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Acknowledgements

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PHOTO CREDITS: page 10–12 Bucks New University; page 14 Glasgow School of Art; page 15 Sheffield Hallam University.





The Sylvia Adams Charitable Trust

Introduction

Design & Rehabilitation is an RSA initiative, begun in 2009, to teach design to people with spinal cord injuries as a route to independence, resourcefulness and greater control over their lives. This is a report on a series of pilot design workshops, co-ordinated by the RSA, for rehabilitation inpatients and expatients of three spinal injury centres in partnership with the design departments of three local universities. Funded by the Sylvia Adams Charitable Trust, the workshops took place between October 2011 and February 2012.

For 250 years the Royal Society for the encouragement of Arts, Manufactures & Commerce has vigorously supported good design, encouraging invention and enterprise for the common good. In the 20th century, this support was directed at championing good professional design and excellence in undergraduate design education. While these traditions continue, the RSA has also begun to explore how else – above and beyond the impact of professional excellence – society can benefit from design.

During my tenure as Director of Design, RSA Projects I developed an argument that design is essentially a kind of resourcefulness: the ability to make something functional or useful out of what's available. Designers are deliberate and practised in this resourcefulness and make a living out of it. But the RSA argues that this resourcefulness would be better distributed - and society enhanced - if design were released from its narrow definition as a professional activity and thought of as something that everyone has some potential to do.

The RSA's design programme therefore aims to help more people use design to change their world. The Design & Rehabilitation project is a concrete example of this inclusive approach to design education. In this phase, three universities took up the challenge of devising a design-training model for people both in rehabilitation for spinal cord injury and living with their injury after discharge, working closely with three of the UK's eleven specialist units for SCI.¹

Each project took inspiration from

the design workshop prototyped in November 20102 by the RSA and Back-Up, the national charity for spinal cord injury. The participants in this workshop were more than informed witnesses to a design process performed by creative professionals. They were themselves actively designing: completing hands-on, practical tasks and imaginative challenges. The workshop was organised around principles of observation and analysis which are crucial in design and which lead to creative breakthroughs and opportunities. Luke Delahunty, the Back-Up volunteer group leader, said after the workshop "Analysing and breaking something down as a designer helps you think 'What can I control here?' It's a powerful concept", while Dean Hay, another participant said, "I think it's absolutely brilliant. Disabled people have a unique perspective and design will help them use that to solve their own difficulties".

While the RSA workshop was an inspirational model, the optimal methodology for teaching design to

people in rehabilitation remained open to definition, and the RSA invited three universities with highly regarded design faculties to propose other approaches: different exercises and thematic frameworks, different research questions, but retaining the principle that the spinal cord injured participants are themselves the designers. These approaches are described in the following pages, along with the feedback, findings and outcomes generated by each project.

Emily Campbell

Former Director of Design, RSA Projects and Project Director of RSA Design & Rehabilitation

^{1.} Spinal Cord Injury. SIU (Spinal Injury Unit) is the other acronym used widely by the NHS and disability charities and in this report.

^{2.} RSA report: Design & Rehabilitation: a three day workshop in design for people with spinal cord injuries, March 2011 www.thersa.org/__data/assets/pdf_file/0007/562642/Design-and-rehab.pdf

The partners

The first project was led by Bucks New University, working with the National Spinal Injuries Centre at Stoke Mandeville hospital in Buckinghamshire. Bucks New University is known as an outstanding institution for teaching furniture & product design and is located in High Wycombe, the traditional centre of furniture manufacture. The project was conceived in collaboration with their Faculty of Health. The second was led by Glasgow School of Art and Strathclyde University working with the Queen Elizabeth National Spinal Injuries Unit (QENSIU) of Glasgow's Southern General Hospital. Glasgow School of Art has been one of the UK's flagship art schools since it opened as a Government School of Design in 1845 and moved into its iconic buildings designed by Charles Rennie Mackintosh in 1909; Strathclyde is internationally recognised as a leading university for engineering. The third project was led by Sheffield Hallam University's Lab4Living research centre working with the Princess Royal Spinal Injuries Centre at Sheffield's Northern

General Hospital. Lab4Living brings healthcare, design & engineering specialists into collaboration with members of the public, particularly addressing the challenges of ageing and health.

Approach or research questions of the partners

Stoke Mandeville

Stoke Mandeville, the largest spinal injuries centre in the UK and widely recognised by the public as a centre of excellence, is pioneering new approaches to integrating modern 'life skills' into rehabilitation alongside the more established elements of physiotherapy and occupational therapy. It recognises also that spinal injury centres and charities have emphasised participation in sport almost to the exclusion of other activities, and is keen to develop other routes to social integration and employment for their patients. Dr Allison Graham, consultant physician at Stoke Mandeville, responded keenly to the RSA's initiative and identified design as potentially a very powerful vehicle for the teaching of hand and thinking skills that would encourage creative and critical engagement with the physical world; and in some cases could become a vocational route to a new career for patients.

Stoke Mandeville hoped to establish a structure and methodology for teaching design which could become permanent and a model for other centres to follow. It undertook to integrate the pilot into the weekly rehabilitation schedule at Stoke Mandeville, rather than making it an optional evening or weekend activity. By integrating the design training into the working week, Dr Graham felt that Stoke Mandeville could stress the importance of preparing people for transition back into health and wellness comprehensively, not just as good wheelchair-users.

Dr Alison Shreeve, Head of the School of Design, Craft and Visual Arts at Bucks New University, seeking to evaluate the social role and utility of making and design-thinking, proposed a research approach that would inform both potential future projects in health, and teaching and learning in art and design. She asked two research questions at the outset:

- What can we learn about teaching art and design to our own students through engaging with a programme of rehabilitation?
- What difference did this intervention make to individuals on the programme and what are the implications for further rehabilitation programmes for spinal injuries patients?

Bucks New University proposed a highly practical design programme in eight sessions or 'stages of design' – introductory imagery, observation, reflection, interpretation and insight, invention, evaluation, review and record – each incorporating sketching, prototyping and keeping a diary.

Alongside this practical programme they proposed an analytical approach to the teaching intervention, asking what the patients were being asked to do and why, in order to explore underlying

assumptions of learning and teaching and to discuss the impact of such assumptions on a group of people who have not specifically or vocationally chosen to study art and design. They would be particularly alert to barriers to understanding or engagement and to unforeseen learning outcomes.

Recognising that such a project would be difficult to evaluate, Shreeve proposed that data would be generated through tutor observation and reflection on video footage of the activities in conjunction with a small research team. Participants would also be asked to keep a reflective journal/sketchbook to provide insight into their understanding of the activities, which might be different to those of the tutor. At the culmination of the programme Shreeve also proposed a focus group run by an experienced researcher and spinal injuries nurse in the Faculty of Health. As an ethnographic approach to understanding the impact of the activities on individuals participating in the design programme, the exercise would explore the differences the programme had made to the lives and attitudes of the patients.

Glasgow

The Queen Elizabeth unit at Glasgow's Southern General Hospital is the national spinal injuries centre for Scotland. Its Clinical Director, David Allan, saw in the RSA's project an important distinction from other attempts by designers to 'improve' the lives of people with spinal cord injuries. By making the patients themselves into the designers, he says, the project avoided the risk of designers misconceiving the needs of disabled people or projecting their own design preferences on people in very different circumstances.

2008 was the inaugural year of the purpose-built Research Mezzanine within the Glasgow unit. The Scottish Centre for Innovation in Spinal Cord Injury constantly engages with universities and other statutory bodies to facilitate crossdisciplinary activities, and is moving towards fully incorporating research into the rehabilitation environment and the community.

Consultant in rehabilitation Dr Mariel Purcell said in support of the project: "The very definition of rehabilitation is to maximise a person's physical psychological and social well-being.

Integrating design, initially in the inpatient rehabilitation programme alongside hand therapy, occupational therapy and physiotherapy, will give patients extra skills to optimise their physical potential and quality of life in the future".

Interpreting the observations of these clinical specialists, Professor Alastair Macdonald, Senior Researcher at Glasgow School of Art proposed a project in several stages, commencing with reading and meetings with patients to gain a better understanding of the 'pathway' that patients experience from the acute stage of injury through rehabilitation to their discharge, return to the community, and potential re-admission. This understanding would be reciprocated on the design side by introducing a set of design skills used very successfully in other GSA projects. Macdonald was supported throughout the project by Professor Bernie Conway, Head of Bioengineering at Strathclyde University which regularly works with technology to support rehabilitation; in an academic environment where engineers and scientists take an investigative approach to fitness and other secondary aspects of injury.

Macdonald aimed to understand patients' emotional and psychological highs and lows in rehabilitation and how and to what extent their physical capabilities could improve; to know more of patients' own resilience and resourcefulness; to understand the emerging demographic and whether, for example, rehab for elderly patients might require a particular approach. He would visualise the rehabilitation pathways for later discussion and workshops.

Macdonald proposed commencing with a presentation to patients and staff of the transformative properties of design using recent case studies of design processes used in various settings, predominantly but not exclusively in healthcare; followed by a discussion of the tools and methods used to liberate the tacit resourcefulness of individuals and promote productive relationships. This stage was predicated on the idea that strengthening the resourcefulness of and partnerships between health services, patients, patients' families, friends and community services would be important. The resulting discussion would identify issues that could be explored through a design workshop.

The design workshop was proposed for patients and staff, and would focus on methods of 'objectifying' issues by making them vivid or visual, for example: visual mappings of rehab journeys; developing scenarios of people types and their issues to identify opportunities for innovation and improvement; and a 'what if...' session leading to the rapid generation of ideas using design knowledge, methods, processes and insights and some hands-on rapid prototyping.

Each stage of the project would be used to explore further collaboration and particularly the option of an embedded 'designer-in-residence' at the Queen Elizabeth centre who would effectively become a part of the rehab team, working with staff and patients.

Sheffield

The Princess Royal spinal injury centre at Sheffield's Northern General Hospital is the second largest in the country after Stoke Mandeville and occupies a purpose-designed building that incorporates art work contributed by patients: Clinical Director Dr Kidangalil Mathew observed that the RSA's project has a 'natural fit' with a modern spinal injuries centre such as this. He and colleagues acknowledged that the training would be useful for a recognisable category of patient who seeks to design their own environment and gadgets to accommodate their special needs.

A high proportion of the consultants at this unit are surgeons who, as specialists in the physical and constructive aspects of medicine, have a natural interest in product design. This interest, however, extends to activities that improve the way people think about their life and show people what they can do, rather than can't do. The consultants also saw the potential to link rehabilitation and employment through the project in the longer term.

Professor Paul Chamberlain, Head of Art and Design Research Centre directs Lab4Living at Sheffield Hallam University with an explicit interest in user-engagement and participatory design. The centre seeks wide public engagement in a variety of research projects in design and health, for example by employing older people as researchers in a project on bathroom design, in order

to garner acute user-insights. Lab4Living presented the design and rehabilitation project to Princess Royal and to the RSA as a 'service evaluation' and a pilot study that might lead to a bigger enquiry.

The research team furthermore wanted to establish shared ownership of the project with the SCI participants. They would make explicit the fact that this was a joint enquiry; an opportunity for shared learning and to break the stereotypical view of the designer's role as the 'expert' drafted in to solve functional problems identified by the users. Sheffield Hallam's aims and objectives in the project were summarized as:

- to challenge the perceptions of design among non-designers
- to investigate how design can support self-efficacy
- to understand the opportunities that the development of design skills might present to individuals living with long term disabilities
- to further Lab4Living's work and help define the role and value of co-design and participatory design
- to encourage the transferability of skills and knowledge

Sheffield Hallam aimed to recruit 8–12 participants to the workshops facilitated by a minimum of 3 staff (SHU academics in design and health) at each session. Six workshops were planned, comprising illustrated presentations from design researchers and interactive activities – both individual and group work – to give SCI-participants experience and insight into the role of design and its impact on everyday life.

For continuity, two SHU staff with design knowledge and skills (including making, modelling and prototyping skills, graphics, audio and video editing skills, photography, drawing and illustration) would engage in all the sessions. Relevant experts might be brought in for specific sessions. A member of the research team would be tasked with 'scribing' the session in brief; identifying and recording significant comments and points. Between 3-4 post graduate students would also support each session to help the participants in their activities. Their roles would be strictly to facilitate as instructed by the participants, leaving all design decisions to the participants themselves.

Each session would be recorded using video, and would be closed with informal feedback from the participants asking them their opinions about the session (eg funniest, most surprising, comment of the day). Each session would also be followed by a more formal debrief among the design research and clinical team.

Because of the potentially small numbers and irregular attendance of participants, and the relatively short time frame of the study, Chamberlain recognised that it would be difficult to establish meaningful quantitative data. He proposed an evaluation strategy focused on the qualitative assessment of participants' understanding of design and its potential application to their lives; their confidence levels; and their experience of the opportunities and challenges presented by the workshops.

The project at each centre

Stoke Mandeville

Bucks New University's project combined an expansive vision for design as psychologically 'transformative' with intense observation of physical functions that could be aided by the design of devices. Since the patients who stayed the course both had impaired use of their hands, the workshop gradually centred on devices to aid writing drawing, playing board games and holding drinking glasses. A genuinely collaborative creative exercise, including a visit to Bucks New University's product design workshops, resulted in intriguing prototypes for new product types.

Eight 2-hour sessions were held around a large meeting table in a windowless but pleasant first floor meeting room at Stoke Mandeville Hospital. The workshop began with four very active participants, and participation finally dwindled to two thoroughly engaged

young men, Chris Haynes and Alex Jones with C5–C6³ injuries who not only visited the product design workshops of Bucks New University, but attended the project dissemination event at the Design Council in London. The participants were accompanied by an 'entourage' of partners and assistants who contributed actively to the discussion and design.

The sessions were led by three members of Bucks New University Design Faculty: Carl Clerkin (Senior Lecturer, Furniture Design), Bill Schaff (Department Manager, Creative & Visual Communication) and Libby Callinicos (Senior Lecturer, Silversmithing, Metalwork & Jewellery), accompanied occasionally by students and researchers.

No staff from Stoke Mandeville attended the workshops.

The sessions were structured at the outset to cover the broad stages of design: introductory imagery, observation,

reflection, interpretation and insight, invention, evaluation, review and record. In actuality, the sessions required a high degree of improvisation on account of unpredictable patient attendance.

Carl Clerkin opened the first session with a photograph of his grandmother and went on to describe her many solutions and inventions as an ordinary non-designer, which were, however, analogous to design. He followed this anecdote with other examples of 'hacked' or informal design, and emphasised the value that wide stakeholder groups can bring to the activity of designing.

The second session, scheduled as 'observation', consisted of a brief discussion of observations on design to date, followed by a visit to the ward occupied by two of the patients to examine the spaces and challenges they presented. Because the participants all had reduced finger-grip as a result of their injury, sketchbooks were abandoned as



a tool for capturing observations and reflections.

In the third session ideas from the previous week and ward visit were expanded to a list on flipchart paper of potential projects to work on. Further word lists and simple diagrams were used to capture ideas.

These flipchart lists became the reference point for starting to generate personal insights in the fourth session. An initial discussion of the ideas led into a fast prototyping or 'hacking' activity using lightweight materials. The design activity focussed on shower chairs, urine bottles and drumsticks that could be held by someone with impaired grip.

One patient brought in tools created by his occupational therapist, including a knife, an electric toothbrush, a wash mitt and a wrist strap to shorten the tendons at night.

The designers and participants used foam board, a glue gun, tape, files and matt cutters to create or improve these existing devices. Several prototypes were made and tested for functionality, increased support and rolling motion.

In a brief critique, the prototypes were evaluated and participants asked to state their preferences for material and colour. The design team introduced into this discussion the design concepts of personalisation and aesthetics, and

recommended the 'mood board' as a tool for capturing information.

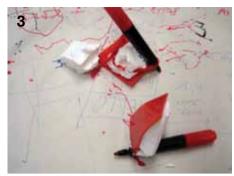
The fifth session met in the patients' wing kitchen - a comfortable place with Wi-Fi access. Carl Clerkin began by reemphasising the utility of personalisation as a route to discovering a design solution, showing how to build a visual palette of information about yourself and your preferences. The repair product Sugru was introduced, and a number of discussions arose: around heat and texture sensitivity, motor movement and loss according to level of SCI. Bill Schaff presented an idea for a handle extension. The two remaining participants identified briefs for themselves and created mood boards, in discussion with the design team.

"The design team introduced the design concepts of personalisation and aesthetics, and recommended the 'mood board' as a tool for capturing information"

Libby Callinicos opened the fifth session with a presentation about the stages of design: identifying problems (objects, spaces or systems); focusing on form and material; exploring issues in a verbal exercise; an exploratory 'style and look' exercise; the collection of personal insights and details, and the growth of 'inclusive design'; and some links to organisations like the Design Council and EnabledbyDesign.4 The design team and participants, reminded of their stage in this process, categorised their ideas for things they wanted to develop: a gripable pint glass, a means of withdrawing an ATM card, game counters inspired by the grip-able surface of Fruit Pastilles, a 'nice' chest strap and an easier-to-use pen. The design team agreed to prototype these ideas in the workshops of the university.

The following week Chris and Alex toured the furniture workshops of Bucks New University and evaluated the prototypes under development, including a metal handle and a cast pen-holder. These prototypes were reviewed at the eighth and final session at Stoke Mandeville.





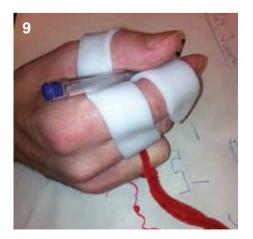












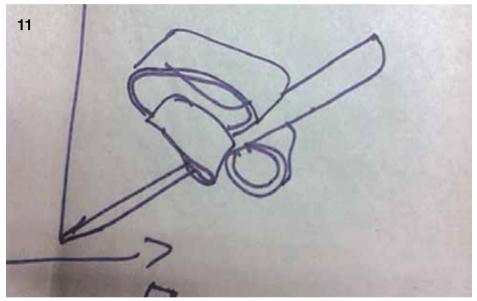
1–2. Resources and prototypes provided by occupational therapy staff at Stoke Mandeville

3–9. Developing prototypes with Bucks New University















10–12. Materials, sketch and prototype from Bucks New University workshop 13. Fruit Pastille and Backgammon counter to illustrate 'Ease versus Challenge'

14–16. Alex and Chris at the Bucks New University workshop with Carl Clerkin

Glasgow

Glasgow School of Art's project was structured in three phases: an 'understanding' phase looking at literature and materials on SCI rehabilitation, a seminar on the potential contribution of design to healthcare and rehabilitation, and a participatory design workshop; the latter two phases involving patients and staff of the spinal injury unit. It was decided to begin the final workshop by deliberately distancing participants from their own disability in asking them to role-play. This process of seeing from someone else's perspective, carried through in visualisation and scenariobuilding exercises, was reinforced and naturally evolved into a strong sense of design as an inherent re-imagining of one's future: a very strong analogy for rehabilitation.

The half-day seminar and workshop were held in the large, light 'Step-Down Unit' of QENSIU. Six discharged expatients and inpatients participated, including two patients on beds and a number of active members of the national charity Spinal Injuries Scotland, associated with the centre.

The seminar and workshop were led by Professor Alastair Macdonald at Glasgow School of Art with contributions from Emily Campbell and Bernie Conway in the first instance; and assisted in the second by a small number of MA design students as facilitators and visualisers.

David Allan, Clinical Director of QENSIU, and consultant physician Dr Mariel Purcell were in regular attendance, along with a small number of ocupational therapists and physio staff.

From reading and references supplied by QENSIU Macdonald developed a simplified patient pathway model to help identify issues that might be fruitful to explore in the design project.

He sought to understand the patient's rehabilitation pathway both as defined by unit, and as experienced by patient, and identified two phases of transition, or 'biographical disruption': one after injury & the second after rehabilitation.

The second project phase, the seminar, aimed to communicate the potential benefits of design methods and processes to a variety of stakeholders (SCI-people, patients and clinical staff) using recent

case studies, and to illustrate how nondesigners can use design tools and processes to release the tacit resourcefulness of individuals. McDonald presented the RSA's original Design & Rehabilitation project, the Design Council's RED

"It emerged that psychological transition can be more important or challenging than the physical transition to the home environment"

Projects,⁵ IDEO's Human Centred Design Toolkit and other experiencebased co- and participative design methodologies as case-studies.

Feedback from discharged patients of the SIU at the seminar was largely autobiographical: individuals recounting their own histories of injury and

attempts to adjust to a new life with SCI. Patients were particularly vocal about the transition to home after rehabilitation. Discharged patients spoke of the comparative lack of structure after being in an SIU, of suddenly having to lead, and even of an 'extended family' being taken away – patients go from an environment where people have similar problems to one in which they are alone and exposed. It emerged that psychological transition can be more important or challenging than the physical transition to the home environment, and this led to quite an expansive range of analogies with design: anticipating situations as well as spatial issues; customising and adapting; controlling image and identity; addressing social experience as well as sport. The idea of taking a 'buddy' home for the first time to 'prototype the experience' was a particularly explicit design metaphor.

Macdonald also acquired an 18-page Acute Services Goal Planning Checklist

Patient pathway by Alastair Macdonald, Glasgow School of Art					
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			
Transition/biographical disruption 1: previous life to rehabilitation unit					
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.					
	Transition/biographical disruption 2: rehabilitation unit to community and home life				
life within QE		d with and adapted to the community and NSIU, SCI survivors are faced with another stment without the peer and professional d in QENSIU			



"Eventually ideas to improve services and environments began to emerge and were captured, and in some cases illustrated, on large sheets of paper; including a changing room with an adjustableheight bed, a revised parking system, and a personal shopping service"





17–19 from Glasgow School of Art design workshop: What if? – imagining and designing an ideal store-based shopping experience

at this event, a document used by the centre which, while it revealed great complexity in the management of functions, appeared - from the design researcher's perspective – reductionist. This document sparked the idea of a complementary tool that might assist the SCI patient him/herself (rather than the clinician responsible for discharge) in tackling the problems of daily life. Some of the problems SCI-people face are what designers call 'wicked' problems: complicated, multi-dimensional and requiring a different combination of skills for different aspects of the problem. It prompted a consideration of what baseline skills could be categorised as design skills.

This in turn led to a pair of hypotheses which were directly examined in the workshop:

- Designers have a particular set of skills they use to tackle problems and provide solutions, and
- 2. Everyone might have that set of skills but not be aware of them or able to use them in a structured way.

And from these hypotheses arose a set of research questions:

- 1. What is the skills set of designers?
- 2. What are the innate skills of SCI survivors?
- 3. Is there a match between designers' skills and SCI survivors' skills?
- 4. If so, could SCI survivors' skills be developed in any way to enhance their resourcefulness in tackling the daily life challenges of SCI?
- 5. If they could, when and how?

At the beginning of the workshop, the SCI participants paired up, and one acted as personal shopper to the other in the pair. They role-played shopping for a particular occasion, which forced them to transfer their thinking to someone else and not just themselves.

The second exercise sought to determine the shopping 'status quo' for SCI people. Participants were asked, with visual clues as prompts, to imagine a visit to a store and recount the experience: what happens, how it makes them feel, and how they think it should be addressed. GSA had supplied a largeformat, printed 'matrix' entitled The Shopping Experience: The Status Quo, onto which student facilitators posted

observations, issues and comments. The resulting 'service journey map' (as a designer might classify it) revealed a range of tangible interactions, triggers and 'touch points'.6

In the final exercise participants were given the opportunity to imagine and design an ideal store-based shopping experience using these issues as a starting point. Facilitators provoked discussion and visualised the ideas while refraining from adding ideas of their own. This exercise was the most difficult for the participants, possibly because the highly problematic 'status quo' had become a fixation that obstructed 'what if?'-type speculation. Eventually ideas to improve services and environments began to emerge and were captured, and in some cases illustrated, on large sheets of paper; including a changing room with an adjustable-height bed, a revised parking system, and a personal shopping service.

Sheffield

Sheffield Hallam's ambition was a coproductive process of discovery: what was people's perception of design? Could/should this perception be changed? And could patients themselves identify potential applications of design? The design project ultimately focused on the ideas of taking control of space (as a patient or SCI-person), and of shifting other people's perceptions of SCI. This focus was not pre-determined but generated by the patients themselves during the workshop exercises.

Sheffield planned six sessions,⁷ to take place in a large, multi-purpose first floor room with windows on three sides and furnished with sofas. The sessions had between 4 and 8 participants throughout; a combination of ex-patients and inpatients, including one person on a bed who attended later sessions in a wheelchair with oxygen tanks, and was too ill to attend one session.

Patients and participants were greatly outnumbered by representatives of Sheffield Hallam University. The project was led by Paul Chamberlain, Joe Langley (Engineer and Research Fellow), Ian Gwilt (Professor of Design and Visual Communication), Roger Bateman (Researcher & Senior Lecturer, Industrial Design), and Claire Craig (Occupational Therapist), with the























assistance of about eight MDes Product Design students.

The hospital was represented consistently by Registrar James White and intermittently by consultant Dr Kidangalil Mathew, with a handful of occupational therapists and physiotherapists on hand as necessary but not actively participating.

The first workshop asked participants to talk about design. Their responses, as well as expressing a sense of distrust, revealed that they associated design principally with art and making money. This was followed by a brief presentation on potato peelers to illustrate the multitude of solutions to single problems generated by design and human ingenuity.

The discussion was followed by a challenge to build the largest structure they could from spaghetti, marshmallows and sticky tape, in 18 minutes. In this well-tried exercise CEOs commonly do worst and children best; and it is said to reveal that one learns best by failing.

The second workshop introduced the concept of observation as a crucial stage in design. Participants were sent off with a camera around the hospital to take photographs, making notes where they encountered any of the following: colour, sounds, barriers, light or dark, evidence of nature, order or chaos, textures or surface interfaces, visual signs or instructions and unusual views or shapes.

Participants were encouraged to interpret this list quite freely – for example 'light or dark' could be physical or perceptual. The photographs were sorted onto a plan of the hospital.

In the third workshop participants were engaged in a lateral thinking exercise exploring the multiplicity of potential answers to phenomena that they had documented in photographs. They were asked to re-group or re-map the photographs and information in order to create a perceptual, rather than spatial map.

Workshop four presented a case study of the design of an electronic hospital communication system by Design Futures. Then participants were asked to re-configure their insights from the photography and lateral thinking exercises into three 'islands', Chaos island, Fantasy Island and the Island of Order. The key design questions that arose were "How can design create a more 'natural'

environment in the hospital?", "How can patients leave a 'legacy' or 'story'?" and "How could adaptations to the environment empower patients and make them more independent?"

In the fifth and final workshop the design challenge was to create a graphic design for a t-shirt that captured and conveyed the essence of the design project and raised awareness of SCI, using a pre-drawn t-shirt template and with the option of asking the design students to draw their ideas. The workshop concluded with a discussion of whether participants' own perceptions of design and its relevance to their lives had changed as a result of the project.

- 3. Injury level is denoted by a vertebra number or numbers in one of the four vertebral segments. From the top to the bottom of the spine these segments are Cervical (C-), Thoracic (T-), Lumbar (L) and Sacral (S). A spinal cord injury will also be classified as complete / partial, ie with some degree of function and sensation remaining.
- 4. EnabledbyDesign is a web based social enterprise that promotes good design to support people to live as independently as possible
- 5. RED was set up in 2004 by the Design Council to tackle social and economic issues through design led innovation www.designcouncil.info/RED/
- 6. 'Touch point' is the term favoured by service designers to denote the point of contact, or interaction, between users and a service, or users and objects, tools or devices.
- 7. One session was cancelled as a result of industrial action

Feedback, findings and outcomes

The following pages summarise under broad thematic headings the findings and outcomes from the project as described variously by the design teams, participants and clinical staff. The material is drawn from interviews, film transcripts8 and notes taken during the workshops; and from a dissemination event held at the Design Council in February 2012 for approximately 50 stakeholders from the partner institutions and associated charities and professional bodies.

Recruiting and retaining participants

The largest barrier to planning and delivering the design projects was undoubtedly the challenge of recruiting and retaining a consistent group of participants. Sheffield Hallam and Bucks both reported a prevailing sense of uncertainty and 'diving into the unknown': the patients who attended would be varied in age, gender, level and date of

injury, health conditions, background and interests; none of which could really be known in advance. Upon starting the project they discovered attendance to be sporadic and subject to conflicting therapy sessions, and some participants were discharged from the hospital before the end of the programme. Similarly, the Glasgow workshop started an hour and a half late because many participants who'd signed up arrived very late or not at all.

For this reason the workshop programme had to allow participants to dip in and out, and to recover time for those who might have missed part or all of a session. The RSA's original idea had been to use design to uncover the resourcefulness of non-designers. However, in actuality, it was the design teams who had to show outstanding resourcefulness – to be creative, adaptable and flexible about how they took participants on a progressive and sequential learning journey. During one presentation at Sheffield a participant asked for the projector to be turned off, disturbed by the intense light: the presentation continued without the visual material that had been prepared.

Embedding an understanding of design

The least equivocal success of the projects appears to have been in provoking a consciousness about design: many participants talked to the camera and in plenary discussions about how much they had been thinking about design since the project started, and how expedient a focus the project had provided for thinking about 'how everyday things work and make people feel'.

This design-consciousness was tracked by Sheffield Hallam in terms of how able participants became to identify potential applications for design. One participant put this simply: 'Now I can

see problems that need addressing'; while the design team themselves interpreted these problems in more discursive, complex and metaphorical ways:

'Chained doors, identified in the photographic exercise, suggested imprisonment, and subsequent discussions focused on concepts, ideas and metaphors based around escape. When someone identified an annoving recorded voice in the elevator, a concept emerged for an elevator voice that said 'Beam me up, Scotty', representing a metaphorical 'escape' for a short period of time between floors... The 'artificial' hospital environment lacks any prompts to indicate the passage of time and the cycles of nature. One participant wanted to plant flowers that brought nature and a sense of time and growth to the environment, and left a legacy for others to enjoy... More traditional design responses were focused on potential adaptions to aid eating, drinking and digital game play.'

Sheffield Hallam noted that assessment of participants' adoption of design-thinking and of the impact of design training on their everyday life was impossible without structured, long-term follow up. However they noted that participants generally were keen to engage in future design workshops.

Sheffield Registrar James White reported positive feedback from participants and noted that some had selected the design workshop over other options. Since some participants were very new to their injuries he remarked on the value of the 'barriers' discussion and the focus on imagining what things are going to be like. It took participants away from thinking about their medical complications to thinking about the future. In the clinical context, he said "We concentrate so much on the acute phase of the injury that we pay less attention to what happens when things have settled down."

Both the design and medical teams in Sheffield are keen to explore the possibility of a follow-up series of workshops, with more focused (ie on specific design problems) sessions over a shorter time scale to overcome some of the attendance issues and provide more consistent and meaningful data for evaluation.

Although the Bucks design team had lots of experience of inclusive design (designing for a wide range of users),

and teaching design to a broad demographic of students, they went into the Stoke Mandeville project aware that teaching people 'who had no intention or likelihood of becoming designers' (the RSA's phrase) was a new context. The design team reported witnessing 'innate design ability come to the surface', and a sense of personal empowerment emerging on the part of the participants.

The Stoke Mandeville participants themselves tended to describe their activity in generic terms as 'mental

"It took participants away from thinking about their medical complications to thinking about the future"

stimulation', 'getting your brain going', a welcome break from physical therapy, rather than design specifically. They did, however, find a sense of resolution in visiting the Bucks design workshops which was a very direct response to sheer materiality and an unambiguous facility for making things. Although both expressed impatience with the uncertainty and circularity of the prototyping phase, they also said that the design sessions had brought out their confidence and ability to adapt, making them aware of 'more options'; 'not necessarily accepting what I've got'.

As with the original RSA workshop, they also highlighted the social aspect of discovering and advancing ideas in discussion, and simply getting to know other people in a semi-formal context, as a significant benefit and relief from being a patient.

Bucks regretted that the design project had not been properly introduced to or integrated with the hospital OT team; and that the channels of communication between the hospital and the university were unclear. They would also recommend 'changes of scenery' – moving the sessions to different parts of the hospital; indeed one of the patients himself wanted an environment that seemed 'more workshop-y', especially after visiting the university facilities.

In the discussion that concluded the Glasgow workshop, participants were asked to identify the kinds of thinking they had used in the exercises using a matrix Macdonald had drawn up.

Although it was anticipated that there would be a clustering of different sets of skills for each of the three activities, participants tended to tick all available boxes. This suggests that the method of obtaining feedback was flawed, and semi-structured interviews might have been more accurate in revealing what skills participants thought they were using.

However, in the three activities the participants did demonstrate, to a greater or lesser extent, that they possessed the same kinds of skills that designers would use for such activities. Looking at the question differently, Emily Campbell asked participants how they would describe the day if the word design weren't available. Their answers can be broadly summarised as: "looking at what might be possible in the future", "perceiving things from a different perspective or point of view", "refining ideas in discussion" and "brainstorming; I mean keep chucking ideas at a problem".

Glasgow School of Art has identified the question of what specific thinking skills participants can take away with them and re-apply as a subject for further study. In particular, Macdonald would like to go back to the Goal Planning Checklist and see patients leave the unit able to manage the functional aspects of their life but also equipped to tackle some of its wicked problems. He envisages a handbook containing a 'lay taxonomy' of design methods and general case studies to help ex-patients deconstruct scenarios (like the shopping experience) into different stages and work their way through them with a set of design skills.

Occupational therapy – design's cousin?

At the dissemination event Emily Campbell remarked that occupational therapists are sometimes confused by the proposition of design training for SCI patients; perhaps because, superficially at least, design seems similar to what they do: looking at the 'whole person', adapting and customising devices and environments, and finding new ways to accomplish tasks. Manuela Schuette (representative of the British Association and College of Occupational Therapists) assured the group that the project 'spoke of something completely

Questionnaire matrix of skills and thinking



RSA Design + Rehab Project: Glasgow 18 Jan 2012

What kind of skills and thinking do you think you used during these three activities?	1 personal shopper	2 shopping status quo	3 what if?
thinking as someone else			
researching about other users' needs and preferences			
use of own personal experience			
use of others' experience			
critical evaluation/judgement			
problem identification			
problem solving			
decision-making			
storytelling			
generating ideas			
drawing / visualising ideas			
seeing things in the mind's eye			
playing with reality			
imagining the future			
teamworking			
other			

- Please tick all relevant boxes.
- You may have used some in all three, others in only one, or none at all.
- You may have used some that are not mentioned here and we'd be interested in these too.

different' from the conventional OT practice of prescribing and adapting from standard products. She identified the design approach as 'actually stepping back, thinking about the entire concept and working intensively to produce an outcome, with quick results.' She related this to industrial design practice with its high level of 'user involvement' and iteration - 'They bring a prototype and yet another prototype until it is deemed suitable.' She said that the health and social model in which OT operates does not permit such practices: 'So much is planted in front of us and of our users and there is no alternative.'

'A change in thinking' - hard and soft outcomes

At the same event Stef Cormack, Head of Services at the national spinal cord injury charity Back-Up asked the project partners to describe the nature of participants' 'change in thinking'. For Back-Up, she said, an outcome could be 'feeling more positive about the future; feeling that it's more manageable,' and that a wide range of changes in perception could be linked to positive outcomes.

Chris Haynes, one of the Stoke Mandeville participants immediately pointed out that a spinal cord injury

changes your thinking about everything. With respect to design changing his thinking, he admitted that his ability to design and make things outside of hospital was limited, but said that design had helped him recognise the problem he was trying to solve: 'if I know what the problems are, and I can look on the internet and find things, then it is sort of designing.' His co-participant Alex Jones said that a sense of design gave you options; an expanded a sense of possibilities and choice of what things might be like.

When Emily Campbell asked the group if an 'expanded sense of possibility' could be construed as a measurable outcome, Sheffield Registrar James White gave a robust defence of the 'soft outcome' in healthcare. He gave the example of the acute phase of spinal cord injury in which, with so many variables, it becomes difficult to say which intervention has yielded the outcome. While he accepted that it is often difficult to measure qualitative outcomes in medicine, citing the WHO 'quality of life tool', he said that medical practitioners were willing to be persuaded by nonquantitative data.

Bernie Conway of Strathclyde University assured everyone that the medical community had been working with soft data for some time. He said the really important task was not persuading medical professionals to accept non-quantitate data, but 'to tap into the idea of personalisation. Design is incredibly important in the personalisation of care.' Another delegate suggested that 'self-efficacy', an aspect of personalisation, should be measured. Others mentioned dignity as an outcome, along with 'making something that feels good and is part of your identity' and 'the way you present yourself to the world.'

Design Education

The project has yielded a direct secondary benefit to design education in each partner university, by creating opportunities for design students to work directly with 'extreme users'.9 Although it was remarked at the event that education in design should be 'all about that one to one experience with the users', others pointed out how difficult this is to achieve in reality and with the pressures of time and the increasing bureaucracy associated with ethics and criminal

record checks. A delegate insisted that in spite of these constraints professional designers in education should have formal training in 'how to develop a relationship with a subject' (ie a person who is the subject of your study).

This passage of conversation illustrated how far design has travelled not only away from objects and into less tangible services, but also into the design of individualised solutions, rather than the modernist ideals of standardisation and universal utility.

Selling the programme

Denise Stephens, co-founder and CEO of the internet service Enabled by Design asked at the event how easy it had been to get people involved with the programme, knowing from personal experience that 'selling the idea that design is very useful' is not easy. Bernie Conway interpreted the 'selling' problem as a resistance to innovation in health services 'because it's disruptive', while he noted that having a research centre located at OENSIU had helped to create a hospitable environment for the project. He stressed the importance of a clear message about what you want to achieve and congratulated the partners on good cooperation between teams that allowed the project to move forward in spite of initial resistance. Alastair Macdonald said that clinical leads are palpably 'looking for some things they haven't got', but recalled that in the first meeting with the medical staff of QENSIU it had been essential to get the terms of reference right.

'Selling' the programme had potentially terminal implications for funding. Jane Young, Director of the Sylvia Adams Charitable Trust admitted to not 'getting the concept at all' when it had first been proposed. However, she described the project as she finally understood it in her own eloquent terms: 'Once I got the concept of putting people with SCI in the position of seeing the world through the eyes of a designer, it all became very exciting. Instead of seeing problems they see solutions; they get round it rather than overcome it'.

Young urged the partners to use their 'combined learning' to sell the project further, declaring that soft outcomes are not a problem in the mature charitable sector. She also stressed the importance

of embedding the learning, and of using a cost/benefit analysis as a means of getting OTs and clinical leaders on board.

Alex Jones from the Stoke Mandeville project reminded the group 'You've got to sell it to <u>us</u>' ie the patients, and reflected that the 'buy-in from the right people' at Stoke Mandeville appeared to have been lacking.

Brian Carlin, Chief Executive of the national spinal-cord injury charity Aspire, described 'massive difficulties' in encouraging spinal injury centres to launch a future education programme, because of their existing workload and tight schedules. He asked whether the design training ought to happen post-discharge, perhaps delivered by OTs and launched on a national scale. Like Jane Young, he recommended a clear identification of the benefits of the programme. 'And perhaps changing the word "design". It's not a closed gate to me but to some it is'.

^{8.} There is a film available of the project on the RSA website made by Claire Levy

^{9. &#}x27;Extreme user' is a term coined by the Royal College of Art Helen Hamlyn Centre for Design for anyone who has an acute or unique need for design (on account of a disability, for example)

The learning: adaptable models and accessible language

The project was beset to varying degrees in all centres by the unpredictability of patient attendance. Variables of health and transportation and conflicting therapy schedules all made it very difficult to progress through the workshops as originally planned, even in Sheffield and Glasgow where the project had full and evident support and participation from the medical teams at the highest level.

In such circumstances designers leading the project will be required to show their utmost resourcefulness; they should expect to improvise and think on their feet, while maintaining a focus on a few key design principles or techniques. At Stoke Mandeville one such technique was the mood board - gathering a selection of images or artefacts that, although superficially unrelated to the brief, seem to represent qualities that the design could laterally capture or emulate. In Glasgow the technique of deliberately putting oneself in another's

position by role-playing yielded insight; while in Sheffield it was using a classification or 'rule' – even an apparently arbitrary one in relation to the brief (eg dark and light, chaos and order) - to guide one's search for perceptions and images that expanded participants' sense of invention.

Being run not by a hospital department such as OT, but by external agencies, places a huge communication burden on the hospital staff to raise awareness. The universities' own ability to promote, recruit and retain for the workshops is extremely limited. Furthermore the voluntary status of the workshops – and indeed any therapy – means that the proposition needs to be compelling to patients and staff alike; compelling enough to become a priority activity.

It has been clear from the beginning of the RSA Design & Rehabilitation Project that language is a barrier to

understanding. Design's traditional and formal terms of reference are more or less meaningless to people unconnected with design who have broken their backs/necks; and to the clinical professionals whose duty of care is to these people. This has hindered the progress and full resolution of the project in several ways: for example, patients didn't know what the project was or what to expect; occupational therapists did not in all cases support it or get involved; and fundraising at the beginning of the project was unsuccessful because 'design' was misunderstood.

Therefore this, and indeed any, attempt to involve non-designers in design requires a range of language and examples that non-specialists can understand. Beyond the practical teaching methodologies it tested, the significance of the project is that it took design beyond its associated traditional and formal terms of reference. Of necessity, it found other

ways of saying design; ways to explain or 'sell' design as rehabilitative, therapeutic or constructive to the people concerned with these (latter) things. During the workshops, design was described broadly in the following ways:

- As thinking about the future (for example, tolerating un-prescribed outcomes; anticipating many answers to a question; expanding one's sense of possibilities; releasing authorship in co-design & co-production)
- As personalisation (ie self-empowerment and self-determination eg
 'design isn't function it's what I want'; or customisation as opposed to standardisation)
- As whole concepts, not parts (for example, thinking holistically; thinking of products AND systems together; evaluating a whole service rather than individual products; thinking of experiential 'pathways' rather than itemised pathologies)
- As looking from different perspectives (for example, discussion as the essential process that advances thinking; knowing the person/patient who will interact with a product or service; looking through another person's eyes in order to see the problem more fully)

These are very interesting 'proxies' for design; because each points to design as a mental state rather than a set of technical skills for the manipulation of form. Even the Bucks project, which centred on making objects, employed versions of all these to explain its aims.

The combined learning of the projects is twofold: a set of tested, replicable methodologies and resources for teaching design to non-designers; and new forms of words for design that respond to clinicians' and patients' needs and agendas.

The project also yielded learning about the challenges of external agencies delivering services within the NHS. It appears that, for all the explicit support of clinical directors, it is very difficult indeed to recruit and retain participants, and to rely on a hospital's internal communication system. The most expedient option is to work with charities – in this case the specialist SCI charities Back-Up, Aspire and the Spinal Injuries Assocation – who have already

established platforms in hospitals and are on the radar of therapists and other staff via more easily understood agendas of disability politics, sport and fitness, and – most likely – independent living.

Finally, it should be noted that all three universities have entered into discussion about further projects with their respective SIU. The RSA's Design & Rehabilitation project has opened channels of communication and possibility that will lead to innovation beyond the RSA's original hypothesis about design and resourcefulness.

10. Stoke Mandeville participant

The RSA: an enlightenment organisation committed to finding innovative practical solutions to today's social challenges. Through its ideas, research and 27,000-strong Fellowship it seeks to understand and enhance human capability so we can close the gap between today's reality and people's hopes for a better world.



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