One of the most complex global challenges is improving wellbeing and developing strategies for promoting health or preventing ‘illbeing’ of the population. The role of designers in indirectly supporting the promotion of healthy lifestyles or in their contribution to illbeing has emerged. This means designers now need to consider, both morally and ethically, how they can ensure that they ‘do no harm’ and that they might deliberately decide to promote healthy lifestyles and therefore prevent ill health.

*Design for Health* illustrates the history of the development of design for health, the various design disciplines and domains to which design has contributed. Through 26 case studies presented in this book, the authors reveal a plethora of design research methodologies and research methods employed in design for health.

The editors also present, following a thematic analysis of the book chapters, seven challenges and seven areas of opportunity that designers are called upon to address within the context of healthcare. Furthermore, five emergent trends in design in healthcare are presented and discussed. This book will be of interest to students of design as well as designers and those working to improve the quality of healthcare.

**Emmanuel Tsekleves** is Senior Lecturer in Design Interactions at Imagination@Lancaster, Lancaster University. Emmanuel conducts research on designing creative and technology-inspired health-promoting interventions aimed at improving quality of life. Emmanuel blogs regularly for *The Guardian* and *The Conversation* on design in healthcare.

**Rachel Cooper OBE** is Distinguished Professor of Design Management and Policy at Lancaster University. Her research interests cover design thinking, design management, design policy, design for wellbeing and socially responsible design. She is the series editor of the Routledge series Design for Social Responsibility.
Design for Social Responsibility
Series Editor: Rachel Cooper

Social responsibility, in various disguises, has been a recurring theme in design for many years. Since the 1960s several more or less commercial approaches have evolved. In the 1970s designers were encouraged to abandon ‘design for profit’ in favour of a more compassionate approach inspired by Papanek. In the 1980s and 1990s profit and ethical issues were no longer considered mutually exclusive and more market-oriented concepts emerged, such as the ‘green consumer’ and ethical investment. The purchase of socially responsible, ‘ethical’ products and services has been stimulated by the dissemination of research into sustainability issues in consumer publications. Accessibility and inclusivity have also attracted a great deal of design interest and recently designers have turned to solving social and crime-related problems. Organisations supporting and funding such projects have recently included the NHS (research into design for patient safety), the Home Office (design against crime) and the Engineering and Physical Sciences Research Council (design decision-making for urban sustainability).

Businesses are encouraged (and increasingly forced by legislation) to set their own socially responsible agendas that depend on design to be realised. Design decisions all have environmental, social and ethical impacts, so there is a pressing need to provide guidelines for designers and design students within an overarching framework that takes a holistic approach to socially responsible design. This edited series of guides is aimed at students of design, product development, architecture and marketing, and design and management professionals working in the sectors covered by each title. Each volume includes: the background and history of the topic, its significance in social and commercial contexts and trends in the field; exemplar design case studies; and guidelines for the designer and advice on tools, techniques and resources available.

Design for Transport
A User-Centred Approach to Vehicle Design and Travel
Edited by Mike Tovey

Design for Policy
Christian Bason

Design against Crime
Caroline L. Davey and Andrew B. Wootten

Design for Health
Edited by Emmanuel Tsekleves and Rachel Cooper

Design for Personalisation
Edited by Iryna Kuksa and Tom Fisher
Design for Health

Edited by Emmanuel Tsekleves and Rachel Cooper
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Editors

Rachel Cooper OBE is Distinguished Professor of Design Management and Policy at Lancaster University, where she is Chair of Lancaster Institute for the Contemporary Arts and also Imagination@Lancaster. Her research interests cover design thinking, design management, design policy and, across all sectors of industry, a specific interest in design for wellbeing and socially responsible design. She has published extensively on these topics, including the books Designing Sustainable Cities (2009), Constructing Futures (2010) and Handbook of Wellbeing and the Environment (2014). She is also series editor of the Routledge series Design for Social Responsibility covering topics such as designing for sustainability, inclusivity, service design, sport, health, transport and policy.

She is currently working on Liveable Cities, an Engineering Physical Sciences Research Council-funded six-year research programme working to identify design and engineering solutions that will lead to low-carbon, resource-secure, future cities in which societal wellbeing is prioritised. She is also involved with the Creative Exchange, an Arts and Humanities Research Council (AHRC) Knowledge Exchange hub looking at the growth of the creative industries through exploring the ‘digital public space’. She is Co-Investigator of an AHRC project on DesignValue in Innovation and Co-Director of HighWire (Digital Economies Innovation Doctoral Training Centre).

Rachel is a non-executive director of the Future Cities Catapult, and a lead expert for the UK Government Foresight Programme on the Future of Cities, and is on the Academy of Medical Sciences working group addressing ‘the health of the public 2040’.

She was a member of the 2014 Blackett review on the Internet of Things. She is founding and past president of the European Academy of Design, founding editor of the Design Journal, and a trustee of the Research and Development Management Association. She was a member of the EU Design and Innovation Leadership Board and has undertaken several advisory roles to national and international universities, government and non-governmental organisations.

Emmanuel Tsekleves is Senior Lecturer in Design Interactions, Imagination@Lancaster, Lancaster University. Emmanuel designs interactions between people, places and products by forging creative design methods along with digital technology. His design-led research in the areas of health, ageing and wellbeing has generated public interest and attracted media attention. Emmanuel designs technology-inspired health-related innovations and services that are created by end users and that link the physical with the digital world through playful interactions. His research also looks at exploring the futures that ordinary people would prefer, by using design fictions. He is currently working with people in the early stages of dementia, people with Parkinson’s, with families of children with autism and in
the area of public health on the design of playful technology and interactions that promote healthy behaviours. His current research also looks into how participatory design fictions can be used as a tool to provoke and generate debate around policy initiatives and emergent technology amongst diverse groups in the area of ageing and dementia. Emmanuel is a member of Lancaster University’s multidisciplinary Centre for Ageing Research, Health and Work Forum and blogs regularly for The Guardian and The Conversation on the design and use of technology in health.
Contributors

Charles Abraham is a professor and an applied psychologist specialising in design, evaluation and implementation of interventions to change health-behaviour patterns. He is Head of the Psychology Applied to Health group at Exeter University Medical School and holds honorary chairs at Sussex, Nottingham, Maastricht and Curtin Universities. He was the founding chair of the UK British Psychological Society, Division of Health Psychology and is a practising health psychologist (registered by the UK Health and Care Professionals Council). He has acted as a research consultant to the UK Department of Health, was a member of the National Institute for Health and Care Excellence groups that developed guidelines on ‘Behaviour Change’ in 2007 and extended these in 2013. In 2010–11 he was the scientific advisor to the UK House of Lords Select Committee on Science and Technology, ‘Inquiry into Behaviour Change’. He was one of seven psychologists included in the UK Science Council’s list of the leading 100 practising scientists in the UK, published by the UK Academy of Science in 2014.

Marco Ajovalasit is Senior Lecturer in Human Factors at Brunel University, London. His research interest is in the field of experience-based co-design, human–product interactions, psychophysics and multisensory perception. Particular emphasis is placed on designing the sensory stimuli of products, systems and services for the purposes of meaning, interaction and emotion. He is Principal Investigator of an FP7 EU Grant-funded project ‘Light. Touch. Matters’ (2013–16), which brings together a multidisciplinary team of designers and material scientists for a design-driven development of a fully new generation of smart materials that combine touch sensitivity with luminescence, based on latest developments in polymeric piezo materials and flexible OLEDs for wellbeing and care applications.

Richard Bibb graduated from Brunel University with a BSc in Industrial Design in 1995 and moved to the National Centre for Product Design and Development Research (PDR) to undertake rapid prototyping research. In 1998, he established the Medical Applications group at PDR to conduct research into the medical applications of design technologies including additive manufacturing/3D printing. He moved to Loughborough University in 2008 where he is affiliated with the university’s multidisciplinary Additive Manufacturing research group and he established the Design School’s Design for Digital Fabrication research group in 2014. His research focuses on the application of design techniques and technologies in medicine specifically addressing maxillofacial surgery, prosthetic rehabilitation, orthotics, dental technology and archaeology.

Alison Black is Professor of User-Centred Design and Director of the Centre for Information Design Research in the Department of Typography and Graphic Communication,
University of Reading. A cognitive psychologist by training, her research focus is the explanation of complex information and simplification of complex tasks, using methods and media appropriate to audience and context. Much of her work has focused on health and healthcare, but she also works on communication to support professional and consumer decision-making in areas of complexity and potential risk, such as the communication of extreme weather events and decision-making regarding legal and contractual information.

Christopher T. Boyko is a 50th Anniversary Lecturer in Design at Lancaster University. With Rachel Cooper OBE he is currently examining the relationship between wellbeing and the built environment as part of the UK EPSRC-funded Liveable Cities project. This research builds on previous research about urban density within the planning process and maps sustainable urban design decision-making processes for the EPSRC-funded Urban Futures and VivaCity2020 projects, respectively. Christopher’s general research interests include urban design, sustainability, use of digital technology in cities and wellbeing in urban environments.

Josefin Bravo Burnier is a PhD candidate at the University of Reading. She is also a freelance graphic designer with specialisation in the areas of corporate identity, information design and editorial design. She has experience in leading integral design projects and in handling internal and external work teams.

Matthew Brook is a specialist registrar in renal medicine at the Royal Berkshire NHS Foundation Trust.

Clare Carey is an information designer, director at Studiolift and currently a University of Reading student, researching apps in the classroom.

Valerie Carr works for Snook, an award-winning service design agency with offices in Glasgow and London. She is an experienced service designer who focuses mostly on co-designing health and social care services, improving both the experience of the citizen and the efficiency and effectiveness of service delivery. She has a PhD in Healthcare Service Design and is motivated by creatively addressing the challenges associated with engaging patients and citizens in co-producing public services. Recent clients have included NHS24, Department of Health, Department for Education, Capita, NHS Ayrshire and Arran and Lankelly Chase.

Paul Chamberlain is Professor of Design, head of the Art and Design Research Centre and Co-Director of the interdisciplinary research group Lab4Living at Sheffield Hallam University. Paul’s interest lies in designing and developing tools and methods to encourage and engender social innovation and he applies this with a focus on healthcare, disability and ageing. His work explores the multisensory aspects of design and the role of artefacts that help define pertinent societal questions as much as present solutions. He has led major interdisciplinary projects and delivered keynote lectures at leading international venues on innovation strategies and sustainable approaches to design and manufacture that have played a significant role in supporting regional industrial reconstruction.

Ricardo Codinhoto is a qualified architect with practical, teaching and research experience. Ricardo holds a senior lecturer position within the University of Bath where he is Director of Studies for the MSc on Modern Building Design. Within the Department of Architecture and Civil Engineering at the University of Bath, Ricardo’s research is aligned with the themes studied within the Centre for Advanced Studies in Architecture. Ricardo
has developed research funded by EPSRC, MRC, ESRC and NIHR, including a study commissioned by the Government Office for Science. He is active in a number of research initiatives that relate health and wellbeing to the design, construction and maintenance of healthcare facilities design, construction and maintenance, with a particular focus on older people and people with dementia.

Claire Craig is a reader in design and creative practice at Sheffield Hallam University and is Co-Director of Lab4Living with Paul Chamberlain. Claire has a health background and her clinical work and research interests have focused on quality of life for older people and people with dementia. Her research has explored the role of design and the arts in promoting wellbeing and she has published a number of books in this area. Claire is particularly interested in research methods to engage marginalised communities and projects have included photography as a method in care home research and the potential of critical artefacts as a way of building understanding of the experiences of older people in Europe. Claire lectures nationally and internationally and was awarded a national teaching fellowship in 2011. She also holds a fellowship from the College of Occupational Therapists in recognition of her contribution to the field.

Sarah Denford is Research Fellow in the Psychology Applied to Health research group at the University of Exeter Medical School. She has a background in health psychology and public health. Her research interests include self-management of chronic conditions, evaluation of public health interventions, qualitative methodologies and systematic reviewing. Her previous work has attempted to identify processes that are associated with behaviour change in complex interventions. Her current research focuses on the evaluation of public health interventions, sexual health interventions, and environmental factors that influence alcohol consumption.

Alan Dilani is a professor and founder of the International Academy for Design and Health and the journal World Health Design. He has been engaged worldwide in several universities in the field of design and health developing ‘salutogenic design’, in both medical and design institutions. He holds a Masters of Architecture in Environmental Design from the Polytechnic of Turin, Italy and a PhD in Health Facility Design from the Royal Institute of Technology, Stockholm. His research at the Karolinska Institute, Medical University, which developed a multidisciplinary research approach, led to a new definition called ‘salutogenic design’. He has designed all types of healthcare facilities and has been consulted as an advisor for several ministries of health around the world. He lectures worldwide and is author of numerous articles and books in the field of design and health. Alan was awarded a Presidential Citation in 2010 from the American Institute of Architects, Academy of Architecture for Health for his promotion of high-quality design research.

K. Downey is a doctoral researcher at the Department of Design, Fashion and Business within the School of Materials at the University of Manchester. Her research is an exploration of computer-aided design and additive manufacturing for the design and fabrication of custom-made spinal braces. Part of the research involves understanding how young people and their families can contribute to co-designed braces through design research.

Sarah Drummond is Co-Founder and Managing Director of Snook, an award-winning design consultancy working at the forefront of civic, public-sector and democratic innovation. Sarah focuses on making social change happen by rethinking public services from a
human perspective and regularly lectures and speaks around the globe on service design, innovation and civic engagement. Sarah is a serial idea generator. She has co-founded MyPolice, CycleHack, Dearest Scotland and The Matter. For this work she was awarded a Google Fellowship for her work in technology and democracy.

**Michelle Goonasekera** is at the Oxford University Hospitals NHS Trust, with expertise in renal medicine.

**Marianne Guldbrandsen** heads up the Service Innovation and Strategic Partnership team at Macmillan Cancer Support. It is a human-centric service design team focusing on the future of support and healthcare services. By using design and innovation methodologies the team co-design, prototype and scale new service solutions to support cancer patients and their families, delivered with private, public and third-sector partners. The process builds on expressed and latent needs of people affected by cancer, a knowledge of the gaps in existing healthcare services and the challenges of higher demand and reduced resources. In this context, empathy, creativity, multimethods and co-creation is the only way to innovate successfully. In the past Marianne has worked as an innovation consultant with emphasis on design strategy, user insights/ethnography and service design, for clients such as Mars/Wrigley, Nokia, Nissan, Toyota, Volvo, Ford, LEGO, Walt Disney, Orange, Novartis and Novo Nordisk. Prior to this she worked at the Design Council where she provided strategic direction across programmes such as Independence Matters (aging population), Low Water Living and Reducing Violence and Aggression in A&E. Marianne holds qualifications in design-driven innovation, research, psychology and coaching.

**Sue Hignett** is Professor of Healthcare Ergonomics and Patient Safety at Loughborough University. Over the last 30 years she has experienced the healthcare industry as a clinician, ergonomist, researcher and patient. Her research looks at a wide range of issues including the design of safer systems, building and vehicle (ambulance) design, emergency and CBRNe response, staff wellbeing and an innovative approach to patient falls. Sue is an editor for ‘Ergonomics’, Chair of the Education and Training panel at the Chartered Institute of Ergonomics and Human Factors; and past chair of the International Ergonomics Association Technical Committee on Healthcare Ergonomics.

**Peter Jones** is an associate professor in the Faculty of Design, OCAD University, Toronto. Peter is a co-founder of the Systemic Design Research Network and the Relating Systems Thinking to Design symposia. In his practice with the Redesign Network, Peter has led the design and research of leading resources for clinical, educational and scientific practice throughout the internet era. His research adapts applied cognitive and social methodologies for complex systems in healthcare, governance and organisational design domains. He publishes in design and innovation literatures, including his most recent book *Design for Care: Innovating Healthcare Experience* (2013).

**Alastair S. Macdonald** is Senior Researcher in the School of Design at the Glasgow School of Art. He has a track record of research council-funded research working within multidisciplinary healthcare teams, addressing patient-centred issues in, e.g., physical rehabilitation, spinal injury, dementia, infection control and malnutrition. Using collaborative co-design and mixed-method approaches with substantial stakeholder involvement to address complex healthcare challenges, he and his team have developed a number of innovative healthcare interventions, using iterative narrative and prototyping methods.
Victor Margolin is Professor Emeritus of Design History at the University of Illinois, Chicago. He is Co-Editor of the academic design journal, Design Issues, and is the author, editor or co-editor of a number of books including Design Discourse, Discovering Design, The Idea of Design, The Designed World and The Politics of the Artificial. Margolin has been a visiting professor and lecturer at numerous colleges and universities throughout the world. Margolin was presented with a Lifetime Achievement Award by the organisers of the LearnXDesign conference in Chicago in 2015, for his ‘exemplary contributions to design history, research, education and practice’ and a Lifetime Achievement Award by the Design Research Society in 2016.

Susan Mawson originally trained as a physiotherapist and worked initially in South Africa. While there she learned to develop novel seating and sleeping equipment out of cardboard boxes for the children living in the Cape flats townships. On returning to the UK, she completed her BSc (Hons) in Physiotherapy and her PhD in Stroke Rehabilitation. Sue is Director of the NIHR CLAHRC YH and Professor of Health Services Research in the School for Health and Related Research at the University of Sheffield, where her role is to develop stronger links between researchers at ScHARR, the NHS, industry and the voluntary sector. She has a specific focus on rehabilitation research into novel interventions and technologies for people with disabilities, older people and people with long-term conditions.

David Meredith is based at the Royal Berkshire Hospital NHS Foundation Trust.

Massimo Micocci is a Design PhD student within the School of Engineering and Design at Brunel University. His research focuses on human-centred design, and in particular on the application of a new generation of smart materials that can sense touch and respond with luminescence in the field of care and wellbeing applications. His research aims to classify key products’ features that affect the user with positive experiences by using design techniques such as virtual and tangible prototypes. Massimo’s first aim is to make available for designers a toolkit for meaningful experiences iterate over time.

Sarah Morgan-Trimmer is a social scientist working in the Psychology Applied to Health group at the University of Exeter Medical School. Her research experience is in qualitative methods, process evaluations of public health, randomised controlled trials, evaluation research, research on socioeconomic inequality and conducting research with children. Her current work is focused on understanding not just whether health interventions work but how they work, through developing process evaluation methods for complex interventions.

Jeremy Myerson is a professor and leading academic, author and activist in design and innovation. He holds the Helen Hamlyn Chair of Design at the Royal College of Art, London and is Visiting Fellow at the Oxford Institute of Population Ageing, University of Oxford. He is also Director of the Worktech Academy, a new global knowledge network exploring the future of work and workplace. A former journalist and editor on such titles as Design, Creative Review and World Architecture, he founded Design Week magazine in 1986 and later co-founded the Helen Hamlyn Centre for Design in 1999, which he directed for 16 years until autumn 2015. The author of more than 20 books in the field, his most recent titles include Time and Motion: Redefining Working Life (2014) and Life of Work (2015). He has consulted with governments and businesses around the world, and sits on the advisory boards of design institutes in Korea, Switzerland and Hong Kong.
Lenny Naar is a design strategist at HELIX Centre – short for Healthcare Innovation Exchange – inside St Mary’s Hospital, London. The team uncovers root problems and co-designs solutions to improve healthcare at scale. Lenny recently co-founded Prescribe Design, a community aimed at expanding the role of design and designers working in healthcare. As Lead Design Strategist at Aetna’s innovation group Healthagen in San Francisco, he worked on creating digital tools to engage patients and clinicians. Formally trained as a communication designer, Lenny worked with Paula Scher at Pentagram Design on large-scale brand projects and has also held positions with Doblin, SYPartners and Smart Design.

Anna Olsson-Brown is a medical doctor and research fellow in Molecular and Clinical Pharmacology at the Institute of Translational Medicine at the University of Liverpool.

Jari Pallari is Vice President of Operations and Innovation at Pofdo and previously has been a research and development manager at Peacocks Medical Group. He has been at the forefront of the additive manufacturing healthcare frontier, with a decade of experience in the medical applications of the technology, participating in a number of research projects in the area.

Abby Paterson graduated from Loughborough University with a BSc in Industrial Design and Technology in 2008. In 2013, she was awarded a PhD, which focused on novel applications of computer-aided design and additive manufacturing technologies for custom-made orthoses. In 2012, she became Lecturer in Computer Aided Design at the School of Materials, University of Manchester. Abby returned to Loughborough University as Lecturer in Industrial/Product Design in 2014, where she is now a member of the university’s Additive Manufacturing research group and recently formed Design for Digital Fabrication research group. Her research interests span the development of 3D scanning protocols and customised computer-aided design/manufacturing methodologies for a range of industrial, product and fashion design applications.

Alison Prendiville is Senior Researcher at the School of Graphic Design at LCC, UAL London. Her research focuses on design for service in local government and healthcare sectors. She has recently completed, as Co-Investigator, the AHRC-funded Mapping and Developing Service Design Research in the UK and the AHRC Design for Service Innovation and Development. Currently she is working as Co-Investigator on the AHRC-funded Public Collaboration Lab with Central St Martins and Camden Council. Her research interests also encompass design and digital anthropology. She has an MA in Design Management and an MSc in Digital Anthropology from University College London.

Gail Ramster is Senior Research Associate at the Helen Hamlyn Centre for Design Work and City Research Lab, exploring how people-centred design and co-design approaches can be applied within different settings including urban planning, community development and employee wellbeing. She joined the centre in 2009 working on projects with both academic and industry partners. Gail began her professional life as a mechanical engineer working in the UK, USA, France and Spain before completing an MA at the Royal College of Art and moving into industrial design, information design and wayfinding. She is one of the creators of the Great British Public Toilet Map; a website and database developed from the TACT3 research project funded through New Dynamics of Ageing that holds the largest database of publicly accessible toilets in the UK.
Debbie Rosenorn- Lanng is an executive coach (holding the Institute of Leadership and Management, ILM Level 7), a visiting professor with Henley Business School and a visiting lecturer with Keele University. She has over 20 years of experience as a doctor, seven years of which were as a hospital consultant. During that time frame she gained over 20 years of experience in medical education. She is an approved Royal College of Physicians educator. Her area of special interest is Human Factors in Healthcare, which is also the title of her book published by Oxford University Press.

Chris Rust is Emeritus Professor of Design at Sheffield Hallam. His principal interests now are in independent creative work rather than an academic or institutional role. His research has been concerned with the role of tacit knowledge in design, arising from experience of research projects in which design plays an instrumental part in investigations into problems in other disciplines. Chris has taken an active role in the development of practice-led research and doctorates in design and the creative disciplines. He has also been developing and running the Nether Edge Bikebus, a practical Design and Social Action project to get more people cycling in his part of Sheffield and a narrative song documentary about the history of war in the 20th century. Chris was the chair of the Design Research Society Council 2006–9 and has been a committee member in several other prestigious committees and conferences. He has been invited to give talks on practice-led research in several universities across Europe.

Aaron Sklar is Managing Director of Experience Strategy and Design at Healthagen and Co-Founder of Prescribe Design. Throughout his career, Aaron has led design teams focused on improving people’s quality of life, health and wellness. Prior to joining Healthagen he spent 14 years at IDEO, an award-winning global design firm where he managed projects for more than 50 international organisations. Aaron has been published by the Rockefeller Foundation, GOOD magazine and in the HIMSS book Engage!

Jane R. Smith joined the University of Exeter Medical School as a post-doctoral Research Fellow in November 2012 to support the work of Professor Charles Abraham, which focuses primarily on the development and evaluation of evidence-based interventions to promote health-related behaviour change. Jane brings to this role her skills in quantitative health services research and broad interests in psychosocial aspects of health and illness. Her research includes systematic reviews, randomised controlled trials of complex interventions and process evaluations alongside interventions, development and testing of outcome measures and other related, mixed-methods research investigating the role of behavioural and other psychological factors in health, illness and healthcare.

Gabriella Spinelli is Reader in Design Innovation in the Department of Design at Brunel University, London. She is interested in research exploring the relationship between identity, behaviour and artefacts. In the last five years her research has focused on how the design of products, services and systems can support the wellbeing of the ageing population. Gabriella’s research is people-centred to ensure integrity and inclusion. She has attracted research funds from EPSRC, ESRC, TSB, Innovate UK and commercial schemes. She is a visiting scholar at the Royal College of Art and an associate editor for the Journal of Design, Business and Society.

David Swann is a graduate of the Royal College of Art, gaining his PhD in 2011 and MDes in Industrial Design in 1991. David began his academic career in 1992 at the University of Huddersfield and in February 2015 joined the Sheffield Institute of Arts at Sheffield Hallam University as Principal Lecturer. David’s design research is grounded in global

Samantha Van Beurden is a PhD candidate in Medical Studies as part of the Psychology Applied to Health group at the University of Exeter. Her main research interest is in facilitating behaviour change through impulse management. In 2008 Samantha obtained her BSc in Psychology from the University of Plymouth which was followed by an MSc in Psychological Research Methods in 2009.

Karel van der Waarde gained his PhD from Reading University and has owned a design-research consultancy in Belgium since 1995. The company develops and tests patient information leaflets, medicine packaging, instructions for use, forms, medical protocols and the information architecture for websites. Karel teaches part-time at the Basel School of Design and frequently publishes about visual information design. He is a life fellow of the Communications Research Institute (Melbourne, Australia), a board member of the International Institute for Information Design (Vienna, Austria) and editorial board member of Information Design Journal, Journal of Communication Design and Visible Language.

Emma Vaux is Consultant Nephrologist, Director of Quality Improvement at the Royal Berkshire NHS Foundation Trust and Associate Medical Director of the Royal Colleges of Physicians Training Board, leading core medical training and national recruitment, the ‘Learning to Make a Difference’ quality improvement programme and the ‘Making Every Moment Count’ pilot enabling trainees of all specialties and grades to develop quality improvement skills as part of their usual training.

Sue Walker is Professor of Typography in the Department of Typography and Graphic Communication at the University of Reading and Director of the AHRC-funded Design Star Doctoral Training Centre. Her research interests include the analysis and description of graphic language, in particular the relationship between prescription and practice in everyday documents, typographic design for children and information design in public service. She is an active participant in the Associate All-Party parliamentary group on Design and Innovation, Co-Chair of the Information Design Association and Fellow of the Design Research Society.

Daniel Wolstenholme undertook a first degree in neuroscience before training and working as a nurse. During this time, Dan completed an MMedSci in Nursing and Healthcare Studies and lectured on pre- and post-registration nursing courses within the School of Nursing at the University of Sheffield. Following this Dan worked in research management and governance in Chesterfield and Sheffield Hospitals before taking up his role as project manager and clinical researcher on the user-centred healthcare design project within CLAHRC SY. Dan’s own research interests lie in exploring the potential of the theory and practice of design in healthcare.

Andy Young is a design and innovation consultant, an ideas person with a passion for start-ups and entrepreneurship. He works across the private, public and third sector designing for customer experience and has a particular interest in making things happen at the intersection point between service design and technology. Andy’s expertise as a service designer, prototyper and his background in product design mean his capabilities extend across the full spectrum of design. He believes in asking difficult questions and challenging why things are the way they are.
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Negotiating design within sceptical territory: lessons from healthcare

Alastair S. Macdonald

Abstract

Recent co-design initiatives demonstrate successful healthcare innovation and improvement without the need for designers, potentially problematising design’s legitimacy in and contribution to this sector. In arguing the case for design, the author explores design’s value in the healthcare research domain, where the randomised controlled trial is regarded as the gold standard for scientific evidence. Two case studies are presented, one of the development of a visual tool for stroke rehabilitation, the other of a food-management and nutrition-monitoring system, describing design’s contributions within larger multidisciplinary healthcare research teams. These illustrate the value of designers’ methods in generating visual narratives and physical prototypes and their role in simultaneously eliciting and embodying particular forms of evidence while making progress in providing a tangible and interactive glimpse of the future.

Introduction

Designing in healthcare settings

Designers working in the healthcare setting could adopt a number of positions. Contrasting three, they could: i) act as sole designers, consulting as required; ii) involve and empower other, non-designers, to design alongside themselves, thereby extending the design team; iii) relinquish their own involvement, provide the tools and processes they use and let others, i.e. non-designers, get on with the designing.

Donetto et al. (2014) summarise the achievements of a decade’s work in improving patient experiences in healthcare settings, first planned for and piloted in a head and neck cancer service at Luton and Dunstable NHS hospital in England (Bate and Robert, 2007) in a model that has come to be known as experience-based co-design (EBCD). What is significant about EBCD is the scale of uptake in the healthcare community over the decade since that first pilot, across several countries, the accessibility, usability and adaptability of the tools and processes to local requirements and resources by non-specialists, the value of that critical mass in developing and reporting case studies to share experiences and outcomes, the continuous improvements to tools and the finely calculated economic benefits. More recently this work has led to the development of a more cost-effective ‘accelerated’ form of EBCD (Locock et al., 2014).

What is interesting about EBCD is that we can witness an approach and process almost exclusively conducted without the involvement of professionally trained designers. We can witness the logical conclusion of the desire for the democratisation of design reflected in
recent discussions which develop the understanding of design from one of a practice comprising activities which were once regarded solely as those of the ‘professional’ (e.g. industrial) designer providing a ‘solution’ to a problem to the point where design is seen as a ‘distributed social accomplishment’ (Kimbell, n.d.) where ‘stakeholders are co-designers and designers are another kind of stakeholder’ (Kimbell, 2009). EBCD pushes this further: designers are not stakeholders in this form of co-design. This appears to be ‘designing without designers’, arguably a truly democratised form of designing which doesn’t require designers per se any longer. Should designers rejoice?

This EBCD phenomenon seems to have made significant progress in a manner that may make many designers feel uncomfortable. However, are external, professional designers the best people to be designing within healthcare? Or, are those whom Sanders (2001) defines as the ‘real virtuosos’, with their deep insights and expertise derived from delivering and experiencing its services, best placed to identify and address issues from within? The evidence from EBCD’s grand projet appears to suggest that the healthcare professionals and patients involved can do a pretty good job without designers. It is not only from healthcare that we face this attitude. Siodmok (2014) reinforces this point with respect to the use of design-led approaches in government policymaking, stating that: ‘Design is too important to be left to designers’, citing three reasons why: ‘90% of design decisions are not made by designers… designers are not the only source of creativity, ingenuity and innovation… ideas are not the only problem… ideas are everywhere… the difficulty is in making them happen’ (Siodmok, 2014). This leaves us facing such questions as, is this ‘mission accomplished’ for design? Is EBCD a form of democratised design legacy? Is there any longer a role for designers and, if so, what might their contribution be?

One easy win in this discussion would be to cite the more traditional product design engineering model with its highly practised range of expertise in healthcare equipment or device design, concerned with the combination of expertise in usability, ergonomics, aesthetics, interaction design, materials specification, component packaging and manufacturability, etc., but we might also have to concede that often the initial ideas for innovations can come from the clinicians and practitioners themselves. But maintaining our focus on co-design, which is defined by Donetto et al. (2014: 45), as ‘a complex social intervention whose impacts and outcomes are difficult to evaluate and cannot be reduced solely to the design solutions it generates’, can we see different kinds of effects and outcomes if designers are involved in co-design within healthcare?

Despite the substantial growth of interest in – and practice of – design involvement in the healthcare sector, one commentator claims that design: ‘does not yet fit into the conventional clinical organisation, and institutional practices have not established meaningful positions for design’ (Jones, 2013: xv). ‘Healthcare as a domain is strongly influenced by scientific tradition and evidence-based practices. Designers will be expected to understand and adapt to the domain rather than the language of design and user experience’ (2013: 17). But already EBCD, working from within the healthcare system, seems to refute this as its practice uses narrative-based techniques to elicit experience as a platform for co-design activity, rather than more ‘scientific’ types of evidence. The EBCD project provides many examples where experience has been used as the basis for co-designing successful and cost-effective improvements to services and patient and staff experiences ranging from those which are small-scale to those which are more process design-oriented (Locock et al., 2014). However, having raised the spectre of the potential redundancy of designers’ involvement in the healthcare setting it is now incumbent on this author to argue the contrary case.
Jones’ (2013) statement above raises the interesting issue of the scientific tradition and what is regarded as evidence in its practices. This takes us into the realm of the randomised controlled trial (RCT), regarded as the ‘gold-standard’ for evidence. Macdonald and Robert (2014) have stated that ‘the findings of RCTs or the mandating of quality improvements often do not sit comfortably with the complexities of daily life within a healthcare organisation’. Therefore, can we reconcile some of the tensions of the scientific tradition and the complexities of daily life by exploring ways of integrating, e.g., ‘gold-standard’ evidence-based approaches fundamental to scientific legitimacy and judgement-making in the biomedical sciences tradition with the more socially oriented concerns and narrative-driven evidence of the user experience, by identifying and exploiting a legitimate contribution from designers?

The issues and questions raised above are now explored in two case studies of collaborative research and development conducted by the author and colleagues, where design approaches and methods were introduced and integrated into the overarching research methodologies of multidisciplinary teams concerned with developing innovative healthcare interventions.

Case study 1: physical rehabilitation following stroke

Introduction

This first case study is essentially concerned with discussing two separate but interrelated issues: 1) the integration of qualitative methods and a participative co-design approach into a traditional RCT design; and 2) the different approaches to evidencing the effect of a novel prototype visual method, co-developed within the trial design, as an aspect of a complex intervention, for its efficacy in improving the experience and outcomes of rehabilitation following stroke through a set of Phase II RCTs (exploratory) as defined by the MRC and following MRC guidelines for the evaluation of complex interventions (Craig et al., 2008).

The development and evaluation of the visual method has been described previously in some detail (Loudon et al., 2012, 2014). Briefly, the visual method uses motion-capture and motion-sensor technologies to provide data which are visualised onto a prototype virtual mannequin of the patient in ways that allow real-time visual feedback of movements and communication of complex biomechanical data associated with body and limb movements in an accessible manner for both stroke patient and therapist (Figure 17.1).

The problem/issue

The biomechanical concepts of human movement, e.g. forces, moments, angles, velocity and acceleration, although important to assist in improving physical rehabilitation, are ones which the general public and most health professionals, including therapists, understand poorly. The formats used for representing these concepts and biomechanical data have been the sole preserve of biomedical engineers. Consequently, despite almost 40 years of research, biomedical engineers had been unable to represent this data in a format largely usable by anyone outside their own discipline, particularly by rehabilitation therapists or by their patients. These therapists and patients had not been involved in the processes of either the formats of the presentation of data or the design of the interventions. As a consequence, clinicians had to assess patients’ movements by eye despite the inaccuracies and missed observations caused by such an approach, with patients having their problems explained to them verbally or using less-than-ideal methods such as mirrors, tables or graphs, or sometimes through video.
Biomechanical preoccupations

Naturally, biomedical engineers have tended to be preoccupied with quantitative biomechanical metrics, e.g. in a patient’s manner of walking (gait), speed, step length, symmetry of steps while walking, angles of movement of limbs and with the various forces exerted during dynamic movement. This is illustrated clearly in the primary and secondary outcome measures that were used to evaluate if the use of the visual interventions improved outcomes in the three stroke trials in this study. For example, in the lower limb stroke trial the outcomes measured, in each participant, the differences in the walking velocity, step length, spatial symmetry and temporal symmetry between baseline and post-intervention assessments.

Utilitarian use of designers?

The biomedical engineer’s interests, as project lead, in inviting designers into the core team was to exploit their novel visual method, prototyped and developed in previous work, to visually present biomechanical data and information in a user-accessible manner for the RCTs. This involvement of the designers could perhaps be seen as ‘utilitarian’, due to the method’s potential for improving outcomes evaluated through quantitative metrics familiar to the biomedical field as defined above. A further attractor here was the designers’ use of a participative co-design approach to guide the further development of the prototype visual tools to the versions used as interventions in the RCTs.

Figure 17.1 One of the visual tools developed for the ‘lower limb stroke’ feasibility trial showing a visually correct target angle indicated by a coloured ‘fan’ scale which moves as the patient moves. The patient has to lift their leg sufficiently to enter the coloured zone and this angle can be customised for each individual and for each stage in the rehabilitation process.

Source: © envisage, 2012
Negotiating design within sceptical territory

Quantitative outcomes

Had the use of traditional biomedical engineering quantitative outcome metrics prevailed as the sole method of data acquisition and analysis in these trials, as might have been the norm in an RCT design of this nature, the in-depth experiences of the stroke survivors and therapists and what was important to them, as distinct from what was important to the biomedical engineers, would not have been understood. For example, it was reported in the findings of the lower limb trial that ‘All groups demonstrated improvements in most parameters, with changes in spatial and temporal symmetry being relatively small’ (Thikey et al., 2014). The statistics in the tables of the findings of the other two stroke trials bear out similar preoccupations with these types of quantitative outcomes (Carse et al., 2014; Jones et al., 2014), whereas discussion and analysis of ‘experience’, although acknowledged, is limited to short statements such as, ‘Importantly, all experimental participants were able to engage with the virtual avatar and expressed that they found it useful to see how they moved’ (Thikey et al., 2014).

The requirement for mixed methods

Lewin et al. (2009) highlight the importance of integrating qualitative processes into quantitative trials: ‘Complex healthcare interventions involve social processes that can be difficult to explore using quantitative methods alone… Qualitative research can support the design of interventions and improve understanding of the mechanisms and effects of complex healthcare interventions.’ This reminds us of the above definition of co-design by Donetto et al. (2014: 45). In joining this study, the designers, as the originators of the visual prototype and the participative co-design process by which it was – and would be further – developed, required to integrate their own qualitative people-centred methods and processes for the development of the prototype visual interventions into the methodological design of the RCTs. In the design of the overall research methodology, the challenge was to integrate the established ‘gold-standard’ evidence-based approaches fundamental to judgement making in the biomedical sciences with those more concerned with understanding users’ experiences.

A qualitative methodology, described in Macdonald (2014), introduced by the designers, involving interviews, observations and focus groups (Figure 17.2), ensured that patients’ and therapists’ feedback was considered to assist in the co-development of the intervention before the RCTs and also to improve understanding of the effects of these complex interventions during and after the RCTs. Savory’s framework was useful here as it sets out a series of four ‘ideal strategies’ for ‘incorporating PPI [public and professional involvement] into the wider process of translative healthcare research involving technological innovation’ (Savory, 2010). This framework helped highlight the different attitudes amongst the research team to PPI and to how patients and professionals were involved. Qualitative methods were adopted in each of the four key phases of the trial: intervention design, pre-trial, during-trial and post-trial phases.

Insights from qualitative data

The capture and analysis of extensive qualitative data throughout the four phases of the RCTs provided explicit insights into the experiences of therapists and stroke survivors. Some of these were elicited by conventional means, such as interviews. Other data were elicited through prototypes. For example, in one of the pre-design stage focus groups, where the designers had produced a number of early-stage visual prototypes to explore what features in these
might be appropriate to them for their rehabilitation purposes, on seeing these the stroke survivors likened themselves to ‘wounded animals’ trying to heal, or of ‘feeling like a two year old’ learning to walk again, having to go through a transitional phase of readapting to the lack of – or relearning – the functioning of their body. From a therapist’s perspective, acknowledging survivors’ difficulties with speech, it can be very challenging to establish whether patients have understood the aims of the rehabilitation and what they are being asked to achieve. Strategies normally adopted at this time include physical prompts, diagrams and verbal prompts as it is crucial that the patient understands what is being asked of them. These early visual prototypes, as could be evidenced, generated different kinds of responses through patients seeing representations of themselves and their condition in a potentially new ‘future’ tool for rehabilitation.

The study’s findings (Macdonald et al., 2013) suggest that visualisation software can be used in the context of stroke rehabilitation with benefit to both patients and therapists and that through the visualisations: survivors better understand the key aspects of their rehabilitative tasks; an interactive rehabilitation environment is created whereby both patient and therapist are able to communicate and discuss key issues and progress; the visualisation of the patient’s own motion provides an aid to their understanding of their movement problems and the purpose of their rehabilitation tasks; the visual representation of the movement and the overlay

![Workshop with stroke survivors providing feedback on pre-trial stage prototype visualisation tools during their development](image)

Figure 17.2 Workshop with stroke survivors providing feedback on pre-trial stage prototype visualisation tools during their development

*Source: © Alastair S. Macdonald, 2011*
of specific measures relevant to their rehabilitation provides a medium for improved communication between the patient and the therapist; and the combination of quantitative measurement and clear visual representation of the measures provides an objective tool for therapists to monitor progress and communicate it to patients.

The question of whether these kinds of results could have been achieved without the involvement of designers and their iterative prototyping method is returned to in the Discussion section.

Case study 2: monitoring nutrition in older hospital patients

Introduction

This second study discusses the development, through a participative co-design process, of an innovative technology-based system for addressing issues of malnutrition in older hospital patients. Briefly, the proposed system enables the recording of a person’s daily nutritional intake against a series of personalised daily targets set for protein, calories, nutrients and fluids, prompting the system to alert food managers and ward staff to deliver extra foods and fluids as appropriate if these daily targets are in danger of not being met. The system was iteratively developed through a narrative-generating and prototyping process, starting with paper mock-ups derived from earlier evidence-eliciting stages, finally as a demonstration prototype assessed through a heuristic peer-evaluation process from feedback at a series of conference seminars and exhibitions rather than, as in case study 1, through RCTs. The description of the development and evaluation of the system has been described previously in some detail (Macdonald et al., 2012; Comber et al., 2012; Moynihan et al., 2012; Thompson et al., 2014).

The problem and current preoccupations

The alarming scale of malnutrition in hospitals, particularly amongst older patients, provides the context here. The current situation is predominantly one of a totally inadequate ‘one-size-fits-all’ meal provision service, currently a complex agglomeration of imperfect systems, often with conflicting interests, out of sync with one another, fragmented by a task-driven mentality, a limited awareness of the total system and with no workable way of monitoring the nutrition intake of patients, each of whom has their own individual requirements for calories, protein, nutrients and fluid intake. Isolated interventions, such as ‘protected mealtimes’ (to prevent the disturbing of patients by clinical staff) and ‘red trays’ (to identify nutritionally at-risk patients) had been found ineffective in addressing this problem which had traditionally been seen as one involving the expertise of nutritionists, dietitians, food scientists and front-line ward staff (i.e. those largely concerned with identifying patients at risk and their individual nutritional requirements). The urgency of addressing this issue had been recognised to the extent that this research was commissioned through a special competitive ageing nutrition call, part of whose brief suggested the application of innovative technologies might assist in addressing this problem. In this case, design formed one of the core investigating disciplines, attractive due to its co-design, visualisation and prototyping competencies.

A collaborative approach

Because of the very fragmented nature of the current system and the diverse roles and tasks of all those involved in it, it was essential that everyone was brought together through a participative
co-design and co-development process. This involved a ‘food family’ (FF), i.e. those concerned with nutrition, food production, food supply, delivery and catering, as well as ward staff, nurses, physicians, speech and occupational therapists. It also involved key stakeholders (KS) from groups such as the UK’s NHS and older people representatives. These were all engaged, in various configurations, in a series of workshops and events over the duration of the project, from the mapping of existing systems to the iterative process of creation and refinement of the new prototype system. As it was a multidimensional project it also included the development of new food and drink products.

Narratives, mock-ups and prototypes

In the course of the development of the proposed prototype system, two principal narrative forms emerged. Both required developing a ‘commons’, a space where ‘individuals bound by a common cause… a dynamic organization of individuals and groups formed by the desire to address an issue’ (Le Dantec and DiSalvo, 2013) could tackle this work, as well as the means – the ‘infra-structuring’ (Björgvinsson et al., 2012), to enable the collective mobilisation of the FF and KS who were essentially co-opted into the design team.

The first narrative form related to the status quo prompted by, e.g., visual mapping of food journeys and the pre-preparation, preservation, storage and reheating of meals, and also understanding the patients’ and ward staff’s experiences of mealtimes. Various tools were designed for use to engage the KS and FF to help elicit and assemble their fragmented knowledge, insights and experiences to build, from the evidence, the ‘big picture’ in easily sharable visual formats. These tools took a variety of forms, mostly graphical mapping and visual prompts, to allow for a collective discussion and verification of the current system.

The second narrative form was very much a consequence of stimulating thinking through a number of activities using a range of mock-ups and low-resolution to more refined prototypes about how the experiences, insights and expertise of the FF and KS could be shaped into an improved and workable system taking advantage of new technologies, part of the commissioning brief (Figure 17.3). These narratives were made manifest through an iterative co-prototyping process, ‘bringing into being’ this innovative (yet still hypothetical) system as a means of opening up, discussing and experiencing the possibility, in a very tangible way, that things could be quite different. These narratives were multidimensional. From the patient’s perspective the narrative, supported by the prototypes, helped understand, e.g., how the service presented itself through an easy-to-understand and easy-to-use interface in welcoming him/her and in presenting and assisting in the selection of meal options. From the ward nurse’s perspective, this was about, e.g., how the system ensured that food intakes met each individual’s daily targets, so here the narratives and prototypes explored what role the various service elements and technologies could play in helping to plan for and respond to a patient’s nutritional needs and to enable monitoring of intake. Similarly, this allowed a catering manager to, e.g., keep track of the inventory and particular dietary needs. This set of narratives was iteratively developed, in text form initially, then through story-board scenarios and brought back to the FF and KS for comment. A further stage was the version which appeared in the touring exhibition of the prototype and which appeared on the animation video on the website. Both narrative forms described above were a form of collective sense-making: the first, of an understanding and critique of the present system; the second, of a preferable, hypothetical – yet still tangible – future alternative.

Running concurrently and interconnected with the development of this type of narrative was the iterative prototyping process, which was used to probe and explore possible future
Negotiating design within sceptical territory. The use of mock-ups and prototypes gave permission to ask the kinds of questions about how to proceed – ‘if we used this, could it be like this or that…?’ or ‘if we had this…?’ allowed wrong turns and dead ends to be identified early and to allow progress in a more productive direction. Here, prototyping took a number of forms. An improvised form of service prototyping involved building and enacting a simple system, using low-resolution prototype materials for ideas that were generated during workshop activities (such as mock-ups of interactive screens, food menus and food trays), and testing this through role playing. In contrast, a ‘mini-meals’ trolley, which formed part of the total system, was developed as a full-scale prototype, from initial computer-aided design concepts, evaluated for its thermodynamic performance in keeping different foods at different temperatures, and for ergonomic performance by the FF in a dedicated workshop.

The core of the proposal was a smart monitoring and management system comprising software and interfaces, including patient- and staff-facing interactive screens used for presenting food menu options, recording individual food intake and monitoring progress – against an individual’s needs – towards daily nutritional targets. A ‘wipe-away’ food-monitoring app using a photo of the meal linked to a smart nutritional database on the patient’s bedside touch-screen terminal was also developed. Initially built by team members as a tablet-based mock-up (Figure 17.4), this was then worked up as an Android prototype for testing with
the FF and KS. This was further developed, as a large touch-screen version, externally, due to the sophistication of the data and screens which required to be included for the ‘public’ version touring to conference meetings of gerontology, design, nutrition, geriatric medicine and hospital-catering societies. Again, the question of whether these kinds of results could have been achieved without the involvement of designers and their particular tools and methods is discussed below.

Discussion

In the Introduction a case was suggested by this author that, due to the reported evidence and positive outcomes of the EBCD grand projet, designers might appear – to some – to be sceptically regarded as largely redundant in healthcare-related co-design, leaving this author the challenge of identifying a legitimate case for designers to be involved in the co-design and co-development of healthcare-related interventions and innovations. As far as this author can determine there is no other programme of the scale and durability as EBCD being promoted in the name of ‘design’ within healthcare and which is able to be replicated in and adapted to so many different settings by independent groups, while demonstrating economic benefit alongside service innovation and improved patient and professional experience. This represents not only a significant achievement for EBCD but also a significant challenge for designers, more so when various techniques in co-design, regarded by some designers as belonging to
their own design lexicon, are considered by proponents of EBCD as better conducted by non-designers:

I am less convinced of the unique or added-value of ‘designers’ in the relational work needed to underpin co-design. We have always managed to find fantastic facilitators of these processes within NHS organizations with a combination of ideal skill sets and professional (typically nursing) knowledge (and not to mention positional authority)… but less so as facilitators of the whole process from start to end (not least because many of [designers’] skills (seems to me at least) are duplicating those of staff in healthcare organizations already but also because I think lots of the benefits of EBCD would be lost if external designers ‘hold the ring’ – I’m thinking of personal development for NHS staff, staff engagement & ownership and the broader, cultural benefits I think EBCD can engender.

(Robert, 2015)

As a concession, EBCD proponents have identified stages in the co-design process where designers may have a distinct, albeit limited, value and contribution: ‘I guess I’m saying yes to seeing a real potential benefit to involving professional designers at the latter stages of an EBCD project (but struggling to see how to make that happen at scale)’ (Robert, 2015).

There are points here this author can also concede and which might provide a stark reminder of the need to clearly articulate which deep skills lie truly within design’s specialist lexicon and which skills are shared across other disciplines.

To recap, two case studies were presented above, one of the development of a visual tool for stroke rehabilitation, the other of a food-management and nutrition-monitoring system, describing the design team’s approaches and contributions within larger multidisciplinary healthcare research groups. They illustrate the designers’ intention to use design as ‘a set of practices aimed at realising a certain desirable future’ (Storni, 2013), to generate narrative forms and prototypes within a ‘commons’ (Le Dantec and DiSalvo, 2013), through designing situations, activities and materials, i.e. ‘infrastructuring’ (Björgvinsson et al., 2012) to engage all involved. What the author hopes to illustrate through the two cases cited here is the distinctive design contribution and its value in both simultaneously eliciting and embodying particular forms of evidence (through quantitative and qualitative data) while making progress in providing a tangible and interactive glimpse of the near future. With reference to this chapter’s introductory discussion there are instructive lessons emerging from these studies, explored further here.

Case study 1: stroke rehabilitation

In case study 1, pre-trial interviews with both therapists and stroke survivors followed prior glimpses of early visualisation prototypes prompting discussion of how and in what ways to proceed to benefit patients in therapy. Examples of the therapists’ narratives of the imagined future benefits can be found in Ballinger et al. (2016). These are borne out in the findings from the trials themselves. Throughout the four stages of the RCT, the role and effect of the visual prototypes is evident, i.e. the process by which these were iteratively co-developed and how these prompted and mediated types of discourse which would not have been possible using more conventional qualitative methods such as interviews, filmed narratives and focus groups. The rehabilitation session may have been regarded previously by the biomedical engineering community in research of this type as a largely ‘clinical/technical’
challenge to restore function and, from a research perspective, of how to collect, measure and present quantitative biomechanical data to use with the patient to help achieve correct movement: trials and their interventions would be designed on this basis. However, once one starts acquiring the type of qualitative data captured during the development and use of the prototype visualisation tools, it becomes evident that the rehabilitation session is as much an intensely social as a technical challenge. During the design and pre-trial phases of the RCT, the nature – and various iterations of – the prototype visualisation tools came to be understood, by this author, as being simultaneously technical and social in nature. The visual interventions proved not only to be a technical mediator in assisting therapists and patients to respectively communicate and understand correct posture, movements and progress but also a social mediator, acknowledging and responding to the patients’ and therapists’ needs for clearer mutual communication and understanding, as a consequence reducing the social and technical distance between these players. Captured here is a form of evidence different to that of interest to the biomedical engineer, rich not only in the instrumental narrative of therapist-patient trying to achieve correct movement, but of how the patient and therapist actually converse and interact during rehabilitation sessions. Clearly evidenced also is the underlying narrative of individuals’ disrupted lives, their wells of emotions, hopes and aspirations, the frustrated communications and the expressions of achievement and disappointment – the real challenges, experiences and complexities of their daily lives – all of which may affect the efficacy of any intervention if these factors are not acknowledged within a trials context.

This work integrates both a scientifically ‘legitimate’ evidence-based approach together with a narrative-generated experience-based approach. This is an outcome prompted by the visual prototypes; what these do is allow one to not only imagine, but to tangibly witness and experience the possibility of how different the rehabilitation setting and session could be, and collect evidence on its benefits.

Case study 2: nutrition

Unlike the setting of the stroke rehab therapy session, in which there was an intimate correspondence between the stroke survivor (and perhaps their carer), the therapist and the clinical lead, the series of evolving case study 2 prototypes collated and embodied the collective insights, experiences and expertise of its many stakeholders currently working in a highly fragmented system and proposed a way of making a coherent sense of this through (eventually) a feasible electronic solution which located the care of the patient at its centre. They also provoked, from initial paper mock-ups through to the more advanced elements of the demonstration prototype, conversations between the many different stakeholder communities about what would work or not, eventually about what would make such a system possible and workable. Prototyping offered a tangible and interactive glimpse of a preferable and hypothetically workable solution. The iterative prototyping process provided a means of mobilising collective will and stimulated new kinds of conversations and ideas, many of which are recorded in the end-of-project and impact reports for this work and the many outputs produced by the team (ESRC, 2013).

Beyond research, towards implementation

Both cases describe innovations dependent on existing but not fully exploited technologies. In case study 1, such a system has become feasible, technologically and economically, since the first prototypes were developed over a decade ago. For case study 2, progressing the food-management
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and nutrition-monitoring prototype into an implementable system was beyond the resources available for this exploratory developmental project. For either to progress, there would still be the very real issues of, e.g., feasibility trials and, if successful, scalability. At a pragmatic level, there would be challenges of the integration of these innovations with current software systems and platforms while negotiating all the attendant issues such as ‘platform fatigue’ (Jones, 2013: 19), i.e. the learning of new interfaces and new procedures for accessing and logging into multiple systems, together with the problematics of dysfunctional interfaces (Naughton, 2014).

A case for design?

Would it be essential for designers to be included in teams to develop the types of solutions proposed in the two cases above? The author hopes a convincing argument has begun to be made, illustrated by examples of the deep and distinctive expertise required to develop the two solutions presented. The iterative and participative manner of prototype development both elicited and cumulatively embodied ‘evidence’ into tangible and interactive solutions. Siodmok (2014), while acknowledging that the context of his discussion is with regards to the use of prototyping in policymaking, states: ‘to prototype generates imperfect truths but with the right approach it also generates data about the future’ and also ‘evidence of what works and, more importantly, what does not, can be very powerful’. Siodmok acknowledges that prototyping is not a widely used term (in policymaking) and that this kind of practical tool and the lab in which to explore this is in its infancy. At the time of writing, an examination of the EBCD toolkit on the King’s Fund website provides no guidance on prototyping, only providing methods more familiar to qualitative research, e.g. interviews, filming, focus groups, and ‘brainstorming’ sessions.

Coughlan et al., citing cases of the effectiveness of rapid prototyping in the healthcare setting, discuss the value of prototyping in such terms as: ‘building to think’, ‘giving permission to explore new behaviors, relieving individuals of the responsibility to consciously change what they do’, ‘in a nonthreatening, low-risk way’, as ‘learning tools’, to ‘learn quickly’, ‘to explore and communicate propositions’, ‘tangible, created so everyone can grasp the idea’, ‘as “transitional objects”… objects that support a change from a current behavior to a new behavior’ (Coughlan et al., 2007). Similarly, Sanders and Stappers discuss designers’ ability to ‘make things that describe future objects’ stating that ‘making is a significant activity for designers’ citing how prototyping can play a number of roles and how, e.g., ‘in making, people can bring their insights to the surface’, ‘allow the testing of a hypothesis’ and because prototyping ‘allows people to experience a situation that did not exist before’ (2014: 6).

Integrating evidence-based research and experience-based design

Hagen (2014) calls for the bringing together of ‘user experience design and participatory approaches with the evidence-based models which traditionally underpin health promotion, intervention and treatment’, identifying differences and challenges in integrating these two approaches. Certainly case study 1 explores this territory and highlights the differences and tensions between the medical-scientific approach evidencing the biomedical outcomes alongside the more psychosocially oriented approach evidencing the engagement, two-way communication and shared understanding from the qualitative data. Both cases used prototype methods, building to think with, to elicit new narratives and to understand effects and, as Hagen acknowledges, ‘which perspective [i.e. experience or evidence] has greatest influence can shift depending on the context of the intervention’. Hagen goes on to say (within the
context of a discussion of mental health): ‘Being able to enrich the application of medical models… through an understanding of people’s everyday lived experiences… as well as their behaviours around technology, greatly increases our chances of building products and services that will actually be used and have impact.’

Mutual collaboration?

To be clear, this discussion is not one pitting a preferred social model against a scientific biomedical model as clearly the value, indeed necessity, of integrating the two are acknowledged in discussions of both cases above. Both provide an opportunity, as Parker and Parker (2007, cited in Carr et al., 2011: 13) state, in arguing the case of integrating evidence-based design and experience-based approaches in healthcare, of ‘completely redesigning the script and modes of interaction between services and people’. Nor, to be equally clear, is this an argument against EBCD, which has evidenced significant results by exploiting and mobilising latent design capability amongst non-designers and using forms of adapted design methods and tools, along with others, in its online toolkit.

However, despite their separate achievements, and rather than using only those methods and tools largely familiar to – and comfortable for – their respective communities, it is this author’s contention that EBCD-based practitioners and non-EBCD-allied designers could mutually benefit by exploring together their respective strengths and limitations. On the one hand EBCD-based practitioners could capitalise more on designers’ skills in using prototyping and visual methods both as a means to conduct research and make tangible a greater range and type of possible near-future solutions than appear to be currently generated using EBCD. On the other hand, non-EBCD-allied designers could accommodate less frequently encountered notions of scalability, adaptability, repeatability and rigour in evaluation. Clearly concessions and adjustments are required on both sides but the common ground has already begun to been explored by Robert and Macdonald (2017) citing, within a larger discussion, a case study of each of their respective approaches to developing complex interventions within RCTs.

Conclusions

What remains? As far as lessons for design, as highlighted earlier, EBCD, through its significant achievements, throws design a set of challenges it should note and address. One is the scale and durability of EBCD’s grand projet which, with its every new project, offers EBCD the opportunity of demonstrating its ability to be replicated in and adapted to different environments with different problems, a key principle to establishing legitimacy within healthcare: ‘Replication, not only collaborative parallel studies but also independent replication, is needed to understand generalizability of findings’ (Fanelli, cited in van der Steen and Goodman, 2015). EBCD has demonstrated this kind of viability and legitimacy through a programme of sustained innovation, accumulated evidence and costed improvement. This ability for replication may perhaps be part of what Jones refers to, when he states that ‘designers will be expected to understand and adapt to the domain rather than the language of design and user experience’ (Jones, 2013: 17). Design in healthcare involving designers has no such programme to match this. Is a programmatic approach covering a series of related studies required, by design, to build legitimacy, to avoid duplication and one-off, standalone studies, many of which are currently poorly reported and lack robust evaluation – in healthcare terms, an issue identified in Chamberlain et al. (2015: 52)?
Marsh (2010), in a discussion referencing Gorb and Dumas’ (1987) paper ‘Silent Design’ where Gorb and Dumas anticipate the ‘design without designers’ narrative implicit in EBCD, highlights the usefulness of design-led methods, ‘within the intangible world of services [which] include techniques to creatively explore ideas through customer or user research’ and through ‘visualisation methods that designers use to express ideas; and quick low-risk prototypes that help them learn about the best way forward through hands-on experimentation’. But Marsh goes on to say ‘design thinking can help silent designers find their voices, as a voice coach might. The singing part, however, is quite a different matter.’ Many of these voices have been elicited both through EBCD and more bespoke approaches to design-led healthcare research. The case for making these voices really sing, utilising the added value of the designer’s skills and craft in visualising and prototyping, perhaps as one way forward through designers working more closely with the achievements of EBCD, has hopefully begun to be made more convincing here.

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