Accessing and Navigating the Mental Health Landscape in Scotland: Opportunities for Digital Innovation

Tara French
The Innovation School
The Glasgow School of Art
Forres, UK
t.french@gsa.ac.uk

Tine Thorup
The Innovation School
The Glasgow School of Art
Forres, UK
t.thorup@gsa.ac.uk

Gemma Teal
The Innovation School
The Glasgow School of Art
Glasgow, UK
g.teal@gsa.ac.uk

***Abstract*—In this paper we describe a project that aimed to understand the landscape of mental health services in Scotland towards identifying preferable forms of support and opportunities for digital interventions, from the perspectives of people, families, carers and service providers. Design researchers at The Glasgow School of Art worked together with people with lived experience of mental health services to understand the current journey of finding support, experiencing support and thriving. Shorter public engagement events were also held in order to reach members of the public who do not currently access mental health services but who may do so in the future, as well as gather insights from a wide range of people regarding experiences of mental health support, forms of self-care and preferable support options. A new concept for a digital resource to support access to mental health support emerged. We report the findings from qualitative, design-led mapping of lived experience and present the emerging concept for a digital resource to help navigate the complex landscape of mental health services in Scotland.**

Keywords—mental health, navigation, lived experience

I. Introduction

Mental health is a global issue that impacts many aspects of everyday life. Similar to other countries, for people living in Scotland there is an increasing prevalence of mental health issues among hard-to-reach groups and people living in areas of socio-economic deprivation [1]. Mental health service providers and people affected by mental health have called for a transformation in Scotland's approach to mental health, shifting the focus from crisis intervention and maintenance towards preventative approaches that support good mental health and wellbeing for everyone in Scotland, by right [2]. A lived experience review of mental health services in Scotland further supports this shift, to ensure that prevention informs system and service design [3].

The landscape of mental health services in Scotland is complex with many different organisations providing different types of support. The current use of technology in the provision of services and support is largely focused on providing online interventions to alleviate symptoms and support coping and self-management through resources such as computerised Cognitive Behavioural Therapy [4] and a library of digital apps [5], some of which are currently being tested by the NHS. However, there is a lack of resources which aim to support the wider population and those who may develop mental ill health in the future.

A. Access to health information

The Internet and mobiles devices now provide immediate access to health information for people who are searching for support and advice for health-related topics. A study of online health seeking behaviour in the North East of Scotland found that 68% of patients surveyed had previously searched for health information online with one in four patients being influenced to attend an appointment with a health professional as a result of the information found [6]. However, understanding and assessing the value of health information available (which is largely unregulated) requires a level of digital health literacy in order to prevent negative outcomes [7].

Online information regarding mental health is distributed, with individual organisations providing information pertaining to the support provided by that organisation. There is a lack of a single, national resource that provides general but regulated information about a wide range of topics for those who are currently experiencing mental ill health and those who may be seeking information for themselves or others.

The use of design methods and approaches in the context of mental health to explore experiences and develop interventions is an emerging field. Previous studies have employed Experience Based Co-Design (EBCD) to collaboratively develop service improvements for inpatient units [8], improve psychosocial recovery [9], and develop online therapy for young people with psychosis [10]. Research suggests that involving end-users through co-design can lead to better quality of care, enhanced system performance and can, in turn, result in improved health outcomes [11].

In this paper we report the findings from a qualitative, design-led engagement project that aimed to support a larger piece of work around developing unscheduled mental health services and accessible online resources. The engagement research aimed to understand the landscape of mental health services in Scotland towards identifying preferable forms of support and opportunities for digital interventions from the perspectives of people, families, carers and service providers.

II. Methods

A. Design-Led Approach

The use of design research approaches such as Participatory Design and Co-Design in the field of digital health is gaining increasing recognition for the value and

benefits of involving end-users in the design and delivery of services that will affect them [12]. Design methods and approaches have been traditionally used in human computer interaction in the design of interfaces and user experience but more recently have grown to be popular much earlier in the design process to ensure products and services meet identified needs.

The design-led approach at the Innovation School, The Glasgow School of Art, has been applied within the Digital Health and Care Institute (DHI) Innovation Centre to support the co-design of services, systems and health and care experiences with practitioners, people with lived experience, academics and industry partners. The person-centred approach supports exploration and creation of 'preferable' solutions to complex societal challenges to innovate systems, pathways and experiences of care. The value of design in the context of health and social care innovation lies in the strengths of design practice in visualisation, strategic roadmapping and co-design. The visual language of design gives form to complexity in a way that creates shared understanding among those who are creatively engaged in the design process. The visual exploration of a shared problem space such as health and care generates insights that can be translated into tangible opportunities and actions for meaningful change.

Deploying expertise in visualisation, strategic roadmapping and co-design, the design research group at the Innovation School support partners and participants to create a vision of a 'preferable' future by dynamically and iteratively prototyping solutions, resulting in transformed services, pathways, systems and experiences across health and social care.

In the current project, a design-led approach was employed to support engagement and involvement of members of the public and people with lived experience in the exploration of the landscape of mental health support in Scotland. The approach offered a way for these voices to inform the design of future services and forms of support for mental health, and to do this in a person-centred way.

B. Public engagement: Pop-up approach

Creative engagement with members of the public was designed using a pop-up approach [13]. A pop-up approach was employed in order to reach members of the public who do not necessarily currently access mental health services, as well as a wide range of citizens and carers to gather insights into any experience of mental health support, forms of self-care and preferable support options. Pop-ups were held in locations across the North East of Scotland at pre-existing public events. Conversations started with general questions regarding wellbeing, e.g. 'what keeps you well?', leading to more focussed questions around how people look after their mental health.

C. Mapping workshops

Mapping workshops using designed tools were employed to understand access to and experiences of people who are currently accessing mental health services. The workshops provided a safe, collaborative space for participants to share their experiences of accessing and receiving support for mental health. Participants were supported to map their experiences individually or in small groups to understand the journey of finding, receiving support and thriving (see Figure 1). The mapping also provided a way to identify needs and opportunities for new forms of support, and to further understand the role of digital mental health services (challenges and opportunities) and what the expectations would be from digital mental health services.

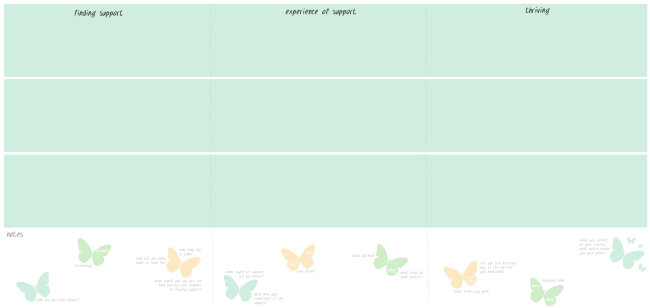

Fig. 1. Example of the workshop mapping tool (T.Thorup)

III. FINDINGS

Insights generated through each of the design engagement activities were clustered thematically per engagement. The insights generated across the engagements were then analysed thematically to identify emerging and recurring themes across all activities.

The following section outlines the emerging insights around finding, experiencing support and thriving, and also the overall key themes and areas of opportunity that resulted from each engagement.

A. Emerging insights: finding, experiencing support and thriving

Participants shared their experiences in a narrative style (beginning – middle – end), which clustered around three phases, which we describe as 'finding support', 'experiencing support', and 'thriving' (see Figure 2). One theme which cut across all stages of the mental health journey which is of particular importance was the intermittent or cyclical nature of need.

The cyclical, relapsing and remitting nature of many mental health experiences meant that people needed to find and access support intermittently, which was a challenge if circumstances had changed i.e. moving to different location, changes in staff and services, or being 'off the books' (discharged by the service). Participants highlighted the need for the reassurance of a 'safety net', i.e. a fast way back into services at the early signs of a possible relapse, catching them before things became bad. This idea was also described as having 'weak and strong' ties to the medical system, whereby strong ties are in place during challenging periods when more support is required, and weak ties exist to permit re-engagement with services if and when required. A person's safety net also encompassed knowing yourself well enough to recognise symptoms and having a plan in place for this in advance, whilst well. A safety net could be things or people or systems.

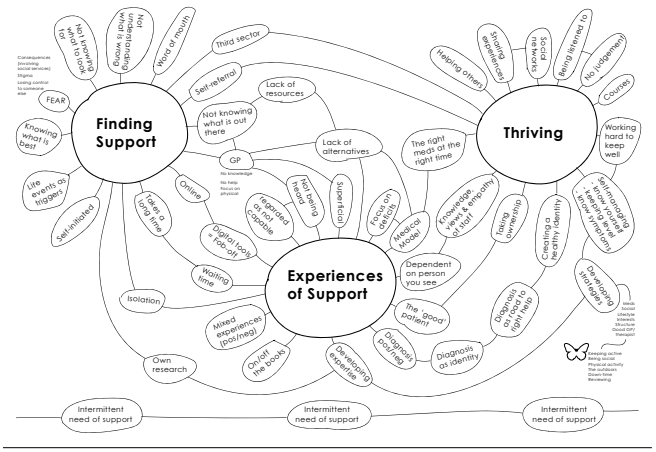

Fig. 2. Emerging insights of finding and experiencing support and thriving (T.Thorup)

a) Finding Mental Health Support: The 'finding support' stage tended to be focussed around self-initiated support and information seeking through various approaches such as online, through the health service or by meeting other people with similar issues. Word of mouth and local advertisements helped participants find the right person and form of support. Although it was mentioned that events can be poorly attended, and it is hard to ensure people are aware. In some cases, online information provided a way for people to develop their own knowledge of their condition and support available. Some participants thought online support should be supplementary with many participants emphasising the importance of face to face support.

A central barrier to finding support was not knowing what to look for, where to look or who to ask. Finding information took long periods of time and participants often felt they had to seek out information themselves and lacked an overview of what was out there. Leading on from this was not knowing if something was good or not, or relevant to their specific circumstance. Word of mouth often played a key role in determining the choice of support, but finding the right person to ask/trust also took a long time. Participants (including carers) wanted to know the big picture about what services (statutory and community/third sector) were available, what/who they are good for, how they access etc. in order to empower themselves to choose, and to know if they are eligible, what the capacity of the service is, how long they would wait and if self-referral was possible. Participants also commented that many initiatives are short lived so it is difficult to know if something is still in existence. Participants hence stated the importance of clear information describing the benefits of the support available, suggesting that this could enable people to determine which support would be best to seek depending on their circumstances.

b) Experiencing Mental Health Support: Experiences of support were very mixed across the types of service/support accessed and received and relied to a great extent on the person seeing them. Participants reported that everyone needs help to find a form of support that will work for them, and relationships were also stressed as important in order to find the health and care professional and peers that work well with the person. The type of support also differed according to the stage of the journey/trajectory, with different services supporting different needs. The different types of services described included: National Health Services (NHS), charity and third sector organisations, and peer support groups. The importance of statutory services' knowledge and awareness of what is available in the community was highlighted and requires an integrated approach to knowledge sharing to ensure seamless transitions and experiences.

In experiencing support, participants were again becoming self-knowledgeable and highlighted the importance of knowing what resources are available, such as social care, to enable support to be given to remove other stressors that can contribute to, or exacerbate an issue.

c) Thriving: Each participant's journey was unique, and experiences and needs varied. Common experiences were found in 'Thriving' where participants placed importance on ownership and self-management through using the knowledge they had gained about themselves during their journey to better understand what worked for them. This also involved recognising the signs and symptoms that indicate they may need additional support. Participants developed a personal expertise about their needs and most benefitical support through their lived experience.

Strategies employed during 'thriving' included outdoor activities and exercise, healthy eating, social/peer support activities, and also an emphasis on structure and discipline. Less emphasis was placed on external and clinical support at the 'thriving stage' and if present seemed to be something that was in the background as a 'static' foundation or maintenance rather than an action by the participant e.g. continuing to take medication.

Learning and sharing experiences with others was suggested as a way to support other people to identify what might work for them and also the signs and symptoms that may suggest they need support. Many participants mentioned helping others as being very helpful for their own mental well-being.

B. Key themes and areas of opportunity

Throughout the engagement process, participants identified opportunities for change and generated a range of potential solutions. Six thematic areas emerged which also identified key challenge areas (see Figure 3). The emerging themes encompassed the process of illness and recovery from the earliest stages, in which people began to conceptualise their distress as abnormal; the recognition that they are struggling to manage this distress on their own; their decision to seek help; their search for appropriate sources of help and information, and determining the availability of these resources, their navigation of these structures (for example eligibility criteria, waiting times etc); learning what works by testing out different forms of help and support; learning what is expected by services; establishing a way of working that fostered autonomy, gradually taking more control and, eventually reducing their support in a way which contained

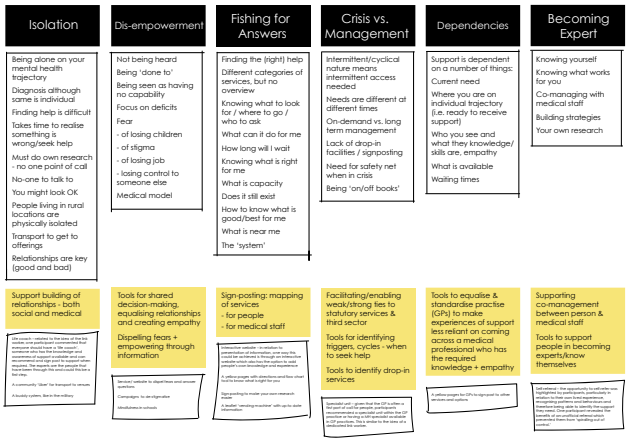

Fig. 3. Recurring themes and areas of opportunity (T. Thorup)

their anxieties about relapse, and 'left the door open' in case of future need.

Participants described initially being naïve in the areas of 'Fishing for Answers' and 'Becoming an Expert' but, through long and sometimes bewildering experiences, they learned to navigate and eventually develop mastery. It can be seen that while these themes encompassed 'self-management', they also relate to a much broader set of highly complex processes, requiring time, considerable self-directed searching, learning and higher-order 'meta' cognitive tasks that unsurprisingly participants struggled with during times of significant distress.

Participants also highlighted areas of recommendations for change which addressed the challenges identified (see coloured boxes in Figure 3). The recommendations included specific ideas suggested by participants that could help to overcome the barriers to navigating and managing mental health services and support.

IV. OPPORTUNITIES FOR DIGITAL: SIMPLE SIGNPOSTING CONCEPT

The key insights and themes emerging across the project led to the design of a concept that aims to overcome many of the challenges experienced when searching for mental health support and navigating the complex landscape of services. The concept of 'Simple Signposting' emerged as a design response to speculate how an online resource could help people to find the right support at the right time for mental health. The concept offers a way to enable people to find the most appropriate support for what they need at the time by showing a map of community services, and a map of wellbeing (self-care). The concept could also provide tools to support people in how to ask for help, how to search online for local contacts, information, and offering stories shared by others with lived experience. The concept would also help people to prepare for engaging with services by providing information of what to expect from the services and support available. Simple Signposting addresses the need to shift to a more preventative and proactive model of mental health that aims to support people to overcome fears and lack of health literacy when searching for support, providing 'ways in' to services, whilst removing the stigma which is often experienced in relation to mental health.

As outlined by previous research included in the introduction, there is a need to provide information and support in an accessible and timely format to enable both people who are currently experiencing mental ill health and those who may experience mental ill health in the future to find and access support to meet their needs at that time. The Simple Signposting concept provides a way to address this gap in digital mental health support provision. Given the short nature of the project it was not possible to test and prototype the concept with participants. As such, future research will explore the infrastructure required to integrate such a resource within the existing landscape of service provision and will explore with future users how this concept might address identified needs, the content and form of information required, and how future interactions and experiences may be enhanced when seeking to find and access mental health support. Further research will also explore a life course approach to enable a level of personalisation across the lifespan to meet the needs of specific groups.

ACKNOWLEDGMENT

We would like to thank our project partners in the Mental Health Cooperative and the Digital Health and Care Institute. We would also like to thank all our participants who gave up their time to take part in each of the design-led engagements.

REFERENCES

[1] Scottish Government (2017) Mental Health Strategy 2017-2027 [online]Retrievedfrom:http://hub.careinspectorate.com/media/500590/mental-health-strategy-2017-2027.pdf

[2] Scottish Mental Health Partnership (2016). Why mental health matters to Scotland's future.

[3] Mental Health Foundation. (2016). A review of mental health services in Scotland: Perspectives and expereinces of service users, carers and professionals.

[4] Beating the Blues [online] Retrieved from: https://www.beatingtheblues.co.uk

[5] NHS Digital App Library [online] Retrieved from: https://apps.beta.nhs.uk/?category=Mental%20Health

[6] Moreland J, French TL, Cumming GP. The prevalence of online health information seeking among patients in Scotland: a cross-sectional exploratory study. JMIR research protocols. 2015 Jul;4(3).

[7] Moreland J, French T, Cumming GP. Exploring Online Health Information Seeking in Scotland. InPAHI 2015 (pp. 73-80).

[8] Larkin M, Boden ZV, Newton E. On the brink of genuinely collaborative care: experience-based co-design in mental health. Qualitative health research. 2015 Nov;25(11):1463-76.

[9] Palmer VJ, Chondros P, Piper D, Callander R, Weavell W, Godbee K, Potiriadis M, Richard L, Densely K, Herrman H, Furler J. The CORE study protocol: a stepped wedge cluster randomised controlled trial to test a co-design technique to optimise psychosocial recovery outcomes for people affected by mental illness in the community mental health setting. BMJ open. 2015 Mar 1;5(3):e006688.

[10] Wadley G, Lederman R, Gleeson J, Alvarez-Jimenez M. Participatory design of an online therapy for youth mental health. InProceedings of the 25th Australian Computer-Human Interaction Conference: Augmentation, Application, Innovation, Collaboration 2013 Nov 25 (pp. 517-526). ACM.

[11] Boyd H, McKernon S, Mullin B, et al. Improving healthcare through the use of co-design. J N Z Med Assoc 2012;125:76–87

[12] Bowen S. Critical theory and participatory design. In Proceedings of CHI 2010 Apr.

[13] Teal G, and French T. Designed engagement. In: Design Research Society 50th Anniversary Conference, 2016 June, Brighton, UK