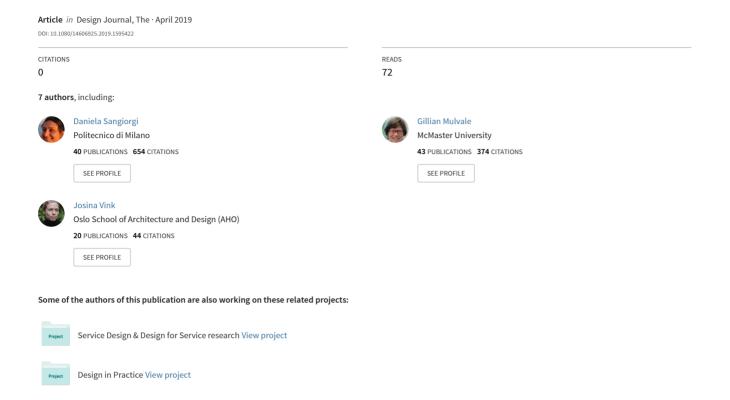
# Designing in highly contentious areas: Perspectives on a way forward for mental healthcare transformation





# The Design Journal



An International Journal for All Aspects of Design

ISSN: 1460-6925 (Print) 1756-3062 (Online) Journal homepage: https://www.tandfonline.com/loi/rfdj20

# Designing in highly contentious areas: Perspectives on a way forward for mental healthcare transformation

Daniela Sangiorgi, Michelle Farr, Sarah McAllister, Gillian Mulvale, Martha Sneyd, Josina Elizabeth Vink & Laura Warwick

**To cite this article:** Daniela Sangiorgi, Michelle Farr, Sarah McAllister, Gillian Mulvale, Martha Sneyd, Josina Elizabeth Vink & Laura Warwick (2019) Designing in highly contentious areas: Perspectives on a way forward for mental healthcare transformation, The Design Journal, 22:sup1, 309-330, DOI: 10.1080/14606925.2019.1595422

To link to this article: <a href="https://doi.org/10.1080/14606925.2019.1595422">https://doi.org/10.1080/14606925.2019.1595422</a>

	Published online: 31 May 2019.
	Submit your article to this journal 🗗
ılıl	Article views: 1
CrossMark	View Crossmark data 🗗



# **Designing in highly contentious areas:**Perspectives on a way forward for mental healthcare transformation

Daniela Sangiorgi<sup>a</sup>\*, Michelle Farr<sup>b,c</sup>, Sarah McAllister<sup>d</sup>, Gillian Mulvale<sup>e</sup>, Martha Sneyd<sup>f</sup>, Josina Elizabeth Vink<sup>g,h</sup>, Laura Warwick<sup>i</sup>

Abstract: There is growing interest in service design to support transformation in mental healthcare. Early research in this area has shown some promising results, but has also revealed the contentious nature of this work. A better understanding of the complexity of design in mental health is needed to support the development of approaches that are appropriate for this context. As such, the aim of this paper is to examine areas of contention and related strategies employed when designing for mental health transformation. To realize this aim, a qualitative multiple case study of ten service design initiatives in mental health contexts was conducted. The analysis revealed five interconnected contentious issues: organizational constraints; ensuring meaningful participation; culture clashes; power dynamics; and systems approaches. These contentious issues are detailed and related strategies from various cases are put forward, providing a rich foundation for the ongoing development of service design approaches in mental health.

**Keywords:** Mental health, service design, participatory design, contentious issues, strategies

<sup>&</sup>lt;sup>a</sup>Dipartimento di Design, Politecnico di Milano, Italy,

<sup>&</sup>lt;sup>b</sup>The National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care West (NIHR CLAHRC West) at University Hospitals Bristol NHS Foundation Trust, UK,

<sup>&</sup>lt;sup>c</sup>Population Health Sciences, Bristol Medical School, University of Bristol, UK,

<sup>&</sup>lt;sup>d</sup>National Institute for Health Research Clinical Doctoral Research Fellow, Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care, King's College London, UK;

eHealth Policy and Management, DeGroote School of Business, McMaster University, Canada,

<sup>&</sup>lt;sup>f</sup>Bristol Health Partners Psychosis Health Integration Team, UK,

gExperio Lab, County Council of Värmland, Sweden,

<sup>&</sup>lt;sup>h</sup>CTF - Service Research Center, Karlstad University, Sweden;

School of Design, Northumbria University, Newcastle-upon-Tyne, UK

<sup>\*</sup>Corresponding author e-mail: daniela.sangiorgi@polimi.it

# 1. Introduction

Designing for mental healthcare transformation is attracting a wide interest in both design and health research, where participatory approaches, such as service design, are recognised as valuable ways to address complex challenges and support recovery. The recovery model of care, now explicitly adopted in contemporary national policy across Canada, England, Italy, Sweden and many other Western countries (Amering, Mikus & Steffen, 2009; Davidson, Mezzina & Rowe, 2010) is based on Anthony's (1993) internationally accepted definition of personal recovery:

'[Recovery is] a deeply personal, unique process of changing one's attitude, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful and contributing life, even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.'

Recovery-orientated care grew out of the service user movement of the 1960s and 1970s as part of a backlash against psychiatry and the dominance of the bio-medical model (Chamberlain, 1990) and its history of long-term institutional care. A recovery orientation challenges traditional patient-clinician roles, by bringing together both professional and lived experience expertise in a process of co-production that supports people with mental health concerns to identify and manage their own health and social care needs (Phillips, Sandford & Johnston, 2012). A recovery orientation also calls for people with lived experience of mental health issues to be directly involved in designing and planning mental health services.

While there is still variation in the provision of recovery-orientated care, this model is considered the gold-standard in many Western countries (Roberts & Boardman, 2013). Despite this recognition, emerging user-led and co-produced practices remain marginal and struggle to become the norm (Slade et al., 2014). The lack of uptake may reflect the fact that a recovery-orientation can be seen as contentious for several reasons. First, a recovery philosophy challenges the limits traditionally set on people with mental health concerns and supports them having control over their own lives (Jacob, 2015). Second, a recovery approach can be seen as conflicting with traditional bio-medical treatment options, placing less emphasis on diagnostic labels and tools, which some people with lived experience of mental illness, particularly those with psychosis or borderline personality disorder, find deeply oppressive (Perkins et al., 2018; Speed, 2006). Third, recovery oriented care favours a more integrated and community-based approach, centred on the individualized health and social care needs of people with mental health concerns and their families. This can be threatening to existing services that operate within siloed institutional structures. Fourth, service workers may resist the greater involvement of people with mental health concerns in service design and delivery, which may be viewed as an intrusion of unskilled workers in their jobs (Pestoff, 2006). Finally, healthcare organisations are traditionally risk-averse and can fear the impacts that empowering service users through co-production might have on the individuals involved and the services they deliver.

In light of this resistance, service design approaches are being embraced as a way for services to engage service users and to help to overcome some of the concern mentioned above. Service design is a human-centred, creative and iterative approach to service innovation (Meroni & Sangiorgi, 2011) that puts people at the centre, both as a focus of design research and as partners of co-design processes. Rooted in design studies, service design research and practice emerged as a consequence of the increasing relevance of the service sector for growth and sustainability globally (ibid). Since service design's practical start in the 2000s, the public sector was debated as one of the primary areas for intervention given its need for radical change (Parker & Heapy, 2006), with healthcare

transformation as a core concern. Appreciated as a complementary approach to quality improvement across different areas of healthcare (Bate & Robert, 2007), service design has gained momentum for its ability to leverage patient-centricity and collaboration in service innovation processes (Malmberg et al., 2019). The engagement of patients and staff in service design is acknowledged as one approach to balancing service relations (Donetto, Tsianakas & Robert, 2014), while favouring the evolution toward co-produced forms of care (Freire & Sangiorgi, 2010). The growing number of design labs set up in healthcare organisations to support innovation and cultural change reveals the increasing recognition of service design's value in this sector (Molloy, 2018).

In mental health systems, service design is increasingly employed as a creative and participatory approach to supporting ongoing transformation. Service design has been called out as an important process and mindset for transformation that enables wellbeing and improves service outcomes (Anderson, Nasr & Rayburn, 2018). While the service design approach is aligned with several other collaborative approaches within the mental health system, it stands out for its focus on experience and integration of multiple stakeholder perspectives (Mulvale, Miatello, Hackett, & Mulvale, 2016). The creative methods and tools of service design are often employed within mental health to help draw out the lived experiences of stakeholders to inform the design of solutions that most effectively meet their needs (Nakarada-Kordic, Hayes, Reay, Corbet & Chan, 2017), orient existing services toward recovery (Carrera, Sangiorgi, Foglieni, Segato, & Lucchi, 2018), or build design capacity in organizations to enable ongoing systems transformation (Pierri, Warwick, & Garber, 2016), and often working on all these goals simultaneously (Szücs Johansson, Vink & Wetter-Edman, 2017). Service design principles have also been adapted into the process of Experience based Co-design (EBCD) to support quality improvement processes that have shown promising results, such as in reducing complaints in acute mental health settings (Springham & Robert, 2015). However, within these service design initiatives, several tensions have emerged around issues such as participants' barriers to active participation (Tobiasson, Sundblad, Walldius & Hedman, 2015) and agency as design is decentralized within the mental health systems (Pierri, 2017).

While service design initiatives to transform mental healthcare are promising, they are also controversial as they can challenge ideological paradigms, traditional treatment approaches and professional hierarchies. Mental health services can be a site of contestation and designing for transformation in this space must account for these complex dynamics. Compounding these issues is the movement from promising experiments within single services toward wider transformations across mental health systems. Amid this complexity, these challenges become increasingly intertwined and multi-layered and are difficult to disentangle in practice. Like the proverbial Gordian knot, these issues may appear intractable. However, paradoxically, we propose that service design may be well positioned to navigate these areas and aid in untangling these knots with the right considerations. Given the complexity and controversial nature of mental health, there is a pressing need to begin comparing and consolidating some of the accumulated experience to build a foundation for future service design work in this area. Without synthesizing and sharing the lessons learned from existing service design projects in mental health, there is a risk that service design does not evolve its practice to better meet the contentious nature of this work and that new practitioners entering this space are unprepared for the nuanced challenges that surface. As such, the authors of this study came together to collaboratively reflect on the contentious issues they faced in their projects and aggregate tested strategies designers and service design teams might adopt to address these issues.

# 2. Methodology

This paper brings together an interdisciplinary team of researchers investigating and applying service design approaches to encourage paradigmatic changes in the ways that people with mental health concerns are perceived and supported. Collectively, our experience touches on converging areas of study, such as nurse-patient therapeutic engagement, peer support, co-production and recovery within mental healthcare systems in Italy, United Kingdom, Canada and Sweden. To examine the areas of contention and related strategies when designing for mental health transformation, we used a qualitative multiple case study design (n = 10), informed by Yin (2009). Drawing on ten cases enabled an in-depth exploration of the multifaceted issues faced when using a service design approach, and an understanding of the commonalities in how these were addressed in various mental healthcare settings.

### 2.1 Case selection

A case is defined as a discrete project that used a participatory service design approach to transforming mental healthcare. As this research represents the first synthesis of contentious issues in designing for mental health, the cases were drawn from authors' own practice using the following criteria:

- 1) Service design project that aimed to make significant changes to a mental health service or system;
- 2) Met contentious issues that, in the opinion of the researchers, arose with particular acuity in the mental health context;
- 3) Active attempts had been taken to address and overcome these contentious issues within the project.

An overview of each case is provided in Table 1. The cases reflect a variety of jurisdictions, settings, contexts and populations, targeting changes within a single service, across multiple organizations, and throughout systems. Study duration also varied from 8 months to 3.5 years. The ten cases selected were at various stages of development when the analysis was conducted. Some were at exploration stage (i.e. gathering data to explore experiences of care), while others were at the implementation and evaluation stages. However, they all exhibit characteristics that illuminate key contentious issues and design strategies for working in this context.

# 2.2 Data collection and analysis

The data collection strategy was to capture each author's reflection-on-action (Schön, 1983) from their own cases and to use this experiential knowledge to help in the generation of theory. To compare and contrast these reflections-on-action, two data collection matrices were developed. The first captured the data relating to the contentious issues experienced in each case. The second captured the promising design strategies used to address the contentious areas in each case. Each author populated the matrices with details from their own cases, which enabled large amounts of data to be easily displayed, compared and interpreted (Miles, Huberman & Saldana, 2014).

Qualitative thematic analysis (Miles et al., 2014) facilitated within and across case pattern matching. The data analysis was conducted in four iterative steps:

1) Each author individually clustered their data into areas of contention related to their case(s) and strategies they found useful to overcome the issues of contention



Running with Scissors, 13th International Conference of the EAD, University of Dundee, 10-12 April 2019

Table 1: Details of selected cases

Title	Description	Location	Context of Mental Healthcare	System Level	Patients	Project Phase	Duration and Status
Case 1	Applied service design to foster co-production and recovery across the services of a mental healthcare unit	Brescia, Italy	Community & mental health services offered by general hospitals	Organisational level	Adult	Planning, exploration, co-design	1 year (completed)
Case 2	Applied service design with young people to imagine how a green area of an expsychiatric asylum could foster social inclusion	Brescia, Italy	Formal community	Single service	Youth	Planning, exploration, co-design	8 months (completed)
Case 3	Co-designing support for people to live well through and beyond trauma and crisis	West of England, UK	Formal & informal community	Single service	Adult	Planning, exploration, concept	Seeking funding for co-produced bid
Case 4	Supported a shift toward partnering with people with lived experience of mental health and addictions in the review, design and delivery of services across sectors	Toronto, Canada	Formal & informal community (participation from specialized & general hospitals)	System level	Youth & Adult	Planning, exploration concept & implementation	3.5 years (completed)

Case 5	Co-designing an intervention to improve nurse-patient therapeutic engagement on acute mental health wards	London, UK	Dedicated mental hospital	Single service	Adult	Planning & exploration	3 years (6-months in)
Case 6	Co-designed online support and a new youth intake process for a mental health clinic	Karlstad, Sweden	Formal community	Organisational level	Youth	Planning, concept & implementation	2 years (completed)
Case 7	Co-designed a community perinatal mental health service	England & Wales, UK	Community services offered by charities	Single service	Adult (perinat al)	Planning, exploration, co- design & implementation	1.5 years (implementation ongoing)
Case 8	Developed experience apps and co-designed prototypes to improve coordination of care across settings for youth with mental disorders	Southern Ontario, Canada	Formal community, primary care & hospital	System level	Youth (Transiti on stage 16-25)	Planning, exploration & co- design	3 years (complete)
Case 9	Co-designed prototypes for improved transitions to adult care for youth with mental disorders	Hamilton region, Ontario, Canada	Services for transitional age youth (primary care, community & hospital)	System level	Youth (16-25)	Planning, exploration, co- design & implementation	3 years (implementation ongoing)
Case 10	Co-designed prototypes for improved employment support for transitional age youth	Hamilton Ontario, Canada	Employment support services for youth with mental health issues	System	Youth (Transiti on stage 16-25)	Planning, exploration & co- design	1 year (complete)



Running with Scissors, 13th International Conference of the EAD, University of Dundee, 10-12 April 2019

- 2) A meeting was held to collectively examine each case. We grouped similar contentious issues into higher order codes, making note of the cases that related to each code;
- 3) We then individually clustered the codes into overarching themes. A consensus meeting was held, where we collectively decided on the final overarching themes;
- 4) We then individually assigned strategies from the cases that were employed in response to the different contentious areas we identified.

# 3. Findings

## 3.1 Contentious issues

Several contentious issues were identified when doing service design in the mental health context, which may also apply when designing with other marginalized populations. Our analysis of the ten cases revealed five areas of contention: organizational constraints; ensuring meaningful participation; culture clashes; power dynamics and systems approaches. In this section, we present an overview of the contentious issues, followed by the strategies we used to address them across the 10 cases (see Table 2). We begin each subsection with contentious issues that were particularly acute in the mental health domain (signified by \*), followed by more general issues we faced.

### **Organizational Constraints**

Organisational constraints can set the context and parameters for what is possible within a service design process. Within the mental health context, there were two particularly contentious issues. First, the emphasis on person-centeredness within service design processes can run into constraints with respect to eligibility criteria, diagnostic categories and treatment protocols within mental health organizations. In particular, a recovery approach recognizes that there is no 'one size fits all' set of supports, and instead that personal recovery journeys are unique to each individual. Second, the traditional focus of many mental health services is on managing acute mental health crises. It can be difficult for organizations to place priority on service design processes, that may focus on improving self-management outside of clinical settings. More general organizational constraints to the service design process may also exist. For example, healthcare organizations may be fearful of risks to the individuals involved in service design processes and may be reluctant to devote time to service design rather than direct care delivery. Organizations may also be reluctant to invest in staff service design training with associated long-term payoff, rather than investing in a more immediate need for new services. More generally, it can be difficult to secure management support to implement service design outcomes, when these are not known in advance. Competing priorities, organizational tensions, professional boundaries, and the rigidity of service provision can all be difficult dynamics to manage.

### **Ensuring Meaningful Participation**

Ensuring meaningful participation can be a particular challenge in the mental health context. Authors of all cases pointed to the need to consider the capacities of different participants, and their motivations for wanting to be involved in service design activities. People with mental health concerns may be motivated by the need to be heard, to hear about experiences of others, or because they feel that sharing their own experiences may improve services for others. For some, symptoms or health status may influence their ability to stay involved in a design session or remain involved in a service design process over time. Differences in motivation may also influence continued

Copyright © 2019. The copyright of each paper in this conference proceedings is the property of the author(s). Permission is granted to reproduce copies of these works for purposes relevant to the above conference, provided that the author(s), source and copyright notice are included on each copy. For other uses please contact the author(s).

Table 2. Contentious issues and design strategies in the cases

Overarching Themes	Contentious Issues	Design Strategies
Organizational Constraints	PERSON CENTREDNESS VS. RIGIDITY AND FRAGMENTATION* - Tension between recovery as an extremely personal, subjective and nonlinear experience and the rigidity of and misalignment across some service provision (Case 1, 3, 4)	Consider personalization (e.g. decreasing support) of care provision when designing for new/improved services and interfaces to favour service adjustments along the recovery journey (1)
	CRISES VS. PREVENTION* - Issues supporting self-management outside of existing services because of mandates of the organizations supporting co-design process (Case 6)	Building self-management into organizational redesign and new mandate (6)
	OPERATION VS. PROJECT TIME - Tension between focusing service	Getting buy-in from organizational leadership to dedicate percentage of staff time to service design process (5, 6)
	provider time on existing services and seeing service users or investing time in the development of new services (Case 4, 5, 6)	Ensuring early buy-in from service user groups, to advocate and support co-design work within the service (5)
	DESIGNING VS. LEARNING DESIGN - Issues between priorities of developing new services or building service design capacity for the long term (Case 5, 6)	No proven design strategies to date

Meaningful Participation	PARTICIPANT CAPACITY & MOTIVATION* - Different participants' abilities and motivations to participate and engage with codesign and co-production (Case 1, 2, 3, 4, 5, 6, 7, 8,9, 10)	Intentionally reach out to marginalized people through alternative community platforms rather than recruiting just through existing services (3, 4, 7)  Allow for different roles and levels of participation and identify trusted "intermediaries" that can mediate and evaluate feasibility of engagement (1, 2)  Identifying some short-term tasks and simple activities which can work as entry points is crucial to guarantee engagement in all the process phases (2)  Continued engagement of vulnerable groups requires strategically aligning with their varying motivations for involvement and designing processes that meet those varying needs with extra support as required (7, 8, 9)  Offer ongoing means to participate, as well as one-off sessions that go to spaces where people are already gathering (4, 5)  Consider working with an established service user group to ensure ongoing peer support for participants e.g. ResearchNet model (Springham, Wraight, Prendergast, Kaur & Hughes, 2011) (5)  Including co-design participants' contributions in subsequent meetings and workshops
	CONTINUED ENGAGEMENT* - Diverse motivations for involvement can hamper continued engagement through the various co-design stages during a lengthy project (Case 2, 4, 6, 7, 9, 10)	to help communicate where their contribution is having an impact (2, 7)  Offer roles and opportunities for participants to grow, learn and lead throughout the process (4, 6, 7)  Importance of "intermediaries" (e.g. psychologists) to monitor the ongoing condition of participants and their needs to re-arrange the design intervention in real time (2)
	EXPECTATIONS VS. IMPLEMENTATION* - Problems working on something and raising expectations of vulnerable people that does not have guaranteed funding for implementation (Case 1, 2, 3, 4, 5, 6, 8, 9, 10)	Being clear to participants from the beginning that transformative change takes time and that there may not be immediate uptake of co-design outputs (3, 5, 6, 8, 9, 10) Where possible, securing support of managers and system leaders in advance to act upon produced outcomes and improvement ideas (5, 8, 9, 10)

	AUTHENTIC VS. TOKENISTIC ENGAGEMENT*: Overcoming	Facilitators must take the time to listen fully and not put process and timelines ahead of participants (7, 8, 9, 10)
	scepticism that engagement is tokenistic (Case 4, 5, 7, 8, 9, 10)	Allow participants to work through their differences constructively and avoid tendency to default to suggestion of more powerful groups (8, 9, 10)
		Provide co-design training for key participants to create confidence in ability to contribute to or lead process (5, 7)
	IMPACT OF INVOLVEMENT* - Involving people with lived experience in the process who are at varying degrees of wellness and	Design an engagement process that recognizes and honours different participant motivations such as: to be heard and validated; to place one's own experience in context with experiences of others; to contribute to improving experiences for others (7, 8, 9, 10)
	capacity, and opening up hard issues and triggering individuals	Over-recruit most vulnerable groups to support continued representation in engagement (8, 9, 10)
	participating in the co-design process (Case 1, 4, 7, 8, 9, 10)	Provide material support for engagement through, honoraria, arranging transportation, etc. (8, 9, 10)
		Hiring a peer support worker (or expert by experience) to support people with lived experience throughout the process (4, 5, 7)
		Consider working with an established service user group to ensure peer support for participants e.g. ResearchNet model (Springham et al., 2011) (5)
	PAY & COMPENSATION - How to pay and compensate people with lived experience involved in co-design of services (Case 3, 4, 5, 6)	Provide stipends to compensate for the time of people with lived experience, for example, following INVOLVE guidelines (INVOLVE 2018) that set out fair payment for study participants (3, 4, 5)
Culture Clashes	SOCIAL VS. MEDICAL MODELS* - Moving away from medical models,	Using people's stories to illuminate inter-connectedness and need for incorporation of social determinants of health (4)
	to understand the lived experience of service users and explore lived experience so that breakdowns can become breakthroughs (Case 3, 4, 5, 6)	Use improvisation/role-play rehearsal to explore alternative responses to situations that appreciate lived experience and receive feedback (4)
	DEFENSIVENESS OF TRADITIONAL HIERARCHIES* - Service providers	Support inclusion of all voices by skilled facilitation that recognizes core values of each group (5, 8, 9, 10)

	defensive of their own expertise and knowledge when enhancing the role of mental health service users in co- design and co-production (Case 3, 4, 5, 6, 8, 9, 10)	Place lived experience of service users at the centre of deliberations to counterbalance structural power of professionals (8, 9, 10)  Design tools for service providers to better take and receive feedback (4)  Build capacity of vulnerable participants over time (8, 9, 10)
	AWARENESS & ACCEPTANCE - Different levels of awareness of what co-design & co-production mean and different levels of acceptance across mental healthcare services (Case 1, 4, 5, 7)	Conduct exploratory and preliminary research into existing values and perceptions around co-design production and recovery to consider possible convergence or areas where conflicting values can co-exist and allow for experimentation (1, 5, 7) Ensure common understanding from outset as to the approach being taken and the value of it (7)
	EXPERIENCE-BASED VS. EVIDENCE-BASED - Tension between the principles of the co-design approach and the traditional 'evidence-based' approach (Case 4, 5, 7)	Combining both experience (through story and perspective sharing) and more traditional forms of evidence (e.g. reports, articles and theory) to validate direction (4, 5, 7)  Draw on existing co-design literature and other project examples to communicate value and validity of approach (7)
Power Dynamics	PEER VS. SERVICE PROVIDER DIVIDE*  - Conflict between creating a "peer" label to create positions for people with lived experience, but inadvertently creating a false divide between peers and other service providers (Case 4)	Using the ladder of engagement to reflect on and challenge the current role of peers in the service or system (4)
	PEOPLE & THEIR FAMILIES* - Tensions between needs of people with lived experience and their families (Case 4, 5, 9)	Creating separate groups for people with lived experience to contribute without others present (4, 5)

LIFE CIRCUMSTANCE* - Valuing everyone's time and existing commitments of diverse perspectives (Case 5, 8, 9, 10)	Creating separate groups for people with lived experience to contribute without others present (5)
INTERSECTIONALITY* - Tension related to a focus on addressing inequity for people lived experience vs. other forms of power and oppression within the system e.g. race, sexual orientation, immigration, physical disability, etc. (Case 4, 9)	Developing tools and strategies to support reflection on different sources of power in organizations (4)  Providing training for project leadership and all project stakeholders in anti-oppressive practice and anti-racism (4)
COLLABORATION DESPITE CONTENTION* - Not undermining the peer/consumer survivor movement while working with more mainstream organizations to increase peer involvement, inclusivity and balance (Case 4)	Calling out conflict and power dynamics within the room during collaborative activities (4)
WORKING WITHIN AND OUTSIDE HEALTH SERVICES*- Partnering with formalized, institutionalized mental health service providers as well as other stakeholder groups (Case 1, 2, 4, 6, 8, 9)	Harness awareness of strategic priorities of policy-makers and granting agencies to find/recognize opportunities to advance co-design ideas (8, 9, 10)  Share knowledge gained with advocacy organizations who can apply pressure to decision-makers to advance co-design ideas (5, 8, 9, 10)  Holding ongoing conversations and consultations with people from consumer survivor/peer movement (4, 5)  Facilitate encounters between health service providers and other stakeholder groups through co-design activities to stimulate idea generation and identify hidden resources (1, 2)

	GRASS ROOTS DRIVEN VS. TOP DOWN DIRECTIVE- Ensuring a bottom up approach as opposed to a top down approach (Case 4, 5, 7)	Creating regular spaces for people from across sectors and levels with diverse background to meet and collaborate with ongoing attention to power dynamics (4)  Starting project with no pre-defined goals and ensuring every decision is taken based on co-design activity, rather than top-down drivers (7)  Inviting an expert by experience trained in co-design to facilitate co-design events (5)
	CONTROL & RESPONSIBILITY - Challenges related to ownership and control of the process staying with the design team vs. partners and those who have resources (Case 2, 3, 5, 6, 8, 9, 10)	Building ownership through ongoing capacity building with service providers and service users throughout the process (2, 3, 6)
Systems Approach	WORKING ACROSS SYSTEMS* - Separate governance and funding barriers can hamper implementation of cross-sectoral co-design ideas to improve service coordination (Case 1, 2, 4, 8, 9)	Conduct a system mapping exercise to ensure a wide range of organizations and sectoral representation (8, 9)  User recovery journey maps as support to identify gaps and misalignment across services to identify opportunities to design in the 'holes' to better bridge existing provision and look for bridging and orienting solutions and roles to guarantee continuity of care (1)  Create a governance structure that forms an eco-system that works together motivated by a common desire to improve service user experiences of service coordination and integration of services (8, 9)
	NEED FOR SOCIETAL CHANGE* - Societal change and culture change needed when supporting people toward full recovery (Case 2, 4)	Secure support of higher authorities that span multiple services (8, 9)  Mapping the underlying social structures and mental models contributing to the current system (4)  Favour hybrid spaces and initiatives, outside traditional service locations, that work toward social inclusion and societal change (2, 3)

DIFFERENT LEVELS - There are different interacting issues and levels within an ecosystem, ranging from individual to societal levels. It can be and difficult to know where to begin and work (Case 1, 4, 5, 8, 9)	Support community to advocate for government policy change through different avenues, including policy reports (4)
SYSTEM CONSTRAINTS - Physical (e.g. space design), organizational (e.g. roles and work model) or legal constraints (e.g. payment system) that constrain the application of co-production and recoveryoriented solutions (Case 1, 3, 4, 6)	Acknowledge constraints and work at the edges to experiment and demonstrate value that can lead to better funding or opportunities for larger scale change (1, 3)

engagement over time. Furthermore, some staff may resist the greater involvement of people with mental health concerns in the design and delivery of mental health services. Some staff may anticipate criticism, while others might question the capacity of individuals who they have seen struggle with acute symptoms. Another issue is the tension that arises between creating enthusiasm for the work that will motivate engagement, versus the risk of raising expectations of service change that may not be realized. Related to this is the issue of ensuring that engagement is authentic. Many people may be sceptical that their input will actually make a difference and fear their engagement may be tokenistic. Consideration must also be given to how being involved in a service design process may influence participants themselves. Asking participants to share their lived experience could trigger individuals who are at varying stages of wellness. All these challenges in the mental health context compound more ubiquitous issues with regard to how to pay or compensate people involved in service design work.

### **Culture Clashes**

Different paradigms, values, language, assumptions and experiences can all be sources of culture clashes when it comes to adopting a service design approach. For example, recovery reflects a movement away from medical models toward understanding the lived experience of service users within a broader social context. Both recovery and service design consider social factors as being integral to promoting the well-being of the person, in a way that does not preclude but recognizes more than biological considerations. Compounding these culture clashes that are particularly acute in the mental health context, are cultural issues that arise with service design more broadly. For example, for many mental health services there are different levels of awareness and acceptance of what co-design and co-production mean. There is also a related concern that service design may meet resistance from proponents of an evidence-based approach, who may see the experiences of a relatively small number of service users and caregivers as anecdotal rather than evidence-based. Placing greater focus on understanding the diversity of core values, and how these can be honoured and worked with across perspectives can be essential to foster mutual understanding across stakeholders and different cultures and values in mental health services (Mulvale, Chodo, Bartram, MacKinnon, & Abud, 2014).

### **Power Dynamics**

Service design projects are often hosted by institutions that are built on various power structures such as expertise, bureaucracy, financial resources, and discourses that construct power inequalities. For example, service providers may have deeply entrenched hierarchies within health contexts, such as hospital settings, that can create defensiveness in service design projects. Hierarchy issues may be particularly acute in service design projects involving people with lived experience as peer supporters, creating a false divide between peers and professional providers. Giving service users and families an equal voice in service design can threaten these hierarchies which may be subtly present during multi-stakeholder design sessions. There are also power dynamics that can arise between people with lived experience and their families, where there can be disagreements over who knows what is best for the person. In several cases power imbalances arose when it came to the pragmatic issue of when to hold a design session so that all could attend in light of differing life circumstances. In one case, service providers refused to attend on weekends, while family members resented losing time from paid employment to attend. In such situations, the group that compromises may feel their needs are not being respected. Clashes over whose needs to prioritize were also experienced in two cases when it came to focusing on people with mental illness as a group, without giving due consideration to other forms of power and oppression within health systems, such as with respect to race, sexual orientation, immigration, and physical disability among

others. Concerns also arose in one case about how to work with mainstream organizations to increase peer involvement, without undermining the work of advocates within the consumer survivor movement, who may place greater emphasis on moving away from mainstream organizations. These mental health related issues were overlaid with more general power challenges that can arise when change is motivated by grassroots pressure rather than a top-down directive, and the issue of transferring ownership and control of the process away from the design team.

### **Systems Approaches**

The need to address people's multiple needs within a recovery orientation often implies that service design not only occurs within a single service, but across multiple services within and outside the health services. This in turn often means that in the mental health context, there is a need to work across multiple systems (e.g. health, social services, education, justice, etc.), which each have separate governance and funding structures that can be impediments to coordinated service design processes. Complicating things further, is the fact that change within these services and systems can only be effective within the context of broader societal change to support people with mental illness as valued members of society. This requires, for example, shifting perceptions of people with mental illness to overcome stigma and promote social inclusion. Operationalizing service design in such a context requires recognition of the multiple and interacting issues and levels within the system that will influence service design outcomes for people with mental illness. For the practitioner, it can be very difficult to know where to focus attention and where to begin the process of service design in this context. Understanding the context also means being attentive to the system constraints on what is possible. These could pertain to physical space, organisational roles, existing workflows, legal constraints and economic incentives that shape the behaviour of different provider groups and funding available.

# 5.2 Strategies

Table 2 outlines the design strategies that were used across the various cases examined here to try to address each of the contentious issues. Here we highlight several tested strategies for each of the thematic areas above.

### **Organizational Constraints**

Important strategies that can assist in overcoming organizational constraints include getting buy-in from leadership to allow pre-specified amounts of staff time to be dedicated to the service design process. It is equally important to get buy-in from service user groups to inform and support service design efforts.

### **Ensuring Meaningful Participation**

To assist with engaging marginalized people, it was important to reach out through community platforms, rather than strictly through existing services in some cases. In other cases, trusted intermediaries such as a psychologist or established service user group were important to assist with engagement. Other strategies were to identify some simple activities and tasks that could act as entry points to engagement and develop an understanding of participant motivations to help support continued participation. It was also important to ensure supports were available to anyone who might experience a setback. It was critical to be clear to participants from the beginning that transformative change may take a long time to achieve to avoid setting false expectations and to obtain support of managers and leaders in advance to act on related service design concepts. Other pragmatic strategies were providing appropriate stipends, over-recruiting the most vulnerable

groups, supporting participants with transportation to facilitate attendance, and having a peer support worker present to support them throughout the process.

### **Culture Clashes**

One strategy to assist with acceptance of co-design approaches was to explore values and perceptions of participants about service design and recovery to identify where there may be convergence or conflict. Another strategy was to hold open stakeholder discussions to ensure a common understanding of the process from the outset and to understand where conflicting values or priorities can co-exist. There is also an important role for facilitators to allow participants to work through their differences constructively and take the time to fully allow this to occur rather than defaulting to solutions proposed by more powerful participants. One approach to doing this is to place lived experience of service users at the centre of deliberations to counterbalance the structural power of professionals. To overcome concerns about the rigour of service design approaches, it may be beneficial to combine both experience and more traditional forms of evidence to validate the ideas being put forward and to position service design approaches within the literature and examples of successful applications to build support for the approach.

### **Power Dynamics**

Key strategies to address power dynamics was to start the process with no pre-defined goals or top-down drivers, and to build ownership and capacity among service users and providers throughout the design process. It was also important to foster critical reflective practice within organizations and create regular spaces for people to meet and collaborate across sectors with ongoing attention to power dynamics. Facilitators may need to call out conflicts and power dynamics that may arise during collaborative activities and it may be beneficial if the facilitator is a person with lived experience.

### **Systems Approach**

Considering the complexity of mental health service design, it is important that designers become aware of strategic priorities of granting agencies to recognize opportunities to advance service design ideas within and beyond the health service. It can also be beneficial to keep advocacy organizations, particularly the consumer survivor and peer movement, apprised of emerging findings. These groups can pressure decision-makers at different levels to move ideas generated into practice. Co-design activities themselves can facilitate encounters between stakeholder groups to enable them to identify hidden resources in a cross-sectoral context, and to experiment and demonstrate value that can lead to better funding or opportunities for larger scale change. Taking the time to conduct a system mapping exercise, can help to ensure wide organizational and sectoral representation when working across systems, and similarly, mapping social structures can help to identify initiatives that can foster social inclusions and societal change. Developing user recovery journey maps can also identify gaps and misalignment across services. Securing the support of higher authorities that span multiple services may help to develop a governance structure that can ensure organizations to work together to improve coordination focused on service user experience.

# 4. Discussion

The authors' experiences in engaging people with mental health concerns and their families in the co-design and co-delivery of mental healthcare illuminates several interconnected contentious issues and practical challenges. These issues begin to resemble the proverbial Gordian knot (see Figure 1), which is notoriously hard to untangle.



Figure 1. The Gordian knot of designing for mental health systems transformation

Traditionally, service design tends to focus on improvements within a single service, despite people with mental health concerns needing to use services within and across organisations that are often poorly coordinated. Thus, transformation must occur from individual through to national governmental levels. To avoid culture clashes, and reinforcement of power dynamics, service design requires skilled facilitation, which understands the structural relationships and values of key stakeholders at these various levels.

Responsible service design must account for organizational constraints in terms of the challenges of meaningful engagement and the need to act upon improvement ideas that people have deeply invested themselves in to produce. Working within and outside of healthcare systems is important, such as partnering with grass-roots survivor and peer movements to campaign for wider changes which support social justice. This grass-roots approach may need to be coupled with top-down policy pressure on healthcare organisations and funders, to operationalize service design across diverse contexts. New forms of local governance, that favour sustainable ways to engage very diverse actors in the co-design of services and initiatives for mental healthcare, should be the object of debate and study.

The authors have deliberately chosen to present potential design *strategies*, rather than methods or tools, to recognise the need for designers to create detailed, long-term plans to address the interconnected, complex nature of many issues present in mental health contexts. This was also done to avoid the implication that there is a scientific universality to designing for mental health, when in fact, the strategies call for care and attention to be paid to the nuances of the participants' needs and context. The design strategies are also presented as the most promising *to date* but given the relative youth of service design practice in this context, it is imagined that these will be superseded as service design is increasingly recognised as a sustainable approach to change. Like the Gordian knot, it is unclear where to begin with these strategies, but perhaps a combination will loosen the ties that currently bind attempts at system transformation and create space for new ideas to be embraced.

Most of the current design strategies pay particular attention to the potential needs of those with lived experience of mental health asserting the need for designers to create activities that enable various types of engagement, from one-off events to leading roles, to respond to the varying motivations and abilities of participants. Designers must ensure that these do not perpetuate the idea that those with mental health concerns are unable to take central roles in service development, but instead provide flexibility and choice to accommodate people's changing needs. In presenting these strategies, this paper calls on the service design community to consider their responsibility to those with lived experience at each stage of the project; not only to provide a positive, meaningful experience to shape their future care, but to also mitigate against the potential negative impacts of participation by building in specific, expert support.

The effective and genuine participation of all stakeholders involved is key to creating the most effective outcomes for all parties. Senior stakeholder buy-in often holds the key to unlocking the staff input, resources and commitment to deliver a successful project. However, in a sector with strong, active user groups, the buy-in from service users is of equal importance. Many of the strategies presented aim to address knowledge gaps to obtain permission or commitment, as well as consider logistical barriers to engagement, which can result in an unequal representation of voices. Designers must also be mindful that they do not unduly reinforce divides, inequalities or power dynamics that exist between stakeholder groups, services or systems. Instead, designers should aim to challenge some of these existing dynamics, encourage the formation of new relationships, and push the mandates of organisations to better accommodate the needs of people with mental health concerns. Keeping control in decision-making processes can be unconscious, ingrained, and embedded within hierarchies (Dimopoulos-Bick, Dawda, Maher, Verma & Palmer, 2018), thus critical reflective practice and dialogue is essential (Farr, 2018).

The contentious issues and design strategies presented in this paper reflect the collective experience of the authors in the emerging area of mental health service design from 10 cases across four countries. In doing so, this work is the first to systematically identify issues of contention in this area and document a wide spectrum of related design strategies. However, the cases analysed were at various stages, with different populations and in specific contexts which limits comparability and generalizability. More research is needed to understand these issues and related strategies in other, especially not Western, contexts. In addition, further investigation is needed into how to make this knowledge and these strategies available, where relevant, for various mental health communities to support transformation and spread service design approaches beyond the design community.

# 5. Conclusions

Our design strategies illustrate the need for a systemic perspective on mental healthcare transformation that goes beyond traditional service providers, to leverage local resources, engage society, favour social inclusion and support dialogue with policy makers and funders. Without this wider picture, the proverbial Gordian knot of mental healthcare remains hard to disentangle. Our perspectives on ways forward in designing for mental health transformation include service designers taking a situated, reflexive, context-sensitive and holistic approach, which may require upskilling and the translation of suggested design strategies into tested practices, methods and tools. Service designers and researchers need to take a more systemic account of situations and evaluate their design interventions so that these strategies can be consciously developed and lessons learned shared between communities. While we see the area of designing for mental healthcare transformation as one of great potential for positive societal impact, there is a need to build awareness of the contentious nature of this practice and support the ongoing development of design strategies to deal with these complex dynamics.

# References

- Amering, M., Mikus M., & Steffen, S. (2012). Recovery in Austria: mental health trialogue. *International Review of Psychiatry*, 24, 11–8.
- Anderson, S., Nasr, L., & Rayburn, S. W. (2018). Transformative service research and service design: synergistic effects in healthcare. *The Service Industries Journal*, 38(1-2), 99-113.
- Anthony, W. (1993). Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, 16, 11–23.
- Bate, P., & Robert, G. (2007). *Bringing user experience to healthcare improvement: The concepts, methods and practices of experience-based design*. Abingdon: Radcliffe.
- Carrera, M., Sangiorgi, D., Foglieni, F., Segato, F., & Lucchi, F. (2018). Developing recovery oriented services and co-production in mental healthcare: Building- up on existing promising organisational practices. In A. Meroni, A. M. Ospina Medina, & B. Villari (Eds.), *Conference Proceedings ServDes2018 Service Design Proof of Concept* (pp. 414-426). Linköping: Linköping University Electronic Press.
- Chamberlain, J. (1990). The ex-patients movement: where have we been and where are we going? *The Journal of Mind and Behaviour*, 111, 323–336.
- Davidson, L., Mezzina, R. & Rowe, M. (2010). 'A life in the community': Italian mental health reform and recovery. *Journal of Mental Health, 19,* 436–43.
- Dimopoulos-Bick, T., Dawda, P., Maher, L., Verma, R., & Palmer, V. (2018). Experience-Based Co-Design: Tackling common challenges. *The Journal of Health Design*, *3*(1), 86–93.
- Donetto, S., Tsianakas, V., & Robert, G. (2014). *Using Experience-based Co-design (EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions.* London: King's College London.
- Farr, M. (2018). 'Power dynamics and collaborative mechanisms in co-production and co-design processes'. *Critical Social Policy*, *38*(4), 623-644.
- Freire, K., & Sangiorgi, D. (2010). Service design and healthcare innovation: from consumption to coproduction to co-creation. In S. Holmlid, J.-V. Nisula, & S. Clatworthy (Eds.), *Conference Proceedings ServDes. 2010: Exchanging Knowledge* (pp. 414-426). Linköping: Linköping University Press.

- INVOLVE (2018). Payment for involvement work. Retrieved November 22, 2018, from <a href="http://www.invo.org.uk/?s=payments">http://www.invo.org.uk/?s=payments</a>.
- Jacob, K. S. (2015). Recovery model of mental illness: A complementary approach to psychiatric care. *Indian journal of psychological medicine, 37*(2), 117.
- Malmberg, L., Rodrigues, V., Lännerström, L., Wetter-Edman, K., Vink, J., Holmlid, S. (2019). Service design as a transformational driver towards person-centered care in healthcare. In M. A. Pfannstiel & C.Rasche (Eds.), Service Design and Service Thinking in Healthcare and Hospital Management; Theory, Concepts and Practice, (pp. in print). Cham: Springer International Publishing AG.
- Meroni, A., & Sangiorgi, D. (2011). Design for Services, Farnham: Grower.
- Miles M., Huberman, M., & Saldana, J. (2014). *Qualitative Data Analysis: A Methods Source Book.* London: Sage.
- Millar, S. L., Chambers, M., & Giles, M. (2015). Service user involvement in mental health care: an evolutionary concept analysis. *Health Expectations*, 19(2), 209-221.
- Molloy, S. (2018). Innovation Labs in Healthcare A Review of Design Labs as a Model for Healthcare Innovation. OCAD University, Toronto. Retreived on November 22, 2018, from <a href="http://openresearch.ocadu.ca/id/eprint/2364/13/MOLLOY SEAN 2018 MDES SFI MRP.pdf">http://openresearch.ocadu.ca/id/eprint/2364/13/MOLLOY SEAN 2018 MDES SFI MRP.pdf</a>.
- Mulvale, G., Chodos, H., Bartram, M., MacKinnon, M. P., & Abud, M. (2014). Engaging civil society through deliberative dialogue to create the first Mental Health Strategy for Canada: Changing Directions, Changing Lives. *Social Science & Medicine*, 123, 262-268.
- Mulvale, A., Miatello, A., Hackett, C., & Mulvale, G. (2016). Applying experience-based co-design with vulnerable populations: Lessons from a systematic review of methods to involve patients, families and service providers in child and youth mental health service improvement. *Patient Experience Journal*, *3*(1), 117-129.
- Nakarada-Kordic, I., Hayes, N., Reay, S. D., Corbet, C., & Chan, A. (2017). Co-designing for mental health: creative methods to engage young people experiencing psychosis. *Design for Health*, 1(2), 229-244.
- Parker, S., & Heapy, J. (2006). The Journey to the Interface How public service design can connect users to reform. London: Demos.
- Perkins A., Ridler J., Browes D., Peryer G., Notley C., & Hackmann C. (2018). Experiencing mental health diagnosis: a systematic review of service user, clinician and carer perspectives across clinical settings. *Lancet Psychiatry*, http://dx.doi.org/10.1016/ S2215-0366(18)30095-6.
- Pestoff, V. (2006) Citizens and co-production of welfare services: Childcare in eight European countries. *Public Management Review*, *8*(4), 503-519.
- Pierri, P. (2017). Decentralising Design. Raising the Question of Agency in Emerging Design Practice, *The Design Journal*, *20*(sup1), S2951-S2959.
- Pierri, P., Warwick, L., & Garber, J. (2016). Embedding design in a mental health network, In N. Morelli & A. de Götzen, F. Grani (Eds.), *Proceedings of ServDes. 2016. Service Design Geographies* (pp. 580-585). Linköping: Linköping University Electronic Press.
- Roberts, G., & Boardman, J. (2013). Understanding 'recovery'. *Advances in psychiatric treatment, 19,* 400–409.
- Schon, D. A. (1983). *The Reflective Practitioner: How professionals think in action.* Michigan: Basic Books.
- Slade, M., Amering, M., Farkas, M., Hamilton, B., O'Hagan, M., Panther, G., ... & Whitley, R. (2014). Uses and abuses of recovery: Implementing recovery-oriented practices in mental health systems, *World Psychiatry*, 13(1), 12-20.

- Speed, E. (2006). Patients, consumers and survivors: A case study of mental health service user discourses. *Social Science & Medicine*, *62*, 28–38.
- Springham, N., Wraight, S., Prendergast, C., Kaur, J., & Hughes F. (2011). ResearchNet: Research as recovery. *Mental Health and Social Inclusion*, *15*(1), 34-37.
- Springham, N., & Robert, G. (2015). Experience based co-design reduces formal complaints on an acute mental health ward. *BMJ Open Quality*, *4*(1), u209153-w3970.
- Szücs Johansson, L., Vink, J., & Wetter-Edman, K. (2017). A Trojan horse approach to changing mental health care for young people through service design. *Design for Health*, 1(2), 245-255.
- Tobiasson, H., Sundblad, Y., Walldius, Å., & Hedman, A. (2015). Designing for active life: Moving and being moved together with dementia patients, *International Journal of Design*, *9*(3), 47-62.
- Yin, R. K. (2009). Case study research: Design and Methods Fourth Edition. London: Sage.