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A PICTURE OF DESIGN IN MENTAL HEALTH

Mapping research at the intersection of Design and Mental Health

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Abstract

This chapter outlines the intersections of design research with mental health in the UK and Europe, and considers challenges and future directions for designers working with the mental health service sector.

In discussing our own research (An Internet of Soft Things 2016), we noticed a frequent conflation of mental health with special needs and dementia, and a confusion of professional care practices and theoretical models in reports of design research projects. This provided the motivation to conduct a literature review identifying and describing the intersection of mental health and design research, intended to map the current state of play and lay the grounds for future work.

This review aims to map the overlaps between two bodies of literature: the mental health sector has a history of using creative and co-design methods to improve services, while design is keen to contribute participatory methodologies, and service design approaches to the field. The literature of each domain, that is, mental health and design, is experienced as inaccessible to the other, and very infrequently used (Chamberlain et al 2015). A recent review of the involvement of young people in the design of e-mental health services has also been undertaken by researchers in Australia (Orlowski et al 2015), but as far as we were aware, when we commenced this research in early 2016, there was no meta study available at the intersection of design with mental health undefined by population.

A descriptive analysis of the review suggests: a lack of critical reflection on the theoretical models being used, either by the project team, or by diverse stakeholders; under-reporting of the potential personal and ethical impact for researchers working within design; a predominance of research concerned with technological solutions and the design of assistive digital devices; and strong interest in the benefits of participatory and creative practices. Key challenges include the need to develop models of design based not only on need, or a lack, but on potential at both a practical and philosophical level; a widespread use of misleading or generic terminology across mental health services; and the complexity, fragility and dynamism of the care provision domain in the UK and Europe.

1. Mental health

It is widely acknowledged that 1 in 4 people in the UK will experience a mental health problem each year (Mind 2016, and that there is a need to take a far more proactive and preventative approach to reduce the long-term impact for people experiencing mental health problems, for their families, and to reduce costs for the National Health Service (NHS) and emergency services (NHS Independent Taskforce 2016). Pressures on the system include an aging population, and over-reliance on informal carers, who have in turn become a socially excluded group (Gray et al., 2010). Mental health difficulties can be highly complex and less easily perceived and explained than physical health issues, and despite an estimated cost to the economy of £105 billion a year, roughly equivalent to the cost of the entire NHS, the sector remains under prioritised, receiving 13% of NHS funding (Centre for Mental Health 2014). Those affected by long term mental health issues report feeling overlooked and hurried

through a health system, at a time when they feel at their most vulnerable; accustomed to having no voice and little say in their recovery process, many are left feeling powerless, unheard and marginalized. Costs are compounded by the high levels of social exclusion experienced by people with mental health problems, and the relevance of social factors in supporting mental health is well-recognized (Benjamin 2014, Fostvedt and Alasker 2014, Holttum 2014, Jones et al 2013, Oh 2014). Crisis intervention and home treatment teams have been introduced across the UK, with informal carers recognized as a fundamental element of mental health service provision (Bradley 2015). In May 2013, the 66th World Health Assembly adopted the WHO's Comprehensive Mental Health Action Plan, recognizing the essential role of mental health in achieving health for all people, calling for more effective leadership and governance for mental health, and better integrated mental health and social care services in community-based settings (World Health Organisation 2013). In the same year the UK National Health Service mandated action towards parity of esteem between mental and physical health, as set out by the government in the Health and Social Care Act in 2012 (Centre for Mental Health 2013).

The range of mental health conditions people live with is extensive and in the UK typically organised around three-tier systems. Individuals present to their local general medical practice (primary care), are referred for specialist assessment for treatment (secondary care), and may access social and third sector (charity) services alongside or after treatment (tertiary care). Services are not well integrated, are funded differently, and particularly in the third sector, can be fragile and temporary (see Cottam for accessible case studies on the complexity of care services in the UK, 2018). We do not have space in this chapter to detail conditions, but it is worth noting that different theoretical models lead to different views on the usefulness of diagnosis, and also to different professions (i.e. psychiatry, psychology, and psychotherapy). For the designer, a useful A-Z of mental health is maintained online by Mind, the UK's largest mental health charity (2013); Mind also provides mental health awareness training to industry, managers and research teams. The DSM (Diagnostic and Statistical Manual of Mental Disorders), now preparing its sixth edition, provides a more comprehensive overview of diagnostic conditions (American Psychiatric Association 2018). This publication underpins medical diagnostic practice in the USA. The diagnostic medical model is however, critiqued by many as contributing to stigma, issues such as diagnostic overshadowing (ref) and poor service-user experience. For example, consider the publications of the Service User Survivor Network (Beresford 2010), and practitioner critiques from a humanist viewpoint (eg Johnstone 2014).

2. Design research and authors' motivation

Design research increasingly collaborates across disciplines, drawing methodology, practice and theory from fields such as psychology, sociology, anthropology, and strengthening relationships between academic institutions and industry. Environmental, social and cultural challenges can be helped by design innovation and by opening up the design process and increasing transparency. Service and Transformation Design approaches continue to develop, enhancing shared capacity to facilitate change across organizational and community contexts. The potential for these design methods within mental health is evident (Cottam 2018, Sangiorgi 2011), and recent conferences illustrate growing interest in the potential for new forms of design to respond creatively: see for example Design4Health (2018), the Design Research Society SIGWELL tracks at DRS conferences (2016, 2018), and the AHRC Does Design Care symposium at Lancaster University (2017).

Our own motivation for carrying out this literature review came from our efforts to put the theory of humanist Carl Rogers into practice as a participatory design research framework (Kettley et al 2016), and our increasing consternation when other design efforts did not, or could not, tell us what theoretical model or framework informed their work. We became increasingly aware that, particularly

in multi-sector and multi-disciplinary projects, individual stakeholders and team members may also have been trained in diverse and sometimes incompatible theoretical models, giving rise to managerial and personal difficulties, as well as potentially compromising the ethical processes of projects. The goal of this review is therefore to describe where design research meets mental health, and we hope it will encourage further discussion and knowledge exchange across design, mental health and research contexts.

3. Scope and methodology

The six-month review¹ included academic publications between 2010 and 2016, limited to UK and European research. An analysis of the grey literature was beyond the scope of this review². Ten databases were identified as the core search locations: Art Bibliographies Modern (*Proquest*), Design and Applied Art Index (*Proquest*), International Bibliography of Art (*Proquest*), SCOPUS (*Elsevier*), PsychINFO (*Proquest*), Web of Science (*Thomson Reuters*), International Bibliography of Social Sciences (*Proquest*), Applied Social Sciences Index and Abstracts (*Proquest*), PsychARTICLES (*Proquest*), and the British Humanities Index. Further search areas, primarily academic institutions and research professionals, were located via the Service Design Research UK Network (2018). A search strategy was developed using single terms and combinations of terms, to locate the intersections of the two subject areas. This was an iterative process, with search terms developed around the domains of both mental health and design. An initial search undertaken using SCOPUS indicated terms which were overly general in locating the specific intersection of the two subject areas, and keywords were identified through emergent themes³. This led to a final search string, which was then run across each database (figure 1).

¹ The second author was funded as a research fellow for six months through quality related funding by Nottingham Trent University, UK to undertake the work.

² Grey literature is unpublished material, e.g. technical, annual and government reports, conference papers, or newsletters. A Google search using the following string was used: “*experience-based co-design*” OR “*co-design*” OR “*participatory design*” OR “*collaborative design*” OR “*practice-based design*” AND “*mental health*” OR “*mental illness*” OR “*emotional wellbeing*” OR “*psychiatric care*”. The top 100 results were taken, and duplicates were removed leaving 28 papers in scope.

³ DESIGN methodology - predominantly indicating relational and experiential aspects, eg- “*co-design*”, “*experienced-based design*”, “*user-centred design*” and variations; DESIGN practice: acknowledging creative engagement eg- “*craft*”, “*making*”, “*participatory arts*”, “*textiles*”; MENTAL HEALTH experiencing eg; “*wellbeing*”, “*emotional*”, “*relational*”, “*person-centred*”, “*awareness*”; MENTAL HEALTH in terms of medical/disease model eg; “*diagnosis*”, “*psychiatric*”, “*mental illness*” and various diagnostic labels (dementia being the most prevalent); STAKEHOLDERS in terms of populations eg; “*service users*”, “*mental health communities*”, “*patients*”, “*healthcare professionals*”, “*carers*”; STAKEHOLDERS in regards to outcomes eg; “*empowerment*”, “*recovery*”, “*engagement*”, “*wellness*”, “*social inclusion*”

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( TITLE-ABS-KEY ( "co-design" ) OR TITLE-ABS-KEY ( "experience-based co-
design" ) OR TITLE-ABS-KEY ( "participatory design" ) OR TITLE-ABS-KEY ( "user-
centred design" ) OR TITLE-ABS-KEY ( "practice-based design" ) OR TITLE-ABS-
KEY ( "human-centred design" ) OR TITLE-ABS-KEY ( "collaborative
design" ) OR TITLE-ABS-KEY ( "co-production" ) OR TITLE-ABS-KEY ( "inclusive
design" ) OR TITLE-ABS-KEY ( "empathic design" ) AND TITLE-ABS-KEY ( "mental
health" ) OR TITLE-ABS-KEY ( "emotional wellbeing" ) OR TITLE-ABS-KEY ( "mental
illness" ) OR TITLE-ABS-KEY ( "psychiatric care" ) ) AND PUBYEAR > 2009
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Figure 1
final search string

1731 results were returned and screened to assess whether they were in scope by asking the following question:

'Does the paper include description of design processes or thinking, alongside consideration of mental health or wellbeing issues, or specifically refer to design methodology or practice within a mental health context?'

Papers were excluded if found to be non-European in origin and/or focus, written in a language other than English, or published before 2010. This resulted in 179 publications found to be in scope.

A further 134 results were contributed from an expert review with the research team of the *Internet of Soft Things Project* project, giving 310 results. An extensive review of these full papers left a final 131 publications considered to be accurately located at the intersection of *both* domains (figure 2).

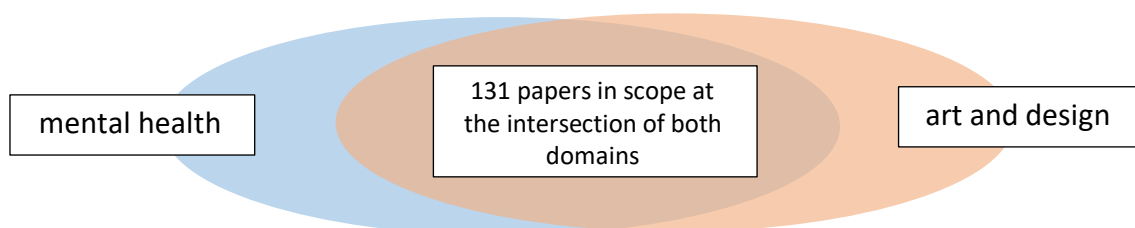


Figure 2
final papers in scope

EMERGENT THEMES / DISCUSSION

The 131 results were read and iteratively categorised. This manual open coding process gave us the four major themes discussed here: lived experience; collaboration; experiential engagement and creative practice; and the theoretical framing of technology. This discussion does not go so far as to present a category map of relationships between the publications or analytical themes, but uses key illustrative examples from the results to describe the landscape of research approaches at the intersection of mental health and design research.

Lived experience

It is evident from the literature compiled through this review, that increased recognition of the 'service-user experience' is beginning to emerge in mental health service provision. Bradley (2015) provides a brief overview of the literature to date which has focused on 'co-production' within mental healthcare in the UK, including service user and carer involvement and collaboration. The paper identifies a distinct gap in communication, between the carer community and mental health professionals and questions whether co-production approaches can address this chasm. The paper further questions the cultural and ideological shift required from staff, service users and family members to undertake co-produced care and acknowledges the challenges to service redesign and new roles in practice. The same publication highlights the danger of increasing expectations on service providers to undertake shared decision-making and co-production in the absence of practical guidance. Co-production of care, although reflective of an intention to work empathically with service-users and families, requires attentiveness and commitment to the "triangle of care" - with carers and service-users actively contributing personal skills, resources and expertise. Locock et al (2014) suggest improving patient experience to be a priority for the government and the NHS, emphasising the need for greater understanding of service-user experiencing and opportunities to directly affect care planning. Carer and service-user involvement in co-production can help contribute to a wider perspective of mental health difficulty, beyond symptom reduction, and experience-based approaches make room for greater understanding of those engaged in the process of both design and research (Cooper, Gillmore and Hogg 2015, Russ et al 2013). From the grey literature, the following are referenced here for their concern with co-production: The Design in Mental Health Network (DIMHN) (2018), Slay and Stephens' literature review on co-production, commissioned by Mind (2013), and the National Survivor User Network (Davie 2011).

The potential of participation in creative activity and arts engagement in terms of recovery processes and wellbeing, is evident (Abbotts and Spence 2013, Crawford et al 2013, McKeown et al 2016, Pollanen 2015, Stacey and Stickley 2010, Stickley and Eades 2013) and collaborative approaches to service development, which look to incorporate the lived-experience of service-users, are beginning to emerge (Arblaster et al 2015, Bradley 2015, Bredski et al 2015, Larkin et al 2015, Peterson et al 2012). However, the use of experience-based approaches is still relatively novel in mental health settings (Larkin et al 2015).

Collaboration

The concept of collaboration and 'working with', is increasingly evident within UK health services. The NHS 'Five Year Forward View' refers to new relationships with patients and communities (NHS England 2016), and an NHS independent taskforce report (Feb 2016) highlights the specific need to re-energise and improve mental health care across the NHS through innovative approaches in order to meet increased demand and improve outcomes. Larkin et al (2015) consider inpatient mental health services in the UK to be unsatisfactory for both service-users and staff, reporting on three qualitative research studies concerned with stakeholder experiences of hospitalization during early psychosis, as a starting point for translation into service improvements developed in collaboration with service-users, carers, community, inpatient staff, and management. The paper considers an adapted form of

experience-based co-design (EBCD); a participatory action-research method for collaboratively improving health care services. The use of EBCD is still relatively novel in mental health settings; Goodrich and Stanley (2014) include a successful case study of an initiative at Oxleas Foundation Trust, while Larkin et al (2015) discuss adaptations to the methodology and the implications of using EBCD with vulnerable populations in complex services. Carr et al (2011) investigate connections between evidence-based and experience-based methods in the re-design of services.

Experiential engagement and creative practice

Our review revealed a large number of papers concerned with the benefits of creative practice and engagement in participatory arts to mental health. The potential of participation in creative activity to support wellbeing improvement and 'recovery' is highlighted in mental health policy and commissioning guidance such as the Department of Health's *No Health without Mental Health: A Cross-Government Mental Health Outcomes Strategy for People of All Ages* (2011), and Health Scotland's *Good Mental Health for All* (2016). This theme includes both engagement in activity, where a focus on creative 'doing and making' are seen as therapeutic in themselves, as well as social inclusion and group support. Group engagement in craft activities is perceived as highly supportive of mental health and wellbeing, and there is a prevalence of creative activities within occupational therapy in Sweden (Mullersdorf et al 2012). However, there is limited empirical research on the intervention of creative activities within mental health and extended health services (Fostvedt and Alasker 2014). Caddy et al (2012) respond to a call for quantitative outcome evidence about the therapeutic relationship between creative activity and mental health. The study examines the mental health outcomes of inpatients participating in art and craft-based creative therapies at a private psychiatric hospital over a five-year period. Research findings established that participation in creative activity holds potential benefits for those experiencing mental health problems. Crawford et al (2013) examine the value of approaches to mental health which are based on creative practice in the humanities and arts, and their potential contribution to mutual recovery. Further qualitative evidence can be found in those papers concerned with the role of community centre-based arts, leisure and social activities in promoting adult well-being and healthy lifestyles (Jones et al 2013), engagement in crafts as a coping mechanism, stress reduction and enhancement to wellbeing (Pollanen 2015a and 2015b, Argyle and Winship 2015). Burt and Atkinson (2012) consider the relationship between quilting and wellbeing for the wider population without taking a 'problem based' approach. Their qualitative, interview-based study, uncovered social, emotional and cognitive processes identified as being connected to emotional wellbeing. Benjamin (2014) is unusual in explicitly stating a humanistic Rogerian theoretical framework when reporting on the therapeutic benefits of a creative artists support group, connecting creativity with mental health. A further uncontrolled study commissioned to address concerns about lacking evidence of the effectiveness of participatory arts engagement, indicated those with mental health needs found participation (in the arts) highly beneficial to recovery, reporting increased sense of empowerment and social inclusion. Interest in the positive results from this study among senior managers at the South Essex Partnership University Foundation NHS Trust led directly to the establishment of Open Arts in 2008. The aim of Open Arts has been to promote well-being and social inclusion by providing relaxing, welcoming art groups in community venues for people with mental health needs. Their approach embraces concepts derived from the field of art therapy, complemented by Rogerian principles of facilitated learning (Margrove et al 2013). McKeown et al (2016) examine the experiences of mental health service users in a community-based arts programme at Tate Modern; the study combined object handling and museum visits with arts and craft activities. Morse et al (2015) examine the effects of museum outreach sessions on confidence, sociability and well-being measures for mental health. Dijana and Sasa (2010) address creative

expression as means of assisted communication for Alzheimer's disease patients, offering a brief overview of the influence of creative media on the development and maintenance of communication skills, and thus on the development of patients' social interactions. Although diagnosis based, they take a relational rather than problem-based approach. In 2011 the UK Crafts Council responded to a government agenda to determine and measure the nation's wellbeing as a basis for future policy. Their report acknowledges the absorption experienced in making activities as clinically proven to increase levels of mood-enhancing serotonin, inducing relaxation and promoting mindfulness. The benefits for 'wellbeing' and emotional health are presented, highlighting improvements to chronic stress and reduction in feelings of isolation and depression, facilitated through participation with others (Yair 2011).

Technology, User-Centred Design, and theoretical framing (modality)

We report here on a range of approaches to technology in mental health, but point to the wealth of published research that finds a natural resonance between problem-solution models in design and the medical model of symptom reduction. It appears that computer-based psychotherapeutic interventions for mental health difficulties often work to a diagnostic label, and we are concerned that user-centred design essentially asks for a medical model. This is not an issue in itself, and we have already mentioned our own bias towards the humanistic; what is concerning is a more general lack of explicit theoretical framing, or modality. A distinct number of related publications also point to the repeated limitations of research in the literature, including modality (or 'models') of care (Doherty et al 2010, Orlowski et al 2015, Wykes and Brown 2016). The implications of the lack of theoretical framing should not be underestimated; consider the recent discussion in the British Medical Journal on its policies regarding reportage of studies using qualitative methodologies (Greenhalgh et al 2016).

Wykes and Brown focus on e-therapy rather than electronic patient records and discuss the potential issues for implementation of e-health in mental health, including "considering models of therapeutic support" (2016: 3). So too do Doherty et al (2010), although related research continues to be categorised by diagnosis or type of technology; Doherty et al advise that the researcher refrain from getting involved with the relative benefits of diverse theoretical models, without explicating the link between the design research methodologies and such models (2010). Those publications that do mention modality tend to do so implicitly through terminology and research expectations: Bauer and Moessner (2012) unreflexively adhere to the medical model, seeking to support data collection for optimisation of interventions, and the concept of 'traditional' care becomes aligned with face-to-face therapies; while Hilgart et al (2012) acknowledge there is little research to inform design and development of internet interventions, which support 'behavioural change' and 'symptom reduction'; and Valenza et al (2014) focus on the applicability of wearable technology to monitoring, diagnosis, and treatment, all of which align with a medical model. Others focus on the behavioural model (e.g., Lin and Ramakrishnan 2013) or work from populations defined by diagnosis (Ellis, McCabe et al, 2015). Dual diagnosis describes a deliberate focus on more than one presenting pathology, assuming a relation between them; Elison et al (2014) consider e-therapy in terms of supporting alcohol related dual diagnoses; Kim and Cho (2013) study a personalised e-textile based smart healthcare glove for the wellbeing of an older female through analysis of cardiovascular dynamics within a bi-polar population. Physiological responses are understood in connection to a *psychiatric* difficulty. Others focus on the regulation of emotion or mood, often as part of managing behaviour change, as helpfully reported as part of a wider theoretical discussion by Desmet (2015).

Methodological explorations of participatory practices are also evident in studies with people living with cognitive and sensory impairments, on the autistic spectrum, or living with dementia: Frauenberger et al (2011) and Parsons et al (2011), seek to include children and young people in the design process of technologically enhanced learning environments, using storytelling to bridge the gap between system design and the 'imaginary' world of the child. Malinverni et al (2017) study the need for high quality inclusive interdisciplinarity in the design of games for children on the autistic spectrum to support social initiation behaviours. Adults with communication difficulties are often excluded from design research, but Gaudion et al (2015) look at collaborative methods to support this population, to allow their unique perceptions to be included. In participatory work with people living with cognitive or sensory impairments (as distinct from mental ill-health), others are examining the need for unique, individual methods development in response to highly individual participants (Hendricks et al 2015), and considering the well-being of dementia patients whose identity is scripted through standardised design, including clothing (Iltaanen-Tahkavuori et al 2011). Qualitative studies of user experience and involvement in the development of assistive technologies are also undertaken from the perspectives of mental health service users' population (Goodwin et al 2016, Godwin 2012); these could be considered at the person-centred end of a continuum of theories of care and the person.

4. Key findings, recommendations for design research and future challenges

In this section we provide an overview of the current findings from this literature review:

First, the philosophical modalities (theoretical framings) underpinning different services are not immediately visible within the literature. Categorising papers via modality is a complex process due to the lack of acknowledgement from design sectors.

Secondly, the potential for personal impact for the designer/researcher when working within the mental health sector is an ethical issue which remains predominantly unspoken. There is much in regards to ethical practice which is not made transparent within the research methodologies, including practical issues such as informed consent.

Thirdly, technological developments and the design of assistive digital devices for mental health represented the largest category of papers. The design approach within these studies is predominantly User Centred and problem-based, which effectively asks for a medical or disease model by engaging in design for a diagnostic label or disorder (a needs-based, or lack-based approach).

Fourthly, there is a growing acknowledgement of the mental health and wellbeing benefits of participatory arts and creative practice. These activities when undertaken as group practice, also present opportunities for increased social inclusion and engagement. Outside of the UK, Norwegian Mental Health reforms have incorporated 'inclusion in society' as necessary and supportive of emotional wellbeing.

Fifthly, language can be very misleading and meanings can vary across context and subject area. In particular the term 'person-centred' is widely used across design and varied mental-health settings.

Similar terms are used to promote diverse fundamental care philosophies. Widely used or generic terminology can make precise searches difficult.

This review was constrained to Europe and the UK between 2010 and 2016, and did not include an analysis of the grey literature; it is therefore limited in its scope and a significant amount of research remains to be done in mapping and developing design's relationship with mental health. Doherty et al (2010) point out that there may be over 550 models of therapy in use, but the 'big three' could be usefully added to design's vocabulary through existing frameworks such as for instance Sanders and Stappers' map of human-centred design practices (2008). These three models are: Cognitive-Behavioural models, Relational/Social/Humanistic models and Disease/Medical models.

In this way we argue that a design researcher does not need to become 'an expert' in one theoretical model of mental health care, but can, and should, develop a reflexive overview of the key underlying theories that shape attitudes, methodologies and diverse ethical practices. It is our hope that our review of literature can contribute in this respect.

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