when it comes to the design of healthcare buildings (Verderber, 2010). Which has negatively affected the way the working staff perceive their working environment, as well as their interaction with this environment which has diminished and in many cases has triggered stress and anxiety (Blustein *et al*, 2004).

## The scope of the review

Health as defined by World Health Organisation [WHO] is: "a state of complete physical, mental, and social well-being, not merely the absence of disease and infirmity" (Larson, 1999). This definition strongly considered the association of wellness to 'health' as a concept, which was reflected in the 1978 WHO declaration on the Primary Health Care [PHC].

The National Wellness Institute considered wellness as a multidimensional terminology. A popular model adopted by many universities, corporates, and public health programs encompasses 6 dimensions: Social, Occupational, Spiritual, Physical, Intellectual and Emotional (Roscoe, 2009).

Renger *et al* (2000) defined wellness as consisting of physical, emotional, social, intellectual, and spiritual dimensions, and added environmental wellness to emphasize the important impact of one's surroundings on his/her wellbeing [the concept was also discussed by Sackney, Noonan, and Miller (2000)]. Accordingly, PHC built-environment is expected to reflect this conceptual model that refers to both practices and beliefs (Shoultz, 1997; World Health Organization [WHO], 1978).

Despite this fact, the built environment of current outpatient clinics does not engage the full meaning of health. Many outpatient clinic designs make users feel stressed and anxious due to factors like difficulty of interpreting way-finding signs, crowded, stuffy, featureless working and waiting areas, dull colours, lack of adequate natural lighting, etc. (Hartig and Staats, 2006). "The frustration levels of both patients and clinicians have probably never been higher. Yet the problems remain. Healthcare today harms too frequently and routinely fail to deliver its potential benefits" (IOM, 2001, p.1). The persistence of institutional and narrow functionally oriented approaches of healthcare design - in which high priority is given to functional efficiency - has largely neglected environmental qualities that consider the psychological, social and spiritual needs of staff and patients. These psycho-socially supportive design elements should be reflected as a clear strategy of healing (Clarke, 2006). Indeed, despite the fact that reducing staff stress and fatigue through a healing and supportive environment seems like an obvious goal, there are relatively few studies that have dealt with this issue in any detail (Ulrich *et al*, 2004).

Psychosocially-Supportive Design is a model that offers a possible paradigm for health wellness endorsed by the design of the physical environment, in particular within healthcare facilities. Considering how physical environment could impact wellness factors, this model would be a

useful framework to guide healthcare design to promote health (Dalton and McCartney, 2011). Dunn (1977) also emphasized the interrelated nature of wellness, body, and environment, formulating a dynamic equilibrium when balanced (Dunn, 1977; Foster and Keller, 2007). Therefore, such a design approach is anticipated to augment the sense of coherence and fitting to and into the place, which in turn would influence positively upon human behaviour and the activities taking place in these settings. Design from a salutogenic perspective defines, not only the causes of stress, but endorses wellness factors that support health processes for patients and working staff. When employed, such design should support human rationality, which motivates and engrosses the space users both mentally and socially. The straightforward function of psychosocially-supportive design is to start a mental progression that, by attracting a person's attention, may remove or, at least, reduce nervousness and concerns, bringing about positive psychological changes. Psychosocially-supportive design should challenge minds in order to create pleasure, stimulation, creativity, satisfaction, enjoyment, and admiration. According to the science of the psycho-neuro-immunology, the effects of the environment on the immune system and nervous system occurs through the design features that are stimuli that directly affect the psycho-neuro-immunological system (Dilani, 2009). The brain perceives design characters and qualities - and relates them to the central nervous system - in relation to the effect of exposure from the surrounding environment. Both functional efficiency, which is presentenced in the required standards/design recommendations, and psycho-socially supportive design are crucial to accentuate the quality of the physical environment, and to create/enhance effective health settings (Dilani, 2001).

Biophilic design theory is the use of natural innate human affinity towards nature, known as biophilia, to influence positively human's psychology. Dissimilar to "phobia" – being the dislikes and fears that people have of things in the natural world – Philia is the attraction and positive feelings that people have toward certain habitats, activities, and objects in their natural surroundings. The term was first used by Erich Fromm to describe a psychological orientation of humans being attracted to all that is alive and vital (Heerwagen, 2009). In his book "The Biophilia Hypothesis", Stephen Kellert argues that the physical representation of nature, views of nature, symbols of nature, and other natural objects and design elements, would charm and respond positively to the inherent human affinity towards nature and consequently induce a constructive familiarity with the built environment (Kellert and Wilson, 1995). Therefore, biophilic design is an intimate amalgamation of the natural world with the artificial world of buildings. This merger could involve bringing flora into buildings, using natural materials and surfaces, sanctioning natural light, etc. The incorporation of biophilic design elements should enhance human's functioning and health through the establishment of nature-informed habitats for humans to live and work in (Kellert *et al*, 2011).

Psychosocially-supportive design theory is based on the awareness of human's interaction with the surrounding environment through mental processes that endorse the response of the neural system to the external stimuli and the informational fields that exist in the natural environment. The biophilic design model is based on the established positive psychological effects of the natural environment, and nature's ability to provide restoration from stress or attention fatigue (Kaplan and Kaplan, 2009). The two theories are thought to be congruent and there is a great opportunity to employ a biophilic design approach to inform psychosocially-supportive designs. This paper

investigates, through a comparative literature analysis, how outpatient-clinical settings can benefit from biophilic design association.

## The study plan

This paper reports on literature review analysis that aims to enhance the psychosocially-supportive design of outpatient clinics by exploring biophilic design connotations and by defining and extracting biophilic elements/parameters that could be employed within the clinical settings, to strengthen the caregivers' wellbeing and to reflect an authentic concept of 'HEALTH'.

A thorough literature review reconnoitring the biophilic design concept has been done in order to understand and define variable biophilic design attributes. This review search has been followed up by review analysis to delineate the connection between the psychosocially-supportive design and the biophilic design approaches. The final stage of the study was to contrast and compare the resulted parameters against NHS design standards of outpatient clinics and required infection control regulations stated by the relevant regulating bodies. Furthermore, the resulting parameters were confirmed by further hospitals evidence-based literature. The final outputs will include design attributes of biophilic design that can be employed to enhance the design outcomes in the outpatient clinical zone.

Although the socio-cultural dimension is an important factor that influences the psychological perception of space, it is not a subject of investigation in this research. Most literature on the biophilic design model involves only the merger of nature and the natural features in architectural design by considering nature as the main source influencing and inspiring the biophilic design approach. Therefore, the research results are relevant to the natural dimension of the healing space, being a universal and international language of all human beings. Yet, it is important to mention that these results could be subject of further identification and refinements based on the socio-cultural perspective of the users.

## The outcomes

According to the reviewed literature, the paper identifies two biophilic design categories of design attributes which could be employed in the psychosocially-design of outpatient clinics; the first is specific biophilic design features such as water, plants, natural materials, etc. The second determines specific forms and shapes - understood to be biophilic - for these variable design elements as well as other design constitutions.

## Recommended biophilic design features for staff wellbeing in outpatient-clinical areas

In this section the paper identifies biophilic design attributes supported by EBD and the psychosocially-supportive design literature. These design parameters are anticipated to improve the outpatient clinics physical environment qualities.

## Water

John Ruskin stressed the importance of water in any beautiful Homeric landscape which must include a fountain or other water feature (Korpela and Hartig, 1996) (Kellert *et al*, 2011). In addition, Roger Ulrich emphasised that water elements in the design produce high level of user satisfaction (Grinde and Patil, 2009). In general, water features are characterised by their qualities, quantities, clarity/colours, movement and sounds. Within outpatient clinics, water features could include small fountains, ponds, water falls, or even fish tanks, used indoor or outdoor. However, the effective use of water inside outpatient clinics requires more complex processes of purification and disinfection. Therefore, it is recommended that indoor installation of any water feature must be treated as infection controlled milieu by utilising combined water purification and sterilising systems supplemented with automatic water refresh cycles (Fraise *et al*, 2012).

## Fresh Air and Natural ventilation

The value of increasing the rates of outside air delivery into buildings to improve health and performance is very evident in research. As a responsive act, ASHRAE has updated its standards from 10cfm to be 20cfm per person as minimum in office buildings (Kellert *et al*, 2011). However, when considering natural ventilation in the design of outpatient clinics, it might not be clear whether it should occur through operable windows or through a mechanical system that incorporates dehumidification, filtration, thermal comfort, etc. Referring back to the relevant scientific body of knowledge; much research in Europe and Scandinavia promotes the benefits of fresh air over processed air (Seppanen and Fisk, 2001). In outpatient clinics, access to fresh air could be more beneficial than in many other building typologies, especially when considering the negative sides of air conditioning systems in healthcare facilities such as air born infection, sick building syndrome (SBS), complaints of soreness of the eyes, dryness in the throat and other forms of discomfort, fresh air could (Sundell *et al*, 2011)

## Sunlight

The human body produces Vitamin D when exposed to natural sunlight. Vitamin D, besides being essential to human life, has been shown to elevate mood and decrease depression as well as help prevent heart disease, many forms of cancer, Type I Diabetes, and osteoporosis (Grant and Holick, 2005). The quality and quantity of the lighting that individuals receive, and the time of day they receive it, is also crucial to their well-being (Edwards and Torcellini, 2002). Medical staff spend most of their working days indoors in outpatient-clinical rooms, with limited exposure to sunlight and in many cases exposed to cool fluorescent light. Recent academic work has shown that exposure to widespread full-spectrum fluorescent lighting is linked to detrimental effects, of different types, on health such as: incidences of stress, reduced productivity and well-being, poor health and lifespan reduction (McColl and Veitch, 2001).

The inclusion of sunlight in outpatient clinics must respond to the functional purpose of each zone. An even light distribution in the consultancy area is needed; glare and dark shadow patterns should be eliminated, filtered and diffused light is highly recommended. On the other hand, controlled light and shadow patterns in the rest areas could be more relaxing and natural. In addition, light as a shape and form e.g. directed light on an art piece or specific natural scene in an outpatient zone can create a stimulating effect.

## Natural Plants

Several studies discussed the mental restoration process and the effects of restorative environments mainly the exposure to natural faunas on psychological well-being (Berto, 2005). Research suggests that visual interaction with natural plants and gardens facilitates recovery after psychological stress (Hinds and Sparks, 2008) (Herzog, Black, Fountaine, & Knotts 1997; Herzog, Chen, & Primeau, 2002; Kaplan, 1995; Kaplan R., 2001; Purcell, Peron, & Berto, 2001; Tennessen & Cimprich, 1995; Ulrich, 1984; Ulrich *et al*, 1991; Berto, 2005). When discussing the design of outpatient clinics, several experimental and EBD studies showed that the view of nature is much correlated with reducing pain, depression, fatigue and stress (Berto, 2005) (Ulrich *et al*, 2008) (Aries *et al*, 2010). Other EBD studies demonstrated that the viewing and the direct contact of natural plants in the workplace reduce staff stress and fatigue, as well, increase the level of staff satisfaction in their working environment (Lundin, 2012) (Ulrich *et al*, 2008). Therefore, natural plants should be an essential part of the outpatient clinics design strategy (Ananth, 2008). For example, the architect might consider green planted facades, green roofs and interior green walls in the design of the outpatient-clinical buildings.



Figure 1: Natural plants and design strategies<sup>9</sup>

### Large Windows (windows become doors concept)

Several studies observed the direct and indirect effects of large windows on job satisfaction, intention to quit, and general well-being in workplaces. The impact of three specific influencing mechanisms was examined: general level of illumination, sunlight penetration, and view (Andrade *et al*, 2012). The main concept of using large windows in outpatient clinics is to allow better access to views of natural landscape (Huisman *et al*, 2012), natural daylight and fresh air penetration. However, the NHS design recommendation of primary care settings requires clear glazing, providing an outlook for patients and staff, whereas, privacy in C/E rooms, and in treatment rooms, should be maintained. Windows should be easy to clean, both on the inside and on the outside. Avoid Solar control glass that may affect the analysis of skin colour/tones (Estates, 2010, p.10). On the other hand, it is highly recommended that primary healthcare designers adopt the concept of 'windows become doors' (Kellert *et al*, 2011). Engaging this concept in outpatient-clinical settings,

<sup>9</sup> Sources:

<http://www.marvelbuilding.com/natural-walls-green-living-plants-greenwall.html/detail-view-of-natural-walls-with-green-living-plants>.  
<http://www.sulit.com.ph/index.php/view+classifieds/id/8402947/Elite+Living+Wall+-+Vertical+Garden+and+Green+Walls>  
<http://aboutagarden.wordpress.com/category/professional-gardener-training-program/page/2/>

following the NHS design recommendations for primary care settings (Estates, 2010) (Billings and Grayson, 2010, p.6), would enable better interaction and movement between indoors and outdoors as it would enable further outdoors activities for staff wellbeing, such as walking during breaks, handling discussions with patients in a space that takes advantage of natural beauty and reduces stress, etc.

### Natural Materials

The use of natural materials inside outpatient clinics is highly recommended as a biophilic feature. Indeed, people in general prefer natural over artificial materials (Kellert *et al*, 2011). Therefore, the use of natural resources should be part of the design strategy at a variety of different levels (Salingaros, 1995). There is a great opportunity to employ natural finishes and materials in outpatient clinics such as natural wooden floors, stone cladding, pebbles and rocks, etc. Additionally, the structural system could reflect this concept through the use of timber frames, bearing stone walls, etc.

### Geology and Landscape

*"If you are surrounded by good design, it seeps into your work. Imagine if you could push back your chair and walk into a garden for inspiration."* (Kellert *et al*, 2011, p.38). According to biophilic theory, outpatient clinics are supposed to be extrovert places, with well-designed outdoor gardens that include real natural components, such as verdant vegetation, natural fauna, water features, etc. Designed landscapes, adjacent to the different functional spaces of outpatient clinics, are crucial for staff wellbeing and patient experience as they can act as healing gardens and as a retreat or a place of respite for staff and visitors. Geology and landscape can be pictured in the design of the outpatient clinics through open court-yards that allow sunlight to reach the inner spaces of the clinics, landscaped sheltered corridors - either semi-open or isolated by glazed screens - that allow safe passage of users. Organic landscapes can include natural geology, topography and natural elements such as stones, sand, rocks, water sources, etc. (Ulrich *et al*, 2008).

### Recommended biophilic design forms and shapes for staff wellbeing in outpatient-clinical areas:

The positive effect of biophilic design encounters a holistic design approach represented in the principals of design, form-making and structural system. Throughout the history of architecture, entities, shapes, and processes that have natural representation acted as a source of stimulus for buildings' users. Conceivably the most noticeable example of this muse is patterns often contains ornamental representations that are reminiscent of the flora and fauna. Famous architects such as Antoni Gaudí used to depict and employ patterns from natural structures to achieve efficient and attractive built architecture (Joye, 2006).

Biologically-based designs employ simulators from nature that involve the specific geometry and proportions of natural forms (Feuerstein, 2002). This part of the review analysis explores and defines shapes, motifs, and proportions from the natural world that would inspire the design of outpatient clinics in order to add novel ideas that can improve the design outcomes and the healing effect of the physical environment in primary care settings. Finally, this part of the review reveals that the relation between nature and architecture based on nature-based forms and

organizations has been known as an essential and valuable part for human emotional and cognitive functioning (ADAMU, 2012; Feuerstein, 2002; Grinde and Patil, 2009; Gruber, 2008; Gruber, 2011; Joye, 2006; Joye, 2007; Kellert *et al*, 2011; Zari, 2007b).

### Botanic Motifs

The shapes, forms and patterns of plants including tree and columnar support/tubular forms are important design elements of the built environment in healing spaces (ADAMU, 2012) (Gruber, 2008). These representations often simulate plant forms such as foliage, branches, ferns and bushes, to be employed both naturally and metaphorically in the design details and patterns of the outpatient clinics (Kellert *et al*, 2011).

### Oval and spirals shapes

Oval and spiral shapes forms are often supple, flowing and adaptive in responding to forces and pressures found in nature. Natural features are thus rarely revealed as straight lines and right angles as found in the human structures and manufactured products. Therefore, resisting shapes with straight lines and right-angles found in the rigid building shapes of large scale modern hospitals might not be in harmony with the biophilic design approach (Kellert *et al*, 2011). On the other hand, people generally prefer designs that resemble the tendency of organic forms (Salingaros, 1995). Egg and oval shapes could be successful design elements in outpatient clinics buildings facades, interiors and exterior landscapes (ADAMU, 2012) (Kellert and Wilson, 1995). These shapes would engage important expressions of smoothness, natural flow, and ornaments (Senosiain, 2013).

### Arches, Vaults, and Domes

Arches, vaults and domes in the built environment copy forms found in nature including beehives, nest-like structure, shell-forms and cliffs (Senosiain, 2013) (Ball, 2011) (Christopher *et al*, 1977). These forms can be used in the outpatient clinics for both decorative and functional purpose. However, it is important to consider the socio-cultural background of the users that might affect their interaction and interpretation of these features (Salingaros, 1995) (Hammond, 2005).

### Fractals, Hierarchy, Ratio and Scale

Elements in nature rarely exist in exact copies of one another. For example trees, leaves or snowflakes may be highly similar but never the same. Variation on a basic pattern is the norm; related and similar forms are called fractals (Harris, 2012) (Zari, 2007a) (Kellert *et al*, 2011). In the outpatient clinics this concept would be very useful to inspire the design of the repetitive consultation rooms and their adjoined spaces. Fractal compositions could be used, as well, in the interior details of clinical spaces in forms of repeated but varying patterns of basic designs such as ornamentations in parallel or closely linked rows that differ slightly from one another (Salingaros, 1995). Other variations could be a schematic diversity based on size or scale. Many pleasing natural and built forms are associated in hierarchical ways, related geometrically or arithmetically (Christopher *et al*, 1977). This schematic correspondence can facilitate the integration of highly complex patterns that might be experienced as chaotic or overwhelming details. The perfect

arithmetic and geometric expressions of this affinity, in both natural and built settings, evolve the employment of the golden proportion and Fibonacci sequences (Gruber, 2011).

### Biomorphy and Geomorphology

A recent study attempted to analyse the self-reported feelings (calm/relaxed/refreshed/revitalized) linked with recent visits to a wide range of natural settings among a large sample of the English population. It found that visits to natural geological landscape such as hills/moors/mountains scored significantly high level of satisfaction among the sample (White *et al*, 2013).

Outpatient-clinic building design should embrace mimic landscape and geology in relative proximity to its structure; this relationship to the ground can lend the building appearance solidity and integration to its surrounding environment, making structures appear integral rather than separate from their geological context (Feuerstein, 2006) (Joye, 2006) (Kellert *et al*, 2011).

### Biomimicry

Biomimicry is a design process that seeks purposeful solutions - inspired from local natural organism or ecosystems - to a specific challenging functional problem, like flexibility, structure, sound control, cooling, warming, etc. For example, solar photo-voltaic cells are inspired from the way green leaves photosynthesis solar rays. However, they do not resemble the leaf in terms of shape or colour (Kellert *et al*, 2011). For the design of outpatient clinics, biomimicry should be considered as an important biophilic approach that could solve technical problems such as flexibility, sound control, infection control, ventilation, etc. (Zari, 2007a) (Gruber, 2011). In addition, biomimicry can be reflected in the structure of small communal primary healthcare units. Designs that mimic invertebrates' processes, such as the physical strength of seashells, could be an efficient and economic construction solution for this building typology (Gruber, 2008).

## Sum-up

The paper re-evaluates the status quo of outpatient-clinic settings that urge a balanced transformation - coping with the increasing working stresses - to improve the general wellbeing of care givers. The required transformation looks into altering common practice in healthcare design (Ham *et al*, 2012) (Naylor *et al*, 2013, p.2) - which focuses greatly on applying the design standards of safety requirements (Grinde and Patil, 2009) (Holmes *et al*, 2006) (Clarke, 2006) to produce prototypical arrangement of archetypal cubical rooms distributed along single or double-loaded narrow corridors - into more cheerful and shimmering designs that cognitively and psychologically communicate with users, particularly staff who spend longer times there. Accordingly, the paper highlights important design attributes extracted from the biophilic design approach to be considered in the psychosocially-supportive design of outpatient clinics in order to enhance users' wellbeing.

Finally, the results of this review are expected to induce many psychological and cognitive benefits to outpatient clinics users, including: stimulating memory; improving attention levels and concentration; enhancing cognitive-functioning; and emphasizing mastery, control, affection, attachment, reverence, and spirituality (Cimprich, 1993), (Namazi and Haynes, 1994), (Kaplan, 1995), (Herzog *et al*, 1997), (Wells and Evans, 2003). It is important to highlight that adopting this

design approach, to develop primary care settings, is a step towards a design-consideration of 'health' as expounded by the World Health Organization.

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## **Cutlery, Composition and Canter: A method for investigating the stigmatising effect of assistive cutlery design.**

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### *Abstract*

*This paper considers the impact industrial design has on assistive cutlery. Literature on designing for the elderly and “other abled” suggests users are embarrassed and often socially stigmatized by using the “assistive” cutlery on the market. Research suggests that the uptake is low due to the appearance of ergonomic products, leading to social isolation. How others perceive the users of such devices and the associated styling of assistive cutlery — not the functionality of the cutlery — appears to be the problem.*

*To test the above hypothesis, a modification of the method used in Canter (1977) — the “Room Interference Protocol” was used. Stimuli were generated using stock images and Adobe Photoshop to ensure consistency and a survey was conducted based upon the “Big Five” personality traits. A pilot survey was undertaken using a convenience sample of first-year students within the Faculty of Design. A second, internet-based international survey was then conducted. The resultant data from the survey indicate that the arthritic and disabled cutlery attributed negative connotations to the users, and that a significant gender effect is also demonstrated.*

*In the context of health and wellbeing, this method allows for a large, internationally distributed sample size with the ability to modify the stimuli rapidly. The key benefits identified with this method highlight the ability to measure the perception of an assistive cutlery user within a social environment. Disabled users require products that enhance their social identity and do not detract from it. The style and aesthetics of such products requires greater attention than they have so far received.*

*This paper forms part of a doctoral research project from Swinburne University of Technology, Melbourne, Australia.*

Keywords: assistive cutlery, industrial design, stigma, room-effect method, arthritis

## Introduction

Assistive products, such as spectacles, walking aids and even wheelchairs have evolved from being prescriptive, generic devices to ones that have been styled and engineered with the end user in mind. Spectacles stand out as an object category where industrial design and styling has elevated a utility object to one of fashion, user-empowerment and consequently a billion dollar industry (Pullin, 2009). Unfortunately the selection of appropriate tools or implements for sufferers of limited grip strength, such as those with arthritis, psoriasis and fibromyalgia, can be regarded as merely functional and not well styled in their aesthetic. Numerous studies have suggested that the appearance of such a product affects the uptake, despite the utility that these devices bring to the user (Benktzon, 1993; Coleman & Pullinger, 1993). This study explores the stigma surrounding these products and proposes the usage of an emerging method of investigation to ascertain problems with current styling and provide the designer with cues regarding the potential aesthetic development and sensibilities of the product for the end user.

## Scope of the research

The investigation into the aesthetics and the stigma behind assistive cutlery was instigated due to a lack of in-depth literature surrounding the topic. Much has been written in regards to the aesthetics, stigma and usage of other ergonomic devices (Caspari, 2005; Coleman *et al*, 2006; de Boer *et al*, 2009), however in regards to assistive cutlery, this has only been done as a small part of existing research studies. In a historic context, cutlery has been utilised as a device that can be used to divide social classes – initially, it was considered to be an inelegant method of eating as using fingers was preferred — however it evolved into a demonstration of conspicuous consumption (Glanville & Young, 2002; Wolfman & Gold, 1994), where myriad utensils were designed, utilised and ultimately codified into an ISO standard.

The aesthetics of assistive cutlery and the stigmas associated have been discussed by researchers (Benktzon, 1993; Torrens & Smith, 2012), however this field is relatively new – with the advent of mechanised industry, cutlery was no longer forged by silversmiths and craftsmen, but by machines. Objects such as the ornately detailed Nelson knife have descended into a ‘tool’ for eating without adornment or consideration to the visual appearance of the object. Much has also been written about the culture of dining, specifically in the preparation and serving of food “as a gift” by elderly women (Sidenvall, Nydahl, & Fjellstrom, 2000) who statistically suffer from reduced grip via arthritis, fibromyalgia or psoriasis (Welfare, 2008). The materiality of the cutlery is also found to be lacking – instead of wood, metal or bone, the user utilises a piece of cutlery that is manufactured from plastic or foam, usually in a “flesh colour” (Torrens & Smith, 2012) which may not aesthetically match other pieces presented on the table, signifying an implied level of disability even though the user may not have an obvious physical manifestation, such as the case with rheumatoid arthritis.

Initially, the aim of the doctoral research was to produce an artefact that could provide a response to the problem, however through an extensive literature review, it was found that while qualitative studies have been undertaken these lacked the depth desired to understand the problem regarding their uptake and desirability, specifically in regards to the aesthetics of assistive cutlery. Within these surveys, questions were undertaken asking the users of the cutlery their opinions of

the aesthetics, however these surveys were limited by the size of the sample groups and geographic boundaries. As the market for such devices is large, it was important to expand the scope globally to provide as much information as possible to designers of assistive cutlery. To undertake this, a quantitative approach was decided; this had not been done in the field prior and would give the investigators the ability to generate a survey that could be analysed using based upon a method from environmental psychology (the 'room effect method') and able to utilise the Big Five (i.e. openness, conscientiousness, extraversion, agreeableness, neuroticism) personality traits to determine how a potential cutlery design may affect the perception of the user. By doing so, a strong case for the aesthetics of the piece could be tailored based upon the results of the survey.

## Literature regarding the existing method

To investigate the potential effect of stigma, a method was appropriated from environmental psychology: the "room inference protocol" method by David Canter (1977). This method was utilised to determine the differences of perception that a change in room had on the model.

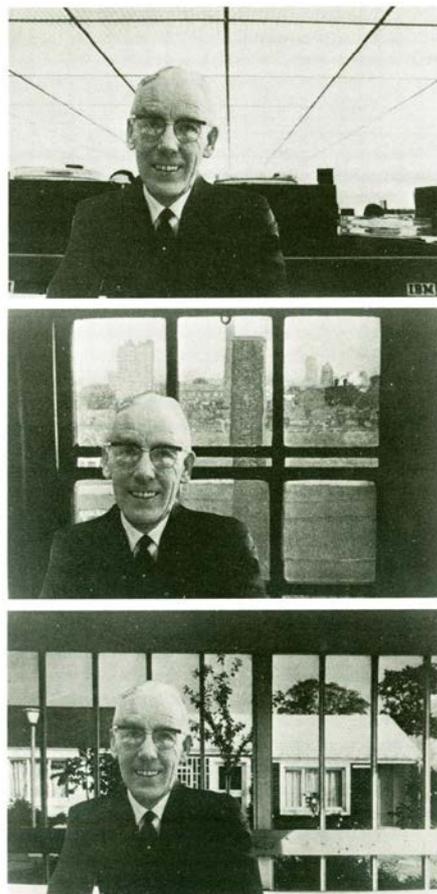


Figure 1: Canter's 'Room Inference Protocol' (Canter, 1977)

Canter's study determined that the appearance of each room was found to have an effect on the perception of the model; such as his intelligence level, financial state, social standing and mental state (Canter, 1977). This method has been successfully utilised in other applications, such as evaluating the effect of automotive market research (Effendi, Hashim, Whitfield, & Jackson, 2009) to assist the development and refinement of new concepts. It was decided to apply this to the study of assistive cutlery through using one scene with two models; the only variable in the scene would be the choice of cutlery. Through this, we can assess if the cutlery itself infers a stigma onto the end user.

Prior publications like Canter's study have used photographs to create and modify their stimuli. Photographs —while able to be taken and utilised by researchers with ease—can be subject to variations in the scene and can require an extensive setup time to maintain control over the image.

By utilising computer-mediated means, the limits of traditional photography (and photomontage) are reduced. Retouching, such as blemishes, altering expressions of models, adjusting lighting, removing or altering backgrounds and replacing props are easily achieved post hoc. By doing so, greater control over the stimuli can be attained, resulting in a high fidelity statistical analysis. As the only variable in the scene is the cutlery itself, the aforementioned advantages become crucial.

To demonstrate the advantages of digital alteration, two case studies – one British and one American – utilising the photograph method are presented herein and the problems surrounding these are identified. These are then contrasted with an example of the refined method utilised by the author.

The first example was by Dunne and Searle (2010) in their study entitled *"Effect of manipulated prestige-car ownership on both sex attractiveness ratings"* where a comparison of perceived attractiveness between male and female models in cars was presented:

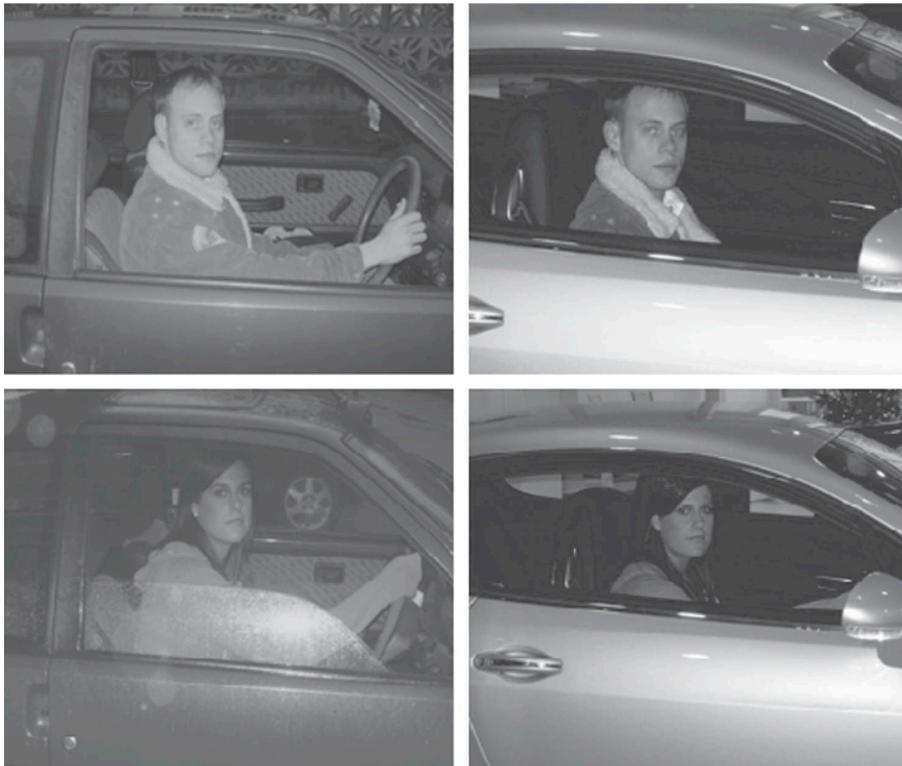


Figure 2. Image used in Dunn & Searle's (2010) research, demonstrating a vast disparity of appearance between images.

The stimuli presented in this study have a strong visual contrast – even between the same vehicles with a different driver. Within these four images, differences in lighting, position of the model, position of the camera, facial expression and background are evident. This 'pollution' of the image can lead to compromised survey data, especially when considering the aim of this study was to measure the attractiveness of the model, based upon which car they are sitting in. One particularly striking difference is the window in the 'affordable' car – in the female image, the window has been raised, with the camera flash being reflected towards the viewer. In the male image, the window is down, showing the viewer more of the male model's clothing, and also over-exposing his face. A study by Lindgaard et. al (2006) suggests that we form a like/dislike opinion of visual stimuli within five hundred milliseconds (500ms), therefore it is of paramount importance that the visuals be tightly controlled to avoid this form of pollution.

In contrast, the study by Rick and Schweitzer (2010) entitled *"The Imbibing Idiot Bias: Merely Holding an Alcoholic Beverage Can be Hazardous to Your (Perceived) Intelligence"* demonstrates far more rigour. The investigators in this study used a photograph, however the control of the scene is apparent; the lighting, positioning of the model, background visuals and composition of the shot is far tighter.



Figure 3. Image used in Rick and Schweitzer's (2010) study, demonstrating a tighter overall composition.

Figure 3. Image used in Rick and Schweitzer's (2010) study, demonstrating a tighter overall composition.

The aim of this study was to assess the perceived intelligence of the model, based upon the beverage displayed in front of her. While the investigators demonstrated a far better model than Dunne & Searle, the image still suffers from pollution – namely the coaster underneath the beer in the second image. This has the potential to 'highlight' the alcoholic beverage and draw attention to it, while the non-alcoholic beverage is unadorned. Utilising digital means, this could be rectified post-hoc, delivering a more accurate and controlled stimuli, which can in turn lead to a more accurate result.

Within the study undertaken by the authors of this paper, the aim was to investigate the effects that assistive cutlery has on the end user. While the above investigations by Canter, Dunne & Searle and Rick & Schweitzer further developed the body of knowledge relating to the perception of people using and interacting with devices, their methods had many flaws in relation to visual pollution. A modified method using digital means was therefore undertaken to ensure a reliable and accurate investigation.

## Revised method

The revised method builds upon the work of Canter, Rick & Schweitzer and Dunne & Searle, and its application within the use of cutlery design is novel.

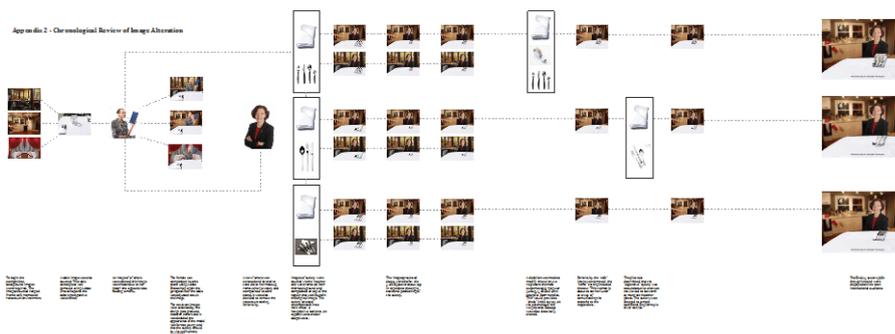


Figure 4. Image detailing the design process for the female stimuli (Renda, 2013)

In this author's study, an entirely digital approach was utilised, primarily using Adobe Photoshop to generate the final stimuli. Photographs of models and scenes were sourced from iStockPhoto and Dreamstime – two leading stock photography websites. As the study was primarily investigating the perception of middle-aged men and women of average appearance and income, details such as jewellery, makeup, height and weight were modified or removed using various tools within the application. The background of the stimuli was also modified; the models (initially only the female) were cut out of their original background and placed upon a series of three scenes – a home, a fine dining restaurant and a café. Levels of blur were also adjusted to reduce visual pollution and focus on the model and the cutlery. Through further investigation within the literature, it was decided to focus upon the home environment.

The cutlery itself went through much iteration; photos were sourced from the various manufacturer websites and were modified to ensure the scale was both accurate (i.e. true to life) and that the positioning of the cutlery was not too obtrusive. Four types of cutlery were used in the study: a traditional "kings" pattern, a set from David Mellor, a lightweight foam-handled assistive set, and an adapted Ikea set, with foam grips and Velcro straps.





Figure 5. Images used in the pilot survey

A pilot survey was undertaken, with the results indicating an average level of attractiveness and age of the model, however the pilot survey indicated that the 'expensive' cutlery (the David Mellor set) did not register as such. By utilising digital as opposed to analogue image manipulation, the investigators were able to modify and appropriately position the stimuli (replacing it with a more traditional looking piece of silverware, which tested well) and ensuring that the scene was as tightly controlled as possible. One of the added benefits of this system was the speed; i.e. modifications can be done at any point of the day, irrespective of a model, site or product being available.

Once the modifications to this had been undertaken, the same process of refinement was utilised with the male model. The resultant images are as below:

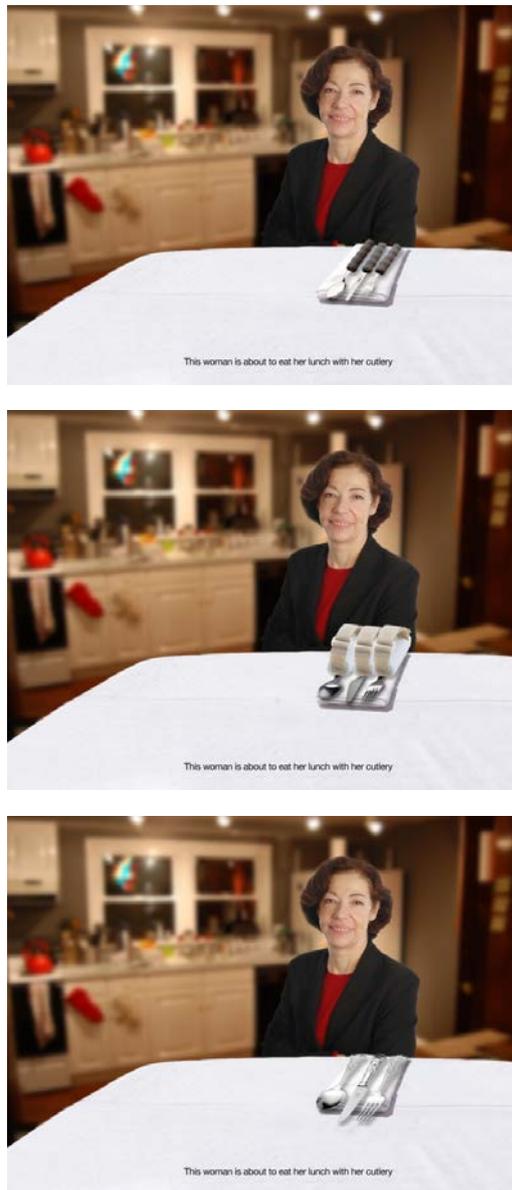


Figure 6. Final female stimuli

Another key advantage of this method was the ability to modify facial expression; the male model used in the stimuli was smiling; this was digitally altered to ensure that his expression matched the female model as closely as possible, ensuring neutrality in the data gathering. This is demonstrated across the following images:



Figure 6. Male stimuli, demonstrating modification of facial expression

The images were uploaded to a survey module online, with the questions based upon the 'Big Five' character traits as detailed prior in the research. This allowed the investigators to extract detailed information about the model, based upon the respondents' answers. The survey was a success, with n=2902 respondents, n=562 of these useable, and subsequent data analysis confirming that the appearance of assistive cutlery does stigmatise the end user, specifically in relation to female users.

## Implications for further research

Within this paper, we have established a case for utilising digital means for generating stimuli for research. As the "room effect method" becomes more widely utilised, it is of paramount importance that the stimuli is as controlled as possible to ensure an accurate result. As discussed, literature suggests that we determine a like/dislike condition within five hundred milliseconds; it is imperative that whatever stimulus is presented to a study participant need to be accurate and free from visual pollution.

This research also highlights the contribution that a professional designer can make in regards to data collection and stimuli generation. Previous tools, such as a simple camera can be utilised to perform this task, however the speed at which it can be performed is reliant on external factors,

such as model and scene availability. Utilising stock photography and digital means allows the designer to modify the stimulus at any time, in any place in the world.

Moving forward, the most valuable advantage of this method is the ability to create the stimulus in its entirety. If a particular prop is not available – perhaps due to it being fragile, expensive or physically large – a photograph can be composited into the image with minimal fuss and the investigation can continue. This is also true for props not having been physically realised; testing can be undertaken on ‘virtual’ models that exist only as CAD data or high-quality renderings. This can significantly save prototyping time and also assist in validation of a particular object. Further developments on this technique may take this into the virtual reality sphere – as opposed to a static image being displayed, the stimulus could be integrated into an augmented reality space, allowing the participant greater freedom to assess the stimulus, as well as adding another dimension to the data-gathering program.

Finally, the method presented in this study has afforded the designers and manufacturers of assistive devices in general a method to investigate the potential effects that a product may have on the end user, and subsequently, a contribution to the body of knowledge in relation to the aesthetics of disability.

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