The Development of Persuasive Design Theory to Improve Patient Engagement with Therapeutic Exercises in People with Rheumatoid Arthritis

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The University of Brighton in collaboration with Brighton and Sussex Medical School
Abstract

This thesis presents the development of persuasive design theory to effect behaviour change amongst patients with Rheumatoid Arthritis (RA). Drawing on research from the disciplines of design, social psychology and healthcare, this study defines ‘persuasive design’ as an area of design research which seeks to change a person’s attitude or behaviour for the benefit of their health and in concordance with their own ambitions. The research aim is to support patient engagement with long-term therapeutic exercise recommendations specifically for the hand. This is achieved by identifying ‘designable factors’ ideas, objects, and environments (virtual and real), which are specific to people with RA and can be identified, examined, understood and selectively influenced to increase the ability and willingness of users to engage with long-term therapeutic exercise recommendations. The research explores existing motivations and interests, embedded within daily life activities that can be targeted to incorporate therapeutic exercise interventions. To achieve this a qualitative research methodology was adopted, consisting of photographic ‘cultural probe’ and ‘photo elicitation’ methods, which were utilised within a focus group setting.

The research demonstrates that traditional product specific approaches to design and those which focus primarily on ‘desirability’, ‘inclusivity’, and ‘mass market’ are not, in their current form, adequate to address the complex therapeutic needs of people living with RA. Three original contributions to knowledge are presented: an advancement of design research methodology; a model of behaviour change theory which is specific to the needs of people with RA, and two practical design solutions: a patient assessment tool and a therapeutic exercise device designed to extend user engagement. Results are also relevant to other areas of healthcare where improved patient engagement with treatment recommendations is required.
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I am also grateful to the following organisations for their contributions and support: the Arts and Humanities Research Council, the Clinical Investigation and Research Unit at the Royal Sussex County Hospital, the National Rheumatoid Arthritis Society and the Brighton and Sussex University Hospitals Trust.
Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

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<td>ARC</td>
<td>Arthritis Research Campaign (now Arthritis UK)</td>
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<td>ARMA</td>
<td>Arthritis and Musculoskeletal Alliance</td>
</tr>
<tr>
<td>ARUK</td>
<td>Arthritis Research UK</td>
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<tr>
<td>ATD</td>
<td>Alan Tye Design</td>
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<tr>
<td>BJD</td>
<td>Bone and Joint Decade</td>
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<tr>
<td>BSMS</td>
<td>Brighton and Sussex Medical School</td>
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<tr>
<td>BSR</td>
<td>British Society of Rheumatology</td>
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<tr>
<td>BSUH</td>
<td>Brighton and Sussex University Hospitals Trust</td>
</tr>
<tr>
<td>CIRU</td>
<td>Clinical Investigation and Research Unit (RSCH, UK)</td>
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<tr>
<td>CP</td>
<td>Cultural Probe</td>
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<tr>
<td>DMARD</td>
<td>Disease Modifying Antirheumatic Drug</td>
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<tr>
<td>DoH</td>
<td>Department of Health (UK)</td>
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<tr>
<td>DOME</td>
<td>Design Out Medical Error</td>
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<tr>
<td>EPP</td>
<td>Expert Patients Programme</td>
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<td>EULAR</td>
<td>The European League against Rheumatism</td>
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<td>FA</td>
<td>Functional Ability</td>
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<td>FBM</td>
<td>Fogg Behaviour Model</td>
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<td>FG</td>
<td>Focus Group</td>
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<td>GCP</td>
<td>Good Clinical Practice</td>
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<td>GSR</td>
<td>Government Social Research (UK)</td>
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<td>HAQ</td>
<td>Stanford health assessment questionnaire score</td>
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<td>HBM</td>
<td>Health Belief Model</td>
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<td>HCD</td>
<td>Human Centred Design</td>
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<td>HHC</td>
<td>Helen Hamlyn Centre (UK)</td>
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<td>HID</td>
<td>Healthy Industrial Design</td>
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<td>IA</td>
<td>Inflammatory Arthritis</td>
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<td>IEA</td>
<td>International Ergonomics Association</td>
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<tr>
<td>NAO</td>
<td>National Audit Office (UK)</td>
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<td>NHS</td>
<td>National Health Service (UK)</td>
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<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<td>NICE</td>
<td>National Institute for Health and Clinical Excellence (UK)</td>
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<td>NIHR HTA</td>
<td>National Institute of Health Research Health Technology Assessment</td>
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<td>NRAS</td>
<td>National Rheumatoid Arthritis Society (UK)</td>
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<td>NSMC</td>
<td>National Social Marketing Centre (UK)</td>
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<tr>
<td>OA</td>
<td>Osteoarthritis</td>
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<td>OT</td>
<td>Occupational therapy or therapist</td>
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<td>PMT</td>
<td>Protection Motivation Theory</td>
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<tr>
<td>PPI</td>
<td>Public and Patient Involvement</td>
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<tr>
<td>PT</td>
<td>Physio- therapy or therapist</td>
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<tr>
<td>QoL</td>
<td>Quality of Life</td>
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<td>RIBA</td>
<td>Royal Institute of British Architects</td>
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<td>RoM</td>
<td>Range of Motion</td>
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<td>RQ</td>
<td>Research Question</td>
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<td>RSA</td>
<td>Royal Society for the encouragement of Arts, Manufacturers and Commerce</td>
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<tr>
<td>RSCH</td>
<td>Royal Sussex County Hospital</td>
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<tr>
<td>S-EDAQ</td>
<td>Swedish Evaluation of Daily Activities Questionnaire</td>
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<tr>
<td>SMS</td>
<td>Short Message Service (usually via mobile telephone)</td>
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<td>SRS</td>
<td>Silver Ring Splint</td>
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<tr>
<td>TPB</td>
<td>Theory of Planned Behaviour</td>
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<tr>
<td>UCD</td>
<td>User Centred Design</td>
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<tr>
<td>UCSD</td>
<td>University of California San Diego</td>
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<tr>
<td>UK-EDAQ</td>
<td>United Kingdom Evaluation of Daily Activities Questionnaire</td>
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<tr>
<td>UN</td>
<td>United Nations</td>
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<tr>
<td>UNESCO</td>
<td>United Nations Educational, Scientific and Cultural Organisation</td>
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<tr>
<td>UoB</td>
<td>University of Brighton</td>
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<tr>
<td>USA</td>
<td>United States of America</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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Foundation Studies

My first degree was completed at the University of Brighton from 2002 to 2005, where I was awarded a First Class (Hons) degree in Woods, Metals, Ceramics and Plastics (WMCP, renamed as Design and Craft in 2010). It was during this time that I became interested in ‘haptics’ - the science and psychology of the sense of touch. My graduate show comprised five projects each investigating a different element of tactile perception and interaction through touch.

After completing my BA, I studied for a Post Graduate Certificate in Further and Higher Education Teaching (PGCE) at Manchester Metropolitan University (Graduating in 2007). Having developed a deeper interest in teaching and learning, I was appointed as a Research Assistant at Brighton and Sussex Medical school to work on a collaborative arts and health research study titled Using Biomechanical data to inform student learning about chair design (2007).1 The study, which aimed to develop innovative models for interdisciplinary teaching, was funded by the Centre for Excellence in Teaching and Learning through Design (CETLD). The successful completion of this project led to a second CETLD-funded research study titled Design in the Clinical Environment (2009).2 The project was a further development of the interdisciplinary teaching model identified during the previous study and moved the focus from the chair to the built environment.

The combination of research interests and making practices developed at undergraduate level and the research skills and professional networks developed during the CETLD project enabled me to develop my own research proposal: to develop treatment interventions for people living with rheumatoid arthritis in the hand. In 2009 I was awarded an AHRC postgraduate studentship award to undertake and complete my PhD studies for this project.

Alongside my PhD studies, I have continued to research into arts/health interdisciplinary teaching and learning.3

Chapter 1: Introduction and Research Context

This first chapter will introduce the aims and research context of this research study. To maximise accessibility this chapter is divided into six sub-sections. The content of each section within this chapter is briefly described below:

**Introduction** - Provides a comprehensive overview of this thesis identifying each of the key aspects to be discussed. This section introduces: the field of ‘Persuasive Design’ and its applications, the scale of RA as a medical concern, and provides an outline of the contributions to knowledge presented in this thesis.

**Statement of the research problem** - Presents the research focus of this study; emphasising the importance of hand function for maintaining a good quality of life, and the need to improve patient engagement with longterm therapeutic exercise recommendations.

**Motivation** - Identifies the key motivations of this research, specifically the need to improve the quality of life of those living with RA and to increase the efficiency and efficacy of treatment interventions.

**Timeliness** - Identifies the current circumstances that emphasise the importance of this study at this point in time. Specific details identified here include: the prevalence of RA, the increasing strain on the healthcare system brought on by the ageing population and the potential that new approaches in design offer in developing solutions.

**Theoretical location of the study** - Positions this research study geographically and theoretically within contemporary knowledge fields. The original contributions to knowledge are identified in the convergence of persuasive design, design thinking and the clinical factors relating to RA.

**Research questions** - Outlines the questions guiding this research. Three questions are identified exploring both design theory and design practice.
Introduction

Rheumatoid arthritis (RA) is a chronic autoimmune disorder affecting approximately 1% of the working age population. The National Audit Office (NAO) estimate that in England some 580,000 adults have RA with around 26,000 new diagnoses each year. RA is more than twice as common in women than in men. Onset generally occurs in adults aged between 40 and 60 years, though it can affect people of any age. Peak prevalence rates are seen in women aged between 65 and 74 years, yet according to the National Rheumatoid Arthritis Society (NRAS) three quarters of people living with long-term RA are first diagnosed whilst of working age. These statistics do not however, capture the full impact of RA or its associated consequences. The ‘synovitis’ of RA - inflammation of the synovial membrane situated at the contact point of articulating bones - affects multiple joints causing widespread pain. The subsequent destruction of the joints can lead to severe disability affecting all aspects of motor function from walking to fine movements of the hand. RA can also affect other organs in the body including the heart, lungs and sometimes the eyes. For those affected by RA the ability to work and live independently is severely compromised. The consequences of this are also social and economic due to the direct costs of treatment interventions and healthcare and the indirect costs of sick pay, loss of working time and lost production.

The financial cost of RA to those who live with the condition, their families and to the economy is considerable. In 2000 there were 1.9 million GP consultations for

4 Department of Health, Services for People With Rheumatoid Arthritis, (The Stationery Office, London, 2009)


inflammatory arthritis and around 46,000 hospital admissions. From 1999 to 2000 the loss of working time and subsequent cost to society and to the economy from RA was 9.4m working days, representing £833m in lost production. The cost to the NHS of managing RA, and complications such as osteoporosis, is an estimated £240 million a year. The NAO estimates the total annual cost of treating RA and its additional consequences, including sick leave and work-related disability, to be £1.8 billion.

This study seeks to improve the health and wellbeing of patients living with RA by developing design theory and two conceptual prototype designs to extend patient engagement with long-term therapeutic exercise recommendations. The purpose is to enable people with RA to engage with therapeutic exercises more easily and effectively within normal daily life: achieving and retaining desired levels of functional ability for longer periods of time, slowing the degenerative effects of RA, minimising the impact of RA on quality of life, enabling patients to stay in work for longer and saving costs for the long term treatment of RA. This study seeks to identify ‘designable factors’ - ideas, objects, and environments (virtual and real), that can be identified, understood and selectively influenced; which are specific to people with RA, that can improve the ability and willingness of users to engage with long-term therapeutic exercise recommendations.

This study takes a design-led approach to collaborative, ‘transdisciplinary’ research. Transdisciplinarity is achieved through the sharing of knowledge and understanding between design, medicine and social science disciplines in a structured fashion and coordinated by the overarching study aims. The research design, application and

analysis are conducted from a ‘design thinking’ paradigm.\textsuperscript{15,16} Within this thesis the term ‘design thinking’ is defined as a creative mindset concerned with: how we conceive of, and understand, the world around us; how we consider and define challenges and solutions; and how we apply outcomes appropriately and sympathetically to requirements. Design thinking enables us to consider new ways of knowing and new ways of discovering and synthesises proposals from different fields of knowledge.

Developed in consultation with patients, consultant rheumatologists, occupational therapists and designers, this study extends our understanding of the nature of patient engagement with long-term exercise treatments, identifies strategies for how these challenges may be overcome, and presents a new model for the role of ‘design’ within collaborative design/health research. The innovative application of the photographic ‘cultural probe’ and ‘photo elicitation’ research methods (described in detail in Chapter 3) has enabled this study to reveal complex, embodied knowledge. These methods identify the intricacies, nuances and contradictions of patient needs and the limitations of currently available treatments. The thesis presents three original contributions to knowledge:

Contribution to persuasive design theory
The primary contribution developed within this thesis is a theoretical model, developed through empirical analysis of existing behaviour change models, which locates designed objects and environments as the principal mediating factor between persuasive influences and the desired target behaviour. The theoretical model also identifies the key influences of behaviour change and both ‘active’ and ‘passive’ forms of engagement.

Contribution to methodology
Existing methods used to assess the needs of patients in the healthcare system solely focus on the problems a patient may be experiencing. In recent years


healthcare strategies have shifted to place greater emphasis on the value of patient empowerment and personalised healthcare (discussed in Chapter 3). To support this change, new assessment methods and new means to gather information about patient needs and daily life choices are required. This thesis presents a design-led qualitative assessment tool which not only provides the patient with the ability to identify problems which may fall outside the pre-defined parameters of existing tools, it also provides the patient with the means to identify opportunities within their existing routines to integrate therapeutic exercise interventions. Furthermore this method can be adopted to monitor an individual for prolonged periods of time and to involve a broader network of healthcare providers, family and friends to support health interventions.

Contributions to design

The final contribution made by this thesis is a conceptual prototype design for a toothbrush which integrates therapeutic hand exercise into daily life. The design adopts a ‘micro-adaptation’ strategy in which the brush handle provides physical resistance for the user to develop pinch and grip strength as part of their own personal hygiene routine. The design also incorporates a small counter that enables the user to monitor progress and work with healthcare teams to set personal goals.

Statement of the research problem

Exercise therapies help to maintain ‘functional ability’ and ‘quality of life’ (QoL), the ability to perform tasks and activities necessary to fulfil daily life activities (self-care, work and social activities),¹⁷ and the level of comfort and enjoyment with which these can be achieved, amongst people with RA. This enables individuals to work longer, live independently and enjoy greater overall health and wellbeing. Range of motion (RoM), Pinch grip and overall grip strength are the three hand functions most widely

believed as having the greatest impact on functional ability and QoL.\textsuperscript{18, 19} The improved level of patient engagement with handheld therapeutic exercise devices is the focus of this study. Devices are available to help maintain each of these hand functions and if used correctly and regularly, current devices are ‘functionally effective’: users can gain demonstrable improvements in strength and dexterity.\textsuperscript{20} The problem, however, is that patients tend not to use them. Often referred to as ‘compliance’, ‘adherence’ or ‘concordance’, patient engagement with healthcare recommendations is one of the greatest challenges to the effective treatment of RA.\textsuperscript{21}

The need to improve patient engagement with healthcare recommendations is recognised throughout the medical sciences. According to the World Health Organization: “Adherence to long-term therapy for chronic illnesses in developed countries averages 50%.”\textsuperscript{23} In developing countries the rates of concordance are even lower. The report continues: “Increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments.”\textsuperscript{24} These statements identify that, although effective treatments are available, people do not always engage with them as recommended. The consequences of poor engagement include increased treatment costs, due to treatments being wasted or less effective, and illness having a greater impact. Long-term engagement with therapeutic exercise programs is even more challenging to achieve due to the demands placed on the individual to fulfil treatment recommendations. Exercise is both physically demanding and time


\textsuperscript{21} World Health Organization., \textit{Adherence to long-term therapies: evidence for action}, (2003): 29


\textsuperscript{23} World Health Organization., \textit{Adherence to long-term therapies: evidence for action}, (2003): XIII

\textsuperscript{24} Haynes, R. B., "Interventions for helping patients to follow prescriptions for medications.", \textit{Cochrane Database of Systematic Reviews} (2) CD000011,(2002)
consuming, whereas pharmacological interventions are not. A further challenge, specific to RA, is that interventions are ‘preventative’ as opposed to ‘curative’, this presents further challenges to patients’ motivations to engage.

‘Preventative’ interventions seek to slow or stop the degenerative effects of a condition. They are usually self-monitored and supported with intermittent check-ups with healthcare professionals. By definition therapeutic exercises are challenging and time consuming. They can also be of low perceived benefit to the patient at the time of engagement, as users are required to invest time and energy now in the hope of achieving benefit at some point in the future. It is these additional challenges which provide opportunity for design-led interventions to maximise the potential of healthcare interventions. Ease of use, functionality, interaction experience, desirability and perceived value are all factors which can be designed to affect the ability and willingness of users to interact with them.

‘Curative’ treatment strategies have powerful intrinsic motivations for patients to engage with them - they provide benefits which are recognised over a shorter period of time and an end to symptoms. The key difference between these two interventions is the perceived cost to benefit calculation. Preventative interventions are costly now with only potential benefits whereas curative treatments are costly now with more rapid returns. There is therefore a need to develop preventative interventions which can be used more easily within normal daily life; effectively reducing the cost to benefit ratio between engagement and benefit.

Although not determined by age, RA is thought to be linked to the biology of the ageing process. Over the past 200 years life expectancy in industrialised nations such as the UK has doubled and most nations are experiencing a continuous upward trend in longevity. This creates a situation in which more people are living with long-term age related conditions, such as RA, than ever before. Poor health

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amongst the older population is set to become one of the greatest challenges faced by governments and healthcare providers globally. In April 2012 the WHO selected ‘ageing and life course’ as the focus of their annual World Health Day campaign adopting the slogan "Good health adds life to years".\(^\text{27}\) The initiative identifies the upward trend in the global age demographic and emphasises the need to “promot[e] good health and healthy behaviours at all ages to prevent or delay the development of chronic diseases”.\(^\text{28}\) The need for efficient and effective interventions, which enable individuals to live independently and to continue working, has never been greater.

Dame Carol Black’s 2008 report ‘Working for a Healthier Tomorrow’ (2008) states that annual economic costs of sickness absence and worklessness associated with ill-health are over £100 billion a year.\(^\text{29}\) The report identifies the need for individuals to take responsibility for their own health, whilst also emphasising the need for healthcare services, employers, government and unions to develop new work strategies which focus on supporting the health and wellbeing of the working age population. In order to achieve this goal the report states that “this will require abandoning the idea that it is inappropriate to be at work unless 100% fit and that being at work normally impedes recovery.”\(^\text{30}\) This statement purposefully challenges the perception that illness and disability always compromises the ability to work. It also suggests a need for the built environment to evolve and actively support individuals with particular needs. Furthermore, Black reports there to be growing evidence that work can in fact be good for health by helping to support independence and sense of purpose, and by helping individuals and their families to avoid persistent low income and poverty.\(^\text{31}\)

\(^{27}\) World Health Organization., *Good Health Adds Life to Years: Global Brief for World Health Day 2012.*, (2012):
\(^{28}\) Ibid
RA has a major impact in many areas of individuals’ lives and not just those traditionally considered to be the domain of medical intervention. RA can lead to low self-esteem, social exclusion, isolation, depression and anxiety. If left untreated it can lead to significant physical disability within a few years of disease onset, leaving people unable to work and increasingly dependant on state benefits.\textsuperscript{32} Patients, their friends and families incur the majority of costs associated with the early consequences of RA. Most commonly reported problems are persistent pain and loss of functional ability - attributable to the combined affects of joint pain and swelling, progressive joint damage and less active lifestyle.\textsuperscript{33} People with RA are also more prone to infections than the rest of the population. This is most likely due to abnormalities in the immune system (which cause RA) but may also be contributed to by medications such as immunosuppressant, Disease Modifying Antirheumatic Drugs (DMARDS) or the long-term effects of steroids.\textsuperscript{34} The combination of these factors has a significant affect on general health, personal sense of wellbeing, and overall Quality of Life (QoL) of those affected. Not only does it have a profound impact on those directly affected but also on the economy and society in general.


\textsuperscript{34} National Institute for Health and Clinical Excellence., \textit{Rheumatoid Arthritis: National Clinical Guideline for Management and Treatment in Adults}. (London: Royal College of Physicians, 2009): 4
Motivation

The principal motivation for this study is to make a difference to the long-term health and wellbeing of people who live with RA. This thesis seeks to present an example of design research and practice which is truly beneficial to those affected and which embodies principles of integrity and meaning. Design plays an important role in influencing how we think and what we do. Applying design principles and practices to the needs of healthcare provides new opportunities to achieve positive change to the health and wellbeing of society. Design practices and strategies can be applied to all aspects of the built environment, both virtual and real, creating experiences that enrich our lives and enable us to live the way we do. The application of persuasive design to affect positive behaviour change amongst patients with RA towards improved engagement with therapeutic exercise recommendations, is key to the realisation of this motivation.

Timeliness

In 2000, the first Bone and Joint Decade (BJD) initiative was launched to improve the health related quality of life for people with musculoskeletal disorders throughout the world. The project focuses on conditions recognised for the excessive burden caused to individuals, health systems, and social care systems; those of principal concern include: osteoarthritis, RA, osteoporosis, and lower back pain. Endorsed by both the United Nations (UN) and the WHO the first Bone and Joint Decade aimed to:

1. Raise awareness of the growing burden of musculoskeletal disorders on society
2. Empower patients to participate in their own care
3. Promote cost-effective prevention and treatment
4. Advance understanding of musculoskeletal disorders through research to improve prevention and treatment.\textsuperscript{35}

\textsuperscript{35} Harris ED, Jr, eds.,“The Bone and Joint Decade: a catalyst for progress”, *Arthritis and Rheumatism* (2001): 44
The emphasis on patient empowerment, education and raising awareness outlined in this initiative highlights the need for interventions that communicate with the wider community and enable individuals to manage their condition actively themselves. Understanding human behaviour and developing interventions which affect behaviour change both within the individual, and within the broader community, offers the potential to develop interventions which are not only more effective and well received, but also more efficient. Furthermore, the current drive towards collaborative interdisciplinary research, supported by government funding bodies and research institutions alike, presents new possibilities for innovations which combine expertise from multiple specialisms. The Bone and Joint Decade has now been extended for a further 10 years to 2020, with the “keep people moving” initiative, which seeks to further extend the impact of the aims outlined in 2000. However, despite the extension of the campaign, evidence for the success of the initiative in the UK is limited. The Arthritis and Musculoskeletal Alliance (ARMA) were tasked with coordinating efforts to promote awareness of the BJD throughout the UK. In 2006 the DoH published The Musculoskeletal Services Framework, a document produced by ARMA, which set out to redesign health services to provide better outcomes for people with musculoskeletal conditions. Although receiving government approval the document did not attract additional funding to support its implementation. Progress towards fulfilling these aims has therefore been slow and of limited benefit to patients.

Developments in technology also present new, timely, opportunities for treatment interventions. The emergence of affordable, powerful computer systems which can in effect, be embedded discreetly into everyday lives through ubiquitous technologies, present new possibilities to support patient engagement with healthcare.

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recommendations. The mass market successes of smart phones, tablet devices and other wearable computers, is evidence of growing popularity and availability of computing technologies. Since the 1990s, technologies designed to support issues of disability and ageing have evolved beyond the general concerns of ergonomics and compensatory assistance towards the more specialised and complex issues of supporting the specific physical needs of the individual and the broader concerns of personal ambitions. The field of ‘Gerontechnology’ defined by Bouma (1992) as “the study of technology and aging for the improvement of the daily functioning of the elderly” is one example of a rapidly growing specialist field within technology research which has the potential to deliver targeted health interventions to individuals with specific health needs. The field seeks to develop products which fulfil the complex physical and social needs of the ageing community through commercially viable, well-being focused, interventions.

Theoretical location of the study

In this thesis theoretical elements from design, social psychology and healthcare practices converge. The most relevant and up-to-date information on design and health, persuasive design, clinical and economic factors of RA, and socio-psychological models of behaviour are outlined and critiqued. The study combines the aims of healthcare interventions and patient needs with socio-psychological models of behaviour and design research practice:

Rheumatoid Arthritis

The National Institute for Health and Clinical Excellence (NICE) guidelines for RA, ‘Rheumatoid Arthritis: National Clinical Guideline for Management and Treatment in Adults’, provide detailed guidance as to how available treatments should be used to greatest effect. The guidelines emphasise the need for: communication and education, specialist support from the multi-disciplinary team, pharmacological disease management, ongoing disease monitoring and complementary treatment support, such as diet and exercise. This thesis is concerned with the role design can play in supporting these initiatives. Focusing on psychological and social aspects of RA and its treatments, the study extends our understanding of patient perceptions and beliefs and proposes the development of therapeutic interventions which support users’ socio-psychological needs alongside physical, therapeutic, and pharmacological interventions.
Behaviour change theory

Behaviour change theory is the wider theoretical framework within which this study is located. Developed in reference to the socio-psychological principles of behaviour change, and paying particular attention to health-specific systems, this study develops a new model of behavioural influences specific to the needs of people living with RA. The model presented here considers an ‘ecology’ of interrelated factors which affect both the ability and willingness of individuals to engage with therapeutic exercise interventions. Focusing on the application of behaviour change theory to the development of the built environment, ‘persuasive design’ is an area of design which explicitly seeks to affect the behaviour of users towards predefined goals. Whilst originally concerned with technology, the field of persuasive design is rapidly evolving to include a much broader range of design disciplines. The role of persuasive design within this study is to facilitate new ways of understanding patient needs and to inform the development of interventions which empower users to take control of their own treatment.

Design thinking

By adopting a design thinking approach this study establishes its creative parameters by seeking to understand the complex interrelated factors that define RA, its treatments and its effects on both the individual and society. This will enable design interventions to be developed which are appropriate and sympathetic to requirements and without presupposing particular outcomes. By bringing together the aims of specialist treatment interventions with the strategic influences of behaviour change theory, the study develops a prototype exercise device which demonstrates how the theoretical aspects of this research can be applied to real-world applications.
Audience
This research is intended for use by the following people:
- Design professionals concerned with developing devices for health benefit
- Health professionals concerned with the treatment of RA
- People with RA and their carers
- Patient support groups

Involvement of People with RA
The study has taken care to ensure the views and preferences of people with RA informed the development of all stages of the study. This was achieved by:
- Recruiting an expert patient to inform the development of the study design
- A series of focus group studies with RA patients to gather original primary research data
- The triangulation of results with RA patients, self-selected from the original cohort of research participants

Research Aims and Measures of Success
- The study seeks to develop persuasive design theory which is specific to the needs of people living with RA
- Design outcomes will demonstrate how the theory presented could be applied to produce conceptual prototype designs from which future commercial product outcomes could be derived.
- The study is not concerned with developing products suitable for comparison against those currently available or in quantitatively assessing the efficacy of its recommendations.
- The study focuses specifically on ‘design specific’ aspects of the treatment of RA and does not concern itself with clinical practices and treatment recommendations.
Research Questions

The effects of RA are costly. Not only to the individual but to the family and friends of those affected and to the wider society. A lack of patient engagement with healthcare recommendations adds further strain. This research study seeks to understand more about the nature of patient engagement with healthcare recommendations and to develop new strategies for the development of future interventions. To achieve this, the following key questions have been identified:

RQ 1. What designable factors, specific to people with RA, should be targeted to affect the ability and willingness of patients to engage with longterm therapeutic exercise recommendations?

Within this study ‘designable factors’ are defined as: any component of a physical, psychological or social system which can be affected in a controlled way to achieve a considered and measurable outcome. This definition is therefore not limited to the physical parameters of a designed object, but includes any other environmental or social system identified as relevant and changeable in relation to the study aims. This question will help to focus the implementation of persuasive design interventions to achieve greatest affect.

RQ 2. What specific motivators, present in the daily life activities, should be targeted to facilitate and sustain longterm engagement with therapeutic exercise interventions for people with RA?

This question primarily focuses on factors which contribute to the willingness of an individual to engage with particular behaviours. It seeks to identify specific activities or interests already valued by the research participant that could be adapted to incorporate therapeutic interventions.
RQ 3. Can motivational and designable factors identified within the study be embodied into conceptual prototype devices intended for long-term therapeutic use?

This question explores the validity of the theoretical conclusions presented within this thesis by exploring the potential for physical applications of this research. Produced as conceptual prototypes, two design outcomes will be presented:

1) A photo elicitation patient assessment toolkit.
2) A conceptual prototype design for a therapeutic exercise device designed to extend user engagement.
Chapter 2. Review of the literature

The second chapter presents a critical assessment of the literature covering all of the relevant key areas that are essential to accurately locate and underpin this study. The chapter outlines and critiques the most significant and pertinent historical, social, economic and theoretical research in the following key areas:

**Rheumatoid Arthritis** - This section defines the key features of RA which provide the focus of this research study. Outlining the clinical definition of RA, its impact on those affected and how it is treated, the challenges and complexity of effective treatment interventions are captured.

**Critique of existing devices** - Identifies the devices currently developed for people with physical disabilities affecting the hands. This section distinguishes a difference between ‘assistive’ and ‘therapeutic’ devices and outlines the benefits and limitations of each in their current form.

**Evolution of design for health applications** - The history and evolution of design for wellbeing will be outlined and discussed. Beginning with Zander Therapeutics (1857), this section identifies the most significant and successful design organisations concerned with health and wellbeing including: A&E Design, Ergonomi Gruppen, The Helen Hamlyn Research Centre and Smart Design.

**Evolution of health focused design philosophies** - Design approaches and philosophies relevant to this study will be critiqued including: Universal and Inclusive Design, Human Centred Design (HCD), Healthy Industrial Design (HID), and Co-design.
Persuasive design - Outlines the emergence of healthcare applications developed through persuasive design theory with particular emphasis on technology rich applications including persuasive ‘gerontechnology’, health promotion ‘apps’ and websites, and ‘exergaming’. This section will describe how technology has evolved and become more pervasive due to the prevalence and affordability of new technologies. Ethical considerations relating to the application of behaviour change theory will also be discussed.

Engagement with healthcare recommendations - This section outlines the complex challenges that affect the ability and willingness of patients to engage with treatment recommendations.

Behaviour change theory This section introduces ‘behaviour change theory’ and ‘persuasive design’. This includes a discussion of ‘self-efficacy’ and the 6 most common elements of behaviour change theories, a critique of models specific to healthcare will also be discussed.

Implications for research - provides a summary of knowledge gained as a result of the literature review, maps the context for the fieldwork study, and presents a new persuasive design model that is specific to RA and improving patient engagement through design.
Rheumatoid Arthritis

The following section defines the key features of RA which provide the focus of this research study. It is necessary to describe RA and its treatments in some detail to illustrate the complexity and difficulty of treatment, and the factors which may contribute to poor engagement with healthcare recommendations. This section provides the clinical definition of RA, its impact on those affected and how it is treated.

What is rheumatoid arthritis?

RA is an inflammatory autoimmune condition in which the immune system, which usually fights infection, damages the synovial tissue (specialised tissue responsible for maintaining the nutrition and lubrication of the joint) within the joint lining, leaving it painful and inflamed. Blood flow to the joint increases causing heat and redness and an increase in synovial fluid. This causes swelling and pain due to stretching of pain receptors in the soft tissues around the bone on either side of the joint. These features result in rapid loss of muscle around the affected joint, and this, along with pain and swelling lead to loss of joint function. RA can affect any synovial joint in the body, though is most common in the small joints of the hands, feet and wrists. The loss of muscle tissue in the hand and the resultant impact on functional ability and quality of life are central concerns for this research study.

![Fig 2.1](original in colour) Pathology of Rheumatoid Arthritis, from National Audit Office, Services for People With Rheumatoid Arthritis, (The Stationery Office, 2009): 4

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41 Resnick, B. "Managing arthritis with exercise." *Geriatric Nursing* 22(3) (2001): 144


Patients with established and aggressive forms of RA are likely to experience symptoms in most joints of the body over time. RA usually affects the same joints on both sides of the body presenting a symmetrical distribution of symptoms. Profound fatigue, a feeling of ongoing influenza-like symptoms, fever, sweats and weight loss are also symptoms of RA. Additionally, up to a third of patients experience ‘rheumatoid nodules’ - hard lumps on the backs of elbows and hands.44 The National Audit Office (NAO) in their paper Services for People With Rheumatoid Arthritis (2009) state:

*Rheumatoid arthritis is associated with a range of co-morbidities, including increased risk of cardiovascular disease, infection and osteoporosis. Severe rheumatoid arthritis can also shorten life expectancy by between six and ten years, equivalent to the impact of diabetes, stroke and coronary heart disease. Depression is also common amongst people with the disease.*45

The term ‘flare-up’ is used to describe times when symptoms intensify and become more severe. Flare-ups are unpredictable and can last from a few hours to several days. Symptoms tend to ease throughout the day as joints and muscles are moved but this is not always the case.46 Living with RA is a constant battle to get symptoms under control with the constant threat of uncontrollable flare-ups. The causes of RA are not fully understood. Various factors may be relevant, including environmental factors, infection, trauma and genetic make-up.47 Additional factors thought to increase the risk of developing RA include smoking and obesity.48

**Clinical definition of RA**

Diagnosis of RA is complex. The similarities between RA and other inflammatory disorders makes diagnosis difficult. According to The National Institute for Clinical Excellence (NICE) diagnosis should be determined by a consultant rheumatologist

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45 National Audit Office, *Services for People With Rheumatoid Arthritis*, (The Stationery Office, 2009)


using a combination of clinical observations, laboratory test results and reference to The American College of Rheumatology (ACR) ‘criteria for the classification of rheumatoid arthritis’, (1987). These criteria were designed for medical research purposes to facilitate accurate communication between researchers and to ensure comparability of data produced. Although helpful in the diagnostic process, the criteria were not designed for diagnostic purposes as they cannot differentiate between RA and other auto-inflammatory disorders. Nevertheless, the criteria identify a series of specific factors which must be present before a diagnosis of RA can be considered:

The American College of Rheumatology (ARC) ‘criteria for the classification of rheumatoid arthritis’, (1987)

Patients must have four of the seven criteria:
1. Morning stiffness lasting at least 1 hour*
2. Swelling in three or more joints*
3. Swelling in hand joints*
4. Symmetric joint swelling*
5. Erosions or decalcification on x-ray of hand
6. Rheumatoid nodules
7. Abnormal serum rheumatoid factor.
*Must be present for at least six weeks.

The ACR criteria, whilst not intended for treatment or intervention purposes, can be used to identify some of the basic needs specific to people with RA that interventions should consider. Symptoms of RA are highly changeable: the severity, intensity and duration of symptoms will vary between individuals and within the same individual over time. In 2010 the ACR and the European League Against Rheumatism (EULAR) worked collaboratively to develop a new classification criteria for RA due to the complexity and limitations of the existing system. Despite this development the ACR criteria remain the most commonly used, though this is likely to change over the coming years.


The impact of RA

If left untreated RA will cause widespread pain and joint deformity and joint damage can lead to severe disability affecting all aspects of physical movement from walking to fine movements of the hand. RA, and the treatments used to manage the condition, can cause many secondary health issues such as obesity, osteoporosis and mental health issues.

“...it has become increasingly evident that the ongoing inflammation and loss of mobility can have other unforeseen circumstances for people with RA... Osteoporosis is also more common, due to reduced mobility, inflammation, and sometimes the drugs they are on (particularly steroids). People with RA are more prone to infections than the rest of the population, probably due to abnormalities in the immune system, and sometimes contributed to by medication (such as the immunosuppressant effects of steroids)”.52

RA can also affect other organs in the body and has recently been identified to significantly increase the risk of premature mortality.53 Currently, there is no known cure for RA. The aim of treatment is to manage disease progression and minimise its impact on the individual using disease management strategies. Where no imminent risk factors are identified, the emphasis is on advice, pain relief and rapid

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rehabilitation through self-help, staying active and supportive physical therapies which seek to minimise the need for sickness absence. According to Dame Carrol Black (2008), “Common mental health problems and musculoskeletal disorders are the major causes of sickness absence and worklessness due to ill-health. This is compounded by a lack of appropriate and timely diagnosis and intervention.”

Not only is RA a particularly debilitating musculoskeletal disorder but the consequences of the condition are often associated with common mental health problems, due to its profound impact on everyday life. Recognised by Zander in the mid 1800’s, the cost of poor health among the working age population affects everyone. The Working for a Healthier Tomorrow report reasserts this issue emphasising the consequences for those affected:

- The individual and their families, through the emotional strain, reduction in quality of life and financial hardship.
- The employer, through productivity losses, costs of staff turnover, loss of skills base, downtime, recruitment and re-training.
- The NHS, through the cost of treating sick working age people, from GP consultation through to specialist care, and the additional cost of treating health conditions that keep people out of work.
- The government - through direct costs of treatment and indirect costs of lost taxes and lost productivity.

The long term consequences of RA significantly affect ‘functional capacity’ (also referred to as functional ability): the ability of those affected to perform tasks and activities which are necessary in daily life such as cooking, cleaning, socialising and working. The Work Foundation (2007) estimate that one third of people with RA will have stopped working within two years of symptom onset and they also identify

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that direct costs increase as functional capacity decreases. As people become less physically able they will become more dependent on others, less likely to work and more likely to become dependent on state benefits. *Pinch grip, overall grip strength* and *hand dexterity* are the three hand functions most widely recognised as having the greatest impact on functional ability and quality of life. Grip strength is also recognised as one of the most reliable predictors of functional disability in RA.

Functional capacity and maintaining ability to carry out a range of daily-life activities is therefore the principal driver for the treatment of RA. Both pharmacological and non-pharmacological treatments are used to try to maintain these movements in patients with RA thereby enabling individuals to work longer, live independently and enjoy better quality of life. This clarifies the point at which design thinking can be applied to greatest effect - optimising the efficacy and efficiency of treatment interventions which improve and support the functional capacity of patients.

**Treating rheumatoid arthritis**

As with diagnosis, the treatment of RA is not a simple or straightforward process. NICE (2009) detailed their guidelines for the treatment of RA: ‘*Rheumatoid Arthritis: national clinical guideline for management and treatment in adults.*’ The guidelines state that “Appropriate management...needs to address not only the impact on

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joints, but also focus on the whole body, the person suffering from the disease, their families and carers, and where appropriate their employers." Currently the treatment of RA is based on a ‘biopsychosocial philosophy’ in which, biological, psychological and social factors are targeted independently based on individual needs.  

- **Biological factors** primarily concern those outlined in the ACR classification criteria (above) and pharmacological (drug) treatments. Joint damage, muscle atrophy and pain are also within the biological domain. Design developments, whilst not concerned with the clinical aspects of RA, should consider biological factors to avoid causing additional damage and support biological treatments where possible.

- **Psychological factors** are principally concerned with the effect of RA on the individuals emotional state. Many patients struggle to come to terms with diagnoses of long term illness - especially when the effects on daily life are profound, as with RA. Psychological well-being is also strongly associated with willingness to engage with education programs and treatment recommendations. This is a significant issue for design development, designed objects intended for daily use must consider their impact on users and, if possible, actively seek to encourage and support users to engage with treatment recommendations.

- **Social factors** are also usually linked to the effects of RA, which can cause fewer choices in leisure activities (usually due to pain and fatigue), leading to low self-esteem and poorer psychological well being. As with psychological issues, social

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61 Luqmani et al. "British Society for Rheumatology and British Health Professionals in Rheumatology guideline for the management of rheumatoid arthritis (the first two years)." *Rheumatology* 45(9): 1167 (2006): 8


63 Luqmani et al. "British Society for Rheumatology and British Health Professionals in Rheumatology guideline for the management of rheumatoid arthritis (the first two years)." *Rheumatology* 45(9): 1167 (2006): 5

64 Luqmani et al. "British Society for Rheumatology and British Health Professionals in Rheumatology guideline for the management of rheumatoid arthritis (the first two years)." *Rheumatology* 45(9): 1167 (2006): 12
factors can provide an opportunity for design to enhance social engagement and promote self-esteem.

**Condition management** The biopsychosocial model is used as part of a condition management strategy for the treatment of RA. Condition management strategies differ from curative strategies because their aim is to slow or stop the degenerative affects of incurable conditions, as opposed to permanently resolving or curing a health issue. This presents significant additional challenges to the patient: treatment is ongoing, progress may be very slow and full recovery may never be achieved. This can have a profound effect on the ability and willingness of patients to engage with long-term healthcare recommendations, especially if those interventions have little or no perceived benefit. Condition management strategies are also expensive and complex to manage effectively. Multidisciplinary teams provide support for pain management, guidance on coping with the disease and encouraging positive attitudes towards self-management and adjustment to the diagnosis of RA. Teams are usually comprised of: consultant rheumatologists, physiotherapists, occupational therapists, psychologists and podiatrists.

The effects of RA vary significantly between individuals and within the same individual over time, as RA is heterogeneous in nature. This makes treatment particularly difficult and expensive for healthcare teams. Furthermore there are a wide range of treatments available ranging from anti-inflammatory and disease-modifying drugs to non-pharmacological therapeutic exercise treatments. The efficacy and side-effects of available treatments vary between individuals and modern drugs, although effective, are expensive. This diversity in available treatments presents its own challenges, both for identifying the most appropriate treatment for each patient individually and, for managing cost. NICE state “...the choice brings with it difficult questions concerning the best sequencing of therapy.” Treatment strategies need to be personalised, adaptable and cost effective. Successful disease management will

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65 Luqmani et al. "British Society for Rheumatology and British Health Professionals in Rheumatology guideline for the management of rheumatoid arthritis (the first two years)." *Rheumatology* 45(9): 1167 (2006): 3

hold RA in remission and enable those affected to enjoy better health. The elements of treatment within the multidisciplinary approach are as follows:

**Drug treatments** Rheumatologists often use a combination of drug and therapeutic exercise treatments to try and slow disease progression and reduce its impact on the daily lives of those affected. Drug treatments have two main aims i) to relieve symptoms, ii) to slow or stop disease activity. Pain killers are used to relieve symptoms - reduce swelling and manage pain. Disease modifying anti-rheumatic drugs (DMARDs) are used to modify the disease process to slow or stop the degenerative effects of the condition\(^67\). Consultants work with patients to identify the most suitable drug treatment for individual needs - balancing benefits with side-effects. Disease modifying drug treatments can be toxic and can cause significant side effects.

**Therapeutic exercise therapies** NICE emphasises the importance of non-pharmacological management of RA. The NICE recommendations stress the importance of therapeutic interventions such as physiotherapy and occupational therapy, and emphasise the role of multidisciplinary teams in facilitating effective care.\(^68\) Alongside drug treatments, patients with RA are encouraged to exercise regularly to maintain functional ability, rebuild muscle tissue and reduce pain and stiffness in the affected joints. A number of treatments are available depending on individual needs, personal preference and availability.

Treatments usually focus on: developing dexterity/range of movement (RoM), muscle strengthening and aerobic/stamina exercises. Generally, these activities are supervised by occupational therapists (OT) and physiotherapists (PT), and supported by patient education programs. Multiple studies identify that exercise therapies can help to: prevent 'muscle atrophy' (deconditioning of the muscle), keep the joints


stable, improve joint function and flexibility, decrease pain, enhance aerobic fitness, improve balance, and decrease the risk of falls.69 70 71

**Occupational therapy** The aim of occupational therapy is to facilitate adjustments to lifestyle and to prevent function loss and to help patients to deal with the challenges of daily living tasks caused by RA.72 OTs work with patients to help facilitate successful adjustments in lifestyle and try to prevent loss of function. If involved early enough after diagnosis, OT’s can help patients regain grip strength and hand function through educational workshops and specialist advice targeting individual patient needs.73

**Physiotherapy** As with Occupational Therapy the aim of Physiotherapy is to maintain or improve physical functioning, with particular emphasis on mobility. The British Society for Rheumatology (BSR) state “Most efforts should be directed at activities of daily living with particular attention to help in the workplace or significant leisure activities. Therapy is believed to complement and enhance the contribution of pharmacological agents to improve and maintain physical functioning.”74

**Psychological treatments** As identified earlier, psycho-social aspects of RA are of critical importance to the success of treatment interventions. A diagnosis of RA can be devastating. According to NICE, studies have shown that pain; lack of control over pain; and dissatisfaction with abilities are all affected by psychological wellbeing, self-esteem and adjustment to the disease75. Furthermore, high levels of anxiety and

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69 Luqmani, R. et al. "British Society for Rheumatology and British Health Professionals in Rheumatology guideline for the management of rheumatoid arthritis (the first two years)." *Rheumatology* 45(9): (2006): 1167


72 Luqmani, R. et al. "British Society for Rheumatology and British Health Professionals in Rheumatology guideline for the management of rheumatoid arthritis (the first two years)." *Rheumatology* 45(9): (2006): 8

73 Mathieu, R. "Early occupational therapy programme increases hand grip strength at 3 months: results from a randomised, blind, controlled study in early rheumatoid arthritis." *Annals of the rheumatic diseases* 68(3) (2009): 400

74 Luqmani, R. et al. "British Society for Rheumatology and British Health Professionals in Rheumatology guideline for the management of rheumatoid arthritis (the first two years)." *Rheumatology* 45(9): (2006): 2

depression were associated with fatigue, pain and poor engagement with treatment recommendations. Additionally, patients who experienced more fatigue were more at risk of pain, were less physically able, felt more depressed, had lower self-esteem, and were less satisfied with the support provided to them. They also showed more reduction in leisure activities, felt less independent and adjusted, and appraised their health as markedly poorer.\textsuperscript{76} This evidence highlights a self perpetuating cycle of poor state of mind, leading to learned non-use, causing a worsening of symptoms and increasingly negative outlook. Psychological interventions including anti-depressants and counselling are therefore an important aspect of the treatment needed to help people adjust to living with their condition.

**Patient assessment measures** A further challenge to achieving effective treatment interventions is the accurate and reliable identification of patient needs. When assessing patients, OTs and PTs use a wide range of standardised questionnaires to assess the level of disability experienced by an individual. Of these, only two offer detailed assessments of daily life activities specifically for people living with inflammatory joint disorders. These are: the Stanford Health Assessment Questionnaire (HAQ) and the Swedish Evaluation of Daily Activities Questionnaire (S-EDAQ). The S-EDAQ is currently being developed into a UK specific assessment (UK-EDAQ). Each system defines a number of broad overarching categories and multiple sub-sections specifying particular activities: HAQ identifies 8 categories with 20 specific actions, the S-EDAQ identifies 11 categories and 102 specific actions.

Each of these questionnaires offers a range of pre-defined criteria for patients to rate themselves against. Standardised questionnaires, however, have a major inherent limitation: they are only capable of identifying issues already recognised; anything not pre-defined within the parameters of the questionnaire is lost. This limitation compromises patient empowerment in a number of ways: Firstly, as previously outlined, the parameters of need are pre-defined, thus maintaining the healthcare provider as the expert defining the ‘solution’; Secondly, each of these assessment methods only seeks to identify the problems experienced by patient. No investigation is made into where treatment interventions may be most appropriately targeted.

Interventions should be developed in relation to key personal and social contexts, regardless of where the greatest problems are experienced.

Whilst existing assessment strategies may be an effective means to gather quantitative data relating to pre-defined parameters, more needs to be done to empower patients to identify problems for themselves and to identify where and when interventions may be most appropriately and conveniently incorporated into their own lifestyle and routines. The patients own forward projection of themselves is inherently denied in this model, the patient is ‘retro-fitted’ to the pre-defined parameters of the questionnaire used.

**Summary of key points**

RA is a inflammatory autoimmune disorder which causes pain, fatigue and flu-like symptoms. There is no cure, and it is often associated with secondary conditions such as osteoarthritis and osteoporosis; RA can also be associated with obesity, due to lack of exercise, and common mental health issues such as anxiety and depression. Inability to work and reduced quality of life are two of the most damaging consequences of RA. Treatments are expensive and complicated requiring individual strategies to be developed and tailored to individual needs. Exercise therapies can provide demonstrable benefits to the health and wellbeing of patients, including pain relief, maintained mobility and flexibility, and can improve an individuals’ perception of their own health. Maintaining hand function is of principal concern.

To be effective, treatment interventions need to be co-ordinated between specialists and exploit the benefits that each intervention has to offer. Particular challenges presented by current interventions include: the difficulty of communication between specialists, the time and costs of ongoing monitoring and the development of optimal treatment strategies. A further challenge presented by the diversity and complexity of available treatments is the potential confusion to the patient and perceived disparity between individual cases. Patient assessment measures also present a further opportunity for development. Existing measures focus on the level of disability experienced by the patient but none seek to identify opportunities for interventions to be strategically targeted. An understanding of personal and social contexts such as personal interests, professional responsibilities and personal motivations, for
example, would help healthcare providers to integrate treatment recommendations with existing interests and motivations. This approach could be considered a ‘future-casting’ strategy - in which healthcare teams work with the patient to define a future for themselves which is tuned to their own needs and perceptions.

Opportunities for design intervention include: supporting communication between members of the multidisciplinary team; developing new systems to support the monitoring of disease progression over time; and facilitating therapeutic exercise that takes into account personal and social contexts. Before exploring these ideas further it is necessary to further understand the nature of patient engagement with therapeutic exercise interventions.

- Therapeutic exercise movements need to be understood and supported, achieving appropriate levels of simplicity whilst also achieving health benefit is of critical importance.
- Existing assessment tools are limited in their ability to capture patient needs and are not able to identify opportunities for how interventions could be integrated into the existing lifestyle and routines of the individual.
- Improving patient engagement with long-term treatments will improve the health, wellbeing and quality of life of people living with RA. It could also potentially bring huge financial benefits to the cost of RA management.
- Understanding behavioural factors which contribute to engagement is necessary to refine and prioritise design parameters for therapeutic interventions.

Therapists use a wide range of devices to help patients to manage their condition on a daily basis and to overcome some of the additional challenges that physical disabilities bring. The following section will outline and critique the most common devices used and identify opportunities for where further developments should be targeted.
Critique of existing devices

There are an increasing number of devices available for people with RA to assist with daily living and to support healthy movement. However, not all are effective and not all provide therapeutic health benefits. Available equipment can be broadly split into two categories ‘assistive’ and ‘therapeutic’:

**Assistive devices** support people within normal daily life by helping to relieve some of the burden of everyday tasks and activities. A walking stick or a wrist splint can help users to be more mobile and active, for example. The benefits of assistive devices often divide opinion amongst users. For some, they are popular because they have *intrinsic* motivational benefits - they are enabling in *real time*, they simplify daily tasks and often save energy and time. For others, the design of such devices or the fact they are considered ‘specialist equipment’ can be enough to deter regular use. Disease severity and higher levels of disability are significant determinants for user engagement with assistive equipment.77 These devices embody the principles of Inclusive and Universal Design (described in detail in ‘Evolution of health focussed design philosophies’ section). For many, the specialist nature of these devices have come to define a ‘design language of illness’ - they are largely distinguished from mainstream design due to their emphasis on functionality and lack of aesthetic design sensitivity. Attempts have been made to develop assistive devices which are more ‘desirable’ to the user (see fig 2); Silver Ring Splints (SRS), for example, were first developed in 198578 and supportive wrist splints are now available in a variety of colours, such developments, however, are limited. The speciality nature of assistive equipments means they are often expensive. They are also issued by the *prescriber* rather than *selected* by the user which negates the opportunity for personal preference.

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For those who have chosen to adopt assistive devices, or for whom there is no choice, the equipment becomes an invaluable asset which facilitate access to activities which could not be achieved by any other means. There are, however, a number of limitations. Without seeking to undermine the value of such devices for those benefit from them, it is important to recognise their limitations and to be aware of when such equipment can lead to negative effects.

Assistive devices help to address some of the problems experienced as a result of functional loss but they do not address the underlying problems. In some cases, long-term use can contribute to worsening functional ability. The pain and swelling of RA, for example, can cause muscle atrophy and reduced joint mobility. To overcome this, patients need to remain active and to rebuild joint strength and dexterity during times when disease activity is under control. Assistive devices limit the range and complexity of movements required to complete a task, therefore reducing the physical benefit of engaging with that action. They relieve the need for users to develop their functional ability. This can lead people to become more dependent and less able, and exposed to increased risk of further physical problems in the future. When not used appropriately, some assistive equipment can become a further catalyst, speeding-up the negative effects caused by the condition itself. In this instance it can be concluded that we are in effect designing our own future health problems through the unintended consequences of a failure to understand a bigger picture.
Therapeutic devices are specifically designed to promote exercise and physical mobility, through, for example, building strength and promoting flexibility, thus relieving dependency on assistive interventions. Many currently available therapeutic exercise devices, usually recommended by Occupational Therapists (OT) or Physio Therapists (PT), have proven to be functionally effective. When practised correctly, regular hand exercise can increase hand function and provide demonstrable benefits to hand strength, dexterity and the range of movements in patients with RA without causing additional pain or damage. There is general agreement that patients with RA should rest during an ‘acute flare’ period, during which disease activity increases causing swelling and discomfort, and that exercises should avoid unnecessary injury risks, such as racquet and other high-impact sports. Although there is agreement that therapeutic exercise is beneficial for people with RA but the optimal type, frequency, duration and intensity of exercise therapies are not fully understood.

In 2007, the National Institute of Health Research, Health Technology Assessment (NIHR HTA) programme commissioned a large-scale trial to investigate the clinical and cost-effectiveness of an exercise programme for the management of RA in the hand. The project, titled Strengthening and Stretching for Rheumatoid Arthritis of the Hand (SARAH), which is currently ongoing, aims to provide comprehensive guidelines for exercise therapies which target the rheumatoid hand. Whatever the outcome of this study, improving patient engagement with recommendations is unquestionably important. Currently available specialist devices which are commonly used include: Hand Therapy Exercise Putty, Hand Therapy Balls

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and the Xtensor hand exerciser (see fig 2.2 and 2.3). Cheaper, occupationally focused interventions include soft tennis balls and kitchen sponges.

![Fig 2.5](http://www.orthocare.com.au/files/2009_05_12_17_09_02__5_theraputty_lg.jpg)

**Fig 2.5** (original in colour) Hand putty offered to people with RA to support therapeutic exercise provided by the NHS. Accessed December 2012 from http://www.orthocare.com.au/files/2009_05_12_17_09_02__5_theraputty_lg.jpg

![Fig 2.6](http://www.elitehealthcareltd.co.uk/media/catalog/product/cache/1/small_image/135x/9df78eab33525d08d6e5fb8d27136e95/e/g/eggsercizer.jpg)

**Fig 2.6** (original in colour) Hand exercise devices **Left:** “Eggsercizer”, accessed December 2012 from http://www.elitehealthcareltd.co.uk/media/catalog/product/cache/1/small_image/135x/9df78eab33525d08d6e5fb8d27136e95/e/g/eggsercizer.jpg. **Right:** “Xtensor”, accessed December 2012 from http://www.ohgizmo.com/wp-content/uploads/2009/03/xtensor.jpg

Each of these devices works by providing resistance. The user practices a series of exercises - working against the resistance provided - to build muscle strength and dexterity. Therapists make recommendations based on the movements, frequency and intensity of exercise that will be of greatest benefit to the individual. The problem, however, is that patients tend not to use them. Data identifying patient engagement with exercise therapies specific to people with RA is not currently available. However, it is has been reported that non-adherence amongst some patient groups, receiving
exercise regimens as part of physical therapy, could be as high as 70%.

This lack of engagement is reportedly due to fatigue, fear of injury, pain, or a patients’ own beliefs. These devices are also highly obtrusive, offer little or no feedback to the user and do not support any other activity. For a user to engage with any one of these devices, they must take time away from doing anything else.

There is consensus amongst healthcare professionals that long-term engagement with healthcare recommendations must be improved. The most effective forms of therapeutic intervention are achieved through supervised exercise sessions either as one-to-one tutoring or group activity. Home-based programmes appear to be less successful due to lack of engagement or ‘concordance’, suggesting that engagement is partly influenced by social connectedness: through peer support, shared responsibility, or increased enjoyment. There is, therefore, a need to develop therapeutic exercise devices which are both effective and engaging for long-term use. To be effective, therapeutic exercise interventions must incorporate an optimum balance of therapeutic benefit, usability and personal and social meaning.

Oversimplifying therapeutic exercise interventions could reduce the benefit of such activities to the point of insignificance. The design of such devices is therefore necessarily driven by their functionality. However, therapeutic exercises are, by definition, physically challenging and often time-consuming. They can also be of low perceived benefit to the user at the time of engagement. It is these additional challenges which define the current problems with existing equipment: the perceived efficacy of the intervention, the ability of users to complete the exercises required, the

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90 Luqmani, R., S. Hennell, et al., "British Society for Rheumatology and British Health Professionals in Rheumatology guideline for the management of rheumatoid arthritis (the first two years)." *Rheumatology* 45(9) (2006): 1167


willingness of users to engage, and the motivation to continue with exercise therapies for the duration of their RA (from the point of diagnosis). Design offers the potential to develop new interventions which maximise the effectiveness and efficiency of healthcare interventions. Utilising concepts of: ‘behaviour change’, ‘persuasive design’, ‘perceived value’, ‘simplicity’, ‘desirability’, ‘ease of use’ and ‘functionality’, design can affect the ability and willingness of users to interact with therapeutic exercise devices. The following sections will explore each of these ideas further, beginning with a review of the evolution of therapeutic and health-aware design from the 1850s to the present day.

**Evolution of design for health applications**

This section outlines the evolution of design for wellbeing. Beginning with Zander Therapeutics, selected companies and initiatives will be outlined and discussed with particular emphasis on their approach to design and health. Significant points identified during the review will be summarised at the end of the section and features relevant to the development of this thesis will be highlighted as bullet points.

**Zander therapeutics**

Although not well known today, Dr. Jonas Gustav Vilhelm Zander (1835-1920),\(^\text{93}\) gained worldwide recognition for his contribution to therapeutic exercise therapies in the late 19th and early 20th centuries. It is claimed by Dr Zander that he was the first person to develop therapeutic exercise devices specifically designed to improve physical health of the user, in a measured fashion, with a range of devices collectively able to facilitate whole body exercise.\(^\text{94}\)

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Facilitated by technological developments, Dr Gustaf Zander, a licentiate of medicine (licensed medical professional), developed what he called his ‘medicomechanical gadgetry’ as a means to advance the already popular practice of ‘medico-gymnastic therapies’. These therapies were structured, specialised, physical exercises, based on the principles of Swedish remedial gymnastics, conducted under the supervision of a qualified therapist to improve specific ailments and benefit overall health and well-being. In 1857 Zander set out to develop his first gadgets, setting himself the following question to answer:

If mechanical apparatus could be invented which compelled the activity of a certain group of muscles to set it in motion, and if it were possible to furnish this apparatus with a balance-weight which could be increased and diminished at will, in conformity with the laws according to which the muscular strength works, the problem might be considered solved, and an agent would be obtained which not only substituted the gymnast, but would also be able to triumph over difficulties against which he struggled in vain.95

Within this aim Zander identifies that mechanical devices can be used to extend the benefit of medico-gymnastics. He proposes that developing equipment capable of targeting specific physical movements and incorporating resistances tailored to individual needs might fulfil the specific purpose of improving strength, dexterity and healthy movement within the targeted area. He identifies that this method could be used to treat specific clinical conditions such as heart disease, obesity and chronic rheumatism.96

In the early stages of development Zander worked with a blacksmith, a carpenter and a physician to design and produce his exercise equipment; applying his own passion, motivation and mechanical ingenuity to facilitate and guide development. In January 1865, Zander opened his first Medico-Mechanical Institute, furnished with 27 specialised exercise apparatus, in Stockholm, Sweden.97 Perhaps a little ahead of his time, Zander’s inventions were initially met with suspicion and rejected by some


simply because of their use of mechanics to facilitate bodily exercise. Dr Alfred Levertin, former assistant to Zander, states: “This man of genius with his serious intentions and vast medical knowledge was exposed to odious attacks and placed in the same category as notorious quacks by persons who knew neither him nor his apparatus”.98 Over time Zander Therapeutics became very successful and highly regarded throughout the medical profession. Zander went on to develop 37 specialised machines divided into four overarching categories: apparatus for active exercise, for passive exercise, apparatus for mechanical action and specialised orthopaedic apparatus. In 1877 he was awarded an Honorary Doctorate at the University of Uppsala for his trunk-measuring device - developed primarily for the diagnosis and treatment of scoliosis.

http://25.media.tumblr.com/tumblr_ltzq6ng3Jq1qlts9lo1_1280.jpg

Throughout his carrier Zander identified a number of factors significant to the development of therapeutic exercise devices, many of which are still relevant today.

For example, when describing the correct use of levers within mechanical apparatus
Zander states that resistance must be applied “in the strictest accordance with the
physiological and mechanical laws for the action of the muscle”, and that treatments
must be applied “in the most perfect manner”, meaning by this the importance of
tailoring physical exercise around the physical measurements and strengths of
individual people. Levertin identifies the following advantages of the mechanical
gymnastic method:

1. During movement the resistance adapts itself exactly to the natural change
   in the effect of the muscular power.
2. The intensity of the movement is weighed, as in scales, and its exact
degree can be measured.
3. The gradual increase of strength in the movement, so necessary for
   muscular development, can be accurately made and to any degree desired.
4. The resistance indicated by a given number is always the same and
   therefore any necessary regulation of strength of the movement, whether
   increase or decrease, can be made easily and with precision.99

The need for therapeutic interventions to target the specific needs of the individual
remain paramount in modern therapeutics. Indeed, many of the movements
identified in fig 6 can be recognised within modern exercise equipment. The
sensitivity and adaptability of the Zander equipment are arguably the key features
that define his innovation and which account for the popularity that defines the
success of these products.

Zander’s understanding of exercise and therapeutics was not limited to the
mechanics of motion or the benefits of exercise to the body, he was also acutely
aware of the greatest challenges to the success of therapeutic interventions: user
engagement. He stated that generally, people have a preference for ease and that
this alone can be enough to prevent people from engaging with exercise. The
following passage illustrates Zander’s belief in the value of exercise and his
recognition of our tendency to avoid it:

Regular and complex bodily exercise is a necessity the satisfying of which
rewards us by a sensation of well-being, by enjoyment of life and by increase
of mental and physical strength. The neglect of this requirement causes in us,

99 Gustaf Zander and Alfred Levertin., G. Zander’s Medico-Mechanical Gymnastics: Its Method, Importance, and
a feeling of weakness and weariness, depression, and a series of ailments and sufferings which infuse bitterness into our lives, weaken our energy and in manifold ways limit our capacity for work and enjoyment. The need of exercise does not indeed present itself with the same urgency and imperiousness as many others, or, in other words, a man enjoying good health may neglect exercise some time, before the inconvenience makes itself felt. This circumstance offers a welcome pretext for indifference and love of ease; not feeling ill, why this unnecessary trouble?100

Furthermore, this statement identifies the contrast between remedy and prevention. Why invest time and energy into something which offers no perceptible benefit at the point of engagement? In Zander’s Medico-Mechanical Gymnastics: Its Method, Importance, and Application (1893), fatigue, ageing, and poor communication between patient and physician are all identified as specific determinants for lack of engagement.


The timely emergence of medico-mechanical gadgetry is also significant. This engineered approach to exercise evolved shortly after the Industrial Revolution, at a
time when the profound social, economic, and cultural impact of this change were becoming increasingly evident. Zander was aware of the threat that new excesses such as an abundance of food, alcohol and cigarettes and the shift towards knowledge-based economies, facilitated by wealth and growing global influence, had on the health and wellbeing of the educated workforce, leading to lifestyles which were increasingly sedentary and excessively luxurious:

“...merchants, teachers and men of learning who lead a sedentary life, who are chiefly engaged in mental work, who neither will nor can satisfy the want of complex bodily exercise, we cannot understand this indifference, all the more as we know that this excessive mental work is frequently combined with a sensual, effeminate mode of life.” 101 [referring to long work days followed by social events, late nights, dinner parties and smoking]

Paradoxically, there was also a growing recognition within the mass population of the social and economic value of work, and that these factors became significant motivators to maintain health and wellbeing and to engage with therapeutic exercise regimen. Zander specifically identifies the impact of poor health on: the ageing process, susceptibility to illness and muscle atrophy, ability to work and provide for others and the potential to enjoy good quality of life:

We have often seen in our patients that the feeling of incapacity to provide for the wants of their families and of depression at the sight of the gradual decline of their economical circumstances, gave room to a feeling of assurance and gratitude at the return of their strength and ability to work.102

Zander Therapeutics enjoyed worldwide success in the early 20th Century. In 1911 there were 202 Zander’s Institutes globally. This was the peak of Zander’s success and fame.103 However, the onset of the First World War changed the fundamental role and fortune of his institutes. They became rehabilitation centres for wounded soldiers, losing their original elegance 104 and, perhaps, some of their original ideals.

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The centres were no longer able to focus on preventative interventions and maximising the health of the general population. Instead their focus became rehabilitation and dealing with the tragic, human costs of war. Following the paradigm shift from therapeutics to rehabilitation the majority of institutes are reported to have been later ruined by the Great Depression in 1929.\footnote{J. Fischinger, A. Fischinger, and D. Fischinger. “Doctor Zander’s Medico-Mechanical Institute in Opatija.” *Acta medico-historica adriatica: AMHA* 7, no. 2 (2009): 263}

Recognising the significant contributions made by Zander to the field of therapeutics which include: the development of devices designed to facilitate exercise, the need for tailored interventions for individual therapeutic needs, the benefit of exercise on overall health and wellbeing and the need to target patient behaviour to encourage long-term use; what significant developments have taken place since, to further improve therapeutic exercise interventions? What advancements in design have taken place to incorporate these values into everyday life? and what effect have these insights had on the development of devices designed for specific therapeutic applications? The following sections will outline and critique some of the most significant recent and contemporary design and health focussed organisations and practices as they evolved chronologically. Design philosophies concerned with health and wellbeing will then be discussed.

**ICSID**

The International Council of Societies of Industrial Design (ICSID) was officially founded in London on June 29th, 1957.\footnote{“ICSID History.” International Council of Societies of Industrial Design - Partner of the International Design Alliance, accessed November, 2012, http://www.icsid.org/about/about/articles33.htm.} Its aim was to protect the interests of practising designers and to ensure global standards of design. The first ICSID Congress and General Assembly was held in Stockholm Sweden in September of 1959, it was attended by representatives from 23 societies from 17 countries. In 1963, ICSID was granted special consultative status with the United Nations Educational, Scientific and Cultural Organisation (UNESCO), a non-government organisation which encourages international peace and universal respect by promoting collaboration among nations, a collaboration which prioritised “design for


the betterment of the human condition.”\textsuperscript{107} Shortly after this, in the late 1960s, design firm A&E Design (1968) adopted a health focused design agenda.

\textbf{A&E Design}

One of the greatest successes evident in the reported sales of A&E Design was their ability to design products which fulfilled specific health or disability needs whilst also achieving wider popularity in commercial markets. Their products became popular in the mass markets of mainstream industrial design. Founded by Tom Ahlström and Hans Ehrich and still operating as a successful design agency in Sweden, the A&E Design focus is on “designing useful every day products, rather than concentrating on short-lived fashion trends.”\textsuperscript{108} Working primarily in plastics, A&E have produced some exceptionally successful products, such as the Jordan dishwashing brush (1975), which has reportedly sold more than sixty-five million items\textsuperscript{109} and the Vitemölla folding chair, which is used in over 1000 museums globally. Their instruments for hospitals, designed and developed for physical aid manufacturer RFSU-Rehab, attracted wide acclaim:

The extension handle (fig 2.7) for people with difficulty in grasping objects, especially rheumatic patients, is thick enough to give a firm hold but has been made hollow for lightness. It can be positioned at various angles by a simple manoeuvre. \textit{RFSU-Rehab (1977)}\textsuperscript{110}

\begin{footnotesize}


\textsuperscript{110} The Swedish Institute, \textit{Design in Sweden}, Edited by Monica Boman. (Stockholm: Swedish Institute, 1985):
\end{footnotesize}
One of the defining features of the A&E approach was the ‘simplicity’ and ‘honesty’ of their designs. This ‘no frills’ approach combined with exceptional manufacturing quality earned the company a glowing reputation. A&E continue to design, develop and prototype products for a range of industries, including medical devices, sanitary wear and design for disability.\textsuperscript{111} Despite the commercial success of A&E their products are primarily concerned with providing compensatory support for lack of physical ability. Their products do not seek to actively promote exercise and wellness or provide therapeutic support.

**Ergonomi Design Gruppen**

The Ergonomi Design Gruppen, rebranded as “Veryday” in November 2012,\textsuperscript{112} was founded by Maria Benktzon and Sven-Eric Juhlins in 1969. The group was originally comprised of 14 individuals who specialised in hospital equipment, working environments and aids for people with specific physical disabilities.\textsuperscript{113} Throughout the 1970s and 80s the Ergonomi Group developed many of their products through large scale interdisciplinary research projects, combining expertise from end users,
manufacturers and specialist experts to develop products “based on true user needs and abilities, not purely on aesthetics”. Often funded by regional and national authorities, research and development projects accounted for almost half their business in the early 1980s. The group often used film and photography as a means to record and assess user needs. Staff are reported to spend the majority of their time studying people: talking to them, assessing their needs and identifying opportunities for design interventions. Design, as they see it, involves a combination of functional, technical, economic, environmental, aesthetic and cultural requirements.

Fig 2.9 identifies a selection of the most successful products designed by Ergonomi Design Gruppen during the early 1980s. Many products were developed for RFSU-rehab (now part of Etac a home health product developer and distributor):

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115 The Swedish Institute, Design in Sweden, Edited by Monica Boman (Stockholm: Swedish Institute, 1985): 113
Many of these products are still manufactured and distributed today by Etac, the company who commissioned the designs in the late 1970s and early 1980s. This fact is testament to the effectiveness of the original design. However, whilst praised for their ingenuity, functionality and attractiveness in the late 20th Century, these products (along with many others) have, for those who use them, come to symbolise the hugely unpopular ‘special devices’ designed for people with specific needs. These products may still be functionally effective but the features which defined the original success, their modernity, personal and social appeal, and their cultural awareness, are now lost.

The Ergonomi Group were early pioneers of the ‘human-centred’ approach to design. The most recent iteration of their design philosophy ‘Ergonomics³’, extends the traditional definition of ‘Ergonomics’ to include the physical, cognitive and emotional needs of users. Their website explains how their approach seeks to engage users through functional effectiveness, intuitive use and emotional relevance to the end product.¹¹⁶

Derived from the Greek ‘ergon’ (work) and ‘nomos’ (laws) to denote the science of work, ‘ergonomics’ is defined by the International Ergonomics Association (IEA) as:

Ergonomics (or human factors) is the scientific discipline concerned with the understanding of the interactions among humans and other elements of a system, and the profession that applies theoretical principles, data and methods to design in order to optimize human well being and overall system.¹¹⁷

One of the most notable successes of both the Ergonomi group and A&E design, was their ability to design objects which not only satisfy particular health needs but which also attract broad commercial appeal. Their products were available in mainstream stores and their functional superiority made them equally appealing to


those with specific health needs and those simply looking for ‘good’ products. However, despite the Ergonomi design group seeking to develop innovations which actively promote health and wellbeing, they also give priority to assistance, ease and maximised accessibility.

**Royal College of Art**

Whilst much of the early development of design for health benefit can be traced back to Sweden, the Royal College of Art was one of the earliest adopters of health focussed design in the UK. In 1959 Sir Misha Black, one of the co-founders of ICSID, was appointed as the first Professor of Industrial Design at the RCA.\(^{118}\) Black had played an instrumental role in establishing the formal links between ICSID and UNESCO \(^{119}\) which led to the “design for the betterment of the human condition” agenda. As an area of design interest identified by ICSID, research into design for health and wellbeing continued to evolve at the RCA and in 1999 the Helen Hamlyn Centre for Design (HHC) was established under the guidance of Roger Coleman and Jeremy Myerson.\(^{120}\) The aim of the centre, which rapidly established itself as a world leading centre for the advancement of design thinking and issues of human wellbeing, is to explore the role of design as a catalyst for social and demographic change.\(^{121}\) Particular areas of interest include working life, design for ageing and inclusive design. The progression of design research exploring human factors has led to the development of many health focussed design agencies and consultancies. Smart Design, for example, have developed some of the most recognisable and successful products which cater for the needs of people with limited functional abilities.

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\(^{119}\) Vladimir Heroik, “Letter from UNESCO, ref ODG/RIO/ A 264”, 14 September 1960, ICSID archive, University of Brighton Design Archives 10/76.

\(^{120}\) “History”, Helen Hamlyn Centre for Design, accessed December 2012, http://www.hhc.rca.ac.uk/199/all/1/history.aspx

Smart Design

Smart Design, is a design consultancy with offices in New York, San Francisco and Barcelona\(^{122}\), they have become leaders in the field of design for health and wellbeing. Established in 1980 by Davin Stowell, Tom Dair, and Dan Formosa,\(^{123}\) Smart have been longterm advocates of the ‘Universal Design’ philosophy, which seeks to maximise user accessibility (discussed further in ‘Evolution of Health Focussed Design Philosophies’ section below), developing a wide range of products and services which seek to embody the needs and desires of users. The company develop products under humanistic themes such as: ‘Responsible Design’, ‘Humanizing Technology’, ‘Improving Health' and 'Considering Age'. One notable example of their work is the award winning ‘OXO - Good Grips®’ range of products.

These award winning and hugely popular products embody many of the design principles defined by the Ergonomi Design Gruppen. They were originally conceived in 1989 by OXO International founder Sam Farber to support his wife who had arthritis in her hands. The Good Grips range was developed by Smart Design in consultation with a broad range of users, including children and people with arthritis, before their launch in 1991\(^{124}\). These products have received great critical acclaim, including a design award from the Arthritis Foundation. They have achieved great mass market appeal whilst also meeting the needs of the individual. The products are


desirable, functionally effective and, due to popular demand, continue to be developed into an ever broadening range of products.

Nevertheless, the conceptual developments embodied within this range, compared to those developed by Ergonomi, are limited. These products are a clear example of ‘Universal Design’ but since their launch, further developments have primarily focused on reapplying the same idea to more and more devices and products. Whilst this practice may not be problematic in itself it does suggest that the underlying design philosophy driving the development of these devices has not progressed. Many of the concerns identified by Zander in the 1890s, such as challenging “our love of ease” and the need to provide targeted resistances to support muscle development, remain lost amongst most of the products that are currently developed and produced.

Critiqued from a physical therapy point of view, these products are limited in their capacity to incorporate therapeutic benefits into everyday life. They meet the basic requirements of maximising accessibility and desirability, these however, are basic needs common amongst most commercially-driven design practices. The ever increasing range of products within the Good Grips range identifies an evolutionary tendency towards greater specialisation (and marketing): individual tools designed for increasingly specific purposes. Could future specialisations focus on further developing the health and wellbeing elements of these devices, by actively encouraging specific, beneficial, hand movements and exercises within kitchenwares and other everyday household tools and devices?

This idea has been explored before. The image below (fig 2.11) reportedly125 from the May edition of Modern Mechanix (1930),126 a popular engineering magazine in the USA (1928-2001), presents an early attempt to fulfil this ambition: with the “Situflator”, a device designed to inflate car tyres whilst exercising the leg and back


muscles. Although (probably) not a serious proposition, (the magazine is highly collectable and rare, therefore no copy was available to confirm the authenticity or context of the advertisement), this example embodies the concept of incorporating targeted exercises into meaningful real-world applications.


Several attempts have been made to develop a design philosophy which actively benefits the health and wellbeing of the end user. These will be outlined and discussed in the next section.

**Summary of key points**

Many devices designed to facilitate or assist treatment interventions exist. Most are recommended by OT’s and PT’s and focus on either improving joint strength and dexterity or assisting individuals within normal daily life. Some devices are more successful than others yet very few take psychological and social needs into account. Currently available assistive devices can be highly beneficial to users and are often popular due, in part, to their capacity to alleviate burdens of everyday life. Often based on principles of inclusivity these devices are highly functional and practical in everyday life. Existing exercise therapies offer significant, demonstrable, benefits to people with RA. Designed objects are a necessary tool required to
support therapeutic interventions and many examples of functionally effective devices can be found. The challenge, however, is to encourage patients to maintain long-term use. The strenuous and time-consuming nature of exercise devices requires significant motivation, especially when the exercises do not contribute to immediate needs and there is little or no perceived benefit. Long-term engagement is essential to achieve long-term benefits. Several strategies have been used to try to improve engagement with exercise therapies, though most are ineffective. Those which support social groups or intensive one-to-one support are most successful. These however are expensive, time consuming, and not suitable for all patients.

Zander Therapeutics was the first organisation to develop a system of apparatus that could provide targeted exercise therapies to all areas of the body. Their equipment could be tailored to individual needs and could provide demonstrable benefits to the health and wellbeing of users. The challenge of facilitating and sustaining engagement was recognised as was the threat posed by inactive and overly excessive lifestyles and sedentary work. The value of a healthy workforce was also understood in addition to the personal and wider social implications of incapacity and dependency on state benefits. Not only did the Zander Institutes recognise the necessity to maintain physical health, they also recognised the psychological, social and economic impact of poor health. The benefit of Zander’s interventions were recognised and celebrated throughout society, and were actively supported by governments and employers seeking to maximise the health of the population and optimise the efficiency of the workforce. Although largely unknown today, the legacy of Zander’s insights into therapeutics can be seen within modern exercise equipment.

According to Fischinger et.al. (2009): “In Germany, Zander’s name has been a synonym for movement and a healthy life style for some time now; the universal entrance ticket to any fitness studio says: Zander training - healthy strength”\(^{127}\) Furthermore, many current government healthcare initiatives seek to implement goals similar to those set-out by Zander, such as the highly significant: Dame Carol Black, *Review of the health of Britain’s working age population: Working for a healthier*

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Early successes in design development for people with specific needs were made by Swedish design firms A&E and the Ergonomi Design Gruppen. Each firm has achieved notable successes through their innovations and approaches to design. A common strength of these companies was their ability to produce products which met the specific requirements of users with particular needs whilst also achieving substantial market success. These products helped to shift the mindset of design for wellbeing away from ‘special’ towards ‘mainstream’, producing popular items which also fulfilled the requirements of people with specific needs. A practice replicated by Smart Design today.

• Devices currently available for people with physical health needs can be broadly split into two categories ‘assistive’ and ‘therapeutic’.
• Assistive devices are significantly more popular amongst users because of the immediate benefit they provide
• Therapeutic devices, although more beneficial in the long-term, are significantly less popular due to their appearance, limited functionality and low perceived short-term benefit.
• Encouraging users to engage with therapeutic devices presents a particular behaviour challenge which is common throughout healthcare interventions.
• Poor engagement with therapeutic exercise interventions is well recognised but design innovations have evolved away from targeted challenge towards compensatory support and commercial appeal.
• The popularity of assistive devices offers the opportunity to develop targeted interventions into the everyday lives of users.
Evolution of health focussed design philosophies

‘Universal Design’, ‘Inclusive Design’, ‘Co-Design’, ‘Human Centred Design’ (HCD) and ‘Healthy Industrial Design’ (HID), are all design philosophies which seek to develop design outcomes which benefit the end user. Some are focused on inclusivity and accessibility, others on identifying and fulfilling the needs of the user group, and one, HID, focusses on actively promoting the physical health of the user through Industrial Design.

Universal Design

Universal design was originally developed in the USA in the 1980s and 1990s in response to political change and technological evolution. Based on a social model of disability, the aim of universal design is to remove barriers present in the built environment which can cause people with specific needs to become excluded. The theory defines a series of design criteria which aim to maximise accessibility for the greatest number of users.

Architect Ron Mace popularised the term Universal Design in 1985.\textsuperscript{128} His principal contribution to the popularisation of Universal Design theory was to convince others of its value as a design process for all to consider throughout their development. The idea of Universal Design continued to develop and in 1998 Story, Mueller and Mace published ‘The Universal Design File’, a document clearly defining the aims of Universal Design, stating: “The design of products and environments to be usable to the greatest extent possible by people of all ages and abilities.”\textsuperscript{129}

The Universal Design File identified seven principles:

1. **Equitable Use:** The design does not disadvantage or stigmatise any group of users.
2. **Flexibility in Use:** The design accommodates a wide range of individual preferences and abilities.

\textsuperscript{128} Frank Bowe., *Universal Design in Education: Teaching Nontraditional Students* (Westport, CT, Bergin and Garvey, 2000): v

3. **Simple, Intuitive Use**: Use of the design is easy to understand, regardless of the user’s experience, knowledge, language skills, or current concentration level.

4. **Perceptible Information**: The design communicates necessary information effectively to the user, regardless of ambient conditions or the user’s sensory abilities.

5. **Tolerance for Error**: The design minimizes hazards and the adverse consequences of accidental or unintended actions.

6. **Low Physical Effort**: The design can be used efficiently and comfortably, and with a minimum of fatigue.

7. **Size and Space for Approach and Use**: Appropriate size and space is provided for approach, reach, manipulation, and use, regardless of the user’s body size, posture, or mobility.\(^\text{130}\)

Today these principles have, for the most part, become standard practice for designers who engage with ‘human’ or ‘user’ centred design. Not only do they prioritise the end user, but also make clear economic sense - products which are universally accessible appeal to a greater number of potential buyers. Each of the seven principles offers a specific design challenge to be considered when developing: products, environments or experiences, intended for maximum accessibility. Each factor within these guidelines has been developed to simplify the interactions that we have with products and environments, with the specific aim of minimising or removing ‘barriers’ that limit the accessibility of some objects and environments.

### Inclusive Design

Similar to Universal Design, Inclusive Design also aims to maximise accessibility and remove barriers to the use of the design. Inclusive Design evolved in the UK and is based on the principle of ‘social inclusion’, that objects and environments should be designed in a way that ensures they can be used by everyone, regardless of ability, without the need for adaptation or modification.\(^\text{131}\) Roger Coleman, co-founder and co-director of the Helen Hamlyn Centre (1999-2006), was a key pioneer of the Inclusive Design approach. He worked closely with John Clarkson, Director of the Cambridge Engineering Design Centre, University of Cambridge (1997-2012), to


develop and promote its use throughout the design industries. Coleman and Clarkson have published extensively on the subject for over a decade, including: Inclusive Design: Design for the whole population (2003); Countering Design Exclusion: An Introduction to Inclusive Design (2003); and the Inclusive Design Toolkit (2007).

Whilst unquestionably valuable to some users and entirely suitable in many circumstances, simply designing objects and spaces to be easier to interact with could in fact bring damaging secondary consequences to the physical health of users. For those who have physical health needs there is increased temptation to use simplifying technologies and devices due to the assistance and support they provide. Whilst ‘enabling’ in the short term, such devices and environments could affect user behaviour in a way that leads to greater dependency and less physical strength and dexterity, reducing functional ability and quality of life in the longer term. There are countless examples of ‘enabling’ assistive devices which simplify or remove the need for physical exertion, such as specialist knives, cutlery, key holders, jar and tin openers, pens, reaching and gripping devices and clothing aids. An infinite number of ‘assistive’ devices could be developed for almost any physical action. Whilst no single device is likely to cause a loss of function a general preference towards over-assisted living could. This concern in not a criticism exclusive to Universal or Inclusive Design approaches, many design philosophies place particular emphasis on ‘ease’ and ‘low physical effort’. The potential negative effects of over-assisted living are humorously illustrated in the Walt Disney film, WALL-E (2008), in which humans, living on a spaceship, are provided “...with everything [they] need to be happy.”\footnote{Wall-E, directed by Andrew Stanton, (2008, USA, Walt Disney Pictures)} This includes floating chairs which continually transport passengers to wherever they want to go, continual connectedness to visual and audio media and robots who provide services to fulfil all additional needs (see fig 2.12 below). Although anecdotal, and situated in a fantasy world, a misplaced emphasis on assistance could lead to excessively sedentary lifestyles, though hopefully not as extreme as this!
User-Centred Design

User-Centred Design (UCD) is an approach to design characterised by the inclusion of ‘end-users’ during the design process. Within this model people who accurately represent the target market for a product would be invited to offer critical feedback at decision making points throughout the design process. The intention of this model is to ensure that outcomes closely align with user requirements and preferences. The term ‘user-centered design’ originates from Donald Norman’s research into human-computer Interaction (HCI) design in the 1980s, which he developed whilst head of the Cognitive Science Research Laboratory at the University of California San Diego (UCSD). The term became widely used after the publication of a co-authored book titled: User-Centered System Design: New Perspectives on Human-Computer Interaction (Norman and Draper, 1986). ‘UCD’ is now used broadly to refer to a range of design approaches and methods which involve end-users at some point in the design process, although is most commonly employed in the computer sciences.

IDEO an innovation and design firm founded in 1991, with offices throughout the USA, Europe and Asia, adopted the principles of UCD and defined their own

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Human-Centred Design (HCD) philosophy. The IDEO HCD model seeks to integrate the needs of people with the possibilities of technology and the requirements for business success. The model features three core principles: ‘desirability’ - what do people desire? ‘feasibility’ - what is technically feasible? and ‘viability’ - what can be financially viable?

The HCD model (Fig 2.13) provides a simple and easily accessible approach to design which can be applied by professional and novice designers alike. Guided by user preferences, the model requires constraints to be identified from the outset, thus enabling achievable, real-world outcomes to be identified and developed quickly. The quality and suitability of outcomes will, however, be dependent upon the skills of the designer to interpret information gathered from the user group and to apply this knowledge to the development of innovative design outcomes.

Fig 2.16 (original in colour) Illustration of IDEO’s model of Human Centred Design, from IDEO, Human Centred Design Toolkit. Vol. 2 (Authorhouse, 2011): 7

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The IDEO approach seeks to understand the needs and desires of the end user, and to develop innovative design interventions using the best and most appropriate means available, within the constraints of the project. IDEO use both analytical strategies and generative techniques to identify, capture and expand the aims of their clients. Examples of products developed through this design approach include, among many others: the ‘KwikPen’ insulin pen for Eli Lilly and Company (2007), and the ‘transcutaneous’ - needle-free, vaccine delivery system developed for Intercell (2008).

The evidence suggests that each of these products meet the needs of all parties. The products have been developed to fulfil the desires of the end user, whilst utilising the materials and technologies available, and meeting the commercial needs of the client. These products not only present a solution to a problem but define a shift in how immunisations and drug treatments can be administered.

Healthy Industrial Design

Alan Tye developed his own design for wellbeing philosophy Healthy Industrial Design (HID) throughout the 1980s and 90s. Presented as a means to produce practical solutions, rather than an in-depth conceptual theory, the HID philosophy is implicit.

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Throughout Tye's design work. Although only available with limited detail, the specifics of Tye's theory are available within the literature. The HID model postulates four criteria from which design solutions should be developed: A = The needs of the healthy human, B = The task or job to be achieved, C = Habitual conditioning of the user, D = Material means at our disposal.

The model states: “The balance of A, B, C and D is formed into solutions, typically three, ranging from ‘radical’ to ‘achievable now’. This gives the client a choice depending on the marketing circumstances.”

Importantly, this model identifies “habitual conditioning of the user” as a particular factor for design consideration. The significance of habit on behaviour was implicit in Zander's understanding of our motivation to exercise and engage. Furthermore Tye, like Zander, also recognised the benefits of stimulating healthy movement within daily life activities; presenting the concept of ‘Sananomics’, the application of healthy movement and body use to products, as essential elements of the HID philosophy. Tye states: “SanaNomic means ‘Health Law’ as opposed to the ‘Work Law’ of

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ergonomics". The priority of the SanaNomic approach is to support the health and wellbeing needs of the user above other design requirements. The ergonomic approach seeks to support the physical needs of the user to minimise risk of injury and maximise work efficiency and productivity. The HID philosophy also considers the need for balance between under and over support. In his article published in the May 1991 addition of the RSA Journal Tye states:

In order for the body to remain healthy it has to ‘work’. The design of products should encourage the body to work in a healthy way but not, of course, to an extent where stress is caused. Herbert Spencer, the philosopher, once wrote: ‘Each faculty acquires fitness for its function by performing its function; if its function is performed for it by a substitute agency, none of the required adjustments of nature takes place, but nature becomes deformed to fit the artificial arrangements instead of the natural arrangements.’

Tye points to his professional esteem and awards in design as evidence of the success of his design philosophy. Most notable of these is the design of his own studio in the Chiltern Hills, England, completed in 1994. The ATD studios won a 1996 Royal Institute of British Architects (RIBA) award and was praised by the jury for its tranquility and peacefulness. Despite its acclamations the HID philosophy offers no examples of designs which are measurably ‘healthier’ than other design approaches. Whilst the ATD studios achieved lasting commercial success and critical acclaim, it is difficult to identify the specific health benefits achieved by the products developed by Tye using his HID approach. Although not presented as a mass market product, Dane Whitehurst’s ‘Cliffhanger Mug’ (fig 2.16) is a good example of how the HID philosophy could be conceived within a product form.

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139 Alan Tye,. Healthy Industrial Design, edited by Alan Tye Design Studio (Tring: Alan Tye Design Studio, 1999): 2
141 Alan Tye,. “HID and Seek.” FX Magazine, (September 1996): 47
This project is presented by Whitehurst as a “Seat of the pants workout for the domestic thrill seeker”. The mug provides a climbing hold instead of a handle to present a more challenging way to tackle a cup of tea - thus providing an additional physical challenge. This kind of intervention certainly would not be appealing to everyone, not least because of the obtrusive and excluding nature of this example. There is no choice about the level of challenge presented by the mug; the user either will, or will not, be able to use the product. This example does, however, provide a symbolic representation of how the body could be challenged to work a little harder and specifically, how stronger hands could be developed by means of an existing behaviour. This makes explicit the idea that introducing small, achievable challenges into everyday activities might have the ability to provide physical health benefits.

Such devices would require a paradigm shift in the mindset of users away from ‘mass simplification’ and ‘ease of use’ towards ‘targeted physical challenge’. In this

instance, the focus of design intervention would have to consider behavioural design elements. How could you motivate users to engage with such products? Would users who could potentially benefit from this kind of targeted challenge be willing to incorporate items such as these into everyday life?

Co-design

Co-design or ‘co-creation’ is a recent evolution of human/user centred design. Sanders, in her paper ‘Co-Creation and the New Landscapes of Design’ (2008), considers the similarities and differences between North American and European approaches to design and the role of the end user in the design process. Sanders identifies that the ‘user’ or ‘human’ centred design approaches developed in the USA position the user as the ‘subject’ of the design solution, whereas European design approaches have evolved to consider the user as a ‘partner’ in the process. She suggests that in recent years designers have begun to converge these approaches into what is now recognised as ‘co-design’.

One aim of co-design is to ‘democratise’ the design process and breakdown the traditional ‘roles’ of: user, researcher and designer. Instead, the various stakeholders of a particular project are invited to participate throughout the design process. The aim of this is to generate innovative outcomes which embody the creative, analytical and expert insights of each member in the team. This enables each member to not be ‘restricted by what they know’ but to contribute to all aspects of the design process. The complexity of healthcare intervention lends itself to the co-design approach. Initiatives such as: Patient and Public Involvement (PPI), which seeks to involve patients, carers and the public in the decision making process of healthcare research projects and innovations; and the Expert Patients Programme (EPP), which seeks to educate people who have chronic conditions about how to manage

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their own condition effectively; are two examples of the recent shift in healthcare practices towards patient empowerment which closely align with the co-design ethos. There are several examples of how the co-design approach can be applied to great effect in complex, multi-dimensional projects, such as the RCA Designing Out Medical Error (DOME) project (2012),¹⁴⁷ and SideKick Studios Buddy project (2012).

Led by Jeremy Myerson, director of the HHC, the DOME project is an example of how a co-design approach can be utilised in a clinical environment to develop successful design innovations. The co-design approach was applied to identify and prioritise health and safety issues in the clinical environment and to develop solutions which fulfil the needs of users, service providers and patients alike. The main focus of the initiative was to understand and map clinical processes in a number of environments and identify opportunities in which design interventions could be targeted to minimise the risk of human error. Using this approach, design innovations were developed to improve infection control, hand hygiene, medication administration, vital signs measurement and information handover. Outcomes not only seek to provide the tools to improve safety but also to effect behaviour change amongst users.¹⁴⁸

SideKick Studios Buddy project¹⁴⁹ is one example of how the co-design approach can be used to great effect. The project (currently ongoing) seeks to improve Talking Therapy services, for people recovering from mental health issues, using digital product interventions. Developed in collaboration with South London and Maudsley NHS Trust and volunteer service users, the project has evolved through several design and development phases. Proposed designs include: a mirror that connects to social network site Twitter; a social network-connected ‘mood radio’, which publishes the user’s current emotional state when they set the radio dial; and the current SMS-based system, which prompts the user to record their mood once a day through text messaging.

¹⁴⁷ "Designing out Medical Error (Dome)." Royal College of Art, accessed December 2012 http://www.domeproject.org.uk/index2.html


The evolution of this project away from physical, designed products and towards social networks and clinician friendly records and communication systems, is evidence of the ability that co-design has of developing outcomes suitable for the needs of all stakeholders. This approach does not pre-determine the parameters of outcomes. Solutions developed using this approach should, if applied thoughtfully and effectively, meet requirements efficiently and effectively.

**Summary of key points**

Universal and Inclusive Design philosophies were developed to raise design standards and avoid exclusion by design. The overarching aim of each philosophy is to simplify user interactions with the designed environment to avoid creating unnecessary and avoidable barriers which may prevent some individuals from being able to engage. Whilst highly popular, and appropriate for applications concerning access and the general population, these approaches to design have limitations, especially when considering exercise and therapeutic applications. Indeed some aspects of Universal and Inclusive Design directly contest the aims of therapeutics i.e. to promote exercise and movement through targeted challenges. Understanding this contention identifies a risk that we could in fact be designing our own future problem, ‘over-assisted’ or ‘over-simplified’ living could lead users to become
increasingly dependent on supportive equipment, which could in turn render users less physically able. For design interventions to be truly effective, efficient and beneficial to the user, further considerations need to be made which consider, among other things, the effects that the objects and environments we design have on users when considered over prolonged periods of time. There is clearly a need to avoid design exclusion and, for the purposes of health promotion, this should be developed to meet the needs of the individual in line with best available knowledge on health and wellbeing.

User, or Human-Centred approaches to design offer opportunities to gain insights from users about their own preferences and needs. This can be an effective way to adapt and appropriate simplicity factors in design. The IDEO model in particular offers guidance as to how design strategies should be formulated to ensure outcomes are achievable and appropriate to currently available resources, technologies and materials. The HID model is a particularly innovative approach which proposes a significant paradigm shift in how we conceive of health-aware industrial design. The model however is under-represented in the literature; limiting critical assessments of its efficacy to speculative judgements. A number of factors for further consideration within this study are identified by the HID model, specifically: achieving an optimum balance between under and over support within design, and the consideration of ‘habitual conditioning’, already present in the behaviours of the user group.

The model of Co-Design presented here identifies the potential for collaborative, insightful and well-targeted design interventions to be developed. The application of this method, however, must be carefully managed and considered. Whilst disciplinary specialisms may help to identify and appropriate the abilities and skills of particular individuals, they may also inhibit progress if considered too literally. The co-design approach helps to overcome this by empowering each member as an individual as opposed to a specialist with a particular role to play.
Design thinking offers significant, insightful benefits that have the potential to significantly improve the health and wellbeing of society. However, there is no, single, existing approach suitable to guide the development of design outcomes which unequivocally and actively promote health and wellbeing. All approaches to design give priority to a particular ‘design bias’ - particular priorities which guide the development and production of outcomes. Zander and Tye both present a clear priority for physical health and wellbeing: Zander through guided and supported engagement, and Tye through the built environment. Each of the product examples presented had a design bias towards commercial success, each providing a degree of assistance to the user. Universal and Inclusive Design philosophies focus on mass accessibility, ease of use and simplicity. The Co-Design approach emphasises user-centredness and fully integrated collaborative development. Each approach provides notable benefits and limitations. Zander’s institutes, for example, though highly effective, are undoubtedly the most expensive.

Undoubtedly there is an opportunity to establish a series of design specific criteria to guide the development of physical devices for people with RA. The criteria will aim to ensure that future products are adequately, and routinely designed to meet the needs of both the individual and the healthcare teams alike. In broad terms the design criteria should include the following key points:

- The design bias should clearly focus on physical health and wellbeing.
- Designs should be developed to become the preferred choice of the user, rather than a secondary alternative.
- Accessibility is important but should not be integrated at the expense of healthy movement and exercise.
- Empowering all stakeholders in the design process will help to ensure design outcomes are effective, meaningful and relevant to the real needs of the design problem.

These factors offer broad guidelines to consider when developing design interventions to benefit people living with RA.
Persuasive Design

In one way or another all forms of design influence our behaviour. Whether applied through marketing, product, service, environment or interface design, consumer behaviours, actions and attitudes can be affected by design. The application of design to affect behaviour change is, however, not always purposefully applied by designers or indeed recognised by consumers. Persuasive design, as presented here, seeks to intentionally affect behaviour in carefully considered ways towards pre-defined goals that are more humanistic in scope and go beyond the ‘linear’ business model that is only concerned with selling the product. If applied successfully, persuasive design can be a powerful tool to support social, environmental, economic, educational and healthcare change. The field of persuasive design makes explicit the intentions, methods and applications of design that are aiming to create change in the behaviour of users.

Evolution of persuasive design

The field of persuasive design was first initiated in 2002 following the publication of BJ Fogg’s book *Persuasive Technology: Using Computers to Change What We Think and Do*. Fogg, originally a graphic designer with a passionate interest in propaganda, is now a social scientist with an interest in new technologies. He first defined the field as ‘persuasive technology’ this being “interactive computing systems designed to change people’s attitudes and behaviours”. From this point onwards the field has quickly evolved and gathered momentum. In 2006 the first international persuasive technology conference ‘PERSUASIVE 2006: Persuasive Technology for Human Well-Being’ was held in Eindhoven, The Netherlands, 2006. The journal *Persuasive Technology*, published by Springer, was also released alongside. Since its conception, literature exploring the potential of persuasive innovations has matured and diversified, and the boundaries of persuasive technology have broadened. Increasingly recognised as ‘persuasive design’ the field continues to evolve as a rich multidisciplinary research specialism, which seeks to

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apply systems of change through technologies, products and environments. Bringing together disciplines of design, computer science, social sciences, psychology, cognition and philosophy, this field seeks to achieve sustained, long-term, positive behaviour change to benefit services in health, safety, and education.

In addition to Fogg, influential figures who have come to define the field of persuasive design include: social scientist and researcher Dr Maurits Kaptein; Professor of Information Systems Harri Oinas-Kukkonen; and leading technology designer and strategist for 21st Century healthcare Professor Samir Chatterjee. Kaptein’s research is primarily concerned with real-time persuasion profiling, which seeks to develop methods, strategies and applications for technologies capable of recognising, and responding to, user behaviours in real-time.\(^{153}\)\(^{154}\)\(^{155}\) Using quantitative methods Kaptein seeks to distinguish the individual from ‘the social average’ and apply this to appropriately responsive personal technologies. Oinas-Kukkonen’s research is primarily concerned with information systems design and ‘next generation’ web developments. Oinas-Kukkonen’s work has helped to define an emerging area of web science known as Behaviour Change Support Systems (BCSS),\(^{156}\) in which behaviour change is targeted through web based human/computer interaction. The aim of this research is to generate entirely personalised web experiences which are designed to improve information systems and thus influence users towards pre-defined goals such as ‘healthier lifestyles’.

Chatterjee’s work pioneers the application of persuasive technologies for healthcare support. He has developed design innovations for chronic health conditions such as diabetes, obesity\(^{157}\) and post traumatic stress disorder, in addition to comprehensive home monitoring sensor systems for elderly patients.\(^{158}\)


Although primarily developed through technology, health, and commercial domains, the theoretical models developed in the field of persuasive technology can be applied throughout most design practices. Practitioners such as Finnish product designer Johannes Ludvig Daae Zachrisson and London-based researcher and designer Dan Lockton place strong emphasis on elements of persuasion which are specific to the built environment. Lockton for example, identifies 101 methods for influencing behaviour through design in his ‘design with intent toolkit’ - 101 cards each detailing a particular method.\textsuperscript{159} Lockton defines ‘design with intent’ as: “design that’s intended to influence or result in certain user behaviour”.\textsuperscript{160} Framed by a taxonomy of eight theoretical perspectives or ‘lenses’, the cards were developed for use as design tools to inform the development of behaviour influencing design outcomes.

Although this study is not chiefly concerned with the development of new technologies the ‘ubiquity’, practice of embedding computing technologies within everyday objects, and ever increasing ‘pervasiveness’, the prevalence of a particular technology within society, and their increasing affordability\textsuperscript{161} can not be ignored. Indeed, there would appear to be a growing momentum towards the use of new technologies within future healthcare services. The emergence of smart phones, tablets and sensor technologies as well as social networking and health support websites, for example, not only facilitate social connectedness they present new opportunities for the development of new modes of healthcare support. New services already emerging include: ‘app’ based medicine providing information, social connectivity and timely prompts; ‘gerontechnology’, technology designed to serve the ageing society;\textsuperscript{162} and ‘exergaming’ technologies,\textsuperscript{163} gaming technologies specifically designed to promote physical exercise\textsuperscript{164} such as, Nintendo Wii, Wii Fit


\textsuperscript{161} Mike Kuniavsky, Smart Things (London: Morgan Kaufman, 2010): 5


and Xbox Kinect. Many researchers developing these services seek to apply principles of persuasive design to improve health and wellbeing. Key areas of concern include preventative health interventions such as motivational technologies\(^{165}\) and health information systems\(^{166}\)\(^ {167}\) in addition to interventions which seek to support the treatment of long-term health conditions including diabetes\(^ {168}\), obesity\(^ {169}\), addiction\(^ {170}\), and autism\(^ {172}\).

### Apple Store

There are numerous examples of applied persuasive design throughout business and marketing practices and in commercially available health and wellbeing focussed products. Computer company Apple, for example, as reported by online ‘blog’ site Gizmodo\(^ {173}\) provide staff training and handbooks to guide the language and behaviour that staff use when talking to customers to avoid negativity and promote positivity and a sense of empathy. The article explains that when staff discuss a situation with a customer in which a computer has become unresponsive they are trained to actively avoid using words such as ‘bomb’, ‘crash’ or ‘hang’ and instead use the phrases ‘unexpectedly quits’, ‘does not respond’ or ‘stops responding’ to shift the emphasis of the discussion away from definitive problem to temporary concern. These subtle adaptations to language have been developed by marketing

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strategists to persuade potential customers to invest in their products. Whilst anecdotal, this example does provide insight into the kinds of strategies used within commerce to influence potential buyers, it also identifies the kinds of persuasion that people face as part of everyday life in commercial, sales situations.

**Nike Fuelband and Jawbone UP**

Examples of health specific persuasive products include the ‘Jawbone UP’ (2011) and the ‘Nike Fuelband’ (2012) (see fig 2.18). These products mark the start of a new generation of innovations which seek to improve health and wellbeing. The technologies are both striking and useful in their design. Each product seeks to promote healthy behaviours by utilising ‘feedback-loop’, ‘gaming’ and ‘social support’ strategies. The products combine a wearable sensor bracelet with a mobile phone ‘app’ and online social networking. Each technology gathers data, sets goals, and provides feedback to the user. The Jawbone-UP monitors diet, exercise and sleeping patterns and the Nike Fuelband monitors energy, calories, steps and time. Both products encourage new behaviours by establishing personal goals, triggering healthy behaviours through timely reminders and facilitate social motivation using online social networks - which promote competition and comparison between users.

![Fig 2.21 (original in colour)](image)


The most significant design development presented by each of these products is their ‘systems’ approach. The design focus is placed on establishing and sustaining an ‘ecology’ of interaction: a system of interconnected elements comprised of hardware, software and user groups. This not only provides the means to monitor exercise but also actively encourages engagement through alerts, reminders and social network support. Furthermore, the connectedness with other existing popular systems such as Facebook and Twitter, mean that these devices can be used to
extend existing online behaviours and interactions. The wristband for each technology is stylised yet relatively unobtrusive, so can be worn in most circumstances without attracting unwanted attention; data is presented in simple visual forms, accessible directly on a smart phone. Promoting behaviour change in this way utilises the potential provided by new technologies and presents new possibilities for human/computer-assisted healthy living.

**Vitality GlowCap**

A further, perhaps more aggressive, example of persuasive design applied to a product can be seen in the ‘Vitality GlowCap’ device (2010), which seeks to improve patient engagement with drug treatments. The Glowcap is an example of a specialised application of feedback-loop technologies and social support networks to encourage particular behaviours. The product, a replacement cap for medication bottles - combined with a plug-in visual/audio alert device, is designed to improve a patients’ ability to take medication as recommended by healthcare professionals. The lid, which connects to mobile phone networks, provides four separate feedback loops, each intended to support the user in a different way. These are: personal reminders, to assist the user to remember their medication; social network support, providing weekly reports to a nominated person who can motivate and support medication taking; doctor accountability, providing monthly reports to healthcare teams who can adapt treatments to suit existing behaviours; pharmacy coordination, the product can monitor and order replacement medications as required.174

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**Fig 2.22** (original in colour) Vitality GlowCaps, accessed december 2012, from http://www.vitality.net/glowcaps_howglowcapswork.html
“Vitality GlowCaps illuminate, play a melody, and even ring a home phone so patients don’t forget [to take their medication]. They can send weekly emails to remote caregivers, create accountability with doctors through an adherence report, and automatically refill prescriptions. Vitality improves medication adherence, health, and peace of mind.” Vitality is currently testing the GlowCap widely with hospital and physician partnerships and is planning to market to insurance companies once sufficient data is collected. Initial results suggest that the system can have a significant impact on patient engagement with prescription recommendations with some participants achieving adherence rates of up to 98 percent.

Systems such as this, which adopt reminders, alerts, social support and ‘surveillance’-like connectivity with healthcare professionals, although potentially highly effective, raise serious questions as to the autonomy and free will of the user. Whilst persuasive design seeks to affect behaviour change in the user it is important that those developing applications for research have an awareness of the moral and ethical implications of the effects of their use. Most academics concur that appropriate uses of persuasion tactics should adopt the practice of behaviour change without coercion or deceit. This position however, does not adequately address the obtrusiveness, and compromised freedom of choice, that careless applications of persuasive interventions could lead to. To explore this further, the following section will outline key concerns relating to the ethical application of persuasion techniques and define a moral and ethical position for this study.

**Ethical considerations for persuasive interventions**

When considering persuasive design, it is important to pay particular attention to the potential ethical implications of such interventions both in terms of direct and indirect consequences. It is also important for the integrity of persuasive design as an evolving research field to clarify the role and application of persuasion within any given project. Misapplication or careless uses of persuasive interventions could serve to damage the reputation of persuasive design and compromise its potential to achieve positive change. Despite their importance, considerations of ethical implications are relatively underdeveloped within the field of persuasive design. There

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is a wealth of literature available which explore ethics and persuasion, however, as yet, there is limited integration of the two fields.

An important starting point when considering persuasive interventions is to recognise that outcomes do not necessarily justify means, i.e. healthcare interventions which lead to demonstrable improvements to quality of life, or wellbeing, are not inherently ‘good’ simply because they lead to positive clinical change. If, for example, an intervention were to compromise the autonomy or free will of an individual for these ‘desirable’ changes to be achieved, further questions must be answered before the intervention should be considered a positive change. It is also important to differentiate ‘persuasion’ from other strategies such as: control, deceit, coercion or any other form of influence which seeks to affect change in a more aggressive or less transparent fashion. Persuasion can be applied as a means to help individuals make informed decisions about their own choices, but not to force individuals into particular behaviours.

Many behaviour change theorists adopt a position of ‘libertarian paternalism’. First presented by Sunstein and Thaler in 2003 libertarian paternalism is defined as: “an approach that preserves freedom of choice but that authorizes both private and public institutions to steer people in directions that will promote their welfare.” Sunstein and Thaler further explain that this should not be achieved through coercion and that the welfare benefits should be presented as objectively as possible.

This position pinpoints the polarity between spontaneous freewill and predetermined behavioural influence which are central concerns of any persuasive intervention; people should be free to choose, but the benefits of a particular choice should be highlighted. Importantly, this definition highlights the need to avoid restricting choices when seeking to encourage positive behaviour change yet also acknowledges that external influence is sometimes required to assist individuals to achieve particular goals. This approach, often referred to as ‘nudge theory’, has been utilised by the

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UK Government National Social Marketing Centre (NSMC) since 2006.\textsuperscript{180} Now a non-profit community interest company, the NSMC develop ‘choice architectures’, behavioural intervention strategies in which decisions are influenced by the way choices are presented. This approach, however, can be particularly paternalistic and manipulated to the extent that outcomes fulfil the aims of the ‘architect’ above those of the individual.\textsuperscript{181}

A less interventionist approach is the ‘personal responsibility’ model which seeks to help people to help themselves\textsuperscript{182} “People generally want to be able to control their own lives, and to exert ‘agency’ on the world around them.”\textsuperscript{183} The personal responsibility model seeks to empower the individual as much as possible rather than making decisions on their behalf. In healthcare, this concept is present in the model of ‘concordance’, a strategy which emphasises the need to support patient empowerment and autonomy within the development of treatment interventions (as distinguished from concepts of ‘adherence’ and ‘compliance’ discussed in ‘Engagement with healthcare recommendations’ section below). Maintaining personal freedoms and personal choices are unquestionably important, but what if personal choices are divergent, harmful, or costly to others?

Many healthcare interventions are expensive. Long-term chronic conditions such as obesity, addiction, diabetes and RA are particularly costly. Patients who do not engage with healthcare recommendations as advised place additional costs on the healthcare system, the wider economy and society in general. Interventions which seek to enforce adherence would be considered inappropriate and unfair, but conversely, it may also be considered unfair to pass these costs on to others.\textsuperscript{184} Central to this issue is the challenge of trying to help people to help themselves when

\begin{footnotesize}
\begin{itemize}
\item \textsuperscript{180} “The NSMC", The National Social Marketing Centre, accessed December 2012 http://www.nsmcentre.org.uk/content/nsmc
\item \textsuperscript{184} Darnton, A. GSR Behaviour Change Knowledge Review: An overview of behaviour change models and their uses (London: HMT Publishing Unit, 2008): 65
\end{itemize}
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they do not appreciate the suitability of the behaviour change being encouraged. If healthcare recommendations are misunderstood or do not concur with the expectations of the patient, they are unlikely to be adopted. This may also be the case if a patient finds a treatment recommendation to be too restrictive, limiting or non-beneficial. There is therefore a need to assist individuals to make well informed decisions about their engagement with healthcare recommendations and to remove as many barriers to positive change as possible.

Within this thesis it is considered that persuasion can be applied to offer encouragement towards more beneficial or more healthy behaviours but not to enforce or coerce participation in that activity. The principal concern therefore becomes how persuasive interventions are operationalised rather than if they should be used. Persuasion is not inherently bad and throughout history persuasion has been studied and utilised: Law and Education, for example, are two fields of professional practices which directly seek to affect our behaviours and attitudes for personal and social gain. As human beings we are not purely rational. We do not carry out cost versus benefit calculations for every decision we make. We are spontaneous emotional beings who often act on impulse, habit or routine. Our decisions can be swayed by personal preferences, tastes, moods, states of mind, personal beliefs. The challenge therefore is to present and promote therapeutic exercise behaviours in a way that appeals to our personal preferences and resonates with our own aims. This strategy has been recognised and exploited by marketing specialists for decades. Persuasion for health benefit, utilised by the objects and environments that we engage with on a daily basis, is however, largely underdeveloped. There is significant opportunity to develop persuasive design for healthcare applications.

This study seeks to identify and affect behaviour amongst RA patients who are either intentionally or non-intentionally ‘non-compliant’. Design outcomes seek to facilitate or extend patient engagement with long-term therapeutic exercise recommendations. The purpose is to enable people with RA to engage with interventions more easily and effectively within normal daily life. The study does not seek to affect behaviour change through coercion, solicitation, deceit or censorship. The aim is to facilitate and support concordance with healthcare recommendations.
through designed objects and environments. The study seeks to assist individuals to help themselves: to facilitate informed decision making, raise awareness of the benefits of exercise for people with RA and to increase the use of therapeutic exercise interventions. Importantly, interventions developed though this study will not limit choices available to individuals. Furthermore, it will not seek to introduce forceful, compliance-based, treatments which seek to ‘override’ or ‘re-define’ patient behaviours. Instead, this study seeks to work with patients and their existing behaviours to assist with voluntary, incremental, developments in therapeutic health support.

**Summary of key points**

The application of persuasive design is conceived as an intervention which seeks to affect change more directly than concepts of inclusivity, accessibility or desirability. Persuasive design seeks to overtly and actively engage and influence the user and offer complex, personalised, interactions. Whilst primarily developed in the context of new technologies, the principles and practices of persuasive design can be applied broadly across design disciplines. Persuasive interventions generally take a ‘systems’ approach in which the physical intervention is supported by wider social support. Whilst persuasive interventions are becoming increasingly available for a variety of health needs, there are currently no persuasive design products or services specifically designed for people living with RA.

New technologies offer new possibilities for design and for health interventions. The affordability and ever-increasing pervasiveness of personal computing devices represents a growing momentum towards future technology-rich developments in healthcare services. Commercial applications of such technologies continue to lead the way in defining new possibilities and new applications. Increasing levels of personalisation, intervention and influence do however raise new questions about the role of products within our lives, the influences they can have on our behaviour, and to the moral and ethical standpoints that those developing such interventions should choose to take.
Applications of persuasive interventions must be developed with consideration for the impact on the autonomy of potential users. Though some applications may necessarily be more influential than others, personal, biological, psychological, social, and cultural factors should all be considered and accounted for when developing a design outcome. To be successful, interventions should achieve the correct balance between influence and the operation of free will. If products are perceived to be too intrusive, or to compromise the autonomy of the individual, they are unlikely to be accepted into the daily lives of users. There is a long history of persuasive intervention throughout society. The broad application of persuasive intervention for health benefit is, however, under developed.

Key points:
• Design interventions must match the ability and motivation levels of the user.
• Micro-adaptations of existing routines are likely to be achievable and long-lasting.
• Social network support is a particularly powerful motivational factor.
• Feedback loops provide both motivation and a means to monitor progress over time.
• Persuasive interventions are not inherently bad, but how they are operationalised is of critical importance.
• Health-aware persuasive interventions should seek to help individuals to help themselves without being forceful or manipulative.
• Providing consistent, up to date information, is an important aspect of enabling people to make informed decisions about their own health and wellbeing; however, this is not always enough. Sometimes initiatives need to be more interventionist, actively guiding people towards more healthy or more appropriate behaviours.

Understanding how patients engage (or fail to engage) with healthcare recommendations is a huge and complex problem. RA presents a number of specific challenges and concerns for long-term engagement. The terms ‘compliance’, ‘adherence’ and ‘concordance’ are often used to describe the relationship between healthcare teams and professionals. This will be explored further in the following section.
Engagement with healthcare recommendations

Understanding behavioural aspects of user engagement with healthcare recommendations is essential for the development of devices intended for long-term use. Despite the ability of medicines to prevent, relieve and even cure many forms of ill health, people often do not take them as prescribed. This is commonly referred to as ‘non-adherence’. Patient engagement with healthcare recommendations is essential to the success of most treatment strategies, yet, as stated in the introduction, the WHO (2003) recognise that “Adherence to long-term therapy for chronic illnesses in developed countries averages 50%”.185 ‘Adherence’ is a very simple concept: engage with treatment recommendations as advised to minimise the negative effects of an illness or condition. ‘Non-adherence’ or, lack of engagement, however, is a complex problem. Some factors are patient-related, others include the characteristics of the disease, and others, the treatments themselves. Attributes of the healthcare system and service delivery can also have a great influence on patient behaviours.186

Compliance, adherence, concordance

There are several words and phrases used to describe the relationship between patients, their healthcare providers and healthcare recommendations. Over the past few decades there have been three distinctive phases in language use, evident in the literature, which indicate evolutions in our thinking about the relationship between patient, treatment and provider: ‘compliance’, ‘adherence’ and ‘concordance’. Understanding the meaning and philosophy behind the use of each word will help us to understand how theoretical models for the patient/doctor/treatment relationship have evolved over time:

**Compliance** Refers to the extent to which a patient’s behaviour matches the prescriber’s advice. This model is very one-sided - specifically attributing responsibility to the patient who is expected to passively follow directions from healthcare teams without question. The WHO (2003) outline the limitations of this model:

“Initially the patient was thought to be the source of the “problem of compliance”. Later, the role of the providers was also addressed. Now we acknowledge that a systems approach is required. The idea of compliance is associated too closely with blame, be it of providers or patients and the concept of adherence is a better way of capturing the dynamic and complex changes required of many players over long periods to maintain optimal health in people with chronic diseases.”\(^\text{187}\)

**Adherence** The WHO (2003) define ‘adherence’ as: “the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider.”\(^\text{188}\)

This, more neutral, term has been adopted by many as an alternative to compliance, in an attempt to emphasise the freedom of a patient to make their own choices about treatments. This model acknowledge the freedom of the patient to decide whether to follow the doctor’s recommendations or not. The concept of adherence also recognises that failure to engage should not be a reason to blame the patient. Adherence develops the definition of compliance by emphasising the need for agreement between provider and patient and the value of choice for the patient.

**Concordance:** a complex idea relating to the patient/healthcare relationship and the degree to which the prescription represents a shared decision. Ideally interventions should address: ‘patient satisfaction’, ‘empowerment’, ‘understanding of illness’, ‘quality of life’, ‘functional status’ and ‘psychological well-being’.\(^\text{189}\) Here, the idea of

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empowering the patient, informing and educating patients about their condition to enable them to make informed decisions about their own care, is further emphasised, as is the complexity of the relationship between healthcare provider and patient. Although similar to the concept of adherence in its definition, concordance marks a further development away from the concept of compliance. Furthermore, as an ongoing negotiated agreement between patient and specialist, concordance also has the potential to support future focused interventions. However, despite increasing recognition in the UK, concordance is not currently recognised by the WHO.

This evolution of language illustrates how behavioural theories about engagement have moved away from ideas of ‘blame’ and ‘personal responsibility’ to a broader, more complex, understanding of biological, psychological and social needs. This evolution of language reflects the more relational or ‘ecological’ intervention paradigm that is beginning to replace the traditional ‘expert/patient’ model.

**Non-adherence in RA**

Despite a general recognition that each of the definitions outlined above identifies an evolution in thinking, authors of research literature have not always used these terms in the same way. Therefore throughout the following section, when describing work by other people, the terms used by the original authors will be retained.

Lack of patient engagement is widespread across many therapeutic fields. For people with RA, there are a number of well documented factors reported as particularly significant to non-adherence. These include: pain, the complexity of treatment regimen, emotional distress caused by RA, concerns about the causes, perceived continuation of disease progression, and fear of long-term consequences
Each of these factors has a huge effect on the ability and willingness of patients to engage with treatment recommendations and on patient perceptions of the severity and impact of their own condition. This in turn increases the cost and efficacy of treatments and affects concordance in intricate ways.

Literature assessing the extent to which patients with RA engage with therapeutic exercise recommendations is limited. However, it is generally accepted that adherence to exercise therapies is generally very poor - many of the factors outlined above apply with particular emphasis on pain, time and complexity of regimen. The prospect of exercise therapies can be particularly intimidating for people with RA due to the nature of their symptoms. Pain, swelling of the joints, and fatigue for example, are not generally considered to identify a need to exercise more. Indeed, the symptoms of joint swelling and pain are caused by the immune system responding in the same way that it would had the joint been damaged through injury or infection. Therapeutic exercise could therefore be considered a counterintuitive recommendation.

Recovery versus management Recovery or ‘curative’ treatment strategies have powerful intrinsic incentives for patients to engage with them. They provide immediate, or rapid, benefits which are recognised during the treatment intervention. They seek to achieve significant recovery and an end to symptoms. This has a significant motivational benefit to those affected. Furthermore, DiMatteo, (2007), identifies: “patients in objectively poorer health are more likely to be adherent than patients in better health.” Patients who recognise health concerns that require immediate attention tend to respond and act as advised until symptoms improve.

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Longterm health conditions tend not to present the same threat intensity as the threat is fairly constant and ongoing rather than intense and immediate. This is a key difference between acute and chronic conditions.

Therapeutic aspects of Condition Management Strategies,\textsuperscript{194} such as those used to manage RA, have fewer short term incentives; they can offer only longterm gains. Treatment will be considered a success if it manages to slow or stop the degenerative effects of a condition. Patients who follow a therapeutic exercise treatment regimen hope to realise the benefit of their efforts at some point in the future. The timescale of intervention-to-benefit is extended and therefore becomes a more abstract concept for the patient. DiMatteo (2007) states: “Non-adherence is more than 1.5 times greater among individuals who do not perceive a disease severity threat.”\textsuperscript{195} Although people living with RA are likely to be very aware of the threat of their condition, they may be less aware of the long-term threat to joint strength and dexterity caused by lack of exercise and movement. Patients may also become less inclined to engage with specific exercise therapies when drug treatments effectively manage the most apparent or ‘immediate’ symptoms.

The link between ‘time invested in treatment’ and ‘feedback through health benefit’ is central to the challenge of effective condition management treatments. Described in further detail in the following section, social connectedness can play an important role in helping those affected to recognise the benefits of their efforts and to support their ongoing engagement with healthcare recommendations. Talking with family and friends, group education workshops, and healthcare appointments each provide both social support and ‘feedback loops’ - in which the patient receives informal and formal feedback on the progress and status of their condition; thus further motivating


\textsuperscript{195} DiMatteo, M.R. “Health Beliefs, Disease Severity, and Patient Adherence: A Meta-Analysis.” Medical Care 45, no. 6 (2007): 7
and supporting the individual. DiMatteo, (2007), identifies ‘depression’ and ‘social support’ as two major predictors of adherence, stating:

“Perceptions of disease severity threat involve the assessment that a disease to be prevented or treated is serious. This finding suggests the importance of attention to health education, persuasive messages, and the enhancement of patients’ health literacy in promoting adherence. It also points to the importance of the effective management in clinical practice of communication barriers such as language, culture, ethnicity, and social class in helping to enhance patient adherence.”  

As with the biopsychosocial model (identified in the previous chapter), distinguishing between biological, psychological and social factors when considering patient attitudes and behaviours can be a helpful method for deconstructing, isolating and identifying factors which affect patient engagement with treatment recommendations. Each of these ‘domains of influence’ presents particular needs and requires particular considerations. The ability to intervene effectively is, in part, mediated by the ability and willingness of those involved to engage with recommendations. In medicine, these are referred to as ‘intentional’ and ‘non-intentional’ non-compliance factors.

**Intentional and non-intentional non-compliance.** The WHO (2003) state that some elements of non-adherence can be attributed to the patient and others to healthcare providers and the systems which support treatment strategies. These factors can be explored further by discussing ‘intentional’ and ‘non-intentional’ non-compliance.

*Intentional non-compliance* is used to describe situations in which a patient makes a conscious decision to change or adapt a treatment regimen based on his or her own judgement. This may include: missing medication or avoiding exercise if symptoms are in remission; taking additional medication if symptoms flare; or adapting an exercise regimen to fit personal circumstances or preferences. This kind of self-

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196 DiMatteo, M.R. "Health Beliefs, Disease Severity, and Patient Adherence: A Meta-Analysis." Medical Care 45, no. 6 (2007): 526

management can be effective if the patient is truly able to make informed and rational decisions. For example, in the case of pain management this can be straightforward and self-explanatory: take painkillers as required.

For more complex treatment regimens, including exercise therapies and disease modifying medications, this kind of self-management is rarely encouraged. This is due to the ‘detached’ relationship between ‘treatment’ and ‘benefit’, and due to the potentially damaging consequences of ad-hoc concordance; especially amongst individuals pursuing ‘divergent’ or uninformed courses of action. Patient education programs are designed to support patients in making informed decisions about their lifestyle and care.

It is widely accepted that people living with longterm conditions, such as RA, often become expert in their own condition, understanding, through their own lived experience, the intricacies and nuances of their own symptoms; learning when and how to adapt their lifestyle to avoid unnecessary pain and discomfort. When managed in concordance with healthcare teams, formally monitored and adjusted in line with good clinical practice, this can be a highly successful disease management strategy. However, the ability of patients to manage their own symptoms, in concordance with healthcare recommendations, is highly dependent on effective communication between the patient and healthcare teams, clear understanding of available treatments and their uses, and the ability and willingness of the patient to be self-effective.

Non-intentional non-compliance, often referred to as ‘adherence barriers’, occur when a patient fails to engage with recommendations as advised, despite intending to do so. ‘Lack of time’ and ‘complexity of treatment regimen’ are common examples of non-intentional non-compliance reported by patients. The term ‘non-intentional’ suggests that, once identified, removing or minimising these ‘barriers’ will improve engagement. Jack K et al, (2010), conducted a systematic review of barriers
to treatment adherence in physiotherapy outpatient clinics and the following factors were identified as the most significant predictors for exercise non-adherence: ‘low levels of physical activity at baseline or in previous weeks’, ‘low in-treatment adherence with exercise’, ‘low self-efficacy’, ‘depression’, ‘anxiety’, ‘helplessness’, ‘poor social support or activity’, ‘greater perceived number of barriers to exercise’ and ‘increased pain levels during exercise’, as barriers to treatment adherence.\(^{198}\)

The ‘barriers’ listed above identify a number of factors ranging from: an individuals’ personal exercise history and willingness to engage with physical activities; to personal, psychological and emotional factors such as, depression, anxiety and perceived helplessness; and physical symptoms such as pain and discomfort. The ability of individuals to fulfil their own aims to engage with an intended treatment is referred to in the psychology literature as ‘self-efficacy’. A significant amount of research has been conducted to try to understand and influence the factors which enable an individual to behave with self-efficacy. The following section outlines the basic principles of this theory and four of the most widely recognised modes of influence.

**Summary of key points**

Patient engagement with therapeutic exercise is determined by multiple influences ranging from: biological, personal and psychological to social, institutional and cultural factors. The literature seeking to understand this phenomenon has evolved, shifting responsibility away from the individual and towards a shared responsibility. The nature of RA as an auto-immune disorder causing symptoms of pain, swelling and fatigue, is also a further cause of reluctance to engage with therapeutic interventions. Symptoms cause a vicious cycle of: pain, lack of movement, stiffness in joints, lack of ability. Therapeutic interventions seek to counteract these consequences by encouraging the movements that symptoms prevent. The nature

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of therapeutic devices as object which encourage movement are therefore, in the instance of RA, potentially very challenging and distressing interventions.

Helping people to recognise the benefits of therapeutic interventions and encouraging long-term use also present significant challenges. This is closely related to the balance between intentional and non-intentional non-compliance. Whilst not all patients will be equally able or willing to become the master of their own condition, healthcare interventions should seek to educate, support and inform patients. Secondly, supporting patient autonomy and enabling patients to feel as though they have some control over their own treatment is an important factor to encourage throughout all interventions.

- RA presents complex and interrelated behavioural challenges influenced by psychological and social factors.
- Treatments should be more targeted and strategically interventionist, and focus on behaviour change as much as physical and pharmacological treatments.
- Healthcare teams, service providers, designers and patients have a shared responsibility to develop realistic, achievable and effective treatment interventions.
- Interventions should not only seek to provide the means for people to exercise but also the means to help patients make informed decisions about their ongoing care.
- Interventions should target social and psychological support as a matter of priority.

Research has been conducted to understand more about patient behaviour in response to healthcare recommendations; particularly in the field of behavioural psychology. The following section will discuss the key features common amongst most socio-psychological models of behaviour and discuss health specific models in more detail.
Behaviour Change Theories

This section will review the key elements of Behaviour Change theory in the context of health and wellbeing, with a principle focus on key models, theories and frameworks relevant to healthcare interventions and design. The evolution of Behaviour Change theory will be outlined from its roots in ‘economic theory’ to current theories which have informed the development of ‘persuasive design’. Where available, examples demonstrating these principles in practice will be identified.

In recent years behaviour change theories have become increasingly important within psychology and social science research fields. This has led to a wealth of socio-psychological literature which seeks to understand human behaviour and develop theories and strategies to affect it. Over the past decade there has been increased recognition within national governments and international agencies, such as the International Monetary Fund (IMF) and WHO, that understanding and shaping both individual and group behaviours can improve the relevance, efficacy and efficiency of public policies; particularly those relating to community participation, consumption, environmental issues and health.199

The foundations of behaviour change theory can be traced back to the basic principles of economics ‘homo economicus’, which supposes that individuals make decisions based on rational cost/benefit calculations: specifically seeking to maximise personal gain with minimal personal cost.200 Whilst effective and logical when considering business and strategy, this basic economic model is over simplistic when considering the behaviours of individual people. It can be taken to assume, for example, that each person is a sole agent concerned only with their own circumstances, that people consciously consider every decision they make, and that people act with no consideration for the consequences of their actions. Furthermore,


this model cannot account for factors such as, personal preference, habits, addictions, emotions or social pressures.

Economic theory can however be used to predict general behaviours through mathematical equations, based on assumptions that: our preferences are fixed, all information relating to that decision are available and understood, and that this information will be used for optimum gain. The model is particularly effective in self-regulating systems, such as the market place, where deviations are absorbed within the ecology of the system. ‘Socio-psychological’ models seek to build on this to develop our understanding of behaviour by recognising, and accounting for, more of the intricacies and nuances of actual human behaviour; to develop theories and strategies which are relevant to the real-life occurrences of individual and group behaviours.

Self-efficacy

Socio-psychological models seek to extend the basic economic theory of behaviour by investigating the origins of behavioural preferences and incorporating these as specific factors within behavioural models. Self-efficacy is a behavioural concept central to most social and psychological theories of planned behaviour. Bandura’s model (1977) remains one of the most influential, and is evident throughout many of the most commonly used socio-psychological models of behaviour. Self-efficacy considers both one-off and long-term behaviours and has been used extensively throughout the medical sciences to understand and assess patient engagement with healthcare recommendations. Bandura defines perceived self-efficacy as:

“... people’s beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives. Self-efficacy beliefs determine how people feel, think, motivate themselves and behave. Such beliefs produce these diverse effects through four major processes. They include cognitive, motivational, affective and selection processes.”

Central to this theory is the idea that self-efficacy acts as mediating influence regulating the time and effort that an individual invests in a particular behaviour. The theory considers behaviour to be determined by factors that affect our ability and willingness (both actual and perceived) to engage with a particular behaviour. For example, if a behaviour is considered too difficult it will not be attempted even if motivation is high. Bandura identifies four main sources of influence which define an individual's ability to be self-effective; Mastery, Social Value, Social Persuasion and Emotional State:

**Mastery:** “Successes build a robust belief in one’s personal efficacy.”

**Social Value:** “Seeing people similar to oneself succeed by sustained effort raises observers’ beliefs…” Bandura explains that the strength of influence is affected by the level of perceived similarity - “The greater the assumed similarity the more persuasive are the models’ successes and failures.” Furthermore, this ‘connectedness’ or ‘shared value’ must also be present in the activity being observed - “People seek proficient models who possess the competencies to which they aspire.”

**Social Persuasion:** Bandura identifies social persuasion as a potentially powerful, but two-sided, motivator. Stating: “People who are persuaded verbally that they possess the capabilities to master given activities are likely to mobilize greater effort and sustain it…” this increase in effort can lead to achievements which had previously been considered unachievable. However, this self-validation can have negative affects - “...people who have been persuaded that they lack capabilities tend to avoid challenging activities that cultivate potentialities [to fail] and give up quickly in the face of difficulties.”

**Emotional State:** is the fourth factor identified by Bandura as contributing to self-beliefs of efficacy. “People…rely partly on their somatic and emotional states in judging their capabilities.” More specifically - “Mood ...affects people’s judgements of their personal efficacy. Positive mood enhances perceived self-efficacy, despondent mood diminishes it” Furthermore “It is not
the sheer intensity of emotional and physical reactions that is important but rather how they are received and interpreted.”

The ability to be self-effective is an essential factor for long-term healthcare interventions, especially those which are managed with intermittent check-ups. The responsibility for health change, although supported by the healthcare system, will always remain within the individual. Behaviour change interventions therefore seek to empower the individual to achieve and sustain positive behaviour change.

Six principles of socio-psychological behaviour change theories

Whilst extending basic economic theory, most socio-psychological models are based on a principle that behaviour is the product of deliberate action in one way or another. They are principally concerned with factors within an individual’s psyche and do not account for external influences such as cost or access to resources. However, when considering the application of persuasive design theory to physical objects, external factors become extremely important. Physical objects extend beyond the psyche, therefore, our understanding of behaviour change theory must be extended to be applicable to persuasive design. The UK Government report ‘GSR Behaviour Change Review’ (2008) provides an overview of over 60 socio-psychological behaviour change models and their uses. The report identifies that most models are based on 6 common, yet variably defined, factors. The first three are universal, the second three are common but not present in all models:

Firstly, the report identifies personal ‘attitudes’ as a standard feature of all behaviour models. Similar to self-efficacy, attitude tends to be conceived as “the product of a deliberative calculation weighing an individual’s beliefs about a behaviour with the value they attach to those characteristics.” Within most models attitudes are differentiated from ‘beliefs’ and ‘values’ - which are considered to refer to ones broader ‘world view’ and ‘moral positioning’, respectively. A simple interpretation of


this could be to consider this as a factor specific to the ‘willingness’ of an individual to engage with a specific behaviour.

Secondly, subjective, social and personal ‘norms’ are identified as “a guide to how we should behave, and how we expect others to behave”. Theories of personal norms have also been linked to theories of ‘identity’ - suggesting that we define who we are by reference to others. Social norms provide a ‘feedback loop’ between individual actions and the response from our peers and others in society. In this way norms can be considered ‘behavioural regulators’ or, ‘parameters of acceptance’ governed by those who surround us. Social norms are widely recognised as one of the most influential modes of persuasion.

This is an important consideration for the application of persuasive design theory to physical objects. Devices which may be considered ‘different’ by society, or which carry an ‘identity’ which differentiates a single user within a social group, will create expectations and pressures for the user to behave in particular ways. As reported in Chapter 2, existing medical equipment generally carries a visual design language of ‘illness’ and ‘disability’; this theory suggests such devices could be placing pressure on users to behave in a less able way (to conform to the perception of disability), or to risk social exclusion by adopting assistive or therapeutic devices in non-clinical settings. The UK Government Blue Badge Scheme is one example of how an intervention intended to support the specific needs of an individual can become an inadvertent burden in situations where the social perception of disability is misinformed or where social norms create particular behavioural expectations. The badges provide a range of parking benefits and other motoring concessions for people with severe or long-term mobility difficulties. Since their introduction in the 1970s (originally orange badges) anecdotal evidence has been presented by the British media suggesting that some badge users unfairly exploit the benefit system.

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The third factor, ‘agency’, is broadly defined as “an individual’s sense that they can carry out an action successfully, and that their action will help bring about the expected outcome.”\(^{207}\) The GSR review emphasises the importance of agency in determining how much effort we put into a behaviour, or indeed, if we attempt it at all. This can be considered as the ‘ability’ an individual has to perform a specific behaviour. This factor is affected by additional secondary factors such as: state of mind and motivation, and biological factors such as disease activity level, pain and tiredness.

As with Bandura’s ‘social persuasion’ mode of influence, an individual’s sense of agency can be negatively affected by both actual or perceived lack of ability. Perceptions of inability may deter individuals from applying effort to a given task. This can lead to learned non-use and, in-turn, lead to actual loss of ability. Developing a positive sense of agency is an essential element of persuasion and self-efficacy.

The following three factors are less universal - only featuring as independent factors in some models. They are nevertheless worth identifying within this study due to their relevance to persuasive design applied in the built environment:

‘Habit’, refers to automatic behaviours that we undertake frequently. We are not necessarily aware of our habitual behaviours and many become ‘tacit’; ‘automatic’ actions which are either learned or instinctive. The ‘automatic’ element of habit differentiates it from repeated behaviours\(^{208}\) - (actions that may be repeated but which we are aware of). Although not evident in all models, habits can be considered as the behaviours that people engage with ‘by default’ either as the result of a learned behaviour, personal responsibility or personal preference.

Existing habits and routines present valuable opportunities for bringing about behaviour change. Due to the passive nature of habitual behaviours they are less taxing than considered actions. The theory suggests that by introducing small or ‘micro’ adaptations to existing habits, which lead towards the targeted behaviour


sought by the intervention, behaviour change could be achieved in a particularly unbtrusive fashion. As a result the intervention should be easier to incorporate into existing daily life activities than entirely new behaviours that require a new habit or routine to be established.

‘Emotion’ is the fifth factor and perhaps one of the more complex. Darnton suggests that most socio-psychological models embed emotions within other components such as attitude. It is however, also noted that some models identify that emotion can have a powerful ‘overriding’ influence on our intentions and actions; fear for example can be an overpowering emotion that will override other intentions. Educational training, psychological and social support are interventions which could influence the emotional response an individual has when confronted with a treatment recommendation.

Finally ‘contextual factors’, are identified as the factors which an individual cannot control. The effects of illness and the perceptions of others, for example could be considered contextual factors. However, Darnton’s explanation also states that some contextual factors can be influenced by an individual’s perception: level of understanding, ability, access to information and cost, for example, are all factors which are not exclusively external. Individual circumstances will vary significantly with each. Designed objects and environments would also be considered contextual factors within this definition. However, as stated earlier, persuasive design must be considered an extension to existing behaviour change theories and include objects and environments as active agents in the application of systems for behavioural change.

These six factors combine to provide a broad overview of factors which contribute to behavioural engagement. In summary, currently available socio-psychological literature on behaviour change suggests that behaviour is determined by our: sense of agency and attitude towards a target behaviour, and is governed by personal and social norms. Habits, emotions and external factors can each serve as additional factors.

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influences; affecting what we do and how we behave through less self-determined, and perhaps, more instinctive means. The combination of these influences creates a behavioural ‘momentum’ and the behaviours that we achieve successfully become self-affirming and more easily repeated.

Multiple additional factors have been identified by behavioural theorists. Cialdini, Rhoads, Fogg and Kaptein, for example, each present their own principal factors of influence, however most, if not all, can be considered sub-components of those already discussed. Cialdini, distinguishes 6 strategies for behaviour change: ‘liking’, ‘authority’, ‘scarcity’, ‘consistency’, ‘reciprocity’ and ‘social proof’ as principal elements of persuasion. Rhoads, referenced by Kaptein, identifies over 100 tactics and strategies. Fogg identifies a total of 42 strategies and Kaptein identifies 36 persuasion principles including ‘reasoned action’, ‘opportunity’, ‘mood’ and ‘immediacy’.

**Healthcare specific models of behaviour**

Within the literature there are several models which have been specifically developed to understand behaviours related to health and wellbeing. This section will map the terrain of health specific behaviour change theories. The five models discussed below span the psychosocial spectrum from the complex, interrelated factors affecting the individual; to those concerned with the social and societal environments we all live within. Those identified, present both ‘micro’ (personal psyche) and ‘macro’ (social/structural) points of view. Presented chronologically, the complexity and scale of issues concerned can be seen to evolve and grow over time. Following this, the section also introduces the Fogg Behaviour Model (FBM). The FBM is an example of one of the more recent models of persuasive design. It helps to identify when and how persuasive interventions, such as those identified, may be most effectively applied.

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211 Cialdini, R. B., *Influence: Science and practice,* (Allyn and Bacon, Boston, MA. 2001)


**Lewin's Change Theory** (1951) is one of the earliest examples of Behaviour Change theory. It has provided the foundation for most subsequent theoretical developments. This model, primarily concerned with habitual behaviours, presents behaviour change as a three stage process: ‘unfreezing’, ‘moving’ and ‘refreezing’. The ‘unfreezing’ stage involves motivating individuals’ towards change, this includes identifying barriers and potential motivators. The second ‘moving’ stage identifies the transition between intended behaviour and behavioural action, and ‘refreezing’ refers to the reaffirmation of the new behaviour. An important aspect of maintaining the new behaviour is ensuring that ownership of the new behaviour is recognised and supported within the individual.215

This model is particularly popular within nursing and healthcare practices. The ‘identification’, ‘scrutiny’ and ‘changed action’ cycle provides the basic foundation for many behaviour change practices. Further developments of behaviour change theory seek to understand more about the barriers and motivators affecting our behaviours and distinguish differences between planned and un-planned behaviours.

Rosenstock's **Health Belief Model (HBM)** (1960, 1966, 1974) 216 seeks to facilitate preventative healthcare interventions. The model focuses on two aspects of an individual’s understanding of health and health behaviour: ‘threat perception’ and ‘behavioural evaluation’. Threat perception identifies two sub-components: perceived vulnerability to illness or health problems; and anticipated severity of the consequences of illnesses. Behavioural evaluation also identifies two sub-components - those concerning the benefits or efficacy of a recommended health behaviour and those concerning the costs of, or barriers to, engaging with the behaviour. Significantly, this model also identifies ‘cues to action’ - facilitatory triggers which can prompt an individual to act on a desired behaviour. These ‘cues’ can include a diverse range of triggers such as individual perceptions of symptoms, social influence and health education campaigns.


This model is particularly significant to the aims of RA treatment interventions because it aligns closely with the aims of disease management strategies. The HBM has proven to be an effective method for predicting adherence behaviours amongst patients who receive behavioural healthcare recommendations including: use of asthma inhalers; smoking cessation; improved dental care and improved diet.\textsuperscript{217} Although an effective predictor of behaviour, evidence for the efficacy of this model as an effective intervention strategy for behaviour change is limited. This is most likely due to the difficulties associated with quantitatively identifying the impact of preventative interventions against other potential contributing factors. A further limitation is that this model purely focuses on the psychological factors associated with preventative health behaviours. Social and environmental factors are not considered. Importantly this model identifies ‘cues to action’ or ‘trigger factors’ - suggesting that individuals not only require the attitude and ability to engage with a behaviour, but also a trigger or nudge to perform the action at a particular moment in time. This is an essential consideration for behaviour change interventions, especially when considering individuals who are not self-effective or for whom the target behaviour does not relate to existing habits or routines.

The third health specific model to consider is Rogers **Protection Motivation Theory** (PMT) (Rogers 1975).\(^{218}\) This model is similar to the HBM. Both the PMT and HBM theories share the idea that motivation toward protection is the result of an individuals’ understanding of perceived threat and the desire to avoid the potential negative outcome. These theories also share a cost versus benefit analysis component in which the individual is considered to weigh the costs of taking the precautionary action against the expected benefits of taking action.

![Fig 2.24](https://example.com/fig224.jpg)


The PMT, however, also identifies ‘protection motivation’ as an additional mediating factor between perceived threat and intention to change. ‘Protection motivation’ or ‘self-efficacy’ therefore becomes the principle determinant of ones ability to change their behaviour, so that the individual must be sufficiently motivated by their understanding of contributing factors to adopt a change in attitude. This model focusses specifically on the perception of threat and intention to change: actual behavioural outcomes are not identified.

**Ajzen Theory of Planned Behaviour** (TPB) (1986, 1991) remains one of the most well known socio-psychological behaviour models and is also one of the most relevant to healthcare interventions. Fig 2.25 shows Ajzen’s ‘adjusted’ theory of planned behaviour (1991), a later development of the original 1986 model. Three core behavioural influences, now widely accepted as universal factors for behaviour

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change, form the basis of the TPB: The first, *Attitude toward Behaviour*, is defined as “the degree to which a person has a favorable or unfavorable evaluation or appraisal of the behavior in question”.\(^{219}\) The second, *Subjective Norms*, refers to “the perceived social pressure to perform or not to perform the behavior”.\(^{220}\) and thirdly, *Perceived Behavioural Control*, which refers to “the perceived ease or difficulty of performing the behavior”.\(^{221}\) This is assumed to reflect past experience as well as anticipated impediments and obstacles. *Relative Importance* was a later addition to the model and identifies a conscious ‘value’ assessment as an additional consideration. This model has been applied to help predict and guide behaviours and during the development of treatment interventions.\(^{222}\)\(^{223}\)\(^{224}\) This model also identifies actual behavioural outcomes as an additional stage after intention.

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The TPB model has become the foundation of many subsequent behavioural models. This is recognised as a ‘means-end’ mode of action, one directional and concerned with achieving a pre-defined goal. The TPB suggests that: the more favourable one’s attitude towards the behaviour, the greater the social pressure supporting that action, the greater the perceived behavioural control an individual has and the more likely they are to perform the behaviour under consideration. This model utilises the basic principles of rational choice and deliberate decision making (intention), whilst also identifying the possibility of behaviours which bypass this intentionality, such as habitual or emotional actions, defined by the ‘perceived behavioural control’ node.

Ajzen goes some way to explaining key factors for consideration when investigating behaviour change within an individual; the more willing and able we are to action a behaviour, and the more social support we receive, the more likely we are to do so. However, a limitation of this model is that behaviour is presented as a linear sequence of factors, each deliberately considered and leading to reasoned outcome. As complex, autonomous human beings this is not always the case. Furthermore, once the outcome behaviour is achieved the model stops, limiting behavioural change to one-off actions. This is helpful when considering isolated activities but insufficient when seeking to achieve long-lasting behaviour change, especially when the target behaviour is a preventative intervention as opposed to a solution. Also, this model places sole responsibility on the individual to instigate and fulfil a target behaviour and is therefore dependent on an individuals’ ability to be self-motivated and self-effective.

The Main Determinants of Health Model developed by Dahlgren and Whitehead (1991),\(^\text{225}\) provides a ‘macro’ overview of factors identifying the relationship between the individual, their environment and their health. This ‘societal’ model is positioned to provide an ‘ecology’ of factors which contribute to behaviour. The model identifies

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the individual, in this case referring to biological make-up, as the central element beneath four layers of influence. Moving outwards from the centre, these layers are: ‘lifestyle/behavioural factors’, ‘material support networks’ (family, friends, etc), ‘material living conditions’ (housing, the work place, living conditions) and ‘structural environment’ (taxation, government policies, culture).


Adopted by the WHO, this model identifies more of the complexities to be considered when developing behaviour change strategies for real world applications. Dahlgren and Whitehead suggest that interventions should target all levels simultaneously for lasting behaviour change to be achieved. They also identify that each level requires its own ‘feedback loop’, linking interventions and developments between levels. This model identifies the need for widespread systemic intervention to facilitate significant and long-lasting behavioural change.

This is significant for the development of interventions which exist in the built environment. This model suggests that providing objects which only attend to the biological needs of the individual will not be successful because their conception will be too localised to one element of the problem. To overcome this, designed objects and environments must consider both the specific needs of the individual and the wider contexts within which they are situated, and where possible, interact between
levels. The UK government’s FRANK drugs awareness campaign is an example of how the social model of health can be applied to inform the development of health intervention initiatives.\textsuperscript{226} The FRANK campaign combines treatment and support services on personal and social levels through education services and employer initiatives, and supported with a large scale national marketing campaign.\textsuperscript{227}

**The Fogg Behavior Model (FBM)**\textsuperscript{228} (2009, 2011) Finally, the FBM provides a conceptual map of how behavioural interventions can be operationalised by emphasising the link between ability and motivation, and identifying the point at which interventions should be appropriated to individual needs. The FBM suggests: “behaviour is a product of three factors: motivation, ability and triggers, [each of which has subcomponents] … for a person to perform a target behaviour, he or she must (i) be sufficiently motivated, (ii) have the ability to perform the behaviour (iii) be triggered to perform the behaviour.” Also specifying: “These three factors must occur at the same moment, else the behaviour will not happen”.\textsuperscript{229} \textsuperscript{230} As with Bandura’s concept of self-efficacy, Fogg suggests that behavioural activation is dependent on a balance between motivation and ability factors. Fig 2.27 describes this concept as a two value, axis chart.

\textsuperscript{226} Wood, M. "Applying Commercial Marketing Theory to Social Marketing: A Tale of 4ps (and a B)." *Social Marketing Quarterly* 14, no. 1 (2008): 83

\textsuperscript{227} Forster Communications "Frank: Young People and Drugs Awareness." accessed December 2012 http://www.forster.co.uk/case-studies/frank/

\textsuperscript{228} Fogg, B. A behavior model for persuasive design. (Proceedings of the 4th International Conference on Persuasive Technology. Claremont, California, ACM, 2009): 1

\textsuperscript{229} Fogg, B. A behavior model for persuasive design. (Proceedings of the 4th International Conference on Persuasive Technology. Claremont, California, ACM, 2009): 1

\textsuperscript{230} Fogg, B.J., *Persuasive Technology: Using Computers to Change What We Think and Do* (Morgan Kaufmann, 2002)
The model suggests that if a user has low ability they will need to be highly motivated to complete a difficult task and, conversely, if a user has low motivation they will require easy tasks to facilitate engagement. A task which is too difficult and which the user is not motivated to do is unlikely to be attempted and therefore will not bring about behaviour change. This concept of ability matching motivation is both a rational and logical theory and is implicit throughout many socio-psychological models of behaviour. Most learning activities, for example, require a learner to be challenged at a suitable level in order to become engaged. Progressive developments can then evolve towards more challenging tasks. The same principle applies to therapeutic exercise interventions: begin with simple, achievable tasks and progress to more challenging (and more beneficial) exercises over time as both ability and willingness increase.
Summary of key points

Models of behaviour do not determine behavioural actions. Models are a means to understand, and sometimes predict, the way we behave. The benefit of behavioural models is that they enable us to assess and compare theoretical positions, develop structured hypothetical thinking and to identify opportunities for where further developments in research should be focussed. In this thesis, behavioural models have been used as a tool to help identify opportunities for where behaviour change interventions could be targeted for greatest effect and where further developments need to take place. Socio-psychological models of behaviour are limited in their ability to account for the actual behaviours of individual people due to their nature as simplified theoretical interpretations of complex behaviours. They are based on common features and social averages and cannot, therefore, account for the intricacies and nuances of actual human behaviour.

Each of the health-specific models outlined above is closely linked to basic economic theory, which assumes that individuals consider their behaviours rationally, assessing cost/threat versus benefit, before actioning a behaviour. Whilst effective for predicting behavioural deviation from healthcare recommendations, these models are limited in their ability to influence behaviour change due to their limited recognition of habitual or non-intentional actions. Differences between intentional and non-intentional non-compliance, for example, cannot be accounted for within many of these models. Furthermore, socio-psychological models of behaviour are only concerned with factors within the human psyche. They do not consider the effects of physical environments on our behaviours. To consider the application of behaviour change theory to physical design outcomes we need to identify the influences that objects and environments that we interact with from day to day may have on the way we behave. All encounters that we have with others are mediated by the objects and environments that we use or engage with, as part of our normal daily lives.

- Behaviour is determined by multiple influences these can be broadly summarised to be: Ability, Norms, Agency, Habit, Emotion and Contextual factors.
• Socio-psychological models do not consider objects and environments as potential contributors to behavioural actions.

• To achieve long-term efficacy, behaviour change interventions need to consider and apply an ecology of factors to enable the target behaviour to be the most appealing option to the user.

• To achieve initial engagement, interventions need to align with the ability and willingness of users to participate.

• Once engagement is achieved, behavioural actions can evolve incrementally towards those with greater rewards but which present greater challenge.
Implications for Research

This section provides a summary of knowledge gained as a result of the literature review, highlighting key points relevant for the development of this study. A new behaviour change model is also presented, which is specific to improving patient engagement with therapeutic exercise recommendations through designed objects and environments.

Devices available for people living with RA can be split into two broad categories: assistive and therapeutic. Assistive devices seek to reduce the burden of daily life activities by simplifying or removing physical challenge from daily tasks. Therapeutic devices seek to maintain and develop the functional abilities of users by promoting physical exertions in the pinch, grip and dexterity movements. Assistive devices are popular because of their immediate benefits, but have the potential to cause long-term dependency and decreased functional capacity. Therapeutic devices tend to be less popular due to their inherent challenges, low perceived benefit and unpopular image. Currently available therapeutic exercise devices are functionally effective but tend not to be used over prolonged periods of time because they fail to engage patients.

The benefits of physical exercise as part of daily life, and the threat that a sedentary poses to overall wellbeing, have been recognised for over 150 years. Designers have developed countless products to support wellbeing and some have achieved great commercial success. The general trend, however, has been towards the more popular and therefore more profitable assistive devices. Design strategies such as user- and human-centred design have been developed to try to match the the aims of industry with needs of users. However, not all of these approaches consider long-term health implications of their products as part of the design process. There is an overwhelming preference throughout design and health philosophies for design to minimise physical exertions. Whilst this approach is a hugely beneficial and necessary in many circumstances, the way that we apply concepts of ease, simplicity and minimum effort need to evolve if we are to reach a point at which design is successfully applied to actively promote physical health and wellbeing. Whilst attempts have been made by people such as Zander and Tye to integrate active health promotion within the built environment, this approach is not widely adopted within current design practices. There is therefore significant opportunity for targeted challenge to be incorporated into designed objects and environments for
the purpose of promoting physical health and wellbeing. This considered introduction of targeted physical challenge into design does however require a significant shift in how we conceive of the nature and purpose of design for health and wellbeing.

Persuasive design offers a new design paradigm in which the attitudes and behaviours of the user become the target of the design intervention. Biological, psychological and social factors all become considerations for the designer as part of a systems design approach. Ongoing technological developments present new possibilities and new considerations for the appropriateness and extent to which design is applied. The features which define RA and how it is treated offer clear parameters for design interventions, and further emphasise the need for a comprehensive systems approach to design. Patient engagement with healthcare recommendations can be recognised as perhaps the most critical aspect of the healthcare challenge and is central to the aims of this study. Behaviour change theory offers a solid foundation from which an RA-specific persuasive design theory can be developed.

*Within this study Persuasive Design is defined as: an area of design research which seeks to affect a person’s attitude or behaviour, through designed objects and environments, to facilitate and support concordance with healthcare recommendations.*

The behaviour models reviewed within this thesis cover a wide spectrum of factors which are considered to influence how we think and what we do. Some of these factors are directly relevant to the aims of this study. The model presented in the following section incorporates the factors considered to be most relevant to this study.

**Persuasive Design Model for Therapeutic Exercise**

This thesis suggests that the objects and environments that we own, use and interact with, should be considered as additional ‘active agents’, defining who we are and how we behave and therefore must be included in conceptual models for behaviour. They affect our attitudes, position or identity within society, our ability to do things, our emotional state and our access to resources and information. Whilst identified as separate factors within this model they should not be considered mutually exclusive. Many factors are interrelated and co-dependent.
Fig 2.28 (original in colour) Persuasive Design Model for Therapeutic Exercise, T. Ainsworth, (2012)
Agency, the sense that an individual can carry out a desired behaviour. In the case of RA, this is directly influenced by disease activity level and the psychological state of the individual affected. If a patient is experiencing discomfort, low self-esteem or a sense of heightened vulnerability, they are likely to have a low sense of agency; behaviours which had previously been easy to achieve will feel difficult and motivation will be compromised. In this respect effective pharmacological interventions are an important element of patient empowerment. Pain relief and disease modification will have a direct impact on the sense of agency within the individual.

Attitude, patient perceptions of disease threat and severity, and perceived benefits and barriers are core psychological factors that influence an individual’s attitude towards a particular behaviour. Attitude can be closely linked to motivation and willingness to engage. Past behaviour, lifestyle choices, socioeconomic status and political climate also influence attitudes. Designable features such as scarcity, perceived value, fashions and trends, desirability, functionality; each have the potential to affect patient attitudes towards treatment intervention.

Norms identifies the role of others in facilitating and encouraging positive, and discouraging negative behaviours. This factor identifies the opportunity that designers have to develop interventions that actively promote positive social support. The Jawbone-UP and Nike Fuelband each utilise normative social behaviours as a means to actively promote engagement. For people living with RA, support networks could include patient peers, charity organisations, therapists and other carers in the multidisciplinary team.

Trigger refers to a facilitator or catalyst for action. Triggers should be context-aware and provide an appropriate and achievable prompt at the most opportune moment in time. They can be influenced by personal motivations (attitude), social pressures (norms) or the ability an individual has to complete the behaviour (agency). They may be the result of an existing behaviour or routine, or, instigated by disease activity level, medical consultation, or by designed objects and environments.

Active decision-making refers to self-effective, conscious, decision-making. Some individuals are very good at performing particular behaviours, especially if there is an
immediate benefit of doing so, or a particular personal responsibility or motivation. Active, self-effective engagement with long-term therapeutic exercise is highly challenging and requires a high level of discipline and commitment. Triggers can help to support active engagement, however, the receiver must be willing to engage for the behavioural outcome to be achieved.

**Passive decision-making** refers to habitual, emotional or reactive behaviours. Passive behaviours tend to be simple actions that people practice from day to day. Once a habitual behaviour is established it is completed easily and with minimum effort by the individual. The momentum of established behaviours provides an opportunity for therapeutic interventions to be introduced as micro-adaptations of existing routines. If this could be achieved the discipline and commitment required for active engagement could be relieved.

**Designed Objects and Environments** are identified here as the principal mediating factor between influences and desired behaviours. All our interactions are mediated by the objects and environments that surround us. The specific properties of these objects and environments, both actual and perceived, not only enable particular behaviours to occur, but can also function as ‘active agents’ facilitating, triggering and influencing our ability and willingness to perform certain actions. This domain is the specific target of persuasive design interventions.

**Therapeutic Exercise Behaviour** is the overall target which design interventions seek to achieve. Specific details of this particular activity will vary between individuals depending on their own particular needs.

To apply this model effectively, an understanding of the everyday lives of people living with RA is required. Accurate and detailed information about what people do, the objects and environments they engage with, and the activities they enjoy need to be identified. To achieve this, a qualitative primary research study must be developed to facilitate these discussion points and to capture reliable evidence. The following section will outline and critique a number of research methods and define those which are best suited to achieve the aims of this study.
Chapter 3. Methodology

This chapter will outline and discuss the methodology used to conduct the research study. The study design and procedure are outlined in detail. Throughout the chapter, details are given of how the selected methods is expected to answer each of the research questions. To describe each of these elements in more detail and with maximum clarity the chapter is divided into the following sections:

**Research methods**: This section identifies available qualitative research methods and presents a rationale for those selected. A number of qualitative research methods are critiqued for their ability to gather accurate and detailed information from research participants. Visual methods such as: ‘cultural probes’ and ‘photo elicitation’ are presented alongside more traditional methods of: ‘research interviews’, ‘participant observation’ and ‘focus group’s.

**Study design**: Provides specific details of the study and the innovative application of selected research methods. An innovative study design is presented which combines selected elements of the ‘cultural probe’s and ‘photo elicitation’ methods, set in a ‘focus group’ study format.

**Ethical considerations**: Details of the measures taken to ensure good research practice with NHS patients is outlined in this section. A brief overview of the NHS research ethics application completed prior to the study commencement are detailed including: an outline of ethical concerns, details of the consent process, and bulleted inclusion and exclusion criteria.

**Procedure**: Describes the implementation of the study in detail. Including the recruitment, conduct and analysis of the study. Four activities are described 1) Initial focus group session, 2) Photographic Visual Research study 3) Photo elicitation focus group 4) Presentation of findings to participants and assessment of perceived validity of design outcomes.
Research methods

When considering which research methods are best suited to fulfil the aims of an area of research, it is necessary to identify the parameters by which the knowledge generated can be considered to be ‘knowable’ i.e. by what means was the knowledge generated? and what factors ensure outcomes are justified? There are two broad epistemological positions which help to focus these questions: the first is based on a belief that there is a knowable world that is separate from the researcher. Research is used as a means to objectively, gain insights into phenomena that already exist; the second is based on a belief that the researcher cannot be separated from the research. Instead our understanding of the world is constructed during the research process based on interpretations of findings.231

The complex intricacies, nuances and contradictions of human behaviour mean that absolute objectivity is almost impossible to achieve. Therefore an interpretive approach is considered to be a more appropriate and more effective means to gain insights into the everyday lives of people living with RA. Both quantitative and qualitative research methods can be used to gather information about people and their needs. Each approach has its specific strengths and weaknesses. The benefits and limitations of each will be briefly outlined below, followed by a more detailed outline of the methods suitable for this study.

Quantitative research uses statistical information to deduce meaning from research data. This approach is commonly used to test a theory or hypothesis objectively. Results tend to be generalisable and easily compared to results from other studies. They are however limited in their ability to gather detailed information from highly complex or multifaceted sources - complexity often has to be generalised or simplified into definable, controllable parameters, thus providing a statistical interpretation of a research concept or idea. For example, the thoughts and opinions of individual people cannot be accurately, or reliably, captured by quantitative

methods; the intricacies and nuances of individual differences would have to be sacrificed for more general but quantifiable statistical data.

Qualitative research is a loose categorisation of research which explores themes, stories, narratives, language and the intricate details of people and their interactions. Data can be gathered from texts, notes, images, recordings and transcripts and is used to generate new ideas, theories and meanings. When practised in conjunction with empirical research, qualitative research can provide outputs which are both comprehensive and highly detailed. Qualitative methods tend to generate more ‘noise’, often requiring high levels of interpretation to deduce meaning. This presents a particular challenge to ensure outcomes are trustworthy and robust. Interpretive approaches are considered to be more suitable to explore individual perceptions of health and physical activity and the decision-making processes regarding how and why they spend time in various activities.

The research methodology outlined here combines a number of qualitative research methods to gather detailed information about the everyday lives of people living with RA. The study aims to establish a detailed understanding of the complexity of life with RA and the factors which determine patient engagement with therapeutic exercise recommendations; including: symptoms, treatments, work, personal and social factors. The methods will explore the underlying reasons for participation in physical activity and the decisions, motives and barriers involved. The research seeks to extend our understanding of the following key questions:

- RQ 1. What designable factors, specific to people with RA, should be targeted to affect the ability and willingness of patients to engage with longterm therapeutic exercise recommendations?
- RQ 2. What specific motivators, present in the daily life activities, should be targeted to facilitate and sustain longterm engagement with therapeutic exercise interventions for people with RA.

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• RQ 3. Can these factors be applied to inform the development of objects intended for long-term therapeutic use?

There are a range of qualitative research methods capable of gathering detailed information from research participants. How these methods are selected and used and how the data are analysed determines the detail and accuracy of study results. Adopting a co-design approach, utilising the expertise of multiple stakeholders (described in detail in Chapter 2), this methodology was developed in collaboration with an ‘expert patient’ recruited through the National Rheumatoid Arthritis Association (NRAS). The complexity of human factors that affect the ability and willingness of patients to engage with healthcare recommendations presents an opportunity to adopt innovative research methods, capable of developing new kinds of knowledge through means which are not commonly associated with healthcare research, to identify complex human-centred research data and new opportunities for interventions. The findings obtained from such a qualitative approach will then be used to inform the development of new theoretical models capable of guiding the development of effective future interventions.

This section will discuss the range of methods available to obtain detailed qualitative information from research participants. This will include the use of ‘visual research methods’ as ‘respondent-generated’ research data, and an overview of more traditional research approaches such as: research interviews, participant observation and focus groups, to gather new insights about patient needs and the lived experience of RA. Design researchers adopt a range of research methods depending on the kind of information they seek to gather and the kind of design they seek to develop.

**Ethnographic methods**

Hammersley and Atkinson characterise ethnography in the following way: “the search for universal laws is rejected in favour of detailed descriptions of the concrete experience of life within a particular culture and of the social rules or patterns that constitute it”.\(^{233}\) A core conceptual feature of ethnographic methods is that all forms of knowledge, expertise and experience are considered to be variable and therefore

open to critique, a feature particularly valuable when seeking to identify opportunities for new interventions. Ethnography is a methodological approach based on observation, through ‘participant’ and ‘non-participant’ methods in natural settings. This approach is both philosophically and epistemologically different to the established and more traditional biomedical approaches to healthcare research. Lambert suggests:

Using a biomedical approach to problems in qualitative health research results in a narrow investigation of “lay” beliefs (and occasionally, practices), often with the intention of translating these to professionals, to inform ways of improving adherence to their interventions.\(^{234}\)

By contrast, ethnographic methods can gain insights into complex socio-psychological issues that more traditional approaches may not be able to achieve. Within this study an ethnographic approach could be used to observe participants engaging in daily life routines and identify opportunities for where design interventions could be introduced. Direct observation or video recording of activities could potentially enable detailed information to be gathered for analysis and differences between ‘intended’ and ‘actual’ engagement with therapeutic exercise recommendations could be identified and assessed.

There are however, a number of limitations presented by this approach. The act of observation may alter the behaviour of the group being studied. Direct observation in personal settings, such as the home and work environment, would be intrusive, time consuming and expensive. Insights into personal, private or taboo consequences would be difficult to reveal and staged environments will provide very limited insights. It is also likely that a study design of this kind, that seeks to gain insights into everyday behaviours, would be difficult to recruit for.

**Phenomenography**

Phenomenography is an explorative and interpretive approach to qualitative research which seeks to produce a collective analysis of individual experience. Similar to ethnography, phenomenography seeks to describe, understand and analyse experience. One key difference, however, is that phenomenography utilises personal

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accounts of experience rather than observation as its primary means to capture data. Phenomenographic methods, such as structured and semi-structured interviews, are used to systematically explore participants’ experiences and identify conceptual meanings of the phenomenon of interest. Coded analysis is then used to categorise data according to their similarities and differences. Findings describe the different categories of conceptions of the phenomenon from the perspective of participants. Thus, the collective variations of conception of the phenomenon rather than the conceptions of the individual participants are reported. This approach actively avoids creating distinctions between what is ‘real’ and what is ‘perceived’; Barnard, McCosker and Gerber (1999) describe the ontology of phenomenography as follows:

It is argued that there is not a real, objective world on one hand and an unreal subjective world on the other. There is only one world, which is understood and experienced in various ways by people. This world is always both objective and subjective at the same time. Experience is as much object as it is subject. Thus, how an object appears to the subject is synonymous with how the subject experiences the object.

The particular strength of phenomenography is its ability to qualitatively describe the different ways people make sense of, experience, and understand phenomena in the world around them and how these compare across the group. In the context of this study the phenomena to be explored is the lived experience of RA.

Limitations of this approach are; firstly, that findings are solely determined by language. Research participants require the language skills to be able to describe the phenomena accurately and consistently. The researcher requires the skills to accurately and reliably interpret different uses of language and distinguish meaning from spoken words and other, more discrete, verbal utterances. The one-to-one nature of this approach is also a limitation on the context of this study; the interview must be thorough and followed by a detailed analysis to achieve findings that are both meaningful and accurate. This process will be time consuming and of limited value to the aims of this study, which seeks to gain a broader understanding of patient needs.

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**Case study**

A case study model was also considered for this project. A case study model may use a combination of observation, interview, archival and survey methods to investigate complex social phenomena. This approach aims to provide rich and comprehensive data set which can be interrogated and analysed through multiple methods to provide highly detailed and holistic results.\(^{237}\) Findings are presented as descriptive texts which offer both the reader and the researcher the opportunity to interpret findings. Whilst this approach would be largely appropriate to answer the questions posed by this study, there are further opportunities to enrich the data sample. Methods which offer cyclical or repeated data gathering opportunities and those which offer support for a wider range of communication modes, particularly visual, could be adopted to increase accessibility and further strengthen research findings.

**Visual research methods**

Visual research methods have been used for decades. Since the invention of the camera and the videocamera the use of images and film footage in visual research has increased. In recent years, interest in visual research methods has grown across academic disciplines. Artists, designers, social scientists and anthropologists in particular have adopted visual methods to facilitate and enrich their studies, both methodologically and theoretically. The Economic and Social Research Council (ESRC), National Centre for Research Methods Review Paper (2008) states:

> Visual methods offer a range of alternative, diverse and creative possibilities that will expand and support the shifting orientation of social science research and ultimately advance knowledge. Simply put visual methods can: provide an alternative to the hegemony of a word-and-number based academy; slow down observation and encourage deeper and more effective reflection on all things visual and visualisable; and with it enhance our understanding of sensory embodiment and communication, and hence reflect more fully the diversity of human experiences.\(^ {238} \)

Furthermore, visual methods can serve as evocative artefacts for challenging concepts which may otherwise be too narrowly conceived or explored. They can serve as a method of divergence which can illuminate new possibilities and new

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opportunities for investigation, innovation and development. The possibilities for visual research methods are vast. Weber (2008), cited by Prosser (2008), identifies 5 ways in which images can be used within qualitative research studies:

- Images can be produced by participants as data
- Found or existing images can be used as data or springboards for theorizing
- Images and objects are useful to elicit or provoke other data
- Images can be used for feedback and documentation of the research process
- Images are useful as a mode of interpretation and/or representation

The purpose of incorporating visual research methods into this study is to reveal and identify ‘embodied information’ evident in the objects, environments and activities that people choose to engage with as part of everyday life. To achieve this, respondent-generated visual ‘data’ will be incorporated into the study design. This approach will present the opportunity for respondents to make considered contributions to the study by allowing them to select and capture factors which are important to them but which are within the parameters of the study design.

Research produced through respondent generated visual methods is a way of empowering participants by enabling them to identify and prioritise information that is most significant to them and their needs. In this instance the nature of participation shifts from the participant as the focus of the study to the participant as co-researcher. User generated visual research data can then be utilised as conversational triggers during discussion sessions to facilitate focussed discourse. This approach emphasises the inclusive, collaborative, nature of this research and firmly places this as a study conducting research with participants rather than on participants.

The use of participant-generated visual research differs significantly from the more orthodox or traditional approaches to research. More traditional approaches would generally leave the researcher to control all aspects of the study: framing the research (question, hypothesis or idea), designing the study, gathering the data, analysing results and reporting findings.Whilst highly effective and appropriate in many cases, this approach can lead to highly researcher-centric interpretations of the

world around us. Empowering research participants with the ability to present their own first-hand renderings of themselves will help to redress the balance between researcher and researched and reveal insights that could not be achieved by any other means.

This form of participant empowerment is intended to enable patients to reveal information about their lives and the impact of RA on what they do, the decisions they make and the lifestyle they lead. It must however be recognised that when using these methods that the range, depth and willingness of respondent participation will vary. Furthermore, the analysis must take into account the fact that images, especially drawings and photographs, are constructed representations of personal experiences or activities and not “unmediated renderings”\footnote{Prosser, J., A. Loxley. “Introducing Visual Methods.” ESRC, National Centre for Research Methods (2008): 19} of reality. Elements of \textit{significance} and \textit{triviality} can be projected onto images in infinite ways, therefore any form of ‘meaning’ facilitated, represented or embodied in visual research imagery is a negotiation between the creator, the researcher and the participant group. Responding to these images through discussion and analysis requires particular care, attention and sensitivity to personal issues and ethical responsibilities. These points will be discussed in more detail in the section describing the final study design.

\textbf{Cultural probes} were developed by design researchers Gaver and Dunne in 1999 as part of a research project looking at novel interaction techniques to increase the presence of the elderly in their local communities.\footnote{Gaver, B. et al. (1999). "Design: Cultural probes.", \textit{Interactions} 6(1): 21-29.} Though still regarded as a relatively new approach to design research, cultural probes are becoming more widely recognised as an effective approach for gaining in-depth information and sustained dialogue with group members.\footnote{Kuniavsky, M. \textit{Smart Things}. (London, Morgan Kaufman. 2010)} This method invites participants to engage with ‘novel interaction techniques’ designed to provoke inspirational responses and provide qualitative data that illustrates the lives and memories of participants. ‘Interaction packs’ are provided by the researcher that may include: cameras, diaries, maps, dictaphones, photo-albums, postcards etc\footnote{Gaver, B. et al. (1999). "Design: Cultural probes.", \textit{Interactions} 6(1): 21-29.} to facilitate
participant engagement. Participants are asked to respond to the materials through either instruction or intuition before posting the pack back to the research team. These methods enable the research team to see parts of the participants’ lives that could not have been achieved through other means.

Although Gaver and Dunne specifically state “the probes were not designed to be analysed”, the information gathered was informally assessed by the researchers to identify emerging themes and to establish an “impressionistic” account of participant beliefs and desires, their aesthetic preferences and cultural concerns. The interpreted information was then used by the researchers to produce artworks and design outcomes inspired by the information gathered.

The strengths of cultural probes as defined by Gaver and Dunne are numerous. They are able to: i) identify, record and communicate the complexities of ‘real-life’ into ‘snap-shots’ of respondent generated ‘data’ ii) bring narrative and a rich contextual understanding of research participants iii) identify participants’ emotional, aesthetic, and social values and habits iv) provide a wealth of materials from which design developments can be inspired.

There are however a number of limitations with this example which compromise the integrity of outcomes in terms of ‘research’. The process by which respondent-generated content is interpreted and applied is entirely researcher-centred. The team appear to have responded reflexively to research materials by selecting content based on their own preferences or interests. Whilst a degree of reflexivity is often required when assessing qualitative data, especially when that content is visual, doing so without participation from the individuals who generated it can serve to detach that content from its intended meaning. The process becomes an exercise in selective information harvesting as opposed to quantified and grounded understanding.

244 Gaver, B. et al. (1999). "Design: Cultural probes.", Interactions 6(1): 27
There are further, more pragmatic considerations to be made with this kind of approach. Firstly, the cost of materials as providing research materials for an adequately sized cohort of research participants may become prohibitively expensive. Secondly, this approach is very demanding on research participants and so requires a high level of personal commitment. Additionally, specific considerations for research ethics and study procedures must be made due to the highly personal, and potentially sensitive, nature of information gathered.

**Photo elicitation** is a technique widely used for qualitative enquiry. Used to facilitate deeper discussion, photographs, drawings and artefacts can be used to: trigger, unlock and identify personal narratives, social contexts and emotional elements within a respondent group. Prosser and Loxley (2008) describe this approach as “using images as tools via a dialogical process to gain an insight into the lifeworlds of those who participate in our studies.” Images and materials used within the photo elicitation process can be sourced to suit the study aims whether found, designed, researcher-generated or respondent-generated.

One of the key benefits of photo elicitation is participant empowerment. For this to be achieved successfully, the nature of materials used must be carefully selected to support study aims and to maximise participation. Images, drawings, or any other photo-elicitation materials which fail to engage participants could be counter-productive. They could: undermine their willingness to actively participate in the study, lead to trivial or irrelevant responses, distort data gathered or alienate participants. Additionally, the ability for respondents to talk about their thoughts and experiences will vary significantly between individuals depending on multiple causal factors such as: their confidence, language skills, education level or willingness to engage. Using image-based materials such as photographs can enable people to engage in the activity without having to rely on language skills alone.

Using respondent-generated images to facilitate photo-elicitation can help to overcome some of these issues. Individual participants can engage with more autonomy and less inhibition due to their deeper involvement in the production of the elicitation tools. Wider discussion then evolves iteratively as respondents share

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reflexive thoughts, narratives and anecdotes. Respondent-generated content must however, be treated with particular care and sensitivity. Images could provoke emotional responses from individuals, especially if they symbolise or represent personal sensitivities. Measures must be taken to minimise stress and anxiety within the participant group.

**Dialogic research methods**

Inherent to qualitative research methods is the possibility for a large amount of ‘noise’ generated: that is, information gathered which does not help to fulfil the research aims. To limit the amount of noise generated and to provide multiple opportunities for research participants to express their point of view, discussion-based research methods will also be used. Utilising dialogic research methods can further empower research participants. This will provide the opportunity for participant-generated visual materials to be thoroughly examined and discussed, and for personal narratives to emerge and be captured as part of the fieldwork study process. There are several forms of discussion-based research methods such as research interviews, participant observation and discussion and focus group studies.

**Research interviews** usually consist of one-to-one discussion between researcher and research participant. The principal strength of this method is that a researcher can gather detailed and in-depth information about a specific topic or theme. There are several ways of conducting a research interview: face to face or long distance via structured, semi-structured or structured; verbal, written or on video. There are however, also a number of limitations. Firstly, research interviews tend to be very time consuming with each interview having to be organised, recorded and transcribed separately. Secondly, conducting successful interviews which capture the true opinion of the participant accurately and concisely and in line with the research aims, requires great skill from the researcher. Thirdly, data gathered from personal interviews is usually not very generalisable. The recorded information is only evidence of the opinion of one person at that moment in time. The aims of this study require information to be gathered from as many people living with RA as possible. Conducting one-to-one interviews with a sufficient number of research participants to

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obtain a truly representative data sample would be prohibitively time consuming for this study.

**Participant observation** is a method in which the researcher observes the behaviour of research participants from within the group in a ‘naturalistic setting’. Naturalistic observation involves looking behaviour as it occurs in its natural setting with no attempt to intervene on the part of the researcher. The strengths of this research method are that:

i) the researcher is able to collect data on a wide range of behaviours including, body language, spoken word, and social nuances.

ii) the research process is open-ended, following the behaviour of the group to identify research outcomes.

iii) the researcher is able to gather data from a greater range of interactions with participants such as sharing a group activity/workshop experience, informal conversation and subtle interpersonal interactions.\(^{249}\)

Limitations and challenges of this method include: specific considerations of research ethics, such as the relationship between research participants and researcher and what effect this may have on data gathered? The activity that participants are engaging with at the time of observation must be considered and designed to meet study aims and finally, data gathered will be highly interpretive and may require feedback and clarification of observations with research participants to ensure observations have been correctly interpreted. This method offers efficiency to data collection, by studying multiple participants at the same time. However, because this study is seeking information about everyday activities, replicating such events as a group participation activity would be impractical and impersonal.

**Focus group studies** involve guided discussion facilitated by the researcher with multiple research participants. When run effectively, focus group studies can cover a broad range of topics, and gather information which is both detailed and in-depth. This method is highly effective for gathering ‘contextual information’ from participants, information that is not exclusive to the questions asked but which

\(^{249}\) Morgan, D. L. *Focus groups as qualitative research* (Sage Publications, London, 1997): 8
enriches and deepens overall understanding of the points raised and reasons why. Particular strengths of focus group studies include:

i) the opportunity to gather large amounts of information within a short space of time.
ii) the researcher/facilitator is able to guide the conversation to ensure data gathered is focussed on the study aims.
iii) when applied effectively can be very efficient, both in logistical and practical terms and in terms of quantity and quality of data gathered.²⁵⁰

The limitations and challenges associated with focus groups include: recruitment, time management and maintaining research focus. The ideal size for a focus group study will vary depending on the purpose of the study. The aim is to establish a group dynamic which is suitable for gathering both accurate and detailed information that is relevant to the study aims. A group that is too small will not provide a broad enough range of information and a group too large will restrict opportunities for individuals to express themselves.²⁵¹ Also, those recruited must accurately represent the group at which the research is aimed, and for whom participation will not cause unnecessary distress.

To ensure data gathered are truly representative, focus group sessions must be repeated with different groups of participants, until the point at which the data gathered become repetitive and no new themes are identified,²⁵² this is often referred to as the ‘saturation point’. The saturation point of a study will depend on the scope of the study aims. Studies which have a very specific focus will achieve saturation with fewer participants than an open-ended scoping investigation, for example. As with all research, analysis of data gathered will require interpretation. Focus groups present a wealth of multi-layered, verbal and non-verbal information and interpretation is therefore particularly challenging and time consuming and also requires skill for the researcher.

²⁵⁰ Morgan, D. L. Focus groups as qualitative research (Sage Publications, London, 1997)
Additional Considerations
There are a number of additional considerations that should be made before applying any one of the dialogic methods previously outlined in the field: the ‘role of the moderator/facilitator’; ‘development of questions’; ‘recruitment process’; ‘research ethics’; and ‘data analysis’. All must be identified and considered in the study design before the commencement of field research. Not doing so sufficiently will compromise the integrity and accuracy of data gathered and could lead to unexpected difficulties in the research process. Each of these factors are outlined and discussed in the following section.

Key points
There are several research methods available to investigate the questions posed by this study. The focus of this research is to gain insights into the behaviours, attitudes, needs and aspirations of patients living with RA, therefore a qualitative, interpretive approach was considered to be best suited to the study aims. Visual research methods which facilitate respondent-generated research data have been identified as a suitable and empowering means to capture the intricacies and nuances of everyday life experienced by research participants. Combining visual research methods with the more traditional focus group method will provide the opportunity for participants to tell the story of their own lives, in their own words, and to share these narratives with other participants. The accumulation of qualitative data produced via these methods will provide a detailed and accurate account of the real life needs of patients who live with RA.

This study aims to gain insights into the ‘real life’ factors of RA which affect the ability of people living with the condition to engage with therapeutic exercises. These include social influences, practical constraints of individual user lifestyles and the intricacies, nuances and contradictions of motivation and engagement. A focus group research method was identified to be the most appropriate method to gain insight into these factors efficiently and with adequate contextual information to identify the most common challenges. Because this study seeks to understand the impact that RA has on everyday activities, an additional photographic ‘cultural probes’ element was also introduced to the study design this will extend the reach of data gathering into the daily lives of research participants.
Studyn design

Steering group
This transdisciplinary research study combines design theory, design practice and medical science research on rheumatology, specifically RA, its definition and treatment strategies. Combining ideas from disciplines outside of the researcher’s usual knowledge base does present a risk that work produced may not accurately capture the sensitivity or complexity of concepts developed within a different paradigm. Therefore, a steering group was established to inform the development of the study design, to analyse data produced and to critique study outputs. This was to minimise the risk of overlooking significant areas of research relevant to this study and to reduce the possibility of misinterpreting the literature reviewed. The group consisted of academic supervisors, specialist external advisors and an expert patient. Each member was asked to review the study systematically against the project aims at critical development stages and to provide both verbal and written feedback; this feedback was then applied to further inform the study design as the project evolved.

University Members:
- Dr Inam Haq, Consultant Rheumatologist and Head of Medical Education, Brighton and Sussex Medical School. (BSMS)
- Dr Jyri Kermik, Academic Programme Leader 3D Design and Materials Practice, University of Brighton (UoB)
- Professor Jonathan Woodham, Director of the Centre for Research and Development, Faculty of Arts, (UoB)

External advisory members:
- Jane Gillet, Expert Patient, voluntary participation. An Expert Patient position was advertised through the NRAS network.
- Sue Golbey, Rheumatology Occupational Therapist, Brighton General Hospital, Brighton and Sussex University Hospitals Trust (BSUH)
General considerations

The role of the moderator is to ensure that all participants feel safe and secure, that each individual has a fair opportunity to speak and share their thoughts, and that the research is conducted in a safe and comfortable environment. Discussion must be relevant to the research aims therefore questions must be carefully considered and asked in a discursive mode of language that nurtures the input of participants in a non-threatening manner and which encourages all participants to express their point of view.\(^{253}\) To ensure this is achieved effectively a number of group management techniques were adopted, including ‘purposeful small talk’ - to create a warm and friendly environment and ‘subtle group control’ to identify ‘experts’, ‘dominant talkers’, ‘shy participants’ and ‘ramblers’ and ensure everyone has an equal opportunity to speak.\(^{254}\)

Physical environment A number of considerations were also made about the practical aspects of the study, which included: where and when the study took place and the suitability of the physical environment. RA can cause severe pain, disability and fatigue. Two suitable locations where identified and used within this study: the Audrey Emerton Building (AEB), Royal Sussex County Hospital (RSCH), Brighton, UK and the Mayfield House Building, Brighton and Sussex Medical School, Brighton, UK. Each of these locations has full disabled access and good transport links. Any travel costs incurred were reimbursed and refreshments and comfortable seating (with armrests) were provided. To encourage participation, the study was offered at times to suit group members with daytime and evening sessions being offered to provide adequate opportunities for participants with home, work and family commitments to participate.


\(^{254}\) Krueger, R. A. "Designing and conducting focus group interviews." (Unpublished manuscript, The University of Minnesota, St. Paul, Minnesota (2002)
Research ethics

As a designer and non-medic, conducting research with NHS patients presents a number of practical challenges, and ethical considerations, which had to be overcome before the research study could commence:

Firstly, the study had to be reviewed and passed by an NHS Research Ethics Committee (REC), which was completed by the Brighton East REC in June 2010 (REF 10-H1107-28). Secondly, an honorary research contract was required to enable the study to be conducted on NHS premises. This was required to recruit patients and to conduct the focus group workshops. This was obtained from the Clinical Investigation and Research Unit (CIRU) at the RSCH in July 2010. Finally, specific ‘Good Clinical Practice’ (GCP) training was required in order to request informed consent from NHS research participants. The online ‘Epigeum’ training program was completed in February 2012 which consisted of five online courses covering key issues relating to the conduct of research in the NHS.255

The consent process

Posters (appendix 1) were displayed in rheumatology clinics within BSUH hospitals and through online networks of national arthritis charities; ‘Arthritis Care’ and NRAS. Some patients were also informed about the study during attendance at outpatient clinics. Information leaflets (appendix 2) were available for all patients interested in joining the study and given prior to consent being requested. All potential participants who demonstrated an interest in the study were asked to attend an initial screening visit with a clinical member of the research team. During this meeting a member of the research team talked through the information leaflet and answered any questions that arose before making an appointment, at the patient’s convenience, for informed consent to be requested. The screening visit also provided the opportunity to ensure that there were no additional factors that would make participation in this study inappropriate, for example, mental health issues such as depression or anxiety.256 It was also explained to participants that, after giving consent to participate, they reserved the right to leave the study at any time without


256 These kinds of co-existing mental health issues are common in people who have long-term health conditions. Participation in focus group activities could become too stressful.
giving any reason. However, any data already collected with consent would be retained and could be used in the study.

1. Initial discussion with a clinical member of the steering group to introduce the project and to talk through the information sheet and confirm patient understanding.
2. After 48 - 72 hrs a follow-up phone call was made to confirm if the patient would like to participate or not. If the patient did not want to participate, no further contact was made.
3. Written consent was requested by either Dr Haq or Tom Ainsworth on BSUH premises. Patients were invited to ask further questions and asked again if they would like to participate in the project.

Main Inclusion Criteria:
- Formally diagnosed by a consultant rheumatologist
- Diagnosed with RA for more than 2 years
- No significant other illness that could affect ability to take part e.g. malignancy, significant mental illness.
- Between 18 and 65 years of age the (study is focused on the working aged population)
- Must speak English well enough to participate in group discussions without an interpreter.
- Able to attend all three focus group sessions

Main Exclusion Criteria:
- RA not formally diagnosed by consultant rheumatologist
- Not diagnosed with RA for more than two years
- Not aged between 18 and 65 years
- Significant coexisting illness e.g. malignancy, significant mental illness.
- Disease is not being adequately medically controlled
- Difficulty in spoken or written English
- Unable to attend all three sessions
Improving Exercise Devices for Patients with Rheumatoid Arthritis – project flowchart

Patient self-selects to participate in the study in response to posters in rheumatology clinics in BSUH

Patient invited to attend an initial screening meeting. 30 min with member of steering group with GCP training, on BSUH premises during a meeting arranged outside of normal clinical practices.

ACCEPT: written informed consent requested

Activity 1: Focus Group meeting, 90 min group discussion, Audrey Emmerton Building, Royal Sussex County Hospital at a time to suit participants

Participants will be asked to talk about their experiences of exercising with RA

All data gathered will be anonymised and stored in a locked cabinet at the University of Brighton

Activity 2: Photography project, 1-Week.

Participants will be asked to take 27 photographs of objects they use everyday and places they visit regularly.

All data gathered will be anonymised and stored in a locked cabinet at the University of Brighton

Activity 3: Presentation and discussion about images, 90 min group discussion, Audrey Emmerton Building, Royal Sussex County Hospital at a time to suit participants

Participants asked to select 10 significant images and describe them to the group.

All data gathered will be anonymised and stored in a locked cabinet at the University of Brighton

Activity 4: Feedback Session, 90 min group discussion, Audrey Emmerton Building, Royal Sussex County Hospital at a time to suit participants.

The research team present findings to the group for further feedback and to triangulate results.

All data gathered will be anonymised and stored in a locked cabinet at the University of Brighton

DECLINE: No further contact. Treatment as per usual practice

PARTICIPANT OPT-OUT OF STUDY:
Patient will be withdrawn from the study. Any data already collected up to this point with consent will be retained and used within the study, with the exception of photographic images produced by the participant which can be withdrawn by the participant, up to the point of publication, by written request.

No further contact. Treatment as per usual practice
Study procedure

Recruitment  Participation was open to all RA patients aged 18-65 years attending clinics at BSUH, UK and all RA patients seeing the Occupational Therapists at Brighton General Hospital, UK. Potential participants could either ‘self select’ to participate in the study or volunteer in response to recommendation from a member of their clinical care team.

It was anticipated that retention rates would be relatively low for the study due to the commitment required from research participants to complete three research activities over a one month period of time. Therefore an acceptable minimum of 4 participants per group was agreed with the steering group. The study did however, seek to over-recruit to compensate for the anticipated drop-out rates. Participation was available for up to 10 participants per group with the aim of retaining 4-8 participants for each of the three sessions (acceptable minimum of 12 participants combined across all groups). The study was repeated until ‘saturation’ was achieved: the point at which key themes are repeated and no ‘new’ information is gathered. Participants were asked to participate in three research activities:

Activity 1 - discussion group  The aim of each discussion session was to give participants the opportunity to talk about their experience of living with RA and to express their views on currently available treatments. This fieldwork study seeks to develop our understanding of ‘designable factors’ that contribute to patients’ ability and willingness to engage with exercise therapies within normal daily life. The definition of ‘designable factors’ used within this study is not limited to the aesthetic, physical and functional parameters of objects; it is principally concerned with the psychological and social impact of design thinking in healthcare interventions. To explore this further, five key aims were identified:

1. Identify designable factors that contribute to the efficacy of, and adherence to, prescribed hand exercise therapies for patients with RA.
2. Identify new opportunities for design interventions, including where new interventions should be targeted and how they may be implemented.
3. Identify ‘active’ and ‘passive’ modes of engagement already present in normal daily life activities.
4. Develop a speculative design criteria for improved efficacy and efficiency of hand-held exercise devices for patients with RA.
5. Identify opportunities for further research.

To do this effectively, the session primarily focused on an open ended set of questions to map the terrain and identify areas for further exploration.

**Development of questions** The development of questions asked during each phase of this study will now be discussed. Within each focus group session five different types of questions were asked, following a sequence of general to specific, and based on Krueger’s model of focus group interviewing (2002).

1. Opening questions
2. Introductory questions
3. Transition questions
4. Key questions
5. Ending questions

This approach was adopted to encourage participant involvement before identifying the most relevant information. ‘Divergent’ questions were used to expand participant responses and illuminate new ideas and ‘convergent’ questions were used to synthesise emergent ideas and themes. Selected questions will be discussed in detail below.

‘Introductory Questions’ - were designed to get people talking about their RA, to establish a vocabulary and to indicate social and psychological factors that may stimulate further research.

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2.1 When you describe your condition to someone for the first time what do you say?
2.2 Has your attitude towards your condition changed over time?

‘Transition Questions’ - were designed to encourage people to start thinking broadly about factors that may relate to the aims of this study.

3.3 What is your favourite activity or hobby/what do you like to do in your spare time?

‘Key Questions’ were designed to gather specific information about currently available treatments

4.2 Think back over time about the different exercise treatments that you have received for your RA. What worked particularly well?

‘Ending Questions’ were asked to provide participants with the opportunity to reflect on the entire discussion and identify topics or areas that are of central importance to their concerns as the target audience for the research.

5.1 If you could change one thing about your condition what would it be?

**Activity 2 - photographic cultural probe exercise** The aim of the photographic element of this study was to identify designable factors such as objects, situations and spaces, specific to the needs of people with RA, that should be targeted to improve the efficacy of therapeutic exercise and persuasive design interventions. To achieve this participants were provided with a list of 27 statements and asked to take a photograph in response to each. The number of statements was defined by the number of images available on the camera film. Whilst this number was imposed by a limitation of the hardware, the restriction helped to ensure that statements were developed selectively and with direct relevance to the study aims. The statements sought to identify significant places, people, interests, activities, challenges and responsibilities that feature most commonly in the daily lives of research participants.
Participants were provided with a project pack containing a ‘Guideline Sheet’, ‘List of Questions’, ‘Labels Sheet’ and ‘CD’ and were encouraged to use their own camera, if possible (disposable cameras were available on request). The ‘list of questions’ document identified a series of statements relating to everyday life. Participants were asked to take photographs to illustrate each statement in the most accurate way possible for them. In addition to the project pack, each participant was provided with a stamped, addressed, envelope to return the camera to the research team once all images were captured.

This activity was also designed to identify factors that contribute to patients’ ability and willingness to exercise within normal daily life, and to identify opportunities for where new design interventions should be targeted. The statements therefore sought to identify the biological, psychological and social factors affecting people within daily life:

1. This is something I am proud of
2. One of these would be really helpful to me
3. I would like to be able to exercise here
4. This is where I feel most safe
5. At the weekend I spend most of my time doing this
6. During the week I spend most of my time doing this
7. During the week I spend most of my time here
8. I like to spend time with friends here
9. This is someone whose opinion matters to me
10. I wish I had one of these
11. This object is really important to me
12. This is something I want to improve
13. This makes me really happy
14. This is something I worry about
15. This is something that prevents me from exercising
16. I need other people to help me with this
17. This is the favourite piece of technology that I own
18. This is something that frustrates me
19. This is how I usually travel
20. This is something that is expected of me at home
21. This is something I won’t leave home without
22. I use this everyday
23. When I am at home I spend most of my time here
24. These are my hands
25.
26. > These are pictures of me (x3)
27.

This list of images was developed in collaboration with the project steering group, informed by the literature review and overarching study aims, and through an informal pilot study conducted with the researchers grandparents, family and friends. For the pilot study volunteers were asked to complete the photographic exercise and provide verbal feedback based on their experience. For the most part, participants said that they enjoyed the exercise but as a few minor issues were raised about the task, a number of changes were introduced. The wording was changed on some statements to be more clear and open-ended and the use of numbered stickers was recommended as a means to match images with statements after submission.

Activity 3 - discussion group and image analysis The aim of this session was to identify additional thoughts that may have been triggered by the exercise, discuss the images taken and to identify any common or recurring themes.

3.1 Did anything occur to anyone after last week’s session that you would like to discuss?

Identifying or constructing meaning from this kind of data is highly interpretive. Therefore, to achieve maximum clarity within this exercise, each participant was invited to participate in the analysis process. Each participant was given a copy of all images from that group and was asked to order the images into their own categories of personal significance.
4.1 Could you please organise these images into categories that mean something to you.

Participants were then invited to identify emerging themes or images that were most important to them.

5.2 Of all the things we discussed, what to you is the most important?

**Study sessions** Discussion groups were conducted at either RSCH, UK or University of Brighton, Falmer Campus, at times to suit research participants. Each session was recorded using audio and video recording equipment.

Project packs were provided at the end of the first discussion session for the Photographic Cultural Probes exercise. Participants were asked to capture a photograph in response to the statements provided, save the images onto a CD provided and post the images to the researcher, using a stamped addressed envelope provided within one week. Images were coded and printed for use in the next discussion session.

**Model of analysis**

A ‘thematic analysis’ method was adopted to provide a rigorous, robust and grounded approach to data analysis, which identified factors relevant to patient concerns: with this approach, meaning is gathered and theory developed from the primary data with no prior hypothesis. Thematic analysis is an effective qualitative analysis method for “identifying, analysing, and reporting patterns (themes) within data”.

Thematic analysis enables the researcher to establish a detailed and accurate account of complex qualitative data gathered from a wide range of original sources. The process requires the researcher to review and interpret research data and to identify key themes. A multi-phase thematic inductive analysis strategy was developed to ensure research outcomes were robust, accurate and transparent:

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1. Audio information taken from each session transcribed by Tom Ainsworth (TA).
2. Key themes were identified and categorised by TA
3. Key themes were identified by the steering group and compared to TA's themes
4. Key themes were presented to participants at the start of each focus group session. Areas of agreement and disagreements were discussed and explored further.

Data gathered from each focus group were transcribed, and analysed for key themes. Themes were identified in either, one (FG / CP), or both (FG + CP) of the study sessions, looking for areas of agreement and disagreement between the two. Key points emerging from the research findings were discussed with participants at the start of each discussion session to ensure that interpretation of data gathered was representative of participant concerns. User generated images, generated through the cultural probes exercise, were used as conversational triggers to identify additional avenues for enquiry and to explore existing themes in more depth. A combination of written analysis, visual representation and illustration were used to encapsulate and communicate data.
Chapter 4. Findings and Analysis

This chapter presents a comprehensive description of the findings gathered during each of the focus group sessions and provides a detailed analysis of key themes identified during the study. Key findings are summarised at the end of each focus group session. The analysis conciliates the research findings with the research questions and the review of the literature.

Findings: Data gathered from the study is presented as a detailed descriptive text illustrated with images produced during the study. Findings from each focus group session are presented in-turn and selected based on their relevance to the study aims. Significant findings and emerging themes are highlighted at the end of each section.

Analysis: Significant findings and emerging themes are critiqued against each of the research questions. The precision, validity and academic rigour of the methodology is also discussed.
Findings

Study preparation consisted of an 8-month period of formulation, development and peer review, a 1-month period of review by the Brighton East NHS research ethics committee, and a 6-month period of patient recruitment. This culminated in a multi-phase focus group and photo-elicitation study, with three participant groups, conducted over a 7 month period from October 2010 to April 2011.

Research findings are presented below as a rich thematic description of each focus group session. In each case, a description of the question or idea being explored is outlined, participant responses are described, and in some cases supported with a selection of illustrative quotations from the raw data and this is followed by a brief interpretation. A brief summary of key points is presented at the end of each section. Themes identified from the findings will be outlined, discussed and critiqued against the literature review and research questions in the following section.

The key below is used at the top of each page to aid navigation through each of the six focus group sessions and section summaries.

- Discussion Session
- Photo-elicitation Session
- Summary
Group 1 Session 1
Location: AEB, RSCH, 28 October 2010.

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<td>Participant</td>
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<tr>
<td>G109</td>
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</table>

Age Range: 23 - 64
Mean: n/a
Ratio 2:1 (F/M)
Mean: 9.8

The following participants have enrolled with the project but were unable to attend this session: G101, G102, G103

Opening discussion
The session began with tea, coffee and introductions. Participants were then asked to describe what they were hoping to get from their engagement with this study.

Participants’ motivations. There were a number of personal motivators identified by participants as their reason for choosing to engage with this research study: 1) to share a personal design idea; 2) social connectedness; 3) to learn about RA from others with the condition; 4) to contribute to a study for the benefit of others. After introducing themselves to the group and describing what they hoped to gain from participating in the study, participants were asked to describe what they considered ‘design’ to be. Immediately, participants chose to discuss design in the context of RA, describing products they wish they had and how they expect design can be applied to improve devices available to people with RA.
Participant design idea 1. One member of the group had already considered a specific device that she would like to see developed: a swimming aid which would enable her to continue swimming but without experiencing the pain that currently inhibited her.

G107 - ... Just something that can help give a little bit of extra strength to the wrist, to stop the hands getting quite so achy and painful after something like breaststroke....

Participant identified problems with currently available equipment. The group was very quick to discuss problems with currently available equipment. All identified the need for equipment to be functionally effective whilst also attractive and socially acceptable. A strong narrative emerged, with participants sharing stories about specialist equipment that had been allocated to them through the NHS, which they were too embarrassed to use, making them feel self-conscious, even within their own home, about their RA and the impact it was having on their life.

G108 - ...you don’t want visitors coming in saying “ooo what you got one of them for?”, “what’s that?”

There was consensus between participants that much of the equipment issued to them communicated a ‘design language of illness’, explaining that currently available equipment makes a statement to others that you have something wrong with you, and because of this, people ask questions which are not always welcome. One individual had particularly strong feelings about the effect his equipment had on his anonymity within society:

G108 - ...yes, the problem you’ve got and you don’t really want to always discuss it [RA]... it’s something that is personal to you and your family. Your close friends know you’ve got it and they don’t really talk about it. So you don’t really want something that is going to stick out and say “I’ve got…”

This particular example revealed the additional social challenges encountered as a result of RA and the objects used to help manage the condition. The discussion continued with another member of the group (G105, age 23) stating how, whilst working as a care worker, the objects that he encountered in the homes of his patients would influence his perceptions of what he was about to encounter:

G105 – I saw a lot of these devices and they are very unattractive. Every time I’d walk into a house, the first thing I’d think was “ooo there is something
seriously wrong with this person”… I can just imagine what it would feel like for someone to come into your home and just go “oh there is something wrong with you”…

Participants’ understanding of the term ‘designer’ One member of the group identified the ability of design to develop functional devices into desirable objects:

G106 – yeah, but if it was something that was really, you know ‘designer’ design, it can look really cool, cant it?…Even if it is, you know, a real functional item. If it’s kind of cool looking as well you don’t mind it so much, you think “yeah, I’ve got one of those.”

She continued to explain her willingness to engage with ‘designer’ products, identifying exclusivity as a further incentivising factor.

Participant design idea 2. Discussion between three participants (G108, G106 and G105) outlined a need for crutches and walking sticks that do not fall over.

G108 – the worst thing about crutches is you can’t stand them up. Wherever you put them, they fall down.

The participants continued to identify the embarrassment caused by this happening and further emphasised the unwanted attention caused by assistive devices.

Participants’ responses to existing therapeutic devices. Although not intended as a formal assessment of existing therapeutic exercise equipment, images of the X-Tensor hand exercise device were shown and a tub of hand exercise putty, often used by OT’s with RA patients, was handed to the group and passed around. Everyone in the group was shocked by the appearance of the hand X-Tensor device - exclaiming that there was not place for that in their homes; and expressing disappointment with the hand putty. One member said that she might like to sit in front of the TV squeezing the hand putty but no one else was enthusiastic.

Small group discussion activity
The group was then split into two smaller groups and asked to respond to a series of pre-designed questions in conversation with one another. Once complete, participants were then asked to feed back their responses to the group. Participants
were divided into the following sub-groups (G107 + G108) and (G105 + G106 + G109). The questions asked are outlined below followed by participant responses.

**Q. Think back over time about the different exercise treatments that you have received for your RA, what worked particularly well?**

Only one member of the group had been actively encouraged to engage with exercise activities at the point of diagnosis. Some had received a comprehensive exercise regimen as part of follow-up treatment for significant operations: knee replacement surgery, for example. Others reported very little follow-up support following surgery.

None had been told about the benefits of exercise or of the effects that lack of movement an exercise can have on the joints. Most information had been self-sourced through reading online and in books.

Yoga and T’ai Chi were identified as particularly effective exercise activities. A second member discussed particularly positive experiences with self-initiated yoga exercise:

G106 – I remember when I first had rheumatoid arthritis. I was seizing up. I was very lucky because my mum was doing yoga. She took me along to a class, and I just started going to yoga basically, and it really really helped. It really helped because it gave me something to go to, you know, a class to go to, it was a reason to get up in the morning, to go to a class and move. And I felt so much better after doing it as well. You do need to keep moving.

The benefits of this activity are physical, social and arguably psychological. This particular member of the group could be considered ‘intentionally non-compliant’ to drug treatment recommendations. She has rejected drug treatments, through personal choice, since being diagnosed with RA 22 years ago. Instead, choosing to seek out and practice alternative therapies, including hydrotherapy, acupuncture and homeopathy; complementary therapies such as physiotherapy and dieting; and general exercise activities such as cycling and tennis. She repeatedly emphasised the benefit of careful dieting and physical exercise.
Another member of the group G105, the youngest (23 years) and most recently diagnosed (2 years), stated that his exercise came from managing the home, tidying and cleaning. His statement identifies the desire to provide for others, whilst also revealing significant self-perceived disability:

G105 - what I tend to do is …erm… because I live with 2 other people, I spend my time making sure the house is clean because they do both go out and work, so I do consider myself as a like a house man. I do as much as I can before I get too tired in the mornings and that’s kind of my exercise. If I struggle to do something then I have to wait for someone to come home, for them to be able to do it, because I don’t feel safe doing it. Like I wont cook for myself when I’m on my own, I don’t trust myself to use a stove, because I don’t want to injure myself, or break something.

Other group members then discussed this point, empathising with the feeling of vulnerability described, whilst also encouraging [G105] to try to build his confidence and carry on with life as best he can:

G108 – I think what you’re going through is the initial stages, because you, a) you get depressed, in the initial stages, you get very depressed because the future looks very bleak and in the end you turn around and say “I can’t live my life like this, I’m just gonna have to get on and do it.” otherwise your world closes in.

This statement identifies the ‘journey’ which patients go through in learning to come to terms with the consequences of their condition. The nature of this conversation also highlighted the value of social connectedness between individuals who are able to share experiences and advice based on their own lives.

G105 – yeah, its nice to be here with people that understand what I’m going through and with people who’ve already been through it. Because I don’t have that connection with anyone else, I don’t know anyone else [with RA].

**Q. Tell me about disappointments you’ve had with your exercise treatment since you were first diagnosed?**

There was general agreement amongst the group that there were no real disappointments from treatments because they had very low expectations in the first place. All were told that RA cannot be cured and had lived with the condition for a number of years. Most had recognised an improvement in symptoms since engaging with drug treatments. One participant had a particularly bad experience in which they were given very casual instructions to exercise with a “stretchy piece of plastic… if they wanted to” but this was unique amongst the group. In explaining this experience
to other participants the respondent concluded with the following statement, in reference to a physiotherapist:

G108—...and erm...I don’t think they understand, if it’s a physical injury, that they can see, then they are more sympathetic. Because we don’t look like there is anything wrong with us they don’t understand it...and this was a physiotherapist!

One member (G106) expressed disappointment with the pressure to engage with drug treatments. Explaining that she had not seen a consultant for many years because, based on past experiences, she knew they were going to recommend drug treatments. This concern was confirmed, in the weeks prior to the study, when she had attended clinic and was encouraged to adopt drug treatments. Her main concerns with drug treatments were based on “an innate feeling” that the benefits would be short lived and that she did not want to become dependent on them.

G106 - In a way I would have liked to have had it. It would have been, I would have got a break for a while, but it wouldn’t have lasted.

This participant did also acknowledge that the disease progression, evident in her current circumstances, may not have occurred if she had engaged with drug treatments.

G106 - ... and I don’t know, I might, you know, I might not have needed knee replacements if I’d been on drugs, because my knees wouldn’t have deteriorated to the state they got into, but, and my hands may not be deformed the way they are, but I don’t really know.

A second member G109 also reported concerns about drug treatments. Describing how she had accepted a steroid injection once, which was effective, but vowed not to accept one again because the benefit was short-term and because of the potential damage that long-term steroid use can cause to the body. This participant also described a specific consultant who takes people with RA in as in-patients and works with them to identify potential dietary factors for RA.

Not all members of the group were against drug treatments. One member (G108) described how much he benefitted from drug treatments and how forthcoming his consultant was with prescribing them.

G108—...you can have as much as you like, as often as you like.
The group also discussed the differences between individual doctors, consultants and their own personal needs; recognising the challenges that RA presents in terms of diagnosis and treatment but also the need for greater clarity and consensus across the recommendations made by healthcare teams. This discussion identified a tension between *standardisation* and *personalisation* in the treatment of RA. People want to feel informed and in control of their own condition and treatments.

**Q. In your opinion, what needs improvement?**

‘Communication’, and ‘understanding’, were two words that were used consistently between group members. Some felt that their doctors were not as empathetic as they would have hoped, others did not agree. Four members of the group described how upsetting they find their appointments. Stating that they regularly cry during or shortly afterwards. One member identified the language used during some appointments as particularly upsetting:

G109- …and also I’ve seen physios who just use, throw the word chronic around “it’s a chronic condition, its never gonna improve” blah, blah, blah and I don’t think that’s very helpful for anyone actually.

All participants agreed that there was a lot of information available about RA but also said the amount of information available often became confusing. There was a feeling that information should be provided to them selectively based on individual circumstances and needs. Participants described a willingness to be self-effective with treatment recommendations but identified a need for greater clarity from healthcare teams about what they should be doing, when, and for how long. Most said that information available was either too confusing to understand, or was contradictory.

No one within the group knew of any products designed to aid them with exercise within day-to-day life. One member, G105, identified his ‘easy-pour kettle’ as his favourite object within the home. The product heats water as it is dispensed - removing the challenges (and dangers) of lifting and pouring boiling water from a standard kettle. A second member described how her OT had recommended a series of equipment to use in the kitchen. The group agreed that specialist physiotherapists, with particular knowledge of RA, should be made available to them.
Q. Who or what influences your decision to exercise?

This question was largely overlooked by the group due to most participants’ lack of awareness that exercise was a good thing for them to engage with. There was, however, agreement throughout that fatigue or lack of energy, was the primary factor affecting their willingness to engage with physical activities. Each member described their awareness of their own personal limits with regards to physical activity and energy.

Q. If you could change one thing about your RA what would it be?

Fatigue and energy level were reported as the one factor that all respondents would like to improve the most. Pain and discomfort were discussed but most felt these problems were more transient and therefore less problematic overall.

G107 – Yes, that’s the main thing I think. You know any pain or discomfort you get used to but it is just that [fatigue] which doesn’t seem to improve with age [laughs].

G108 – You have good days and you ‘av bad days. And when you ‘av bad days, they are really bad days! I’ve got the same [concerns]. I mean I think, erm understanding and communication could be better, the, the erm [tiredness] could be. I mean I do go exercising because my hobby takes me out, that gives me the incentive...

The second statement above emphasises the changeability of symptoms, presumably as disease activity levels change, in addition to the need for better understanding and communication. Furthermore this statement also indicated the value of personal interests and hobbies in providing an incentive to be active. For those who do not work, having personal interests which benefit from personal commitment and physical engagement could provide sufficient incentive to overcome some of the milder effects of RA.

Final questions

The final section of the discussion revisited the pre-planned questions which were not answered during the earlier stages of the discussion due to the natural flow of conversation. Additional comments and discussion points were also explored.
Q. When you describe your RA to someone for the first time, what do you say?

Most participants said they usually avoid talking about their RA, partly due to embarrassment and partly to avoid burdening other people with their problems. If asked directly they may reply with a statement along the lines of “its an autoimmune disease, the body attacks itself and the joints are affected.” which is usually received with shock. All said it can be difficult to describe although the words ‘pain’, and ‘tiredness’ were usually used but these are rarely sufficient to communicate the real effects of RA. Some preferred to describe their RA in a less direct way:

G107- I would say it is, it has never stopped me from doing anything I, want, really wanted to do. But it is a bit of a nuisance at times.

All participants said they usually find themselves having to explain their condition when they are asked questions from people who notice them limping or moving uncomfortably. There was agreement that simply stating that you have arthritis was not adequate because people assumed it was osteoarthritis. All participants agreed that this general misunderstanding of RA has led to many frustrating conversations in which people follow-up with statements like “oh yeah, i’ve got a bit of that too”. This factor was most problematic for the youngest member of the group who described conversations with his peers who just could not accept why he was not able to go out drinking with them.

One member of the group, G109, said she liked to use informative statements to try to put her circumstances into context, so that whomever she was talking to could relate to what she was saying and the symptoms she was describing “there are 200 kinds of arthritis” or “it can cause tiredness and cold like symptoms”.

There was some discussion and confusion within the group about what exactly RA was, with two individuals questioning whether RA was an autoimmune disorder at all; instead believing that it may be caused by a digestion problem. This point further emphasised the need for patient education and improved communication between healthcare teams and patients.

Photography project brief

The session ended with an introduction to the photography project.
**Group 1 session 1 summary**

- Participants believe that design could be applied to help them to live with their condition more easily.

- Equipment for patients should be *functionally effective, attractive and socially acceptable*.

- Existing devices, in particular those provided by the NHS, attract unwanted attention and communicate a design language of illness.

- There was a significant lack of awareness amongst patients of the benefits of exercise and the consequences of lack of movement.

- Patients who did understand the benefits of exercise had self-sourced the information from the internet.

- Patients enjoy forms of exercise which encourage social engagement and provide respite from symptoms.

- Diagnosis can have a significant negative effect on a patients perception of self and lead to beliefs of inability and vulnerability.

- Diagnosis can become a trigger for lack of engagement.

- Many patients resent having to take medications long term.

- Lack of *communication* and insufficient patient *understanding* are a particular weakness of current treatment.

- Fatigue is a significant barrier to physical activity and the symptom that participants would most like to change.

- Personal commitments such as work and family are significant motivators as are hobbies, personal interests and achievements.
Group 1 Session 2

Location: AEB, RSCH, 11 November 2010.

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<td>Marney Walker</td>
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<td>Jonathan Woodham</td>
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The following participants have enrolled with the project but were unable to attend this session: G101, G103

Opening discussion

The session began with tea, coffee and introductions. Followed by TA feeding back preliminary observations to the group for further clarification and confirmation of accuracy.

Participants’ comments during feedback

When describing the potential role for design to bridge the gap between functional therapeutic devices and desirable consumer goods, participants emphasised the need for mass availability and affordability; with these ‘devices’ possibly being made available through mainstream stores.
After outlining some of the experiences that other participants had had with their treatments G102 was invited to share her experiences with the group. She identified the profound affect that her initial diagnosis had on her quality of life but also said her drug treatment regimen had been highly effective and that her current health was “probably as good as I’m ever gonna get.” She reaffirmed the lack of communication relating to health and exercise with RA:

G102- with regards to things offered to me that might help, certainly not a great deal to help in exercise or things like that. And I didn’t feel, from that point of view it was very helpful.

**Participant exercise and inactivity.** G102 also suggested that complacency with exercise and general inactivity can lead to further inactivity and lower motivation.

G102- I think sometimes lethargy breeds lethargy, and you sort of stop because you’re uncomfortable and its difficult to do.

All members within the group agreed that they had adopted an attitude of ‘carry on regardless’ with regard to daily life activities. The effects of RA were not going to prevent them from engaging with the things they enjoyed doing in life:

G102- *I mean,* this is what, for me, I want to still be able to do all these things without all the associated pain that goes with it. Yeah you do it, and you put up with the pain, because it’s what you enjoy doing and its what’s really good for you, because although you’ve got pain on the one-hand, it uplifts you because you’re doing something that you really enjoy.

Core motivators identified were enjoyment and continuing to engage with the same activities as before disease onset.

**Participant identified design challenge.** G107 reaffirmed her desire for a waterproof wrist splint that she could use whilst swimming to prevent joint damage and inflammation caused by irritation of the joints.

G102 strongly agreed, and explained the problems that she has with her wrist splints when cycling and playing tennis; when cycling the splint makes holding the handle bars very uncomfortable, and the impact-shock of tennis was exacerbated by the metal bones in the existing splint design.
Perceptions of illness and actual use of equipment. There was also a discussion about the assumptions made by OTs and clinicians when offering this equipment. MW, a former OT, suggested that OTs probably do not expect people to be using the kit they offer for sporting activities. The concepts of incapacity, inability, disability and illness run against the will of users to live a ‘normal’ active lifestyle. The purely utilitarian design of existing assistive devices, such as wrist splints, probably would not have been developed with these activities in mind. The attitudes of users and the nature of their needs highlighted the inadequacy of current assistive devices to fulfil the real life everyday needs of users.

Changeability of physical strength. Each member of the group agreed that weakness comes and goes, depending on disease activity level. Flare-ups occur at random but can also be brought on, following overactivity. This further emphasised the complexity and challenge of long-term engagement with exercise therapies.

Information and communication. When identifying the need for improved communication and information services for patients, one participant (G105), the youngest in the group (23 yrs), added that he’d used social networking sites to post questions and retrieve advice and guidance from others who understood his needs due to their own experiences.

G105- I managed to find, an RA page which has, like, got people from all over the world on it. And er, it was really nice to, sort of, I posted a comment about me not being able to sleep and loads of people sent back loads of stuff saying “oh, you should try this...”or, “I do this and this works” or, “perhaps change your mattress”, “do this...”, “do that...”, and all these things seemed to have worked for these people and it was really nice to, sort of, read what they’d put and they were so sympathetic because they understood.

Whilst recognising the benefit to G105, others suggested to be cautious whilst using social sites because of the tendency for some users to use these sites as a means to vent frustrations; “some people just have an axe to grind.”

Benefits of hobbies and other activities. All participants valued their engagement with hobbies and other activities including: photography, swimming, pilates, cycling,
yoga, t’ai-chi etc. All participants also recognised the value of these activities as potential motivators:

G106- It makes you feel more normal really.

The physical benefits of these activities were recognised but it appeared that the real value to participants was the inclusivity: they felt part of a community and not like someone who was being judged because of their own particular needs. Furthermore, if a specific ‘device’ designed to promote therapeutic exercise were to be developed it would have to be convenient to hold and carry around. People did not want extra objects and weight to carry around.

The patient journey and vulnerability

There was agreement among the group that in the early stages after diagnosis they became more cautious due to ongoing pain and a sense of vulnerability. Participants reported avoiding lifting activities, being reluctant to leave the house due to fear of injury and generally avoiding busy or crowded places.

G109- I’m concerned if there’s a big crowd, which I wouldn’t have been in the past … I was in, I think ‘Burning the Clocks’ one year, it was really crowded and I, I kind of, avoid places like that, so I wouldn’t go to ‘Churchill Square’ on Saturday or something or Sunday.

The consequences of this sense of vulnerability can have a huge impact on quality of life. The effects could stretch beyond individual pain and discomfort into all aspects of one’s lifestyle, ability to pursue personal interests and actively to engage with society. Another member of the group did however, point out that this does not have to be the case and that over time it can be possible to overcome some of these challenges:

G106- It depends what you are used to, because I’ve got 4 children, I mean they’ve, you know, they don’t do anything silly, but they, kind of, you get rough and tumble naturally with children anyway. So you kind of, its how you live your life I suppose.

Alternative therapies and drug treatments. When describing the alternative therapies discussed during the previous session one participant did point out that they can be pursued in addition to medication; the two do not need to be mutually exclusive. The choice to engage with pharmaceutical treatments was also discussed
further with one participant (G108) stating that he felt he was making a decision between “a few years good” (using drug treatments), or “a lot of years bad” (without drug intervention). This view was not held by all participants. The general agreement was that decisions made regarding treatments were “a very personal thing.”

The final feedback comments were about the challenges that people with RA have in communicating its effects on their life to others.

**Photo-elicitation exercise**

A comprehensive review of the photo elicitation exercise can be seen within the final design outcomes. Here only selected images will be presented and discussed as guided by research participants. Information which could compromise the anonymity of study participants, their friends or family members has been blurred on all study materials.

The first phase of the photo-elicitation exercise was to get feedback from respondents on their experience of engaging with the exercise. The photography exercise statements were then discussed and participants selected the statements which they thought were most helpful and relevant to their needs. Following this, the group were handed prints of their own images and asked to find those identified in the previous discussion, plus any others which they thought may be of interest. Participant G101 was absent from the session but had completed the photography exercise, therefore participant G109 (expert patient) and JW reviewed these images.

**Participants’ feedback from photography project.** The project brief required participants to take photographs in response to a series of statements designed to gain insights into the objects, environments and activities they engage with as part of normal daily life. Most participants said they found the exercise quite difficult. Specific challenges were: translating intended responses to statements into photographs and, for one member, trying to understand the relevance of the statements to the study aims. This individual found this to be particularly disconcerting because of his desire to help the project. The group were in agreement that further discussion of the
statements at the end of the previous session would have been helpful. Selecting one thing for each statement was also a challenge for some.

**Statement selection** Participants were asked to identify the statements which they believed to be: insightful to real-life needs, most relevant to the study aims and which they believed may be relevant to future design developments. Image statements selected and agreed by the group were numbers:

2. One of these would be really helpful to me
3. I would like to be able to exercise here
12. This is something I want to improve
15. This is something that prevents me from exercising
16. I need other people to help me with this
18. This is something that frustrates me
22. I use this everyday

Of those selected, numbers 16 and 18 were considered to be the most pertinent. Statement number 14, “This is something I worry about”, was identified as causing confusion to one member of the group (G108). Participant G102 said that her response to this statement was “being old and on my own.” At which point G108 recognised the potential value of statement 14 stating “maybe it was just me then”. G102 followed up her comment with personal praise to her husband, present at the session, for his help and support. Highlighting the dependency on loved ones that long-term illness can cause:

G102- In all seriousness, I use you a lot, don’t I (signals to husband). Because of things like lifting saucepans, straining, a lot of the things that I do find difficult to deal with, you are an incredible help for me. It is very difficult having that gadget, they don’t particularly put that gadget on the shelf. [jokes about husband]

Participant G109 was struck by the similarities between her images, taken during the study development phase, and those of the absent participant G101.

**Review of participants’ selected images**

Participants looked through their images to retrieve those listed above and were invited to add any others which they consider to be of interest. Participants were then invited to show and discuss their own images - adding narrative to the visual data gathered. Unfortunately, due to poor time management, this section of the session became hurried.
Statement 2. One of these would be really helpful to me.

**G102** said she had no idea what to put for this statement but that a disabled badge would benefit her greatly. G102 described how although her treatment was currently very effective she still has bad days, during which time she would struggle to carry things. This problem becomes even worse when her husband is not around to help.

**G105** chose to start the discussion. He described how this was a new piece of gaming technology that enables the user to control games without the need for physical controllers; instead the kinect device is able to ‘see’ what you do, enabling you to control the system using your body. He was particularly excited by this technology because it would enable him to exercise within the safety of his home. Noticing the lack of enthusiasm from other members of the group he said “it’s obviously my generation” to which **G106** replied “my children would probably like one of those.”

**G106** described that she would like a ‘cool, designer looking’ gadget to open jars with. The jar opener featured was strongly disliked by the participant who asserted that she does not ever use it. Other members in the group described how rubber gloves can be really effective because they can provide the extra friction required to open jars, and that you do not need to put them on to benefit from them in this way. A rubber ‘friction matt’
was also described as a discrete and affordable alternative. Two further participants also described a ‘One Touch’ electric jar opener that they both used. The problem with this design, however, was the difficulty in replacing batteries. G106 stated that she actually quite liked trying to open things on her own and that she would not use an electric device. Others agreed that they enjoyed the satisfaction gained from opening bottles and jars unaided but did concede that sometimes, when symptoms are bad, this can be an unrealistic goal.

G107 chose to show image G107_10, identifies the object that would be most helpful to her. She chose this image to reaffirm her desire for wrist splints re-designed for use with water aerobics and swimming.

G108 stated that this image displayed a walk-in shower. He described how he currently has a shower above the bath but the onset of RA has made this more difficult to use. He no longer feels steady on his feet and is increasingly worried about slipping. G105 exclaimed that he would also like a walk-in shower and G108 described a device that she has recently purchased to assist her with getting in and out of the bath. This image identifies additional complications and costs involved with maintaining personal hygiene and the need to modify the home to accommodate for the reduced physical abilities.

Fig 4.4 (original in colour) “One of these would be really helpful to me”, G107_2. (2010)

Fig 4.5 (original in colour) “One of these would be really helpful to me”, G108_2. (2010)
Statement 3. *I would like to be able to exercise here*

To save time, participants were asked to place their image in the centre of the table for all to see, and were then invited to narrate their images.

**G102** described her desire to return to the gym. She had enjoyed gym membership prior to onset of RA but now was unable to make full use of it. G102 described how she used a Nintendo Wii to facilitate exercise at home in addition to exercise DVDs, walking and cycling. She concluded her narration by describing her frustration at having to compromise on the exercises and activities that she enjoyed the most. The group all agreed and shared an understanding of this frustration.

**G105** emphasised his desire to exercise within the home environment. He re-stated the safety that he feels in this space, adding that he would feel embarrassed engaging with exercise in a place where others could see him. This image adds context to the Kinect device identified by G105 in the previous statement.

**G106** did not describe her image to the group but it suggested her desire for access to, or exercise opportunities in, park and other outdoor spaces.
G107 recalled walking holidays in the Italian Alps with her husband before the onset of RA. She said that now her symptoms were more under control they are considering another trip. This is a great example of the aspirations that motivate people to engage with physical exercise.

G108 described his desire to return to horse riding. He explained how, before the onset of RA, he had shared ownership of an ex-race horse. He used to groom, ride and feed the horse; he enjoyed the relationship that he had with another living thing, the freedom and the connection with nature that he felt. G108 emphasised how unique this experience was for him.

Statement 12. This is something I want to improve

G102 said she would like to reduce her weight. Something that can be a constant battle with the side effects of medications and the disabling affects of RA. Other members of the group sympathised with this challenge.
G105 said he wanted to give up smoking and improve his health generally, joking that rolling cigarettes is the only exercise that his hands get! Interestingly this is not RA-related, identifying that, although significant, RA or RA related issues did not dominate all of his concerns.

G106 described how she would love to be able to ride a bike again but she has not been able to since having knee replacement surgery, due to damage caused by RA. G102 then described with great excitement that she had recently bought a tricycle, which she loves because it has enabled her to get out on a bike again:

G102- Its so much easier. I feel stable, if the wrists are giving me problems, I can take them [your hands] off because I’m not going to fall off. It’s the best thing that I have bought this year!... oh, its absolutely, fantastic I would so recommend it! If you like cycling, but you’re a bit [nervous], its wonderful! I’m so chuffed!

This image emphasised how active people with RA can be and how far removed activities such as cycling are from the therapeutic exercise devices offered to patients to help them to keep fit.

G107 again used her image to emphasise her wish for redesigned wrist splints that would enable her to continue swimming by reducing the strain on her wrists. Although she used the standard issue splints to swim, she said they are far from ideal and not very hygienic.
G108 identified his hobby, photography, as the thing that he would like to continue to improve. This example again illustrates that RA does not have to dominate all aspects of life, and also the possibility that personal interests could be targeted as incentivising factors for exercise.

Statement 15. This is something that prevents me from exercising

G102 captured an image of the drugs she takes to manage her RA to signify the pain that she experiences at times of high disease activity. This was mentioned by other members of the group during the previous session.

G105 identified fatigue, caused by RA, that had the greatest effect on his ability and willingness to exercise. Fatigue was identified by everyone during the previous session but this is one of only two to identify fatigue in the cultural probes exercise.

Fig 4.15 (original in colour) “This is something I want to improve”, G108_12. (2010)

Fig 4.16 (original in colour) “This is something that prevents me from exercising”, G102_15. (2010)

Fig 4.17 (original in colour) “This is something that prevents me from exercising”, G105_15. (2010)
G106 also identified tiredness. She did not expand on this point any further.

G107 did not provide an image for this statement. Instead she described how there is usually some kind of exercise that you can do, but that fatigue and discomfort can lead to postponement of the activity.

**Fig 4.18** (original in colour) “This is something that prevents me from exercising”, G106_15. (2010)

G108 described how his knee surgery, also required as a result of long-term RA, was the factor which had the greatest effect on his ability to exercise. Interestingly, this was not said during the previous session when the same question was asked.

**Fig 4.19** (original in colour) “This is something that prevents me from exercising”, G108_15. (2010)

**Statement 16. I need other people to help me with this**

G102 this image, representing the difficulty with chopping large and hard fruit and vegetables, led to a narrative illustrating how this challenge had affected the participant’s diet; if no one was available to help, she was no longer able to prepare these foods.

**Fig 4.20** (original in colour) “I need other people to help me with this”, G102_16. (2010)
**G105** described the challenges that he now experienced with cooking. He said that, for him, the main challenge was fear of injury. He will not cook unless there is someone else in the house, often choosing to microwave his food instead of using the cooker.

![Image](image1.png) Fig 4.21 (original in colour) “I need other people to help me with this”, G105_16. (2010)

**G106** described how she is now less able to dress herself. She has become increasingly dependent on her husband to help. The image illustrated her husband helping her to put her coat on because she is limited in her ability to rotate her shoulders.

![Image](image2.png) Fig 4.22 (original in colour) “I need other people to help me with this”, G106_16. (2010)

**G107** took this photograph to represent the challenge that she had with lifting and using heavy saucepans. She described how she and her husband often cater for large groups of people - friends, family, grand children etc - so this is a challenge that she encountered regularly.

![Image](image3.png) Fig 4.23 (original in colour) “I need other people to help me with this”, G107_16. (2010)
G108 described how his ability to maintain his house and garden and to complete household tasks was becoming compromised. He asserted his determination to carry on regardless of the added difficulty adding that he felt, being the man of the house, that it was his duty to carry out DIY tasks, and he felt pride in being able to do so.

**Statement 18. This is something that frustrates me**

G102 also identified chopping as being particularly problematic.

G105 said that many everyday tasks around the home and kitchen frustrated him. He specifically identified opening bottles but expanded the problem to include lifting things and trying to get food and tableware in and out of cupboards.
G106 reinforced the challenge of dressing herself each day. This time the specific example was leggings and boots.

G107 also described the difficulty of opening water bottles. Describing how, on numerous occasions, she has had to return to a shop to ask someone there to open the bottle for her.

G109 added to this discussion that she started to carry her assistive gadgets around with her but it was sometimes difficult to know which gadget she was likely to need. She had often opted to take no gadgets instead of all of them because of their weight and inconvenience.

G108 This image illustrates the difficulty that RA in the hand can have on the micro-movements of the hand and fingers. G108 described his frustrations with trying to pick up small things such as screws and small pieces of paper. All members of the group strongly agreed that this was a particular problem. These are exactly the kinds of movements that ‘pinch-grip’ exercises are intended to maintain. G107 added that even assistive devices, designed to help with opening things or picking things up, often required more force than they were able to provide.
Statement 22. I use this everyday

G102 This image further emphasised the daily challenge of maintaining personal hygiene when living with conditions that affect your physical abilities. The bath was discussed in response to statement 2 as a particularly challenging activity. G108 and G109 both described how devices designed to lower you into the bath are too slow - the water cools before you manage to get in. They also stated that the device needed to be kept dry when not in use, which brought further complexity, effort and time to a previously simple daily task.

G105 This is the easy-pour kettle identified by G105 during the first focus group session. The preference of the user for this particular design was that the water was boiled as it is dispensed, removing the need to lift a kettle of potentially heavy boiling water.

G106 expressed embarrassment when revealing that her make-up was the thing that she uses everyday. There was, however, significance to this image. This was an everyday routine for this individual, it was something that she enjoyed and that made her feel good about herself. These are types of social and psychological factors that health aware design should seek to achieve.
G107 identified her glasses as the one thing that she used literally everyday. G105 and G108 both agreed with this statement. G107 also stated that she wouldn’t go anywhere without her lightweight strong IKEA bag for carrying shopping etc in.

Fig 4.33 (original in colour) “I use this everyday”, G107_22. (2010)

G108 said that he cannot go anywhere without his walking stick. During the first session he described that although he has to take his stick everywhere it does sometimes draw unwanted attention, a problem which was exacerbated when he accidentally dropped or knocked over his stick in public.

Fig 4.34 (original in colour) “I use this everyday”, G108_22. (2010)

G105 added that he would never leave the house without his iPod and mobile phone. The iPod because it contained all of his music and his phone in case of emergencies.

Further notable observations
All respondents had images of both a mobile phone and a computer, with most identifying their phone as the object that they would not leave the house without. Computers were identified as either the favourite piece of technology, or as the thing that people spent most of their time doing.
Group 1 session 2 summary

- Patients wanted equipment to support everyday needs and affordable and available in mainstream stores.

- People with RA wanted to continue with life in the same way as before onset.

- Patients preferred that aids and devices do not emphasise their condition and differences from others in society.

- Currently available equipment was designed according to an unhelpfully narrow conception of the problem.

- Social media sites were often used by patients as information resources.

- Patient needs and requirements for support were continually changing. Daily living activities presented the most significant and frustrating challenges.

- Patients favoured objects and environments that helped them to achieve their goals more easily.

- RA and its treatments, although significant, did not necessarily dominate the personal concerns or aspirations of patients.

- Pain, fatigue, operations, and the side-effects of medications were reported to be principal determinants for lack of exercise.

- The objects that participants chose to engage with regularly offered an immediate functional benefit.

- 100% of participants owned and used both a computer and mobile phone regardless of age, gender, socio-economic status.

- People with RA were interested in engaging with the ‘designerly’ appeal and aesthetic values of design as well as function, and these were important to their social and psychological wellbeing.
Group 2 Session 1
Location: Checkland Building, UoB, 10 December 2010

<table>
<thead>
<tr>
<th>People Present</th>
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<th>Role</th>
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<tr>
<td>Tom Ainsworth</td>
<td>TA</td>
<td>PhD Candidate/ project leader</td>
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<table>
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<tr>
<th>Participants</th>
<th>Age</th>
<th>Gender</th>
<th>Duration of RA</th>
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<tbody>
<tr>
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<tr>
<td>G111</td>
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<tr>
<td>G112</td>
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<tr>
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<td>Age Range:</td>
<td>Mean:</td>
<td>Ratio 3:1 (F/M)</td>
<td>Mean: 12.25</td>
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The following participants have enrolled with the project but were unable to attend this session: G101, G104

Pre-session discussion between participants | learned non-use
Three participants discussed RA between themselves before the start of the session whilst the audio recorders were being set-up. They were discussing how they adapted their movements depending on where they felt pain. One participant described how she feels her compensatory movements could have led to further disability:

G110 - I think what happens is that if something hurts you adapt and use a different muscle group to cope. So lifting handbags now I automatically slide it over my hand and use this part to lift [signals to forearm] because I can’t use my wrist and hands. So you do adapt and because I have adapted I have lost the use, both my wrists are fixed. So my fingers are quite strong and agile still, and I have had a wrist replacement, but there are lots of movements that are painful to do and the temptation is that because its painful, i’m not going to do it, but that of course is dangerous because that other function will eventually go. So I have got to exercise to keep the function that I already have. So that is me. I don’t particularly want to throw darts, you know.

Opening discussion
The session began with tea, coffee and introductions.
Whilst introducing the aims of the study to the group, one member, G113, stated that for her, the monotony of having to follow the continuous regimen of her treatment was a great burden. And because of this she was always reluctant to engage with anything else. She concluded that she would be most interested in exercise activities which could be incorporated into her everyday activities. All members of the group agreed.

G113 - You just get so tired of having to do things. I don’t know how anyone else feels but just taking medication; I have had RA since 1996 and everyday, twice a day, I have to take medication and even from just those few seconds I just think ‘I am so fed-up with having to do this’. And then if you do anything special with your diet that is an additional thing that you have to do, or that you can’t do. I find I get this reluctance to do anything else. So if something could be built into my day-to-day activities that I am going to be doing anyway, that’s what I would enjoy.

Adding that whilst editing her PhD, the repeat strain of using a keyboard and mouse caused permanent damage to her hands - her fingers curved outwards.

Participants’ motivations
Participants described their desire to contribute something to a study that could help others with RA in the future. One described her involvement as “an adventure”; another wanted to share a positive experience with a particular drug treatment.

G110 described how she had lived with RA for approximately 14yrs. Disease progression led her to require foot surgery in 2004 and to quit her job as a teacher in 2008. She said that participating in this study gave her something to focus on. The inactivity caused by her symptoms has led her to become depressed; specifically stating that she felt “useless” because she could no longer do the things she wanted to.

Participants’ experiences with drug treatments
Each member of the group was actively managing their condition with pharmacological interventions. Each described their constant battle with trying to establish a balance between the correct medication and dose, and managing the side effects of each.
G111 explained that he was taking a research drug Etanercept, after developing a liver problem, probably caused by other RA medications. He identified the specific benefit of this drug for him was that instead of taking 6-8 tablets everyday, he could self-inject his medication once per week. Although G111 expressed that self injection caused discomfort, he said, in reference to G113’s earlier comment, that this method felt less frustrating.

**Q. When you describe your condition to someone for the first time, what do you say?**

Most described how they used humour to dilute or deflect further conversation, using terms like “oh, just the usual ‘gammy-itis’”, to make light of their situation and to avoid having to explain the complexities of RA to people. Participants within this group described, as with Group 1, how they were usually led into talking about their RA when people noticed their walking stick, inability to do something physical, or because of visible symptoms, usually the shape of their hands.

G111, the only male within the group and of large build, described how the combination of his size and his intermittent inability to open a jars and bottles was a particular frustration to him because he felt embarrassed by this.

G113 said the distortion in her fingers had become the biggest burden for her. She was able to cope with the physical pain, and the sacrifices made to her social and work life caused by fatigue, but the visible symptoms were the most troubling factor.

G113 - My feet are sore, they are always sore so that doesn’t bother me. The unsightliness has bothered me. I used to wear rings all of the time but in the last three years when my hands went all ‘squiffy’ that has really bothered me because when I hold a wine glass, when I go out for dinner, that’s the thing that really bothers me. The other things I have been able to deal with but not that.

**Q. Has RA affected your ability to work?**

G113 described how she worked fewer hours, and had invested in an ‘ergonomically’ designed mouse to reduce the strain on her hands and wrists. She said it had helped but she now experienced occasional pains in her elbow. She also explained that fatigue was becoming increasingly problematic for her, identifying her
struggles with everyday activities like making the bed and sitting on the floor as specific examples.

G112 also expressed her frustrations with no longer being able to do the things she used to be able to, and the depression that she suffered after diagnosis:

G112 - I’m fortunate, very fortunate. But for those that have not expected to get it [RA] to suddenly find themselves like I was, incapable, useless, unloved, unwanted, can’t get help, you feel absolutely, you know, where am I going? I might as well end it all now! you know, all dramatic. There are times when you do feel really really depressed.

G110 followed on from this statement, describing how she felt that her ability to provide for her family and her ‘role’ as mother had been compromised by RA:

G110 - Daily tasks take on a new meaning when you, let’s say, are looking after a family. People come round for Sunday dinner and, you know, I’m ‘Mum’, I do this, and yes my husband does help, but it’s that feeling that you can’t do the jobs that you have done for so long. Suddenly everything takes twice as long to do.

She went on to describe how this had a profound effect on her confidence and her ability to pursue other interests. All members of the group agreed with this comment.

G111 said that he was now self-employed due to RA. Being self-employed meant that he had more flexibility in his work hours but also meant he had to be well in order to work. This led to a further description of the efficacy of his drug treatment, which he emphasised with a story about how he was now able to play rugby again. G111 also outlined the complex ways that RA had affected his life, his ongoing health fears and his ‘mind over matter’ attitude:

G111 - Yeah, going though the cocktails of drugs and the side effects, and worrying about the liver and not being able to move, evolves into other things as well. The fatigue comes in because you are putting on weight and you’ve got all these other things as well. I can see my friends who are the same age, and older than me, that are more able to do things and I think to myself ‘I don’t want to be like this’. You get very lonely and you reach that point where you think ‘why me? what have I done? why has it hit me?’ but mind over matter.
This dialogue clearly illustrated the biopsychosocial effects of RA. The statement was followed with a question to the group to find out if participants felt their attitude to RA had evolved over time?

**Q. Have your views or attitudes towards RA changed over time?**

Participant G112 said she was now less angry. G110 said that she was in denial initially but when it affected her ability to work she found its effects very difficult to deal with. She also described the stress caused by the need for her to take progressively stronger drugs, her anxiety about the next stages in her life and future treatments, and her fear of losing more mobility. G112 agreed.

G113 described how her attitude towards her RA had changed over time. She stated that now, after living with RA for several years, she had lost some perspective on what she used to be able to do. Instead choosing to live life one day at a time and not thinking back to abilities that she had lost. G113 also described her aim to manage her RA with “humility” and explained how hearing other people describe RA as “a progressive disease” upset her because she believed she was coping very well and her disease progression was being managed effectively. She continued by describing her reluctance to progress through ever more aggressive drug treatments, instead she preferred to seek out and try alternative therapies, such as acupuncture and careful dieting. She concluded by saying that she planned to explore the possibility of cutting out drugs all together next time she meets with her rheumatologist.

G110 responded to this by saying that she resented the dependency that she now has on her medication. Whilst recognising their benefit she described how she was scared to reduce her dosage because whenever she had in the past her symptoms had returned. She also described that the effects of her medication made her feel as though she existed in a drug-induced “state of suspended animation”.

**Participant-sourced alternative therapies**

G111 and G113 then discussed a book by Margaret Hills, which each of them had, that described a range of alternatives to managing RA with drugs. This opened a wider discussion between all members, in which each described alternative therapies.
and dietary changes they had tried. Drinking black molasses and honey, bathing in epsom salts, cider vinegar, and arnica honey were described as ways to remove drug toxins from the body.

This group also discussed the challenges they had experienced with getting in and out of the bath. Staggered, step-like boxes were identified as an effective way to get in and out of the bath. One member stated that she had just had her bath replaced with a shower to overcome this problem.

One member of the group said she had been visiting a McTimoney practitioner, who she recommended but advised this was not appropriate during a flare-up. Another member, G112, described a “lifeline” that she had found in her Kinesiologist who, in addition to his expertise in human movement, was also a dietician. She described how he helped her to identify a number of foods that her body was struggling to deal with. Once she removed these foods from her diet she said she had been “bouncing up stairs 3 or 4 at a time”. Her long-term goal was to regain grip strength so that she could play badminton again. Not all members of the group were as enthusiastic about dieting, one member said she needed a bit of life balance:

G113 - it’s important. Everything they said in all these diets and things, which I did and I lost a lot of weight, but they make you feel so miserable. You’ve got to have a little bit of life balance haven’t you.

G110 described how this desire for ‘life balance’ had led to further problems. She described how her wish to feel better was leading her to eat more, put on weight, and thus more strain on her joints:

G110 - yes, yes. I’m taking Prednisolone and they say “oh you put weight on”, yes I know because Prednisolone makes you feel, supposedly ‘better’, you eat more. I know that it’s because I’m eating too much that i’m fat. It’s not because of the drugs it’s because I’m eating too much. It’s comfort eating because I think ‘I can’t drink, I don’t smoke, I can’t exercise now because my legs hurt’ What can you do? I cook and I eat and I know that is counter-productive because I know its not good to be heavy. My joints are suffering because of it.

There was a general perception throughout the group that “medical people tell you about medication” and that they would not accept treatments that were not scientifically proven. All complained of the costs of alternative therapies but said the benefits, when effective, were worthwhile.
Q. Think back over time about the different exercise treatments that you have received for your RA, what worked particularly well?

Again, nobody within this group had received any specific recommendations to engage with exercise therapies. Swimming was mentioned as a good low-impact form of exercise.

Q. In your opinion, what needs improvement?

All members within this group said that specific advice and guidance on diet should be incorporated into general RA care. Each member exchanged stories about dietary programmes they had tried. Citrus fruits were commonly described as a potential trigger of joint swelling. Blood type and diet were also discussed with specific reference to the book “Eat Right For Your Type”.

Q. If you could change one thing about your condition what would it be?

Again everyone within this group would have most liked to get rid of their fatigue. Pain was discussed, but fatigue was considered to be the greatest problem. One member re-affirmed that it was the distortion of her joints that bothered her the most.

When discussing pain, participants considered it was a temporary and intermittent problem which was most problematic during the earlier stages of treatment. One participant said she used to deny that her RA existed, continuing with life as normal, until her first flare-up, at which point she recognised the severity of her condition and became depressed. G113 gave a detailed description of the pain she experienced because of RA:

G113 - major flare-up is really painful. The most pain that i've ever had was that first flare-up. In my knees and whatever. It is almost like, when you've got a swollen joint, i've found, it's like a knife stabbing into the back of your leg. Literally a knife stab. That is what I call ‘scary pain’. I have never been so frightened of pain as when I had that first flare-up. But since then, I now differentiate between ‘sore’, ‘hurting’, ‘really hurting’, ‘painful’, ‘frightening pain’. After the first one I haven't had it as bad, touch-wood, I won't ever again. To me, when I don't have a flare-up things are between ‘sore’ and ‘hurt’. But you get used to things; you get used to sore feet, you get used to an achy shoulder you just get used to something.

The session concluded with an introduction to the photo-elicitation exercise.
Group 2 session 1 summary

- Patients felt unable to adopt therapeutic exercises due to the discomfort of symptoms.

- The monotony of treatment became an increasingly significant burden to patients over time.

- Patients liked the idea of exercise incorporated unobtrusively into everyday activities.

- Participating in research studies was a significant motivator and could support patients' self-esteem.

- Visible symptoms and consequences of RA caused stress, embarrassment and frustration.

- RA had a significant effect on the ability and willingness of patients to be active in work, their home life and in relation to other interests.

- The psychological strain of RA was one of the most challenging factors for patients to deal with.

- Diet was an area of particular patient interest but was not readily addressed by current treatment and support initiatives.

- Patients were largely unaware of the benefits of physical exercise for their RA.

- Fear, anxiety and depression were common secondary consequences of RA, especially during the first few years of onset.
Group 2 Session 2

Location: Mayfield House, UoB, 4 February 2011

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<thead>
<tr>
<th>People Present</th>
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<th>Role</th>
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<tr>
<td>Tom Ainsworth</td>
<td>TA</td>
<td>PhD candidate/ project leader</td>
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<tr>
<td>Inam Haq</td>
<td>IH</td>
<td>Consultant Rheumatologist/PhD</td>
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<tr>
<td>Participant</td>
<td>G109</td>
<td>Expert Patient</td>
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<table>
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<tr>
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<td>G110</td>
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<td>F</td>
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<tr>
<td>G112</td>
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<td>F</td>
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Age Range: Mean: n/a Ratio 4:0 (F/M) Mean: n/a

The following participants have enrolled with the project but were unable to attend this session: G101, G111, G113

Opening Discussion

The session began with tea, coffee and introductions, followed by TA feeding back preliminary observations to the group for further clarification and confirmation of accuracy.

Feedback from session 1 and participant reflexive comments. TA described how this group had focussed on diet and medication during the first session, specifically identifying how much it had an effect on individual perceptions of health and that, for some, the routine of medication could cause resentment. G110 and G112 reaffirmed this point stating “It’s a regime, not a routine.”

TA then outlined the challenge that some participants had reported in obtaining information about RA treatments and therapies. G112 expanded on this point with a
narrative of her own experience, travelling with a cool box required to sustain her medication:

G112 - I think the worse thing for me, having been 9 months on this medication that i’m on, and being told “you must keep it between +2 and +8 °C”, then all of a sudden, I ran into someone else who was on it and she said “no they have changed the rules since you had that bit of paper, it doesn’t have to be that rigid, you can put it in so-and-so and put it in a car to France. Just put it in a cool box with a pack in it. You don’t need to bother about that”. Of course there was us with this huge great container plugged into the cigarette lighter “is it working, is it working” for a 10 hour drive. And we didn’t need to bother at all!

Participant G110 then described a product that she used so that she could travel with the same medication. She described how hotels usually let you use their freezer and that Airport security were usually fine with it too. G112 reaffirmed that this information should be available online for others to benefit from, stating that she spent hours online reading blogs trying to find out information about which airlines help and which don’t; which hotels were helpful and where these products could be bought.

G104 asked if NRAS (National Rheumatoid Arthritis Society) had been able to help with this kind of information. G112 responded by saying that NRAS had been very helpful for her in the early stages. She had attended their lunch groups for a while but felt as though everyone else was much worse than her. She also didn’t like the fact that they only visited restaurants which had easy wheelchair access.

Photo-elicitation exercise

Participants’ feedback from photography project.

Participants within this group also expressed some difficulty in trying to capture their intended responses to the statements through photography. One participant, G104, described how she had read the sheet of statements 6-7 times, considering what she might do in response, before taking her photographs. When asked if she thought this exercise had helped her to identify the impact of RA on her, she said yes. Although describing the exercise as challenging, the group all agreed that they had enjoyed the experience.
There was some confusion from participants as to the focus of the study. G110 described how her understanding of the project aims had affected the images she had chosen to take:

G110 - yes. For me, I had to keep telling myself ‘this is about hands’ because a lot of my problems stem from my mobility - not being able to walk properly. That made me think differently about the statements because ‘What’s your biggest fear?’ well actually it’s to do with my mobility more than my hand dexterity. Trying to keep it back to what I am using my hands for because that is the remit for the project.

Although hand function is the principle area of concern for this study, the need for this kind of intervention needs to be considered within the context of real life needs. This exercise helped to identify explicitly the need for design interventions which were applicable to broader patient mobility needs.

Not all participants approached the photography exercise by specifically considering the hands. G112 described how she had considered the project more broadly, choosing to respond to the statements whilst thinking about how RA had affected her in general.

One participant reported that she found operating her digital camera to be too difficult. She had to ask her husband to take the photographs for her. All participants reported that getting the number stickers in the pictures could be “tricky”. Describing how in many cases taking the picture became a joint effort, one person holding the sticker whilst the other took the photographs. Other participants used wooden spoons or asked their children to help.

**Participant categorisation exercise**

During this session, each participant was provided with all the images taken by members of that group. They were then asked to sort the images into categories that ‘meant something to them’; this could be based on a word, an activity or an emotion for example. Guidance at this stage was purposively vague as the aim was to allow participants to identify their own themes and point of significance within their
research material, allowing emergent themes to be established and further empowering participants.

![Participants engaging with the photo-elicitation exercise. T.Ainsworth (2011)](image)

Findings will be reported from the open conversation which took place between participants during the categorisation phase of the exercise, in addition to the structured photo-elicitation exercise at the end of the session.

**Participants’ reflections on technology**

G110 commented on the number of computers evident within the images provided by this group. All members had an image of both a mobile phone and a computer in response to the statements.

Because all images were taken by members of the group, participants actively sought clarification from one another regarding the significance of each image - ‘What’s this?’, ‘Is this the certificate?’, ‘Is that work?’. These kinds of questions often led to extended narratives.
This image, for example, is of a computer mouse that participant G110 said she would like to use because of the pain caused by her RA, describing that she currently used a ‘trackball’ style mouse because it did not cause the same level of strain to her wrists. In response to this, G104 stated that although her hands were the area worst affected by RA, it had not affected her ability to use computers. She used computers everyday as part of her work, she regularly typed and used a mouse without any problems, even commenting that people often asked her how she was still able to do her job with RA.

Could this be evidence to suggest that her hands were resilient to these particular movements because she practiced these movements as part of her everyday activities?

**Participants’ examples of adaptation in the home**

Participants also shared advice on devices which they had in the home, such as this door latch attachment, which enabled the user to open doors more easily.
This image captured the struggle that this participant experienced when making the bed. She pushed a walking stick under the mattress and used it as a lever to raise the corner so that she could fold and tuck the sheet underneath. The discussion that evolved from the other participants began with trying to identify the activity taking place - ‘Is this putting trousers on?’, I thought it was ‘opening plastic bags?’. There was general recognition of the challenge involved in this activity and a series of suggested solutions. One member suggested using a wooden spoon to push the sheet under the mattress and another suggested using a car windscreen ice scraper for the same purpose.

**Participants’ respect for one another and personal values**

It was clear from the discussion that all participants treated one another with respect and recognised the potential sensitivity of some images. The following dialogue, involving all members of the group, demonstrated the mutual respect between respondents:

G104 - Who wishes they had one of them? [G112_10 image of lorry]
G112 - Sorry. I’m sitting here thinking ‘I wish I hadn’t put some of these in here’ It makes me realise how off-the-wall my thinking is.
G110 - That’s how I feel about me actually
[group laughs]
G109 - I haven’t thought that about either of you
G104 - Neither have I, apart from that one.
This image was of unquestionable value to one of the research participants:

G112 - because that one is so special to me because it just takes me straight back to being out on the mountains, being fired at, in Bosnia. It is just one of those things that most people will never ever even dream about doing. But how you categorise it because it is so precious and I’ve got three of those, I don’t know how to arrange them.

These examples were significant because they demonstrated the elements of the group dynamic that can not be elicited through the images themselves. The open dialogue and inquisitive nature of the conversations illustrated that participants were willing to share and discuss personal information openly within the group. The photo-elicitation exercise was an effective patient assessment tool and captured information from the respondent that pre-defined questionnaires could not access. These insights identified potential motivational factors which were significant to the individual that would not be easily identified without the cultural probe exercise. Utilising these as motivational incentives is one way that treatment interventions could be targeted more accurately to personal interests.

**Participants’ reflections on education groups**

The group discussed their experiences of RA education programs. G104 described the NRAS program with particular enthusiasm. She described how they discussed all aspects of living with RA including: diet, pain management and medication. G109 was also positive about this program whereas G112 was more skeptical. G104 and G109 were also very excited about the prospect of engaging with the Expert Patients Program (EPP) also run by NRAS.

**Participants’ reflections on the effects of weather and climate on their RA**

The group also discussed the potential effects of environmental factors on disease activity and personal comfort. G112 believed her symptoms were less severe in the warmer climate of southern France. G110 did not agree, saying that her experiences of spending several months of the year in the Canary Islands had led her to believe
that warm weather produced no difference at all in her symptoms. They did, however, agree that the benefit of warmer weather was that one didn’t have to wear as many clothes. Having to wear several layers, when in colder climates, was problematic because of the difficulties with getting dressed.

**Participants’ reflections on exercise**

The group also discussed various factors relating to exercise. All said that for them swimming was more trouble than it was worth. Entering and leaving the pool was difficult but the most substantial challenge was getting changed into a swimsuit in the confined space of a changing room cubicle. G112 suggested that a zip-up swimsuit would help because she could step into her swimsuit and zip it up. G110 expressed her desire to swim to maintain her personal health but the difficulty of getting changed and the heat of the water, however, prevented her from doing so.

G109 described how she was interested in Power Plate exercises. Power Plate she explained is a system designed to develop muscle strength and blood circulation through vibration and instability. The system, built into a small platform similar to a set of large doctor’s weighing scales, caused reflexive muscle actions many times per second. The manufacturers claimed the system could improve overall health and wellbeing with minimum risk of injury. The group discussed the system as a high-tech workout tool that footballers use. Two members of the group were particularly interested in the possibility of engaging with exercise without having to move or even get changed. However the costs of using the Power Plate system were too great for them so this was not a realistic option. A Nintendo Wii system was mentioned but quickly dismissed by one member because of the level of movement required to operate the system, (further emphasising the desire for health benefit without physical exertion).

All participants had been told by their OT or Physiotherapist to be particularly careful to avoid causing damage to the joints when their joints were inflamed. The group returned to a discussion about swimming and concluded that they would like a swimming pool filled with Epsom Salts.
Participants’ reflections on the categorisation exercise

There was agreement between participants that the task was quite difficult. Deciding on which group to put images into and how many groups to define was “tricky”. When asked how it felt to see their images amongst those belonging to the rest of the group, participants highlighted how reassured they felt that their problems and fears were not unique.

Participant-defined categories

Esteem

G110 defined esteem as one of her categories. She described how, for her, one of the greatest impacts that RA has had on her life was lowering her self esteem. She specifically identified that her ability to fulfil her own aims within the family have been compromised:

G110 - I have to say a lot of it, for me, comes down to ‘self esteem’ and the personal side of it; some of the questions “I’m expected to do this” [statement 20] yes, I am expected to do it, and I have always done it, and having Rheumatoid Arthritis is making it difficult for me to fulfil my, you know, not obligations but, you know, the things that you want to be able to do; things like cooking for yourself and cooking for others and looking after your family, and doing jobs that, you know, I’m happy to do and so it makes me feel bad because I am having to think ‘actually I am going to need help with this’. So I have categorised the ‘I need help with this’ as part of the self esteem issue; because, alright, you shouldn’t be afraid to ask for help, and I get it when I ask for it, but it’s that issue of making you feel that little bit less [able] than when you were a whole, fully functioning, human being.

The group agreed strongly with this statement. G112 encouraged G110 not to make comparisons between her life before RA and life now, suggesting that such contrasts would be harmfully negative. G109 said that she also found it hard to not make comparisons, particularly as her abilities varied significantly between days. G104 extended her statement saying that she did not want to burden her daughter with her problems because “she has her own life to lead,” but concluded by saying one of the points she learned at the education group was to accept that you have RA and to not be ashamed to ask for help; further adding that she had put her sewing machine in this category as an example of something that was important to her - the ability to create things. The reflective and analytical nature of this conversation suggested that G110 was going through a transition phase in coming to terms with her RA.
Fig 4.39 (original in colour) “G110 ‘Esteem’ Category” (2011): 1. This is something I am proud of. 2. One of these would be really helpful to me. 5. At the weekend I spend most of my time doing this. 7. During the week I spend most of my time here. 11. This object is really important to me. 12. This is something I want to improve. 14. This is something I worry about. 15. This is something that prevents me from exercising. 16. I need other people to help me with this. 18. This is something that frustrates me. 20. This is something that is expected of me at home. 21. This is something I won’t leave home without. 23. When I am at home I spend most of my time here. 24. These are my hands.

Whilst talking through her rationale for selecting each image in this group G110 described how sometimes her selections were based on the image statements and other times she had made her selection based on the image itself. It is notable within this group that there was a predominance of images which related to home, the kitchen and food. Each of these had been selected based on their relevance to G110’s previous statement about being able to care and provide for others; identifying that she was now, after retiring from teaching, a house wife.
Mobility
G110 referred to the significance of feet, hands, and walking sticks within her ‘mobility’ category as factors which prevented her from exercising. She also described how these images represented factors that worried her, such as not being able to walk or complete physical tasks within the home. G110 also stated that she resented her dependancy on walking sticks, explaining that her stick brought unwanted attention from passers-by and often provoked questions.

Relaxation G110 defined a category for relaxation - identifying environments and activities which made her feel happy and secure. G104 recognised most images and stated that she had put those in a ‘home’ category.

Fig 4.40 (original in colour) “G110 ‘Relaxation’ Category” (2011): 4. This is where I feel most safe. 5. At the weekend I spend most of my time doing this. 7. During the week I spend most of my time here. 8. I like to spend time with friends here. 21. This is something I won’t leave home without. 22. I use this everyday. 23. When I am at home I spend most of my time here.
Pain. G104 defined images which related to pain as a specific category. She described how pain was the biggest problem for her. Images identified areas of the body most commonly affected, frustrations and difficulties caused by pain and medications used to manage RA symptoms.

![Fig 4.41 (original in colour) “G104 ‘Pain’ Category” (2011): 15. This is something that prevents me from exercising. 16. I need other people to help me with this. 18. This is something that frustrates me. 21. This is something I won’t leave home without 22. I use this everyday. 24. These are my hands.]

Family and friends G104 noted that family and friends featured throughout the images. She described how her family meant everything to her and that she didn’t want to burden them with her RA. There was also a conversation about the difference between people who are close, ‘family and friends’, who know you and understand what you are dealing with and, ‘everyone else’, the people who ask questions, make judgements or get frustrated with you.

Technology G104 noted the prevalence of technology throughout the images but did not expand any further. Only three of these images were responses to the ‘favourite piece of technology’ statement, others were objects used most often, most desired, or that offered security.

![Fig 4.42 (original in colour) “G104 ‘Technology’ Category” (2011): 6. During the week I spend most of my time doing this. 7. During the week I spend most of my time here. 10. I wish I had one of these. 17. This is the favourite piece of technology that I own. 21. This is something I won’t leave home without.]

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Physical aids G112 defined a group by their assistive qualities: for example a door handle adaptor and walking sticks. These devices were functionally effective but reported to cause embarrassment to the user. Images identified personal worries about loss of mobility and increased dependency on such equipment.

![Physical Aids Category](image)

**Fig 4.43** (original in colour) “G112 ‘Physical Aids’ Category” (2011): 14. This is something I worry about. 22. I use this everyday.

Kitchen and cooking G109 noted kitchen and cooking but differentiated between the environment and activities that people needed help with. These images identified the environments and the activities that she spent most of her time doing.

![Kitchen and Cooking Category](image)

**Fig 4.44** (original in colour) G109 ‘Kitchen and Cooking’ Category (2011): 5. At the weekend I spend most of my time doing this. 20. This is something that is expected of me at home. 22. I use this everyday. 23. When I am at home I spend most of my time here.

Nature, outdoors and exercise G109 outlined this section, noting that each person within the group had included an outdoor activity in their images. The image statements referred to participants’ desires to be outdoors and active.

![Nature, outdoors and exercise Category](image)

**Fig 4.45** (original in colour) G109 ‘Nature, outdoors and exercise’ Category (2011): 3. I would like to be able to exercise here. 13. This makes me really happy.
Chores around the home and maintaining personal hygiene G112 reaffirmed her concern about not being able to maintain her own personal hygiene, a concern that she identified during the first session. She described that she had been given a device to help clean herself after using the toilet but said she refused to use it. All members of the group recognised this concern. G112 stated the other images were in this category because she disliked all “housewifely chores”.

Fig 4.46 (original in colour) G110 ‘Chores Around the Home and Maintaining personal Hygiene’ Category (2011) 2. One of these would be really helpful to me. 5. At the weekend I spend most of my time doing this. 11. This object is really important to me. 14. This is something I worry about. 16. I need other people to help me with this. 18. This is something that frustrates me. 20. This is something that is expected of me at home. 22. I use this everyday. 23. When I am at home I spend most of my time here.

Home The home was a significant category identified by three of the four participants, with the fourth stating her ‘relaxation’ category had the same meaning. This category commonly identified the environment that people feel most safe within. The bed and soft, comfy, seating were notable recurring items in these images. Mobility issues relating to getting in and out of chairs were also identified.
Participants’ most significant image

Each member of the group was asked to select one image that was most significant to them as a reflection of their participation in this study. This could, for example, be the problem they were most concerned with or something they were most proud of.

Both G110 and G109 selected this image of the sea front in Brighton. G110 described this as the place that she liked to go to when she was frustrated. She often went there when she felt low about not being able to do what she used to, or when she felt that some of her pleasures in life had been taken away. She described how she liked to be by the sea and to ‘people watch’, noticing how happy people tended to be when they were there.

G109 said she was torn between this image and the sunset [G112_13]. G109 described how she also enjoyed walking along the seafront but also said it was a mixed pleasure; she was no longer able to walk as far as she used to and she found it difficult to get to the seafront sometimes.
G112 selected this image of a sunrise as her most significant image:

G112 - That’s mine. Its dawn, there’s no people, it’s hopeful, and I’m alone, and I love it, and it’s warm.

G104 described her problems with trying to open jars and tins as the most problematic factor for her. She stated that, as with members of group 1, she had used a ‘one touch’ electric opener but also had problems with replacing batteries within the device. Other members of the group described alternative methods of opening jars and the session concluded.
Group 2 session 2 summary

- Information and communication services, and reliable sources of advice and guidance were highly valued by patients.

- The photography task was reported to be challenging but enjoyable for participants.

- The photo-elicitation exercise was an effective method to facilitate detailed narrative discussion between participants.

- Patients regularly adapted their behaviours and physical environment to compensate for lack of physical ability.

- Challenges caused by lack of physical ability were complex and diverse, and could affect all aspects of daily living.

- Some patients expressed a desire to be fit and healthy but would not engage with exercises that took them away from normal daily life activities.

- Not burdening others was a particular concern for many patients.

- Making comparisons between current and past abilities could promote negative attitudes within patients.

- Relaxation, personal achievement and security were highly valued goals amongst all participants.

- Movements requiring strength, dexterity and fine motor movements dominated concerns for many patients.

- Activities in the kitchen and bathroom provided the greatest challenges.

- The bedroom and living room were favoured environments for comfort.

- Enjoying the outdoors was a highly valued aspiration for many participants.
Group 3 Session 1
Location: AEB, RSCH, 9 March 2011

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<td>TA</td>
<td>PhD Candidate/ project leader</td>
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<td>Marney Walker</td>
<td>MW</td>
<td>Former OT and Designer</td>
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Age Range: 32-56
Mean: 41.3
Ratio 2:1 (F/M)
Mean: 5.6

Opening discussion
The session began with tea, coffee and introductions.

Participants’ motivations for engaging with the study.
Participants identified a number of reasons for engaging with the study: personal frustrations with their ability or inability to exercise, general interest in exercise, a willingness to share their knowledge of RA with someone who does not have the condition, personal discovery, interest in art and alternative therapies.

Q. When you describe your condition to someone new, what do you say?
G115 started the discussion by describing how she named her RA “Arthur the Bastard”:

G115 - I used to call it “the bastard” but that became a bit inappropriate...and then “Arthur”, I don’t know why. “Arthur, Arthur the bastard”.
(group laughs)

She then shared her thoughts on social stigmas towards people who appear ‘different’; describing how, based on her own experiences, people were often very comfortable to ask questions like “what’s wrong with you? why are you limping?” but
were shocked when given an answer that they were not ready for. She described how she now ‘tempers’ what she says because other peoples’ reactions often made her feel uncomfortable.

**Lack of understanding from family, friends and others in society**

The group then discussed how they believed general society perceived their disability; considering that people probably assumed that you may be walking slowly because you have stubbed your toe or something. They also discussed how part of the problem with trying to communicate RA to others is the lack of visible symptoms:

G114 - Yeah that is a weird one about RA is that its got no, sort of, physical signs, unless, you know, obviously people look closely and say “oh yeah your hands are swollen” or “your fingers”. Whereas a rheumatologist will know straight away based on what they can see. But it has turned me into someone quite crippled, in the past, without medical intervention but its so impossible to describe that because, on the outside, there is nothing there.

The group then discussed the word ‘crippled’ stating that each of them at some point have either used the word to describe their own circumstances or have heard others use it in reference to them. None used it now unless they were trying to convey the extreme nature of a flare-up to those who could not grasp the pain and discomfort they were experiencing.

G101 described how he generally tried to avoid talking about RA often referring to it as “the old war wound” or “oh its just the old shrapnel on the move”. G101 also described how he had experienced hostility whilst out in public because of carrying a walking stick:

G101 -... reactions to it are quite funny really, you know, some people, you get outright hostility; if they see me walking into the pub, I don’t always take my stick but I sometimes do, walk into a shop or a pub or whatever, with my stick. I’ve heard whispers “oh he’s claiming the benefit”, “fraud” you know, that sort of thing.

G115 then responded to this and reaffirmed her observation of judgements made by people in society by stating “people feel entitled to make pronouncements to others”. G114 followed this with a statement outlining how she believed it is the lack of visibility in RA that causes some of these problems:
G114 - it’s like there is an ideal of what disability is but something like rheumatoid arthritis isn’t a part of that accepted notion because a) it affects people of all ages and all health - as in very healthy people who don’t outwardly look [ill] and I think that’s, to me, that’s a really huge issue. It seems to be for everyone that disability is about looking the part and if you don’t, other people find it difficult to accept that because they obviously don’t understand.

G115 further contextualised this statement with an example from her own experience of able bodied users sitting in priority seats on a bus. She described how these people looked for visible evidence of need, such as being elderly and infirm or visibly pregnant, before deciding if they should offer the priority seat they were using to someone else. This created an illusion that suffering with a condition that was less visible is less problematic.

G101 also gave an example from his own experiences of living with RA and trying to communicate its effects to others:

G101 - I think it’s a problem generally that there is not much understanding of RA out there in the wide world and I don’t think that I have actually spoken to anyone where I have actually got to the stage of actually trying to explain what it is. I’ve got over the stage of not being bothered to… who actually knew what it was and even when I tried to explain, to the best of my ability, they didn’t understand it. I was lucky, when I grew up one of my aunts suffered from RA for many years, very very badly as well, and so, I knew what it was, but you just don’t meet people who understand what it is. Even my wife, she’s been through it all with me, and she has been very supportive but, going back to peeling potatoes again, it took me a couple of years to persuade her that I wasn’t shirking peeling potatoes, because I couldn’t hold potatoes that were below a certain size. It had to be a certain sized potato for me to be able to hold it, you know. It’s just a lack of understanding really.

Participants’ feedback on existing equipment

G114 and G115 both described that when they wore their wrist splints or finger splints, they felt increasingly self-conscious and exposed to questions. They both preferred the black wrist braces instead of the salmon colour because “they were less medical”. G114 said she avoided wearing her splints whenever possible because of how they look. She described how they picked-up dirt very easily, which became a further source of embarrassment. An accumulation of fluff on velcro
conveyed to others that you “are a victim of illness”. G114 summed up what she would like from products:

G114 - if we think in terms of products, we want something that is kind of invisible, that will fit into our style, who we are and what we do. Obviously we don’t want anything like a cast or anything that looks too ‘hospitaly’ that signals ill health. So in one way we are saying that we want something that kind of looks invisible; yet, at the same time, I do feel frustrated about its [RA] invisibility...its a communication issue.

Clearly there is a specific design challenge here which needs to incorporate elements of rather paradoxical aims: ‘desirability’, ‘anonymity’ and ‘communication’.

Visibility and disability MW extended this conversation by describing how, in her experience as an OT, patients had described how they benefitted from using their stick in public because it was recognised as a symbol of disability. To have a stick when crossing the road slowly for example, would explain to others why you were walking slowly. The benefit of the stick, therefore, was not just its function but the need that it symbolised. However, users do not always want to convey illness or disability to those around them.

G114 then moved the discussion towards exercise devices by clarifying the aims of this study. She then explained that she had been advised to squeeze a sponge everyday to strengthen her wrist but had never done so. There was a brief discussion about making exercise devices more desirable or stylish but the group moved on quite quickly.

Participants’ understanding of RA
Participants described how even they could not conceive of the impact RA would have on them when it was first diagnosed. G115 described how, had she known what she knew now about RA when she was first diagnosed, she could not have coped. This suggested that, in her opinion, the complexity of living with the condition was practically incommunicable to anyone who has not experienced it.
G114 described how she struggled to believe how many people have the condition because although she had never knowingly encountered it before her own diagnosis she was now aware of how common it is.

**Participants’ discussion about ‘disability’**

This conversation then led to a discussion between participants about how ‘disability’ is defined and prompted G114 to ask if she declared herself ‘disabled’ when asked if she had any disabilities on job application forms? G115 offered the following response, which identified some of the difficulties with this question:

G115 - It’s all in the definition. They have been sending round a thing at work, they are trying to write their own disability policy, and I just find this so interesting because the definition is “a ‘chronic’, ‘persistent’, blah blah blah, ‘long term condition that has a significant impact on your day-to-day ability to do your job”. And I think ‘well, it’s chronic, its long-term, it doesn’t affect my ability to do my job every day, but what happens in my job definitely affects me differently because of it’. And there will be some periods, for the rest of my life, where I haven’t been able to go in because I’m having such a bad flare-up, and they are quite rare, touch wood, but that sense of where the heck do you fit into those definitions? I don’t want to look down on my splints, and I don’t want to accept that bit of me, and I don’t want other people to; but you do kind of feel, and it’s interesting you talking about it being invisible, because to all intents and purposes, no I wouldn’t say that I am ‘disabled’ but on the days when I am so immobilised that I can’t get out of bed, I literally commando crawl along the floor or shuffle along, then yeah, flippin heck, I can’t go to work. I am disabled today. And it’s that kind of yes because this is a long-term condition, this could happen for the rest of my life, so it could have the impact but it doesn’t everyday. But then where do you fit into that? I think its quite an interesting conundrum.

The significant and highly variable symptoms of RA clearly had an effect on how those living with the condition were able to engage with fixed working arrangements. The passage above led to a further discussion exploring how RA had affected the ability of those in this group to work.

**Q. Has RA affected your ability to work?**

G115 described how, whilst working as an hourly paid teacher, she would force herself to work regardless of how bad her symptoms were, even when colleagues recognised the pain and discomfort she was in and asked why she was working. She reported that losing money for time off work was not the main concern for her, it
was more the need to keep going and not let her RA get the better of her. She did also say that once she attained a permanent contract she did take more time off when her symptoms were really bad. G115 also described the effect that immunosuppressant medication had on her ability to fight off common colds. Whilst most people tended to be fine within a couple of days, it could take weeks for her to be well again.

G101 described the ongoing battle that he had with work. He was a free-lance writer so if he was not able to work he could not earn. When asked if he moved to freelance work because of his RA G101 explained:

G101 - no, i’m not saying the two things are related, but I was diagnosed more or less the same time as I went freelance. There are days when it’s more difficult to type, there are days when it’s difficult to sit, days when you just feel so generally ill that you just can’t but I drag myself through. I promise myself a couple of hours lay-down in the afternoon if I get this finished by 12 o’clock or something like that. So it hasn’t affected me getting jobs done yet, I have always managed to get through it somehow.

G114 said that work was a constant challenge for her. The fatigue caused by RA was by far the most inhibiting factor, explaining that she found herself so tired that she became so overwhelmed with tiredness that she literally could not move. G114 further explained that she avoided office work because of her fear of catching office colds etc.

**Participants discuss fear, anxiety and RA**

All participants described how they have become crowd averse. Two described how they had experienced depression and anxiety before the onset of RA and said living with the condition had not helped their state of mind. G114 described how she believed the onset of her RA could have been triggered by stress factors that she had experienced just prior to her first flare-up. G115 explained that she fully believed that stress hormones could also be responsible for her RA. Although recognising that she had not tangible evidence to support her idea, G115 described how she had, from an early age, always internalised her stresses:

G115 - I think if your body is that full of stress hormones and depressive chemically whirring around in your brain I think it has to go somewhere and if your not releasing it anywhere, your body knows it’s under attack, it knows there’s something wrong, and it just turns on itself.
G114 continued to describe her belief that RA can remain latent within people who had a high risk of developing RA, explaining that only when a particular combination of environmental, biological and personal factors happen at the same time, that onset will occur. The discussion continued with further discussion relating how body and mind could influence health and wellbeing.

Q. Have any of you received specific recommendations to exercise?

Only one member of the group had been specifically advised to exercise. This member described that exercise was one of the things she enjoyed most so she had instigated the conversation with her OT. G101 had never seen an OT and was shocked to hear that OT’s were only available if requested. Both G101 and G104 said they would like exercise to be available in the home.

G101 also described how, for him, the greatest frustration was no longer being able to do things that he wanted to do because he was not as physically able. Walking had become the limit of his physical abilities.

G114 emphasised the need to exercise, the need to remain healthy and agile.

G114 - It’s so important though, the exercise because the stronger the body is and the stronger your joints are the more likely you’ll be able to function and the less likely you will be to experience stiffness.

She also described how, for her, the challenge had been learning to differentiate between normal aches and pains and RA. She wanted to exercise and would usually do so even if it was painful but did not want to ‘overdo it’. To understand and monitor her disease activity level would enable her to optimise the rigour of exercise and maximise the benefit, with minimum risk of joint damage.

Q. If you could change one thing about your condition what would it be?

This group were divided in their reflections of what they would most like to change about their RA: G101 said fatigue; G114 was divided between fatigue and pain, but said she was learning to live with her pain more effectively now. G115 said the effects of medication:
G115 - I find that really difficult. I feel that I am quite recently under control again having thought I knew Arthur the Bastard better than I clearly did. I have negotiated reducing my doses of everything and then been really stressed and pent-up and set myself back. So I think I would say I would change the medication. I feel more limited by the implications of the drugs I take than I do the condition.

She went on to say that she was considering trying for children and to do so she would need to stop taking her medication:

G115 - because of the implications of coming off methotrexate 3 months before you start trying to conceive, and there are miracle people who can conceive as soon as they start trying, but there are people who can go for 2-3 years. What could happen to me in those 2-3 years? there are only certain things that you can take during that period and its just another thing that makes me think ‘oh for gods’ sake!’ Those are the things that I think limit me. That’s it, forget the rest of it, it would be that!

Each participant shared a story about their battles with identifying the most suitable medication for them. All had tried several types of medication and two people had experienced very severe reactions. G114 summarised how each of the factors identified by the group had an effect on the lives of people living with RA:

G114 - There is definitely more that one thing about it that changes your life. There is the fatigue, the pain, definitely the medication as well. You are at the mercy of what you take. It affects work as well - your environment suddenly becomes crucial because you can catch all sorts of things when you are on immunosuppressants and then, if you don’t take them, your body stiffens up and you do become deformed. It does cause deformity if you don’t take the treatment.

At this point G101 had to leave due to the session reaching its planned finishing time. G115 and G114 remained behind and were asked if there was anything else they would like to add to the session.

Participants’ reports of isolation caused by RA

Isolation was identified as a significant effect of RA which had not been discussed directly but was implicit throughout most themes explored during the session:

G115 - I think it has run through everything that we have talked about; this notion of we are not ‘disabled’ to the outside world we are fine, why would you want people to interfere? we don’t like being asked what is wrong and don’t like people making comments. But on the other hand, we feel the need for some kind of recognition and I think that is about feeling isolated. And that
whole thing about how do you explain it to people? and the way that you temper what you say because you don’t want to upset them with the language that you use - that is isolating, and the pain is isolating, and the lack of independence - constantly having to say “can you take the top off that for me please?”, “can you undo that for me?”, you know, because that is how I open things [actions twist with hands] and if they are any tougher than that, I can’t do it, that is isolating. To me that is a really important part of all of it.

The conversation evolved to discuss social networking sites, GP visits and education groups. Participants described their own experiences and drew the following conclusions: social networking sites were noted as places to post questions and learn about other people’s experiences, a place to validate your own concerns and confirm that you are not alone. GP visits, or any other visit to a doctor or consultant, were identified as being further isolating. Participants felt anonymous and not recognised as an individual: you visited these places alone, sat in a waiting room without talking to anyone, saw the doctor and returned home in isolation. Meeting others face-to-face and establishing a common understanding and trust were identified as being highly valuable. The problem with this however was that RA was often the only common characteristic between individuals.

G114 reaffirmed her belief that the problem for her came back to feeling vulnerable and she asserted her satisfaction at being able to share her thoughts with this group without having felt threatened:

G114 - I think it goes back to the idea of feeling vulnerable again. That is a part of the problem, I don’t want to feel vulnerable in front of people who know me as healthy, confident and forward looking. They don’t understand RA. We can sit here confidently and talk about our vulnerabilities, without feeling vulnerable. I think that is important.

G114 also discussed her interest in temperature control as a means to manage pain, specifically stating that she would love to have something that could cool her joints down when they were inflamed, in the same way that ice does, but in a form that she could carry around with her. The same was said for heat: there was a need for something that could warm up on demand.
Group 3 session 1 summary

- Visible symptoms of RA attracted unwanted attention from the public.

- There was a general lack of understanding about RA in society.

- There were multiple paradoxes concerning the lack of visibility of RA and its treatments.

- Existing equipment exacerbated the social problems experienced by patients living with RA.

- The current accepted definition of ‘disability’ did not address the complex and changeable nature of RA.

- RA affected patients ability to enjoy and make long-term commitments to work.

- The onset of RA could cause patients to become crowd averse.

- There was a belief amongst patients that onset of RA was linked to stress.

- There was shock amongst patients that OT’s were only available on request.

- Some patients preferred to be able to exercise within the home.

- Patients needed to learn to differentiate between RA and other aches and pains.

- The combination of pain, fatigue, medication and environment were significant factors affecting the ability and willingness of patients to engage with physical activities.

- The feeling of isolation was a significant damaging consequence of RA.
Group 3 Session 2
Location: AEB, RSCH, 15 June 2011

<table>
<thead>
<tr>
<th>People Present</th>
<th>ID Code</th>
<th>Role</th>
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<tbody>
<tr>
<td>Tom Ainsworth</td>
<td>TA</td>
<td>PhD Candidate/ project leader</td>
</tr>
<tr>
<td>Marney Walker</td>
<td>MW</td>
<td>Former OT and Designer</td>
</tr>
<tr>
<td>Participant</td>
<td>G109</td>
<td>Expert Patient</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Participants</th>
<th>Age</th>
<th>Gender</th>
<th>Duration of RA</th>
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<tbody>
<tr>
<td>G101</td>
<td>56</td>
<td>M</td>
<td>6 yrs</td>
</tr>
<tr>
<td>G113</td>
<td>n/a</td>
<td>F</td>
<td>14 yrs</td>
</tr>
<tr>
<td>G114</td>
<td>36</td>
<td>F</td>
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</tr>
<tr>
<td>G115</td>
<td>32</td>
<td>F</td>
<td>9 yrs</td>
</tr>
</tbody>
</table>

Age Range: 32-56  Mean:n/a  Ratio 3:1 (F/M)  Mean: 7.7

Opening discussion
The session began with tea, coffee and introductions. This was followed by TA feeding back preliminary observations to the group for further clarification and confirmation of accuracy.

Participants' comments during feedback
Participants revisited the question of whether RA could be defined as a disability. Discussing that if it was successfully controlled with medication then maybe it should no longer be considered a disability, but if it is was not being controlled and became debilitating then maybe it was. G113 offered a further definition:

   G113 - I think of it as a chronic illness that can be debilitating and for some people it can lead to disability. But I would think of it more as a chronic illness than a disability, in my case.

Two members of the group suggested contacting NRAS for further clarification and advice. Further comments and discussion took place but each of the points raised had already been covered by this or one of the other groups.
Photo-elicitation exercise

Participants’ feedback from photography project.

G101 described how engaging with the photography exercise had made him more aware of themes present in his life:

G101 - the photography bit? yeah, I had great fun actually doing it. Apart from that it was quite revealing really for me, about myself, in that it pointed out to me, if I wasn’t entirely sure about what the themes in my life were that I wasn’t happy with, you know the bits of my life that I wasn’t happy with, because of the RA. It just made it a bit more concrete in my mind.

He illustrated this point using image G101_18 describing how when people asked how RA had affected him his diminishing ability to play guitar was the thing that immediately sprang to mind. He explained that he used to get so much pleasure from playing but now gets so frustrated that his hands would no longer play the way he wanted to, so that he preferred not to play at all anymore.

G113 said the exercise had made her recognise the things that she didn’t want to reveal. The personal nature of the exercise clarified what she wanted to reveal and what she didn’t in the images she took.

G114 described how the exercise had made her recognise how reliant she was on certain objects in the home, especially her computer:

G114 - It was like writing a diary about how much you eat and realising that you eat a lot more biscuits than you should, it was equivalent to that. So I realised I’m spending a lot more time on the computer when I could have done something that was equal to the computer, you know, like instead of going online to say, look at a job application, I could have gone to an actual job centre. You know something like that. I have almost created my own haven. The computer in some ways has made me less likely to go outside. Especially because it is combined with the fact that I have RA, that means it is sometimes more comfortable to sit down; I am then compelled to sit down even more.
**G109** enjoyed the fact that the photography exercise was conducted in her own time because it had enabled her to really consider her images. She also said that hearing the reflexive responses from group members responding to the pictures had led her to consider other things about her RA.

This group also identified the challenge of capturing their response to the statements in photographic form as the most challenging feature of the project. Despite this, all participants stated that they had enjoyed the exercise.

**Categorisation exercise participant comments**

During this session, each participant was provided with all images taken by members of this group. They were then asked to sort the images into categories that ‘meant something to them’; this could be based on a word, an activity or an emotion for example. Guidance at this stage was purposefully vague - the aim was to allow participants to identify their own themes and points of significance within their own research material - allowing emergent themes to be established and further empowering participants.

G115 described how her circumstances had changed significantly since taking her photographs due to two months of flare-up. Images responding to statements relating to ‘worries’ and ‘barriers to exercise’ were completely different to how she felt currently.

G113 expressed surprise at how similar many of the images were. G101 and G114 expressed surprise at how familiar everything captured within the images was, both in their own and those belonging to other group members. G113 also identified ‘people’ within images stating that every time an image captured an activity that someone wanted to do, it was always with another person.

G114 described how she would like a backpack specifically designed for people who suffer from back problems - something that would distribute weight between the shoulders, hips and back to minimise the strain on specific areas.
G109 described how her RA had affected the products she buys. She avoided certain jars, packets and bottles because she knew she could not open them, even with the various gadgets available.

**Participant-defined image categories**

**G101**

**Family, friends, dependents and happiness** G101 expressed surprise at the number of people who featured within the images and how, to varying degrees, they have become, or always have been, or always will be dependent on other people for their various needs. In addition to the images below, each participant identified a close friend, relative or loved one as the person whose opinion mattered to them. One participant identified his children as something that he worried about. These images have not been published below to preserve the anonymity of participants, their friends and family members.

*Fig 4.50 (original in colour) G101 ‘Family, Friends, Dependents and Happiness’ category (2011) 1. This is something I am proud of. 3. I would like to be able to exercise here. 6. During the week I spend most of my time doing this. 8. I like to spend time with friends here. 9. This is someone whose opinion matters to me. 11. This object is really important to me 12. This is something I want to improve. 13. This makes me really happy. 14. This is something I worry about.
Dependency on technology  G101 was also struck by the prevalence and apparent dependency on technology evident within the images. Everyone in this group had included both a mobile phone and a computer within their pictures. Technology featured prominently in the places that participants spent most of their time, objects which were most important to them, and as objects that people would like to improve - thinner and lighter laptop, for example.

Fig 4.51 (original in colour) G101 ‘Dependency on Technology’ category (2011) 2. One of these would be really helpful to me. 5. At the weekend I spend most of my time doing this. 6. During the week I spend most of my time doing this. 7. During the week I spend most of my time here. 10. I wish I had one of these. 11. This object is really important to me. 17. This is the favourite piece of technology that I own. 21. This is something I won’t leave home without. 22. I use this everyday. 23. When I am at home I spend most of my time here.

G115 responded to this group of images by asking “is it good enough?”. She explained that the technology that she enjoyed the most was her second generation iPod. However, the design of this device had changed significantly since this model as the current version was fully touch-screen controlled and, as a result of this change, she was no longer able to operate her iPod. It had become a frustration to her because of its ‘technological development’.
This conversation also led to a discussion between participants about receiving their medication in bottles with ‘child proof’ lids - which they could not open, because of the effects of RA on their hands, and so, had to ask their children to open for them.

**Home and safety** G101 identified that comfort was a significant theme evident in many images. People appeared to have “a nest of comfort” to retreat to where they felt most comfortable, either the home as a whole, or a favourite place within the home, such as a chair, comfy sofa or indeed the aspirational ‘golden carriage’, providing luxury and comfort of the highest standard.

![Fig 4.52 (original in colour) G101 ‘Home and Safety’ category (2011)](image)

2. One of these would be really helpful to me. 3. I would like to be able to exercise here. 4. This is where I feel most safe. 7. During the week I spend most of my time here. 11. This object is really important to me. 19. This is how I usually travel. 21. This is something I won’t leave home without. 22. I use this everyday. 23. When I am at home I spend most of my time here.
Frustrations was the final theme identified by G101. This selection featured images which related to both the effects of RA and more general concerns. It mainly featured personal responsibilities and dependencies on others, but these images also identified lack of time and the need to work and earn money as personal frustrations. Other interests and personal ambitions such as learning a second language were featured. This further highlighted the fact that although RA can affect people profoundly, it did not have to dominate all personal goals.

Fig 4.53 (original in colour) G101 ‘Frustrations’ category (2011) 2. One of these would be really helpful to me. 10. I wish I had one of these. 11. This object is really important to me. 12. This is something I want to improve. 15. This is something that prevents me from exercising. 16. I need other people to help me with this. 18. This is something that frustrates me. 20. This is something that is expected of me at home. 24. These are my hands.

G115

Technology G115 stated that her definition of ‘technology’ “crossed lots of boundaries”. Although the images within this group were the same as those previously identified by G101, she did not believe that technology should be considered solely in terms of the ‘object’, but should also include considerations of how people felt about them and the challenges they presented.
**Life skills and hobbies** as defined by G115, identified the daily routines, interests and achievements that people engaged with as part of normal day to day living - listening to music, brushing teeth, managing time and pursuing personal hobbies and interests. Also, as part of life skills, she discussed the worries and concerns that needed to be managed on a daily basis. In this respect, money and medications were specifically identified.

![Image](https://example.com/image.png)

**Fig 4.54** (original in colour) **G115 ‘Life skills and Hobbies’ category** (2011) 1. This is something I am proud of. 2. One of these would be really helpful to me. 6. During the week I spend most of my time doing this. 7. During the week I spend most of my time here. 12. This is something I want to improve. 13. This makes me really happy. 14. This is something I worry about. 15. This is something that prevents me from exercising. 18. This is something that frustrates me. 22. I use this everyday.

**Safety, self-protection and home** G115 selected the same images as G101’s ‘Home and Safety’ group. G115 noted that most people would not leave the house without their keys, and that, for her, keys were by far the most important thing to not leave home without.

**Love, people, happy** G115 noted that enjoyments and activities identified were exactly what one would expect to see from people, regardless of if they had RA or not. This observation emphasised the need for interventions to be socially acceptable and to fit easily into the ‘real-life’ environments, activities and situations that people
lived within. Interventions should not compromise the user’s ability to participate with those around them.

**Movement, physicality and restriction** G115 identified the desires that people had to be active, the physical limitations of this which were specific to RA, and the general desire to maintain personal health and well being.

**G113**

G113 chose not to physically categorise her images. Instead she categorised her images through narrative; identifying themes and groupings that ‘stood out’ to her whilst reviewing the images. This enabled the same image to feature in several conceptual groups. G113 described how her categories complemented those of other members of the group: ‘family’, ‘safety’, ‘self-reliance’, ‘home’, ‘loved ones’ and ‘achievements’. She further explained her ‘achievement’ section by highlighting that people were still achievement-orientated despite having RA, a point that could be easily overlooked when identifying the problems and consequences of the condition.

She also identified ‘enabling or easing’: she said that she would like things to be made more easy so that she could still do them. She further explained this point with a section entitled ‘dreams and obstacles’. She still had dreams and ambitions but that RA presented a number of additional obstacles that needed to be overcome to enable her to do so.

‘Ability and inability’ was identified, as was ‘communication’ and ‘responsibilities and worries’, both for oneself and for others. The final observation made by G113 was ‘wanting to be’ or ‘trying to be’, explaining that people were trying to engage with everyday activities like walking and cycling whilst dealing with everyday inabilities.
G114

G114 identified ‘private’ and ‘public’ environments as her first category, stating that she believed the distinction between the two was important. She emphasised the need for both safety and freedom: safety in the home and the freedom of the outdoors, factors which were either exaggerated or compromised by the effects of RA. G113 agreed with this point explaining:

your ‘public and private’ is something that I was trying to articulate. It’s that ‘inside and outside’, I don’t know if that becomes a more stark relief than with other people. That if you have an illness or a condition then ‘inside/outside’, ‘public/private’, I think, becomes a bit more prominent an issue in your head.

Private

![Private category image](image)

Fig 4.55 (original in colour) G114 ‘Private’ category (2011) 4. This is where I feel most safe. 23. When I am at home I spend most of my time here.

Public

![Public category image](image)

Fig 4.56 (original in colour) G114 ‘Public’ category (2011) 3. I would like to be able to exercise here. 4. This is where I feel most safe. 7. During the week I spend most of my time here. 8. I like to spend time with friends here. 13. This makes me really happy.
This heightened sensitivity to physical surroundings and the sense of threat or security they convey emphasised the need for sensitively-designed interventions, which take these factors into account.

Would a therapeutic exercise device which was considered acceptable within the home also be acceptable in public environments, and vice versa? Could devices be developed to fit into the activities that people already engaged with in the home, cinema or library; or whilst swimming, walking, or socialising?

**Objects** G114 further differentiated this category, identifying ‘things that people want or want to change’ and ‘objects that people have and use daily’.

**Things that people want or want to change**

*Fig 4.57 (original in colour) G114 ‘Things that people want or want to change’ category (2011) 2. One of these would be really helpful to me. 10. I wish I had one of these. 12. This is something I want to improve. 14. This is something I worry about. 16. I need other people to help me with this. 18. This is something that frustrates me. 20. This is something that is expected of me at home.*
Each of the objects within this category were purposeful, functional or desirable enough for people to use them daily, despite their RA. These objects were either enabling in real time, necessary as part of daily responsibilities, part of daily routine or representative of personal interests and hobbies.

**Technology** was again identified as a specific theme. G114 defined her group as technologies that affected her and that she used. The images in this selection were the same as those identified in G101’s ‘Technology’ selection.
The category **physical conditions affected by RA** contained all of the images identifying hands, feet and walking sticks. The category was a literal and pragmatic representation of the effect that RA has on the body.

**Ethereal things** G114 described this selection of images as “abstract ideas and dreams of a better life.” She stated that these images represented her desire for wealth, time, more energy and life without work.

![Fig 4.59 (original in colour) G114 ‘Ethereal Things’ category (2011)](image)

2. One of these would be really helpful to me. 15. This is something that prevents me from exercising. 18. This is something that frustrates me.

**Participants’ most significant image**

Each member of the group was asked to select one image that was most significant to them as a reflection of their participation in this study. This could, for example, be the problem they were most concerned with or something they were most proud of.

G115 selected this image because she said it captured freedom, blue skies and positivity. She explained that for her, RA was just a restriction; something that curtailed the choices available to her. This image embodied the things that RA isn’t:

![Fig 4.60a (original in colour) “most significant image”, G114_08. (2011)](image)

G115 - To me this is like the ideal - just freedom and climbing over the back fence and not thinking any more about it and not having to think about it all the time and worry about it and other people’s understanding of it. So that would be lovely.
G113 selected this image (fig 4.58b) because, to her, this represented ‘future horizons’, ‘hope’ and the expansiveness of ‘getting out there’.

G114 also selected this image, and for the same reasons as G115 and G113. She added that it represented the opposite of the daily feeling of RA that she experienced, continually anticipating pain. She also joked that it looked a bit like an advert for painkillers!

G115 reasserted that she had not found anything surprising within any of the images. She fully expected family life, friends and relationships to have been predominant values regardless of what other specific needs one had and for movement and physicality issues to have been the greatest problems for people with RA. The significance of this, however, was the disparity between users’ recognition of these values and the designs of currently available devices. What was obvious was that the end user appeared to not have been properly considered, or perhaps valued, by those who have developed devices that were intended to help.
Group 3 session 2 summary

- Engaging with the photography exercise helped patients to recognise, reflect and take detailed account of the effects of RA on their lives.

- Reflecting on the photography exercise enabled patients to identify how their own condition had evolved over time.

- Having RA had a significant influence on the products that patients bought.

- Patients lives were strongly influenced by the opinions of family and close friends.

- Technology (mobile phones and computers) was prevalent throughout all participant groups however, their current functionality was questioned. Were they good enough?

- RA exacerbated the challenges of everyday tasks and could lead to a heightened state of frustration and stress.

- Life skills and hobbies defined part of who we are, what we spent our time doing and what motivated us as people. For this reason they could provide the greatest opportunities for integrated therapeutic exercise.

- Personal achievements, dreams and ambitions should not be forgotten because of RA. Treatment interventions should seek to positively reinforce these intrinsic motivations.

- Public and private environments presented different challenges and opportunities for treatment interventions.

- The objects and environments that featured in peoples’ lives could determine their own challenges, aspirations and achievements.

- Participants tried to be forward-focussed and hoped for a better future.
This section has presented a comprehensive description of the focus group discussions which took place during this research study. In total, fourteen patients participated. Each participant contributed to two focus group discussion sessions and completed the photographic cultural probe exercise. The information presented results in an accurate and detailed narrative of the real life experience of RA, as described by patients in their own words. The findings presented also identify the intricacies, nuances and contradictions of RA and its treatments and the differences and similarities of opinion between patients.

To assess the significance of these findings, and to answer clearly the questions that this research seeks to investigate, the following section will provide a detailed analysis and critique of findings. Common themes will be identified and discussed and strategies for how design could be used to improve the health and wellbeing of patients with RA will be presented.
Analysis

The aims of this study were to: identify designable factors specific to people with RA, which could be targeted to affect the ability and willingness of patients to engage with longterm therapeutic exercise recommendations (RQ 1); identify specific motivators, present in daily life activities, that could be targeted to facilitate and sustain longterm engagement with therapeutic exercise interventions for people with RA (RQ 2); and to explore how motivational and designable factors identified within the study could be built into devices intended for long-term therapeutic use (RQ 3). In seeking to answer research questions RQ 1 and RQ 2, four key themes were identified from the research findings: product opportunities and challenges, patient information and communication systems, the effects of RA and its treatments and patient motivations and aspirations. Each of these will be discussed and situated within the wider context of existing research literature. Following this, a critique of the methods used will be conducted, with particular emphasis on the use of visual research methods in a healthcare setting. In exploring RQ 3, two design interventions have been developed, a toothbrush design which enables the user to exercise the hand as part of an existing daily routine and a patient assessment tool designed to be used by therapists and charity healthcare organisations when working with patients as part of ongoing care. An exegesis for each of these outcomes is provided below.

Critical assessment of findings

Product challenges and opportunities There was a clear preference amongst the focus group participants towards assistive equipment which enabled everyday tasks to be completed more easily and which reduced the level of physical effort required to fulfil a given task. These participant desires align with universal and inclusive design models discussed in chapter 2. The biological, psychological and social strains of RA, identified by participants, undoubtedly contribute to patient preferences towards assistive equipment. Assistive devices offer temporary respite or, at the very least, practical solutions to the everyday challenges exacerbated by the consequences of RA. Devices which are both commercially available and which provide some form of immediate assistance were particularly popular amongst the participant groups, such as the Easy-Pour kettle, enlarged door handle grips and electric tin openers.
This general preference amongst patients for devices which provide assistance is evidence of the broad distinction between ‘assistive’ and ‘therapeutic’ devices as identified in Chapter 2 ‘Critique of existing devices’. Indeed, it is the motivation to provide products which are desirable to users which has driven the development of design for health products developed by organisations such as A&E Design, Ergonomi Design Gruppen and Smart Design. This approach is consistent with the inclusive-, universal-, human-, and user- centred design philosophies discussed in Chapter 2, ‘Evolution of health focussed design philosophies’. The popularity of assistive devices amongst users qualifies the incentive for developing products which prioritise user desires and mass-market saleability. However, whilst highly effective for the development of commercially successful design outcomes, inclusive- and user-centred approaches to design have thus far failed to result in products that meet commercial needs required to justify financial investment and adequately fulfil the long-term therapeutic needs of people living with RA. As outlined in Chapter 2, the priority given to maximising accessibility and minimising physical effort through design may present a significant risk of developing products which provide users with outcomes they believe they want, rather than outcomes which are, in therapeutic terms, more worthwhile. These conflicting aspects of the relationship between user desires and the aims of healthcare interventions add further complexity to the challenge of designing interventions which provide therapeutic benefit and achieve long-term engagement. Utilising user input as part of the design process can be an effective means to ensure that outcomes are appealing. However, if the outcome is intended to fulfil a specific healthcare need, such as therapeutic exercise, user input should only be used in combination with that of stakeholders who can advise on health-specific features, to ensure that the product outcome is appropriately balanced between treatment benefit and user desires.

The functional efficacy of assistive devices and their popularity amongst users provides some insight into the kinds of devices that patients will engage with by choice and those that are used as part of normal daily life. Incorporating beneficial exercise movements into existing devices is one approach that could be effective to improving user engagement with exercise therapies. Research participants identified that devices were more likely to promote active engagement if they: supported users...
to maintain existing behaviours and routines (pg 168, 213, 217), enabled them to use kitchenwares (pg 148, 166, 188, 191), computer interface devices (pg 169, 182, 183, 210) and to support personal hygiene (pg 159, 168, 192); provided benefits that were immediately recognisable to the user, either through functional relevance to daily living or through designed feedback loops; or provided support for social and psychological challenges caused by RA, such as support for personal interests and hobbies, work and engagement with social support networks (this point is discussed in more detail below under the heading ‘Patient Motivations and Aspirations’). Fig 4.61 displays all the objects that research participants reported using daily. Of these, the computer, mobile phone, keys and toothbrush were the most universal. The computer is commonly used for work, the phone for social connectedness and emergencies, the keys out of necessity and the toothbrush as an established part of a personal hygiene routine.

Fig 4.61 (original in colour) Daily-use objects identified by research participants, T. Ainsworth (2012)
The misalignment between the aims of therapeutic exercise interventions, which are necessarily challenging, and user preferences towards simplicity and ease of use, which are often counter to treatment aims, points to the clear need for interventions that directly target behavioural change. This challenge was identified by Zander in the late 1800s and Tye’s HID model (1999) was the first attempt to incorporate behaviour change interventions into industrial design to achieve health and wellbeing gains. Tye’s concept of Sananomics and its incorporation into the design process was an attempt to remove as many potential barriers to healthy movement within the built environment as possible, by understanding the habitual conditioning of the user. Whilst Tye’s work identified the opportunity for targeted physical challenge within design, and presented a model for how this might be achieved, evidence for its effectiveness is limited both in terms of actual and perceived benefit. Nevertheless, the proposition that behavioural factors can be identified, understood and applied to the design process was significant. It provided the starting point from which further behavioural investigations could be conducted and remained a key feature of persuasive design interventions. Indeed, patients who engaged with this research study expressed that they would feel a greater willingness to engage with exercise activities if they were embedded among their everyday tasks.

Within this study none of the participants in any of the focus groups reported using therapeutic exercise devices. In many cases this was due to a fear of movement due to the pain of RA. However, there was also a lack of awareness amongst patients of the benefits of such equipment (discussed further in Patient Information and Communication Systems below) and an overwhelming preference amongst patients towards assistive devices. The “love of ease”\textsuperscript{259} and the general lack of urgency to pursue exercise, identified by Zander in the late 1800s, remain as behavioural factors that contribute to lack of engagement today.

The functional and the visual aspects of available devices, both therapeutic and assistive, are problematic. Therapeutic devices, as identified in the literature review, often do not provide immediately perceptible benefits to the user; the time invested in exercise and evidence of improved functional ability raises the level of commitment required from the patient as they have to maintain and repeat that action over a

prolonged period of time. This may undermine patient beliefs about the benefits of such treatments. Behaviour models such as Rosenstock’s Health Belief Model (1975), Rogers Protection Motivation Theory (1975) and Ajzen’s Theory of Planned Behaviour (1991) each identify patient beliefs about outcomes as a specific factor determining an individual’s willingness to engage. Conversely, pharmacological treatments, such as pain killers and anti-inflammatories, tend to provide rapid relief to symptoms and were, therefore, perceived to be more effective and more beneficial than long-term, therapeutic, preventative interventions. Furthermore, the time-consuming nature of using therapeutic devices and the lack of relationship between their function and existing routines, behaviours, interests or responsibilities presented challenges to engagement. Patients were unlikely to choose to engage with exercise devices if they did not have a particular motivation or willingness to do so. There is therefore a clear need to develop therapeutic interventions which are meaningful to the user. This point is supported by the evidence collected during this study, as all of the daily use objects identified by research participants offer some kind of functional benefit to the user.

The visual appearance of assistive devices and the way in which they are recognised and understood by society also present significant and complex challenges for design. This concern is evident from research participants’ narratives, in which they reflect on their own experiences of using assistive equipment in public places, such as wrist splints and walking aids. Both user and public perceptions of such equipment can have quite complex and contradictory effects on patient experiences. For example, research participants who used assistive equipment to support their daily living needs stated that they felt self-conscious, and at times resentful, of the equipment they had. This was often because the appearance of the available equipment attracted unwanted attention, sometimes leading to comments or judgements from others, or because patients begrudged their dependence on external support devices. The combination of these factors caused the users to feel socially excluded and disempowered. The consequence of this was that patients experienced further psychological and social strain in addition to the already challenging experience of dealing with long-term illness.
Conversely, participants also reported that in other situations, the outward communication of physical disability that was conveyed by the equipment they had (wrist splint or walking stick), could provide justification to onlookers for behaviours that may otherwise be considered inappropriate or unjust. For example a walking stick, is a device easily recognised and understood by onlookers as associated with physical disability and, as such, provides justification for why the user may be crossing a road slowly or requesting a priority seat on a bus or train. These examples, which illustrate the inadvertent consequences of some interventions, provide evidence for the need to consider the real life experiences of users both as part of the treatment process and as part of the design process for treatment interventions. Objects that convey a sense of illness or attract unwanted attention towards the user are likely to be unpopular, even if they are functionally effective. Whilst in some circumstances users may benefit from others recognising their needs, the lack of choice over when their needs are identified and how they are understood, leads many users to simply avoid using such equipment altogether.

**Patient information and communication systems** The second key area of concern identified within the research findings is the availability and reliability of treatment information and the effectiveness of current communication systems between patients and healthcare professionals. The need for improvement was identified both explicitly and implicitly throughout the research findings. Despite the Bone and Joint Decade initiative entering its second term and NICE publishing guidelines emphasising the importance of therapeutic interventions for the treatment of RA, and despite patient initiatives such as the Expert Patients Programme and the Patients and Public Involvement scheme, (identified in Chapter 2), patients who participated in this study were largely unaware of the benefits of physical exercise as part of the long-term treatment of RA. For example, of the fourteen patients who participated in the study, only two actively engaged with exercise activities (yoga and pilates). In each of these cases the patient had an existing interest in physical health and wellbeing prior to diagnosis. Multiple reasons were identified for why patients may struggle with existing information and communication systems including, reliability of information, poor communication with healthcare services, general lack of awareness of RA throughout society, and discomfort with some of the language used to describe RA the nature of RA.
Reliable information, specific to the nature of RA and its treatments, was reported to be difficult to source. Some participants found information to be contradictory or inadequate for their needs. Accurate, up-to-date, and reliable information resources do exist through clinics and online, including for example, NHS, Arthritis UK and NRAS resources. However, many of these services were either underused, misunderstood or overlooked by many patients. Blog and social media websites were often used as an alternative source of information, especially amongst the younger members of the study. Participants reported using these sites to source and discuss treatment experiences, identify useful products and to engage with autonomous peer support networks. The ‘open source’ nature of these resources, in which users are able to share information freely and without expert peer review, could be a factor adding confusion and resistance to healthcare recommendations amongst some patients. Within this study some participants discussed their own theories about the causes of RA, postulating that it may in fact be a problem in the digestive system, or a direct consequence of stress. Whilst the causes of RA are not fully understood, theories such as these are not convergent with current best knowledge and practice. The construction of such theories between non-experts through social media sites, has the potential to lead some patients to develop ill-informed beliefs about their condition which, in turn, lead to a resistance to healthcare recommendations.

The poor communication that was reported between healthcare services and patients has a damaging effect on the capacity of interventions and services to achieve their full potential. Many research participants held a belief that doctors and consultants were only interested in treating patients with pharmacological interventions. Participants also reported that additional forms of treatment, such as dietary advice, physical therapies and alternative therapies, were under-supported. Whilst participation in education groups, such as the Expert Patients Programme, had been offered to some of the research participants, few had been willing or able to participate. This was often due either to personal attitudes towards help groups or the inconvenience of session times.

The general lack of awareness and understanding of RA throughout society was also identified as a problematic feature for those who live with the condition. Participant
experiences reported within this study suggest that there is a general, societal perception that arthritis is the name of a specific condition. The features that define RA, (fatigue, pain, swelling, flare-ups, symmetrical distribution of symptoms), affect patients in ways that are so profoundly different from the common perception of arthritis that their needs and difficulties are often overlooked or underestimated. One consequence of this is that people living with RA do not benefit from the social support and affordances, such as priority seating, that others with equally debilitating but more well understood conditions benefit from without question or suspicion. Several study participants had been accused of fraudulent use of disability badges, or had been subject to abuse from people who did not recognise that they had a health condition that affected their energy levels and ability to move freely.

There was a feeling that the language used to describe the effects of RA is often inadequate to address the complex and changeable nature of the condition. Terms such as ‘disability’ or ‘disabled’ for example, were identified as being particularly problematic because they fail to account for the unpredictable and irregular occurrence of symptoms. The labelling of particular attributes of the condition can also present significant challenges for patients to deal with. For example, the word ‘chronic’, although accurate, can, as identified within the research findings, trigger some patients to become less optimistic about the potential benefits of treatment interventions. The limited gains prognosticated by the language used to communicate the nature of a particular prognosis can reduce the willingness of the patient to respond positively to healthcare recommendations. In this respect, the way in which a diagnosis is communicated to a patient becomes a crucial designable factor which can affect the willingness of an individual to engage with treatment recommendations. A condition-specific lexicon could be designed to assist communication and actively promote positive engagement. Whilst healthcare professionals have a responsibility to communicate particular prognoses to patients, accurately and honestly, this process could be refined so that information is delivered in a manner that maximises the potential for positive response from patients whilst also preserving the integrity of meaning within diagnosis.

The development of a condition-specific lexicon could also be extended to the development of ‘tools’ for patients designed to aid communication with others in
society. Short, informative and factual, statements could be developed and presented to patients as a set of language cards, which could be recited or presented to others, that accurately and succinctly describe important details of RA through carefully designed gambits. Indeed, some participants reported using self-developed statements as a means to quickly communicate aspects of their condition, involving short, easily understood, anecdotes (see group 1 session 1 pg149). The development of this kind of tool would aim to assist communication and empower patients who do not feel comfortable, or confident, talking about their condition to do so more easily. Such an intervention would also help to raise public awareness of conditions such as RA.

The effects of RA and its treatments on patients Understanding the lived experience of RA and the challenges that concern patients most about their condition is essential to developing treatment interventions which are both meaningful and worthwhile. The following section will further summarise the factors that contribute to a lack of engagement with currently available devices. It also identifies a need for interventions that consider the socio-psychological aspects of human behaviour as a means to facilitate long-term engagement.

The consequences of RA negatively affect the ability and willingness of patients to engage with long-term therapeutic treatments. Joint swelling, pain and fatigue, are particularly severe during periods of high disease activity. This often leads to an inability to work and an avoidance of social engagement. The discomfort caused by these symptoms, combined with the patients' own fear of injury, can lead individuals to feel unable and unwilling to engage with non-essential physical movements, even during times when disease activity levels are in remission. This would appear to be counter to the causal relationship between threat perception and protection motivation proposed by Rosenstock’s Health Belief Model (1960, 1966, 1974), and Rogers Protection Motivation Theory (1975). Each of these models suggests that the threat of lost functional ability should trigger engagement with preventative intervention. However, our findings suggest that, the threat of reduced functional ability caused by muscle weakness directly resulting from lack of use was not
significant or immediate enough to motivate active engagement with therapeutic exercise interventions. Loss of functional ability, particularly in the hands, was considered an accepted consequence of RA. This is partly due to a lack of understanding of the benefits of therapeutic exercise and also due to a lack of awareness of the threat of sedentary behaviours. Research findings identify that although patients were concerned with the long-term consequences of RA, for most, this threat is overwhelmed by more immediate needs and responsibilities presented by everyday life.

The threat of reduced functional ability, although very real, is more subtle than the other, more apparent and recognisable, consequences of RA, such as swelling, pain and fatigue. This suggests that the extended timescale between reduced activity and perceptible loss of function, combined with the superior ability of pharmacological interventions to provide rapid relief of the most challenging symptoms, reduces the significance of therapeutic interventions within the hierarchy of treatment priorities of both patients and healthcare providers. Consequently, patients do not adequately recognise the threat of lost functional ability and thus fail to engage the therapeutic treatments required to counteract weakness and mobility loss. There is an opportunity to develop a system which provides feedback loops, that reduce the gap between engagement with exercise and recognisable benefit to a more easily perceptible range. This strategy, informed by Dahlgren and Whitehead’s Main Determinants of Health Model (1991), could be applied throughout the treatment intervention system to link each of the biological, psychological and social elements and achieve a comprehensive and robust ecology of intervention and adaptive ongoing support.

In the same way that pharmacological treatments are closely monitored and actively managed by consultants, exercise therapies should be tailored, monitored and adapted to individual needs continuously throughout the duration of ill health. The devices available to support therapeutic movements should be developed with the capacity to support large-scale personalisation. New technologies, such as web connected mobile devices and ubiquitous wearable sensors, are rapidly evolving as
affordable means to support individualised user experiences. This would help patients to actively engage with their physical wellbeing, build confidence in physical abilities and enable patients to establish their own parameters for exercise and movement regimens. The challenge for design is how to realise and maximise the potential of such systems for health benefit.

In addition to the challenge of threat awareness, other specific aspects of RA and its treatment were also identified as being particularly problematic. For example, fatigue, rather than pain, that was identified by the majority of participants as the greatest barrier to engagement with physical activities. Whilst pain was unquestionably significant, this sample suggested that fatigue was more consequential. Pain was described as a ‘constant’ which could be managed using drug treatments, whilst fatigue was identified as an intermittent problem that did not have an easy or definite solution. The monotony of long-term treatment regimen was also identified as a significant burden. Participants who had lived with RA the longest, and who had established a level of control over their symptoms using pharmacological treatments, described how it was the treatment itself that was now their greatest cause for concern. The side-effects of medications have become increasingly apparent and significant, partly due to secondary issues such as liver and kidney damage caused by drug toxicity and also the psychological strain of medication dependency. The need to take medications multiple times per day or suffer the consequences of uncontrolled RA provided a constant source of torment for many patients.

Psychological strains are evident throughout almost all aspects of RA from diagnosis to lifestyle choices and treatment regimen, and the effects of these strains should not be underestimated. NICE (2009) identifies fear, anxiety and depression as common mental health conditions associated with RA and several further psychological threats were highlighted by this study. Visible symptoms such as joint deformity affecting the hands and difficulty in walking are a constant cause of social as well as physical concern for some patients. Social isolation was also a huge problem. Many patients avoided talking about their RA for fear of becoming a burden to others. An inability to work or socialise, which affects many patients as a result of symptoms, means that
many patients lose friends or have a compromised ability to meet new people and maintain friendships. This can lead patients to ruminate about personal difficulties and concerns. This threat is especially difficult when combined with a tendency to reflect on past abilities that are now compromised by RA.

The built environment also presents a number of specific challenges to patients. The kitchen, bathroom and workplace were identified by participants as those which present the greatest levels of challenge and frustration. Each of these environments serves a purpose within everyday life, therefore engagement is not established through choice but through necessity. Specific challenges are those associated with daily living tasks which require strength and dexterity, such as: cooking, cleaning, maintaining personal hygiene and providing for others. This further illustrates the economic benefits of developing devices which support these activities. Challenges faced in the workplace, reported by research participants, present a more dynamic range of physical and socio-psychological problems. The onset of RA often leads patients to feel vulnerable around others due to pain, discomfort and fatigue; the combination of symptoms and the vulnerability to illness caused by immunosuppressant medications can cause patients to develop a more acute fear of illness and injury and visible symptoms such as rheumatoid nodes and ‘clawing’ of fingers can limit physical abilities and lead to emotional insecurity. Patients also reported feeling less able to make long-term work commitments due to the changeability of their symptoms.

Patient motivations and aspirations In seeking to identify designable factors that motivate patients to engage with therapeutic exercise recommendations it is necessary to understand the motivations and aspirations that are already present within the lives of patients. This will enable the development of design interventions which complement and support patient interests and identify opportunities for where interventions could be most strategically targeted.

Patients with RA do not lack the motivation to fulfil their own interests and ambitions. Research participants repeatedly emphasised their desire to maintain the activities
they pursued before disease onset, regardless of the difficulties caused by RA. The Fogg Behavior Model (2002) suggests that level of motivation is directly linked to the ability an individual has to achieve a specific task. The model suggests that highly motivated individuals can overcome more challenging tasks and, conversely, that people who lack motivation will only be able to achieve tasks which present minimum challenge. Based on this model it could be considered that many existing therapeutic exercise devices fail because the motivation to engage does not overcome the challenge presented. Considered in the context of the Fogg Behaviour Model axis chart (see Chapter 2, ‘Behaviour change theories’), devices would be located below the ‘activation threshold’. Understanding existing behaviours provides an opportunity to identify meaningful motivations which, if incorporated into healthcare interventions, could support long-term engagement. Personal commitments such as work and family appear to be significant motivators, as are hobbies, past achievements and educational aspirations.

Patients generally want to be able to continue to live life in the same way as they did before onset and often prefer therapeutic interventions which do not differentiate them from others. Often patients have a desire to be fit and healthy but are unwilling to engage with exercises that take them away from their other priorities. As outlined previously, fatigue is a significant determinant of engagement. Time and energy are premium assets for a patient to manage as part of daily life to achieve maximum gain. Activities which are most valuable, beneficial or rewarding will take precedence over those which are perceived to be less beneficial or rewarding. Patients enjoy forms of exercise that encourage social engagement and temporary respite from symptoms. Activities such as yoga and pilates were identified several times as particularly enjoyable and effective. The inclusivity encouraged by these groups was reported to be a great benefit because it could help prevent patients feeling marginalised by their particular needs within the social group. This could help the individual to achieve a wider sense of inclusion and wellbeing.

Social inclusion, relaxation and security were all identified as particular priorities by research participants. Family and close friends were identified by research
participants as the individuals whose opinions were most valuable to them. The desire for social connectedness and the heightened level of influence that family and close friends have with one another provides an opportunity to introduce a social dimension to the treatment process for patients living with longterm illness. As with the persuasive design products identified in chapter 2 social modes of intervention could be utilised to provide emotional support and personalised motivation to patients by informing, educating and supporting wider social support systems. The motivation to sustain established behaviours, evident throughout the research findings, identifies a wealth of significant intrinsic motivators, specific to the individual, which have the potential to facilitate or support therapeutic interventions. For example, hobbies such as photography and work involving the use of computers, provide motivational drivers which could, through design innovation, be incorporated into therapeutic interventions via specifically-designed camera attachments or computer interface devices.

The home and, in particular, the bedroom and living room were favoured environments for supporting calmness and relaxation. Whilst these environments have the potential to incorporate therapeutic interventions, the significance of their function as a space to unwind and recuperate suggest that users are unlikely to welcome therapeutic devices, which are necessarily challenging, into that space unless they support the existing routines of the user. Functional environments on the other hand, such as the kitchen and bathroom, provide the opportunity to incorporate tools, such as therapeutic exercise devices, without challenging the established nature of that space. Whilst these are the environments in which patients already experience the greatest level of challenge, introducing small or micro-adaptations to facilitate therapeutic benefit can be a non-confrontational way to encourage change within that space. For these reasons, this research proposes that micro-adaptations of existing devices and routines are more likely to promote engagement among individuals, and especially with those who have low levels of motivation to engage with such activities.
Critical assessment of methodology

Research findings gathered within this study demonstrated the value and potential of adopting visual research methods in healthcare settings. The highly detailed narratives facilitated by the photographic cultural probe element of the study has proven to be an effective method for identifying a wealth of information concerning the everyday lives of patients who live with RA. This method captured the complexity of the condition and its treatments and extended our understanding of the wider psychological and social effects of RA. Furthermore, this approach has enabled participants to identify their own ambitions, interests and needs, on their own terms and over an extended period of consultation to consider their responses carefully, thoughtfully and accurately.

A number of challenges specific to this method were also identified; firstly in terms of difficulties experienced by research participants when engaging with the photographic task and secondly for the analysis of research findings. Research participants identified a number of specific challenges based on their own experience of the exercise, these were: difficulty in translating personal thoughts and planned responses to statements into photographic images; understanding the link between the statements provided and the treatment of RA; and the practical challenge of capturing the reference numbers of statements within each photograph. Despite reporting these challenges all participants completed the task. The challenging nature of this exercise required participants to consider their responses thoughtfully. This helped to avoid reflexive statements and anecdotes which can occur more easily during focus group discussions. The link between image statements and RA was purposefully divergent to maximise the possibility of capturing new insights using this approach. Some confusion from participants is to be expected given the nature of its application as a research tool. The use of reference numbers within images was a necessary aspect of the analysis process, however, an alternative method could be developed, such as, asking participants to link the images to the statements during the discussion group or by developing a web based system that invites participants to upload and annotate images. This, however, would require higher level IT and web literacy.
Analysis of research findings was also challenging. Qualitative research methods often create a lot of data ‘noise’. Significant elements within findings can be difficult to differentiate from factors which are less important or irrelevant. Often the highly interpretive nature of the photographic images meant that meaning was very difficult to decipher correctly without the image creator describing the context, significance or intended meaning of each image. The value of the images are the narratives to which they facilitate. Indeed the particular benefit of this method is its open-endedness. Understanding the existing values and behaviours of patients provides insight into the most opportune, and individual-specific, contexts to which healthcare interventions should be targeted. This method can therefore be used to ‘future-cast’ treatment strategies based on personal routines, interests, hobbies and responsibilities established within a patients’ existing lifestyle. In contrast, existing patient assessment tools tend to assess patients against pre-defined criteria, comparing patient needs retrospectively against existing questionnaires and assessment tools. Whilst making informed decisions based on clinical knowledge and experience is an essential and fundamental aspect of healthcare, methods which ‘retro-fit’ the patient to a set of pre-determined parameters are limited in their ability to capture the intricacies and nuances of individual patient needs.

Participants also identified a number of particular benefits that participation in this study had helped them to recognise, these included: identifying the effects that RA has had on their lives and the people around them; recognising how their own condition had evolved over time (both positively and negatively); providing a sense of purpose by contributing to a study that aimed to help people living with RA in the future. The success of this method as a research tool, evidenced by the findings presented in this study, identifies an opportunity to develop a patient assessment tool which can be used by therapists and charity organisations who work with patients, to identify opportunities for where therapeutic interventions could be incorporated into existing routines and to help to continually explore the complexity of RA and its consequences on those effected.

The next section will identify two specific design outcomes developed as a result of this research study in response to RQ 3. An exegesis of each outcome will be provided and accompanied by a photograph of the object itself.
Prototype design outcomes

The first prototype design outcome was developed from the daily use objects identified by the participant group, in fig 4.61 (pg 224). Each of the objects identified offered the potential to introduce therapeutic exercise into an existing behaviour. On analysis of the research findings, the computer, mobile phone, keys and toothbrush were considered to offer the greatest opportunity due to their prevalence throughout the group.

Computer and mobile phone modifications could be developed in the form of physical computer interfaces or software applications. Computer interface devices, designed to work alongside a keyboard and mouse, could be developed to offer resistance and promote healthy movement to users whilst working on screen. Software systems could be developed for both PCs and mobile phones to provide prompts, reminders and exercise guidance as part of an exercise programme. Systems such as these, however, would require specialist computer science expertise and significant investment in order to develop design outcomes. Therefore these ideas have not been explored further within this study.

Keys offer an opportunity to develop a small scale exercise devices that can be incorporated into the keyring and carried on the person at all times. Whilst the convenience of keys offers the potential for ubiquitous exercise the scale required to maintain the benefit of size, whilst also providing effective therapeutic exercise, is limiting.

The toothbrush provides an opportunity to incorporate exercise into, what is for most people, an established daily personal hygiene routine. The bathroom is an environment in which people invest time into maintaining personal hygiene, grooming and nurturing wellbeing. The environment is functional and private and, arguably, provides a permissive setting that is sympathetic to subtle therapeutic activities. The act of toothbrushing is brief and repeated regularly, it is an archetype of long-term preventative care.
This design facilitates therapeutic exercise for the hand by providing a flexible and resistive toothbrush handle for the user to pinch and squeeze whilst brushing his or her teeth. The design encourages longterm engagement through the micro-adaptation of the daily routine of toothbrushing. The design utilises the inherent
warmth and flexibility of wood, which not only provides a resistance for users to work against in order to develop strength, but also differentiates this design from existing therapeutic devices and defines it as an individual crafted object. The toothbrush is hand crafted from green sycamore, a food-safe wood, and is produced through a process of CNC milling, steam bending and glueing.

Importantly, this design has been developed to encourage exercise without enforcing compliance. The user is not required to utilise the therapeutic features of this design to benefit from its functionality as a toothbrush. Instead, the design utilises the daily routine of tooth brushing to provide a trigger to encourage the user to pinch and squeeze the handle voluntarily; thus emphasising the non-invasive, non-coercive and non-deceitful strategy of persuasive design.

Specific benefits to this design include:

• The toothbrush is part of an established daily routine that most people have adopted from an early age.
• The design is distinguished from mass-produced mass-market products.
• The design encourages the user to take control of their own exercise regimen.
• The design can be adapted to control the resistance of both the ‘pinch’ and ‘grip strength’ actions.
• The design can be developed to incorporate a digital counting device which would enable the user to monitor progress over time and to establish personal goals in consultation with a physiotherapist.
• Further developments could incorporate ubiquitous computing technologies to further support and monitor longterm use through; adaptive goal setting, long and short term performance monitoring and social network connection to promote peer support. This could be achieved through web connectivity and an online support.

This design has been developed to increase the likelihood of users to engage with therapeutic exercises. This is not an assistive device but a device which seeks to facilitate engagement unobtrusively and over a prolonged period of time.
Patient assessment tool

The second prototype design is a Patient Assessment Tool. The design seeks to empower the patient and provide a more formal means to identify opportunities for targeted treatment interventions which are sympathetic to the personal circumstances and preferences of the user.

In chapter 2, ‘Patient Assessment Measures’, existing patient assessment questionnaires were discussed. Whilst existing measures can provide a quantitative assessment of functional abilities, they are restricted in their capacity to identify issues that are not pre-defined within the parameters of the questionnaire. They are also solely problem-focussed; no formal investigation is made into the lived experience of RA, the personal priorities of patients or where treatment interventions may be most appropriately targeted.

The design of the Patient Assessment Tool is based on the photographic cultural probe method used within this study. The tool takes the form of a pack of cards comprising a series of images (taken by patients who participated in this study) that act as conversational triggers, together with selected statements from the original study design.
This design seeks to facilitate open-ended dialogue amongst patient groups by means of photo-elicitation. The cards are intended for use within a group setting, facilitated by a therapist or eduction group leader, to identify opportunities for where treatment interventions could be targeted to achieve optimum effectiveness - based
on individual needs, preferences and circumstances. This cooperative method provides the opportunity for patients to identify their own needs using their own words and for therapists to explore areas of particular interest or concern more deeply than existing patient assessment tools currently allow.

Further development of this tool would be to utilise new technologies such as smart phones, tablet devices and web resources, to encourage and monitor participation in a targeted and more long-term fashion. For example, technologies could be used to prompt individual patients to take photographs of objects and environments that are causing the greatest concern for them and to upload these images to an online database which could be shared with the care team. Such a resource would enable the possibility of a database of difficulties, interests, motivations and treatment priorities to be established for each patient individually and for the effectiveness of interventions to be monitored over time and refined and developed appropriately.

Specific benefits of this design:

- Treatment interventions can be targeted to the specific needs of the patient and be monitored and tailored over time.
- Patient needs are not ‘retro-fitted’ to existing criteria, instead they are identified and prioritised through structured dialogue between the patient and healthcare teams.
- The tool provides the opportunity for both condition problems and treatment opportunities to be identified throughout each of the biopsychosocial healthcare domains.
Chapter 5. Conclusions

RA is a complex and costly condition to treat and manage. The increase in the British age demographic will see more people living with long-term health conditions such as RA than at any other time in history. The personal, social and economic impacts are considerable and should be a concern for all of us. To overcome these challenges, a number of new approaches are needed: conceptions of health and wellbeing need to be reviewed and developed; research methods and intervention strategies must be designed to ensure that the real and long-term needs of patients are identified and understood. In particular, intervention strategies need to be designed appropriately and sympathetically, to address the specific and complex needs of individual cases. This thesis presents a development of design thinking that extends beyond inclusivity in design for health and wellbeing.

The complexity of RA and the effect it has on patient needs and aspirations has a significant effect on the designable factors which contribute to the ability and willingness of patients to engage with therapeutic exercise recommendations. Inclusive and universal approaches to design offer valuable opportunities for people with specific needs to engage with society and to fulfil personal and social aims. These approaches, however, should not be considered the most suitable in all circumstances. Maximising accessibility and reducing the requirements of engagement to that of the lowest common denominator presents its own threats to overall health and wellbeing; namely increased dependence on supportive equipment and a decrease in levels of functional ability. Minimising the level of challenge experienced during physical interactions may be highly appealing and not least to those who live with conditions that affect their physical abilities, however, designing to support these desires has a direct consequence in actively encouraging sedentary, low effort behaviours. Such behaviours can in turn lead to reduced ability and greater dependency. Attempts have been made in the past by both designers and healthcare providers to address the problems of over-assisted living. Tye and Zander for example both understood the threat of over-supported lifestyles and worked to incorporate healthy movement and exercise into daily life experiences, each to varying degrees of success. A key feature, common to the work of both of these
individuals, is their awareness of the need to consider, and design for, behavioural change.

Socio-psychological models of behaviour offer a wealth of insights into the factors that contribute to the decisions we make and the actions we undertake. These models, however, are only concerned with factors within the human psyche. They do not account for the influence of the built environment on how we think or behave. The model presented within this research places the objects and environments that we engage with as the principal factor mediating our actual and intended behaviours.

Understanding the influence of the built environment on our behaviour is a factor of vital importance if we are to design interventions for long-term health and wellbeing. One of the key challenges to overcome, to ensure the long term success of health focussed interventions such as these, is the development of sustainable business models. These are needed to develop interventions that are beneficial for longterm health but that might struggle to achieve commercial success in open business markets due to the challenging nature of incorporating therapeutic exercise into daily life activities.

It is evident that existing approaches to design have not been developed to reconcile the multitude of biological, psychological and social needs necessary to achieve the successful longterm management of conditions such as RA. The idea that design should lead to products and solutions, a premise carried by many existing approaches to design, is also problematic. Whilst resolving problems may be an aim of some design interventions, an assumption that products are the most appropriate and beneficial outcome, or that solutions are always possible, may in fact stem from a failure amongst designers to recognise the true complexity of the issue being tackled. The healthcare needs of people with longterm conditions presents multiple and complex challenges for those designing treatment interventions. There is no single design solution capable of fulfilling the complete range of therapeutic needs required by each patient for the duration of their healthcare needs. Indeed, the clinical distinction between condition management and curative treatments identifies a more realistic alternative approach. Design innovations may be able to meet the needs of a particular individual at a specific moment in time but as the needs of the individual change, so too should the design of interventions. There is therefore a
need to establish new approaches to design which are capable of considering complex ‘ecologies’ of interrelated factors which are adaptive, future-focussed and evolutionary.

Contributions to knowledge
The aim of this research study was to extend our understanding of the nature of patient engagement with therapeutic exercise recommendations and to apply a design thinking approach to the development of future treatments for RA. In seeking to achieve this, this thesis presents three original contributions to knowledge: an advancement of design research methodology; a model of behaviour change theory which is specific to the needs of people with RA, and two practical design solutions: a patient assessment tool and a therapeutic exercise device designed to extend user engagement. A descriptive account of these contributions will now follow.

The advancement of design research methodology for patient led qualitative research - The research methodology used within this research study presents the convergence of cultural probe, photo-elicitation and focus group methods into a coherent and effective qualitative research tool for design and health research. This approach can be appropriated to specific study needs by designers, healthcare professionals and academic researchers for their own research needs. The use of statements to help focus participant responses is an effective means to ensure that research findings are relevant to study aims whilst also capturing the interests and concerns of patients.

The development of behaviour change theory to meet the needs of people with RA - The Persuasive Design Model for Therapeutic Exercise (fig 5.1) (for further details see Chapter 2, ‘Implications for Research’) identifies the key features of behaviour that should be identified and understood when developing therapeutic treatment interventions intended for long-term use. This cyclical model positions designed objects and environments as the principal factors determining patient engagement with therapeutic exercise behaviours. It proposes that designed objects and environments not only facilitate behaviour but are also active in influencing our sense of agency, attitudes and normative behaviours.
Fig 5.1 (original in colour) Persuasive Design Model for Therapeutic Exercise, T. Ainsworth, (2012)
The Persuasive Design Model for Therapeutic Exercise can be applied both as a critical assessment framework to establish a behavioural understanding of a potential user group and as a model through which future design outcomes can be developed. For example, the toothbrush design developed within this study provides a trigger to encourage exercise as part of an established daily routine (see fig 5.1 ‘norms’) without requiring to the user to utilise the therapeutic elements to benefit from its function as a toothbrush (see fig 5.1 ‘agency’). The design encourages the user to become more aware of their functional abilities, provides an opportunity to build strength and dexterity and enables the user to monitor the effects of their physical strength over time (see fig 5.1 ‘attitude’).

**Therapeutic exercise toothbrush and patient assessment tool**

The therapeutic exercise toothbrush presented within this study has been developed to increase the likelihood of longterm engagement with therapeutic exercise for the hand. The design targets the daily routine of toothbrushing as an opportunity to introduce therapeutic exercise as part of normal daily life. The handle design offers a level of resistance that enables the user to exercise both the grip and pinch hand movements easily whilst brushing teeth. Importantly, this design will function effectively as a toothbrush regardless of whether the user chooses to engage with the exercise feature or not. This is to encourage a positive association towards the device and to provide the opportunity to exercise without punishment for not doing so.

The patient assessment tool offers a new form of patient assessment which enables the patient to identify their own needs, frustrations, interests and desires on their own terms and within their personal context. Understanding the real life consequences of RA and its treatments on a patient’s ability to live a happy and fulfilled life provides healthcare providers with the opportunity to develop healthcare interventions which are sympathetic to the circumstances of the individual and, wherever possible, to support their personal motivations and aspirations.
Limitations of this study and opportunities for future research

Four key limitations of this study have been identified:

Firstly, the composition of the participant group is not a random sample of people with RA. Whilst participation was open to anyone formally diagnosed with RA, volunteers are likely to have participated because they have particular interest or sympathy with the questions being investigated. Whilst the research findings represent the opinions of research participants accurately they are not necessarily representative of the RA population as a whole.

Secondly, the efficacy of recommendations and design outcomes presented within this study have not been tested in long term trials with patients. Current prototype designs are not suitable for direct comparison with currently available devices. A further ‘product development’ phase would need to be conducted to produce devices suitable for production and clinical trial. An experimental study would then need to be developed with multiple groups of participants, including a placebo group, to assess the impact that these designs have on long term patient engagement and overall treatment efficacy.

The relatively low number of research participants within this study presents a limitation to the generalisability of research findings to the wider population of people living with RA. Repeating the study in different sociocultural settings will help to broaden the breadth and depth of findings and to develop results that are more generalisable.

Finally, the study has focussed specifically on the ‘designable’ aspects of RA and its treatments, it has not explored all the clinical and therapeutic aspects of the condition in detail. Further larger scale studies could be conducted in collaboration with healthcare specialists to ensure clinical and therapeutic elements are explored and integrated into the study.
The focus of this research study was to identify ‘designable factors’ and motivators, specific to people with RA, that could be identified and selectively influenced to improve patient engagement with long-term treatment recommendations and to investigate if these theoretical conclusions could be embodied into conceptual prototype designs. The specific resistances and hand movements encouraged by the toothbrush concept design require further development to ensure optimum physical benefits are available to the user before its therapeutic efficacy can be assessed. Future research could also investigate the potential of product-focused design derivatives developed from the research outcomes presented within this thesis. Such studies could investigate the development of affordable and robust devices which can be mass produced and assessed through long-term clinical trials.

The limited number of research participants is a common limitation of qualitative research studies which seek to develop new theoretical propositions. Future studies could further refine the accuracy and efficacy of suggested interventions by working with a greater number of research participants in assessment-focused studies and trials. Further developments could also be achieved by working with healthcare professionals to refine the clinical and therapeutic benefit of design interventions. Funding, institutional policies and best practices are continually changing, therefore recommendations will need to evolve and be developed within the context of local needs and opportunities.
### Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td><strong>Accessibility</strong></td>
<td>The degree to which a product, device, service, or environment is available and usable.</td>
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<td><strong>Active Engagement</strong></td>
<td>Conscious, purposeful engagement / taking part.</td>
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<tr>
<td><strong>Acute</strong></td>
<td>(of a disease or disease symptoms) beginning abruptly with marked intensity or sharpness, then subsiding after a short period.</td>
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<tr>
<td><strong>Adherence</strong></td>
<td>The extent to which a person’s behaviour corresponds with recommendations from a health care provider.</td>
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<tr>
<td><strong>App</strong></td>
<td>Also known as an application. A piece of computer software designed to help the user to perform specific tasks.</td>
</tr>
<tr>
<td><strong>Assistive Devices</strong></td>
<td>Objects which help, give support or aid the user to complete a task.</td>
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<tr>
<td><strong>Barriers</strong></td>
<td>Factors that limit the accessibility of some objects and environments.</td>
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<tr>
<td><strong>Behaviour change theory</strong></td>
<td>Socio-psychological research field which seeks to understand human behaviour and how it may be influenced.</td>
</tr>
<tr>
<td><strong>Biopsychosocial</strong></td>
<td>Medical treatment concept in which biological, psychological and social factors are identified and independently targeted based on individual needs.</td>
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<tr>
<td><strong>Choice architectures</strong></td>
<td>Behavioural intervention strategies in which decisions are influenced by the way choices are presented.</td>
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<tr>
<td><strong>Chronic</strong></td>
<td>(of a disease or disorder) persisting for a long period, often for the remainder of a person’s lifetime.</td>
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<tr>
<td><strong>Co-creation</strong></td>
<td>Convergence of USA and European approaches to ‘user’ or ‘human’ centred design. Also Known as Co-design.</td>
</tr>
<tr>
<td><strong>Co-design</strong></td>
<td>Convergence of USA and European approaches to ‘user’ or ‘human’ centred design. Also Known as Co-creation.</td>
</tr>
<tr>
<td><strong>Coercion</strong></td>
<td>Use of force or pressure to obtain compliance.</td>
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<td>Term</td>
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<tr>
<td>Compliance</td>
<td>The extent to which a patient's behaviour matches the prescriber's advice.</td>
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<tr>
<td>Concordance</td>
<td>An ongoing negotiated agreement between patient and expert offering advice.</td>
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<tr>
<td>Condition management</td>
<td>Healthcare strategy which aims to slow or stop the degenerative affects of incurable conditions.</td>
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<tr>
<td>Convergent (questions)</td>
<td>Questions which seek to get closer to particular thoughts or ideas.</td>
</tr>
<tr>
<td>Cultural Probe</td>
<td>Visual research method designed to provoke inspirational responses and provide qualitative data that illustrates the lives and memories of participants.</td>
</tr>
<tr>
<td>Curative</td>
<td>Description applied to a healthcare treatment which seeks to provide an end to symptoms and lead to full recovery.</td>
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<tr>
<td>Deceit</td>
<td>Concealment or distortion of the truth for the purpose of misleading.</td>
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<tr>
<td>Design with intent</td>
<td>Design intended to influence or result in certain user behaviour.</td>
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<tr>
<td>Disease modifying antirheumatic drug (DMARD)</td>
<td>Treatment that can reduce or prevent joint damage.</td>
</tr>
<tr>
<td>Divergent (questions)</td>
<td>Questions which seek to diversify and expand thoughts and ideas.</td>
</tr>
<tr>
<td>Designable Factors</td>
<td>Ideas, objects, and environments (virtual and real), that can be identified, understood and selectively influenced.</td>
</tr>
<tr>
<td>Design Thinking</td>
<td>A creative mindset concerned with: how we conceive of, and understand, the world around us; how we consider and define challenges and solutions; and how we apply outcomes appropriately and sympathetically to requirements.</td>
</tr>
<tr>
<td>Ecology of Design</td>
<td>A systems based approach to design, consisting of multiple interconnected elements including designed objects and environments (virtual and real).</td>
</tr>
<tr>
<td>Enabling</td>
<td>Providing the means for someone to perform an action more easily.</td>
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<tr>
<td>Epigeum</td>
<td>Company providing online training for higher education, healthcare and research.</td>
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<tr>
<td>Term</td>
<td>Definition</td>
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<tr>
<td>Ergonomics</td>
<td>Scientific discipline concerned with the understanding of the interactions among humans and other elements of a system, usually in relation to work.</td>
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<tr>
<td>Established RA</td>
<td>Rheumatoid arthritis disease duration of longer than two years.</td>
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<tr>
<td>Exergaming</td>
<td>Technology-based gaming systems which seek to promote physical exercise.</td>
</tr>
<tr>
<td>Expert Patient</td>
<td>A patient with a particular condition who has received training to work collaboratively with health and social care professionals.</td>
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<tr>
<td>Feedback loop</td>
<td>A process in which information is used to inform decisions about the present or the future. The process can be continually repeated to facilitate continuous reflection and development.</td>
</tr>
<tr>
<td>Flare-up (RA)</td>
<td>State of heightened disease activity level.</td>
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<tr>
<td>FRANK</td>
<td>UK Government drugs awareness campaign.</td>
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<tr>
<td>Functionality</td>
<td>The range of attributes or specific functions that a particular object, product or device may have.</td>
</tr>
<tr>
<td>Functionally Effective</td>
<td>The ability to perform tasks and activities which are necessary to fulfil daily life activities. Also known as functional ability.</td>
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<tr>
<td>Functional Ability (FA)</td>
<td>The ability to perform tasks and activities which are necessary to fulfil daily life activities. Also known as functional efficacy.</td>
</tr>
<tr>
<td>Functional Capacity</td>
<td>The extent to which an individual is able to perform tasks and activities which are necessary to fulfil daily life activities.</td>
</tr>
<tr>
<td>Gaming (technology)</td>
<td>Computer systems which facilitate game playing.</td>
</tr>
<tr>
<td>Gerontechnology</td>
<td>The study of technology and ageing for the improvement of the daily functioning of the elderly.</td>
</tr>
<tr>
<td>Healthy Industrial Design (HID)</td>
<td>Health focussed approach to industrial design developed by Tye design studios.</td>
</tr>
<tr>
<td>Heterogeneous</td>
<td>Diverse in character, different between individuals.</td>
</tr>
<tr>
<td>Human Centred Design (HCD)</td>
<td>Model of design developed by IDEO which seeks to integrate the needs of end users with the possibilities of technology and the requirements for business success.</td>
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<tr>
<td>Term</td>
<td>Description</td>
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<tr>
<td>IDEO</td>
<td>Global design agency established in the USA in 1991.</td>
</tr>
<tr>
<td>Inclusivity</td>
<td>Not excluding any section of society.</td>
</tr>
<tr>
<td>Industrial Design</td>
<td>Design developed for mass production.</td>
</tr>
<tr>
<td>Intrinsic</td>
<td>[motivation] from within the psyche of the individual.</td>
</tr>
<tr>
<td>Lexicon</td>
<td>The vocabulary of a particular branch of knowledge.</td>
</tr>
<tr>
<td>Mainstream</td>
<td>The ideas, attitudes, or activities that are shared by most people and regarded as normal or conventional.</td>
</tr>
<tr>
<td>Mass Market</td>
<td>[products] produced in large quantities for many people.</td>
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<tr>
<td>Medico-gymnastics</td>
<td>Structured, specialised, physical exercises, based on the principles of Swedish remedial gymnastics.</td>
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<tr>
<td>Medicomechanical gadgetry</td>
<td>Physical exercise devices developed, by Zander in Sweden in the 1890s, to target specific physical movements.</td>
</tr>
<tr>
<td>Micro-adaptation</td>
<td>Small adjustments (to existing activities or behaviours).</td>
</tr>
<tr>
<td>Multidisciplinary Team</td>
<td>A group of healthcare specialists who work collaboratively to manage the treatment of individual patients.</td>
</tr>
<tr>
<td>Musculoskeletal</td>
<td>Relating to or denoting the musculature and skeleton together.</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>A medical condition in which the bones become brittle and fragile from loss of tissue, typically as a result of hormonal changes, or deficiency of calcium or vitamin D.</td>
</tr>
<tr>
<td>Participants</td>
<td>An individual participating in research with consent. Also referred to as a respondent.</td>
</tr>
<tr>
<td>Patient and Public Involvement (PPI)</td>
<td>Department of Health initiative which seeks to involve patients, carers and the public in the decision making process of healthcare research projects and innovations.</td>
</tr>
<tr>
<td>Patient(s)</td>
<td>A person, or people, diagnosed with confirmed rheumatoid arthritis. (see also users, participants, respondents).</td>
</tr>
<tr>
<td>Persuasive Design</td>
<td>An area of design research which seeks to change a person’s attitude or behaviour for the benefit of their health and in concordance with their own ambitions.</td>
</tr>
<tr>
<td>Pervasive</td>
<td>The prevalence of a particular technology within society.</td>
</tr>
<tr>
<td>Persuasion</td>
<td>The application of behaviour change without the use of control, deceit, coercion.</td>
</tr>
<tr>
<td>Photo-elicitation</td>
<td>The use of photographic images to facilitate discussion.</td>
</tr>
<tr>
<td><strong>Quality of life (QoL)</strong></td>
<td>Refers to the level of comfort, enjoyment and ability to pursue daily activities.</td>
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<tr>
<td><strong>Range of motion</strong></td>
<td>The distance and direction a joint can move between the flexed position and the extended position.</td>
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<tr>
<td><strong>Regimen</strong></td>
<td>A prescribed course of medical treatment, diet, or exercise for the promotion or restoration of health.</td>
</tr>
<tr>
<td><strong>Respondent</strong></td>
<td>An individual participating in research with consent. Also known as participant.</td>
</tr>
<tr>
<td><strong>Sananomics</strong></td>
<td>Is a phrase developed by the Alan Tye Design studio to define the HID design method. The word combines ‘Sana’, latin for health, with ‘nomic’, greek for law.</td>
</tr>
<tr>
<td><strong>Self-efficacy</strong></td>
<td>The ability to motivate oneself to achieve desired levels of performance.</td>
</tr>
<tr>
<td><strong>Self-management</strong></td>
<td>A term used for aspects of RA care which a person can do for themselves with advice from the primary care team, eg GP, nurse, physiotherapist, occupational therapist and information leaflets.</td>
</tr>
<tr>
<td><strong>Socio-psychological</strong></td>
<td>Adjective that refers to the intricacies and nuances of human behaviour.</td>
</tr>
<tr>
<td><strong>Stakeholder</strong></td>
<td>Any national organisation, including patient and carer groups, healthcare professionals and commercial companies with an interest in the guideline under development.</td>
</tr>
<tr>
<td><strong>Synovitis</strong></td>
<td>Inflammation of the synovial membrane situated at the contact point of articulating bones.</td>
</tr>
<tr>
<td><strong>Therapeutic</strong></td>
<td>A treatment or intervention which is judged, in medical terms, to be desirable and beneficial.</td>
</tr>
<tr>
<td><strong>Touch-point</strong></td>
<td>A business term for any encounter where customers and business engage to exchange information, provide services, or interact.</td>
</tr>
<tr>
<td><strong>Transcutaneous</strong></td>
<td>Passing or entering through the unbroken skin.</td>
</tr>
<tr>
<td><strong>Transdisciplinary</strong></td>
<td>The sharing of knowledge and understanding between disciplines in a structured fashion and coordinated by overarching aims.</td>
</tr>
<tr>
<td><strong>Human-Centred Design</strong></td>
<td>Term applied to approaches to design which include end-users in the design process.</td>
</tr>
<tr>
<td><strong>Inclusive Design</strong></td>
<td>A model for design developed in the UK which seeks to maximise inclusion. Similar to Universal Design.</td>
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<tr>
<td><strong>Ubiquitous</strong></td>
<td>The term used to describe an approach where computing technologies are embedded into everyday objects.</td>
</tr>
<tr>
<td><strong>Universal Design</strong></td>
<td>A model for design developed in the USA which seeks to maximise inclusion. Similar to Inclusive Design.</td>
</tr>
<tr>
<td><strong>User-Centred Design</strong></td>
<td>From Computer sciences. An approach to design characterised by the inclusion of ‘end-users’ during the design process.</td>
</tr>
<tr>
<td><strong>Users</strong></td>
<td>An overarching term referring to a person, or people, who engage with a product or environment. (see also patients, participants, respondents).</td>
</tr>
<tr>
<td><strong>Visual Research</strong></td>
<td>Research method that deals with visual and visualisable forms of information.</td>
</tr>
<tr>
<td><strong>Wellbeing</strong></td>
<td>Refers to the general quality of life of individuals and societies.</td>
</tr>
</tbody>
</table>
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Appendices

Appendix 1: Project recruitment poster

Improving Exercise Devices for Patients with Rheumatoid Arthritis

Are you interested in taking part in a new and exciting research project?

Do you have Rheumatoid Arthritis?

Are you aged between 18 and 65?

If so, please contact your consultant or nurse specialist for more information.

This innovative collaboration between Brighton and Sussex Medical School, Brighton and Sussex University Hospitals and the University of Brighton aims to develop new hand held exercise devices for patients with RA.

For independent advice about the project please contact:
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Brighton and Sussex University Hospitals NHS Trust
University of Brighton
Brighton and Sussex Medical School
Arts & Humanities Research Council

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Appendix 2: Participant information sheet

Improving Exercise Devices for Patients with Rheumatoid Arthritis

Patient Information Sheet

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you.

One of our team will go through the information sheet with you and answer any questions you may have. This should take about 30 minutes. Before making a decision please feel free to talk to friends and family about the study if you wish.

(Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study). Please ask us if there is anything that is not clear.

Part 1

Summary of the study

This study aims to improve the design of exercise devices for patients with rheumatoid arthritis in the hand. We believe that by improving the design of devices we can make it easier for you to exercise within your normal daily life.

What is the purpose of the study?
The purpose of this study is to gather information to help design better treatment aids for patients with rheumatoid arthritis.

Why have I been invited?
This study is for patients diagnosed with rheumatoid arthritis in the hand for more than 2 years and who are aged between 18 and 65 years.

Do I have to take part?
If you are interested in taking part, we will explain what is involved and go through this information sheet. If you decide to participate, we will ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.
What is expected from participants?
Patient input is very important to the development of some treatments. To gain this, we ask patients to tell us about their experiences, so that we can develop and improve our services.

Expenses and payments?
If it costs you anything to travel, to and from, the hospital to take part in this study, we will give this money back to you.

What will I have to do?
If you would like to take part, you will be asked to participate in three activities. It is important that you are able to attend all discussion sessions.

1. A 90-minute group discussion. You will be asked to talk about your experiences of exercising with RA.
2. A one-week photography project. You will be asked to take 27 photographs of objects that you use everyday and the places that you visit regularly.
3. A 90-minute group discussion. You will be asked to select a few photographs and describe them to the group.

What are the potential disadvantages and risks of taking part?
People who are uncomfortable in group situations may find some aspects challenging, you will not need to say anything unless you want to.

What are the potential benefits of taking part?
We cannot promise the study will help you immediately but the information we get from this study will help improve the treatment of people with rheumatoid arthritis in the future.

What happens when the research study stops?
You will be offered the opportunity to receive a regular newsletter about project progress until it is completed.
What if there is a problem?
Any complaints about the conduct of this study can be addressed through the NHS complaints procedure. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. These details are included in Part 2 of this leaflet.

This completes Part 1, if this information has interested you and you are considering participation, please read the additional information in Part 2 before making a final decision.

Part 2

What will happen if I don’t want to carry on with the study?
If you withdraw from the study, no further data will be gathered or recorded relating to you. However, we may use the information collected up to the time of your withdrawal. You can withdraw any of your own photographs from the study, up to the point of publication, without giving any reason.

What if there is a problem?
If you have concerns about any aspect of this study, you should first speak to one of the researchers who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this via the NHS Complaints Procedure. Details can be obtained from www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx

In the event that something does go wrong and you are harmed during the research and this is due to someone’s negligence then you may have grounds for a legal action for compensation against the NHS Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Will my taking part in this study be kept confidential?
During the study, group discussions will be recorded using audio and video recording equipment. All recordings will be anonymous and stored in a locked cabinet in the Centre for Research and Development, Faculty of Art, University of Brighton.
Personal data will be kept for up-to 3 years after the study has ended, research data generated by the study will be stored for 10 years. Research Student Thomas Ainsworth may look at your personally identifiable data, specifically, your name, age, duration of confirmed rheumatoid arthritis and drugs being taken to manage rheumatoid arthritis. Authorised staff from the University of Brighton and from the NHS may also look at this data to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant.

**What will happen to the results of the research study?**
This research will be used as part of a PhD research project. We plan to publish the results of this study in scientific journals and as part of a PhD thesis. We also intend to publish these results on websites and as conference presentations.

**Who is organising and funding the research?**
This research is funded by the Arts and Humanities Research Council Doctoral student scheme. Access to premises and insurance is provided by the NHS Trust.

**Who has reviewed the study?**
This study has been looked at by an independent group of academic people, at the University of Brighton, as part of the formal research procedure. All research in the NHS is scrutinised by a Research Ethics Committee, to protect your interests. This study has been reviewed and passed by Brighton East Research Ethics Committee.

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