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Co-designing wellbeing: the commonality of needs between co-designers and mental health service users

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This paper considers the potential impact of the co-design process on the wellbeing of stakeholders involved in mental health service design. The findings presented here are drawn from semi-structured interviews conducted with both co-designers of a perinatal mental health service, who previously had issues with their mental health and acted as experts by experience, and the service users who accessed the designed offer. These have subsequently been analysed using a General Inductive Analysis approach (Thomas, 2006) to understand the factors that impacted on a participant's wellbeing in both circumstances. Our findings highlight that there are similarities between the factors that impacted on the wellbeing of the co-designers and those that impacted on the wellbeing of service users accessing a mental health service. This paper suggests ways in which the design community might learn from the mental health sector to manage, and potentially improve, co-designers' wellbeing during the co-design process. It also suggests how the role of the designer might need to expand to explicitly consider and manage the wellbeing of co-designers during a project.

co-design; wellbeing; service design

1 Introduction

As the Design profession has moved from designing for people to designing with people (Sanders & Stappers, 2008, 7; Brown, 2009; Blyth & Kimbell, 2011), designers have adopted new roles that allow stakeholders of an issue to play a central part in the design of a solution (Sanders & Stappers, 2008, p. 7). Involving stakeholders in the creation of a service or a product is commonly defined as *co-design*. This term is often used as an umbrella term for participatory or open design processes, but this research understands co-design to involve a group of stakeholders who come together to work creatively through the entire design process; from the definition of the problem space, through to the design of the potential solution (Sanders & Stappers, 2008, p. 7).

Co-design groups are generally comprised of those who can offer expertise on the issue being considered, including professionals, front-line staff, and previous or potential users (Steen,



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Manschot, & De Koning, 2011, p. 53; Visser, Stappers, Van der Lugt, & Sanders, 2005). However, the members of the group, known as *co-designers*, place the experiences of users at the centre of the decision making (Steen et al., 2011, p. 53). Co-design research to date has predominantly focused on the positive impacts of involving stakeholders in this way, including the: higher quality of ideas; improved knowledge about users' needs; and more successful innovations (Steen et al. 2011, p. 58).

However, much of the research focuses on the impact on the *outcomes* of the process (service, system or community, etc.), and there has been little exploration of the potential impacts of co-design on the *co-designers* (Vink, Wetter-Edman, Edvardsson, & Tronvoll, 2016). Those impacts that are discussed are usually outcomes of stakeholders continued involvement in a project or programme, for example, feeling more empowered (Manzini, 2010) or gaining new skills (Wolstenholme, Grindell, & Dearden, 2017). There is little research into how being a co-designer impacts on the individual at different points in the process, or how being a co-designer could have a negative impact on an individual's wellbeing.

The concept of wellbeing is one that is heavily described, but historically ill-defined (Dodge, Daly, Huyton, & Sanders, 2012, p. 222). The term is frequently used interchangeably with 'quality of life' and other similar phrases, without a common, detailed understanding of what it means. For this research, the authors have drawn on Dodge et al.'s (2012, p. 230) definition of wellbeing as "the balance point between an individual's resource pool and the challenges faced". When an individual faces more psychological, social or physical challenges than they have psychological, social or physical resources, this balance is lost, having a potentially negative impact on their wellbeing (Dodge et al., 2012; Kloep, Hendry, & Saunders, 2009). Similarly, not receiving adequate challenge, can also result in a reduced sense of wellbeing, as our resources can 'stagnate' (Dodge et al. 2012, p. 230).

Considered in very simplistic terms, being a co-designer can be viewed as a 'challenge'; this could be seen as a positive challenge, which could help the co-designer to 'flourish' (Keyes, 2002). Equally, as a novice, the stakeholder may not necessarily have the 'resources' to draw on to navigate or enact aspects of the design process, thus adversely impacting on a co-designer's wellbeing.

The issue of wellbeing in the context of co-design is particularly important when working to create new health and social care services, where the issue being focused on could be sensitive or distressing, just as in the case considered in this research. Here, the authors analyse how the design process impacted on the wellbeing of co-designers of a new perinatal mental health service, who had drawn on their own personal experiences to create a new offer, 'Mums Matter'. These impacts are compared and contrasted with interviews conducted with the eventual service users of the co-designed service. The paper presents the aspects of the design process that can have impact on a co-designer's wellbeing, and what can be learnt in this respect from the way mental health services manage wellbeing of service users.

This research offers two contributions to academic and practitioner audiences: firstly, the findings suggest the potential pressure points in the design process and how these might be mitigated against to protect a co-designer's wellbeing. Secondly, the authors suggest how designers' roles might need to expand to explicitly manage a co-designer's wellbeing during the design process.

2 Related Work

An exploration of literature related to this issue has identified two main gaps: firstly, there is no research that explicitly discusses a designer's role in managing the wellbeing of co-designers. Secondly, there is little research that discusses the impact that design can have on wellbeing, particularly the potential negative impacts of being involved in the design process. These issues are discussed in the following sections.

2.1 Designer's role in co-design

Sanders and Stappers' (2008) depiction of the evolution of co-design and co-creation describes designers and users swapping roles, with the designer acting as a facilitator to the process, and the user taking on a more prominent role in decision making. As a result of this shift, the profession has continued to see the development of a new set of roles, distinct from the traditional definition of designer as "a person who plans the look or workings of something prior to it being made" (The Oxford English Dictionary, 2017).

Recent research has identified the 'expanding roles' of design practice (Tan, 2012; Yee, Jefferies, & Tan, 2013). Yee, Jefferies and Michlewski (2017, p. 18) identified seven roles to drive change by design: cultural catalyst; framework maker; humaniser; power broker; friendly challenger; technology enabler; and community builder. All of these investigations have established that designers can adopt multiple roles in a project, often simultaneously, in order to involve as effectively as possible stakeholders in the design process (Tan, 2012; Yee et al., 2013; Yee et al., 2017). However, none of these have talked about a designer's role in managing a co-designer's wellbeing during the process.

2.2 The impacts of co-design on wellbeing

There is a small amount of literature that discusses co-design impacts that can be linked to an individual's wellbeing. Much of it describes the positive outcomes of co-design, including objects, services or systems that improve wellbeing. For example, Zanetti and Taylor (2016) note that "co-creation has shown to improve health outcomes with regard to multiple health conditions". Camacho Duarte, Lulham and Kaldor (2011) similarly noted their co-design project improved "community well-being and safety".

Co-design literature also frequently describes an empowered community as an outcome of co-design, although it is not always anticipated. Research suggests that stakeholders can be empowered by co-design as it is an "active engagement process" (De Couvreur & Goossens, 2011). Such engagement results in "empowered people who take more responsibility for their own well-being and the future" (Szebeko & Tan, 2010). Others describe this empowerment as resulting in 'happier' consumers (Pera & Viglia, 2015). For service design projects in particular, outcomes such as a sense of "community affiliation" (Pera & Viglia, 2015) and "a shared vision of the future" (Reay et al., 2016) can also be linked to wellbeing.

The opportunity provided by design to 'make' something - whether it's social change, or something more tangible - is also seen as having a positive impact on wellbeing (Szebeko & Tan, 2010). Prototyping activities, including designing, making and using, are "framed as sources of happiness, which lead to engagement, new challenges, fruitful relationships and sense of accomplishment" (De Couvreur, Dejonghe, Detand & Goossens, 2013, p. 68).

Despite the claims of positive wellbeing detailed in the literature, "existing research on co-design seems to focus mainly on wellbeing outcomes at the micro or meso-level" (Vink et al., 2016, p. 396). Vink et al. (2016) also describe how there is not yet a clear analysis of how the design process influences wellbeing across levels, entities, types, outcomes, intentions and transformation. The negative impacts of the process on wellbeing are also overlooked in co-design literature, "as a result, conversations about how to reduce and mitigate negative impacts of the co-design process are absent" (Vink et al., 2016, p. 396). Steen, Manschot and Koning (2011) also acknowledge the need to consider "whether the intended benefits are indeed realized", and the "risks of co-design."

There are many aspects of the design process that might feel challenging to non-designers, as they are a departure from standard ways of working and might require a new set of 'resources'. For example, Design frequently addresses 'wicked problems' (Rittel & Webber, 1973; Buchanan, 1992), which are inherently complex, with indeterminate outcomes. This amount of uncertainty can impact on stakeholders, who may be uncomfortable with ambiguity and open-endedness. Depictions of the

design process also frequently describe 'a fuzzy front-end' (Sanders & Stappers, 2008), where designers use divergent thinking to explore all potential factors related to an issue. The multiple directional changes in the 'fuzzy front-end' could also feel alien to co-designers. Designers also have to consider what could be, rather than simply build on what exists (Manzini, 2010; Tan, 2012). However, imagining an alternative future is a difficult task for a non-designer, particularly the shift from the familiar inductive or deductive logic, to the use of the unfamiliar 'abductive reasoning' (Martin, 2009).

There is a need to make clearer the role of co-design in affecting wellbeing and developing the dialogue around the impacts. Vink et al. (2016) suggest opportunities for "designers to better optimize the total value created through co-design". This can be achieved through "considering and managing not only the impacts of what is being designed, but also the impacts of the design process, designers can work to enhance the overall influence of co-design on well-being" (Vink et al., 2016). Vink et al. (2016) believe this is approached by a number of steps, including understanding all impacts of co-design on wellbeing and a "deepening exploration of how co-design contributes to different types of wellbeing".

This paper aims to build on the fourth of Vink et al.'s (2016, p. 398) proposed expansions: "Monitoring co-design's negative outcomes related to wellbeing and discussing opportunities for mitigating or reducing these outcomes." It will do so by considering the factors that impact on a co-designer's wellbeing, and how we can learn from mental health support in how we might mitigate against them.

3 Research Methods

A case study research design was chosen as it "defines topics broadly not narrowly, cover contextual conditions and not just phenomenon of study, and rely on multiple and not just singular sources of evidence" (Yin, 2003, p. 33). This study aims to explore the gaps in knowledge in relation to the impacts of being a co-designer on wellbeing, and as such, this dictated an exploratory design (Yin, 2003, p. 3). An embedded, multiple-case design was chosen, to compare and contrast two different projects that reported impacts on wellbeing, to understand any commonalities and differences between the cases (Yin, 2003, p. 45).

The first case chosen aimed to uncover the impacts of being involved in a co-design process on participants; and the second, to understand the impacts of the co-designed mental health service on the service user. Although both activities had very different purposes (to design an effective service, and to improve a participant's wellbeing), the reflections of both groups appeared to be very similar, and allowed the authors to reflect on what could be learnt about the management of wellbeing from both contexts.

The research was qualitative by nature, in order to explore "well-grounded, rich descriptions and explanations of processes in identifiable local contexts" (Miles & Huberman, 1994, p. 3). For context, an overview of each case is outlined below:

3.1 Case study one: Co-designers

In June 2015, Mind, a federated charity that aims to improve the mental health and wellbeing of people living in England and Wales, embarked on a project to co-design a service for women with poor perinatal mental health. This was part of Mind's broader programme, Service Design in Mind (SDiM), which aims to embed service design techniques and methods into their network of local Minds that deliver mental health services (Pierri, Warwick & Garber, 2016, p. 580).

Up to 20% of women will develop a mental health problem in the perinatal period (from pregnancy to the child's first birthday), including problems such as: antenatal and postnatal depression, obsessive compulsive disorder and postpartum psychosis (Bauer et al., 2014). Mind wanted this work to be led by women with lived experience of perinatal mental health problems, "experts of

their experience” (Visser et al., 2005), to help shape what their organisational response should be. They advertised on social media and received 100 applications from women who wanted to participate, and from this, they selected five women to be part of the co-design team who were paid for their work on the project. Each of these women was from a different area of the country and had a different experience of mental health support; one was supported in a hospital environment, one had private treatment, one received counselling, one accessed cognitive behavioural therapy and one was treated with medication.

These women were also joined by representatives from two local Minds, who had expertise in delivering mental health services for this target group. A service designer from the SDiM team (also an author) was appointed as the facilitator to guide the co-designers through the design process, and the manager from Mind’s Products programme (for which the service was being designed) was present to manage the overall project.

The co-designers led every aspect of the design process from defining the design brief, to detailing the final service concept. The SDiM team acted only as facilitators of the process; planning the workshops that introduced the possible design tools and methods, and the co-designers had the power and permission to make all decisions about the service’s purpose, look and feel.

The co-designers were brought together once a month for a workshop; five in total, one for each stage of the SDiM methodology (see Figure 1).

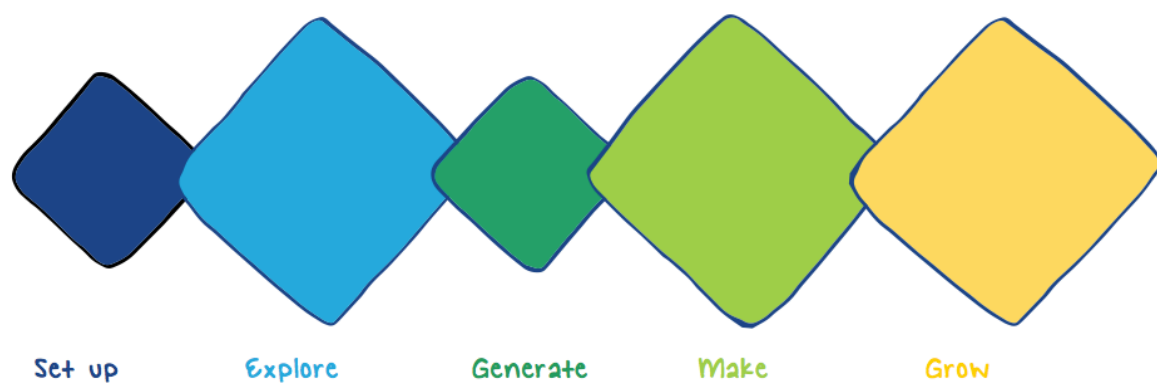


Figure 1: The five stages of the Service Design in Mind methodology (Pierri et al., 2016, p. 581)

In the *Set-up* workshop, the co-designers shared their own experiences of support they received and used this to create a research brief, which guided the work in the early stages. The facilitator introduced the design research process in detail and the co-designers tried out tools and methods, to increase their confidence and familiarity with the process.

In the *Explore* workshop, the facilitator supported the co-designers to create example discussion guides and test them on each other, before finalising the questions to ask research participants. Following the workshop, the co-designers interviewed 20 women with lived experience, 1 relative and 11 experts. Each co-designer reflected on the interviews they conducted to identify the insights that they felt should influence the next steps.

In the *Generate* workshop, the co-designers shared their key insights from the Explore phase. The facilitator helped to map and group similar findings to identify themes and patterns that were then used to write a new design brief. Following the workshop, the co-designers used the design brief to generate ideas about ways Mind could meet those aims, describing their best ideas in a storyboard.

At the *Make* workshop, the co-designers shared their storyboards, reflecting and critiquing them to take forward the aspects of the ideas that they liked. The co-designers combined these to create the ideal service offer, which the co-designers named ‘Mums Matter’, that was then mapped out step-by-step with the facilitator’s help. After the workshop, the facilitator created a storyboard to

describe how Mums Matter would work. Each co-designer then showed this to the women they interviewed to get their feedback on the concept.

At the *Grow* workshop, the co-designers used the feedback from the interviewees to create another iteration of Mums Matter. The facilitator then helped the co-designers to think about the key messages for the service and how Mind would reach out to the women who need support.

In May 2016, following the completion of the workshops, a mental health practitioner with specialist perinatal mental health expertise used the co-designers' design outputs to create the session content for Mums Matter.

3.2 Case study two: service users

At the end of the workshops, the final design for Mums Matter was an eight-week course, which would introduce key content on: how to manage the everyday; dispel myths; and nurture themselves.

Service users could self-refer to access this course, but awareness was also raised through healthcare professionals and other community groups and spaces. Service users were brought together in groups of no more than eight to discuss their feelings and learn about ways to improve their mental health. The service users had access to a fully paid-for crèche, so that they had time and space to share their emotions without needing to look after their children.

In weeks seven and eight, the service users and facilitator met up in an informal setting e.g. a local cafe, to help them get used to supporting each other with their children around.

There was also an optional session, separate to the course, for supporters of the mums (this could be a partner, relative or friend) to learn more about perinatal mental health and how to help them.

Once a mental health specialist created the course content, Mums Matter was run as a live prototype in two local Mind organisations. Prototype one began in October 2016, and prototypes two and three began in February 2017. Key primary care professionals, including health visitors and GPs, referred service users to access Mums Matter. Each potential service user was assessed for their willingness and readiness to attend the service using accepted mental health measurement models. They then attend eight sessions: six in a community building, and two in an informal setting e.g. a local cafe.

3.3 Data collection

In both cases, the primary research method was semi-structured interviews (Robson, 2011), in order to gather rich, descriptive stories from the participants. All co-designers and service users were invited to participate in the research.

The co-designers were invited to take part in an interview after the project had concluded to contribute their views on the process and how it had impacted on them. Four out of the five women involved consented to an interview.

In the case of the service users, each of the mums that attended were asked to share their experiences of the service one month after the service had concluded. Ten out of fourteen service users consented to be interviewed.

For each set of interviews, a discussion guide was created that broadly focused on: what was good about their experience, what could be improved and what were the positive and negative impacts on them, if any. None of the questions asked about wellbeing explicitly, but instead drew out in the discussion details of how the experience (of being a co-designer, or a service user) had affected the participants' psychological, social and physical resources, in relation to their psychological, social and physical challenges, as per Dodge et al.'s (2012) definition.

The same independent researcher conducted all of the interviews with the co-designers and the service users. Each participant gave their informed consent for their interviews to be audio

recorded, transcribed and analysed. All of the women were also asked if they felt well enough to take part in the interview before it commenced.

4 Data analysis

As this research was both qualitative and exploratory, the authors adopted a General Inductive Analysis approach (Thomas, 2006) to build theory directly from the data, without being influenced by pre-defined hypotheses (Scriven, 1991, p. 56). This approach is similar to a Grounded Theory approach (Glaser & Strauss, 1967), but does not require the researcher to be independent of the activity being analysed (Thomas, 2006). As one of the authors was both practitioner and researcher in this study, it was appropriate to draw on this alternative inductive-based approach.

The research data went through four distinct stages:

- data-cleaning;
- first-stage coding;
- building multiple coding collections;
- and identifying themes and patterns.

To clean the data, the interviews were all first transcribed and put into a common format to aid reading of the text. They were then read several times, with hand codes made amongst the text (Glaser & Strauss, 1967, p. 106). Each excerpt of text related to a psychological, social or physical impact on the participant was copied onto a Post-It note, to continue the manual analysis of the data.

Using the Post-Its, quotes were grouped based on perceived commonality. These created multiple coding collections (Tan, 2012, p. 79; Yee, 2010), which were then assigned a title that summarised the meaning or theme of the group. Looking across all these groups then allowed the researchers to identify a set of factors that impacted on wellbeing. With each of the factors, a process of correlating the theory with existing literature, as well as reflecting back on the original data, helped to ensure their plausibility. Aspects of the patterns were also validated with key members of Mind's team to check inter-rater reliability and ensure accurate interpretation of data and outcomes.

5 Discussion

All of the women interviewed reported improved wellbeing, either as a result of being involved in the co-design process, or accessing the Mums Matter service. The co-designers primarily related an improved sense of wellbeing to using their own previous, often negative, mental health experiences, to create something positive for others; using an existing resource to meet a new challenge. Whereas, the Mums Matter service users felt that the skills and knowledge they acquired during the course resulted in improved wellbeing outcomes; providing new resources to meet an existing challenge.

Although the women's positive wellbeing outcomes were attributed to different activities, the women described a number of similar factors that had impacted on their ability to maintain or readdress their wellbeing balance during the course of the co-design project, or the Mums Matter service. These factors are outlined below:

5.1 Commonality of experience

The first notable factor that impacted on the women's wellbeing was meeting others with a shared experience.

All of the women interviewed enjoyed being brought together with women who had experienced the same mental health issues. In the service users' interviews, women described that learning that they were not alone in their experience was crucial to their recovery: "meeting other mums who were in the same position, knowing that there were other people who were feeling the way that you do and it's not that you're a bad person."

Although both the co-designers and service users knew that they would meet women with this shared experience, in the case of the co-designers, they had not anticipated how much this would improve their wellbeing. Each of the co-designers interviewed said that they had not met women who had shared their experience to such an extent. They found this particularly empowering as it helped to 'normalise' their feelings; "I was so relieved that other women who are capable intelligent women in every respect went through mental health problems in that time. I felt less abnormal." As all of the co-designers were all 'recovered' from their mental health issues, the design team had also not anticipated this impact, nor deliberately chosen co-designers who had not accessed peer support, but it proved to be a crucial factor in improving their wellbeing during the process.

In both cases, what was critical to the positive impact was that they were provided with a platform to express their experience without being judged. Within the service context, this was both anticipated and expected, but within the co-design context, co-designers were unsure if they would be drawing on their own experiences directly. One co-designer commented that "the first things we talked about was our experience of perinatal mental illness, so there was never any shyness or awkwardness". For the service users and the co-designers, they felt this opportunity to share, and to be listened to, helped improve their wellbeing, and contribute to positive group dynamics. Explicitly in relation to co-design, this sharing of experiences was attributed to feeling 'valued' and able to contribute something of worth. By being viewed as "experts of their experience", the co-design process helped to provide an opportunity for a negative experience to be seen in a positive way.

5.2 Group dynamics

The second, related, factor that impacted on both co-designers' and service users' wellbeing was group dynamics. As a result of this shared experience and attending the course together, service users formed bonds that often continued once Mums Matter was finished. In some cases, the entire group bonded: "we've set up a WhatsApp group so we talk on there". For some cohorts, more one-to-one friendships formed, with a few examples of two individuals meeting up regularly: "I met one girl and we now see each other quite regularly so that's quite nice, I think I got on well with her". The continuation of relationships outside of the service environment has helped to provide sustained peer support for the mums, which many felt would form a part of their continued recovery.

Conversely, in other cohorts of service users, there were tensions amongst the group, and this impacted on wellbeing throughout the service delivery. Some women described feeling that they did not have the opportunity to share their opinion or experience. One mum felt that her group was often dominated by one person: "there was a girl when we did it who talked a lot and I think if you're not somebody who talks a lot it can feel a bit like a one man show sort of thing". A similar situation was described in another cohort where a mum said that "there were people that had bigger personalities in the group". In both cohorts, mums that had noticed this had felt that this detracted from their wellbeing as it left them frustrated, and unable to participate in the way they wanted.

Similarly, in the co-design group, one co-designer described feeling that her experience had been dismissed on occasion by another member of the group: "there was a woman in the group who I had quite an opposing view to on one aspect of recovery". She went on to describe that an idea she had proposed at the idea generation stage had been 'dismissed' by one person who "rolled her eyes". She commented that the facilitators probably had not noticed this, and she did not want to complain about the incident, as she felt that in general she had a strong connection with the group.

However, all of the co-designers generally felt that they had bonded very well, and that this had helped them to develop a cohesive service in the timeframe as they had a shared sense of purpose and aim. For example: "it felt like we were just one team all on the same level, all equally having a say, it didn't feel like any one person's opinion was more important than anyone else." Whilst giving everybody the opportunity to contribute equally is an understood principle of good facilitation, co-

designers found that the opportunity to supplement a working relationship with personal relationships formed over lunches and breaks was particularly important. In parallel to the service users, they found this became a form of peer support, which has continued post-project: “there was that empathy for each other as we had all been through something, certainly with me they were all so supportive and encouraging”. Recognising that the community needs to bond in multiple ways is important to promote positive impacts on wellbeing in a co-design context, as it can provide social resources to help address new challenges.

5.3 Facilitation

The importance of facilitation in a co-design context (Sanders and Stappers, 2008; Yee, Jefferies and Tan, 2013) and mental health (Repper, Ford & Cooke, 1994) is well established, in order to encourage participation and help manage the aforementioned group dynamics. However, the data shows that the relationship between the women and the facilitator was of equal importance.

In Mums Matter, the facilitator’s primary aim was to improve the mental health of the service users, and so it was anticipated that this role would be an important factor in the wellbeing of the service users. One mum said, “I trust her which is a big thing, I don't trust anyone really, [but] I trust her, I can tell she's genuine”. Another commented that “her being an open, genuine person is fairly integral to a course like that succeeding”.

The Mums Matter facilitator had been recruited and trained with a focus on the personal skills that would be required in this context, whereas the co-design facilitator had not received any mental health-specific training. However, a similar theme was still apparent in this case, with the personal skills of the co-design facilitator being valued over their design abilities. The co-designers remarked on how the co-design facilitator had been ‘encouraging’, ‘positive’, ‘trust-worthy’, ‘patient’, ‘professional’ and ‘relaxed’. Of particular importance was the perceived empathetic nature of the co-design facilitator, with one mum describing her as “very sensitive and considerate of any sensitive areas and emotional issues”. All of the co-designers described trusting the facilitation team; both to deliver the best possible outcome, but also as people they could share their honest thoughts and feelings with.

The Mums Matter facilitator was also in contact with the service users between the sessions of the service to provide support and encouragement to keep them attending. Service users thought this was key to maintaining their wellbeing between sessions. Similarly, one of Mind’s facilitation team spoke to each co-designer between the workshops to see how they were managing with their design activities. Although the ‘check-ins’ were primarily to support the co-designers with the design activity, the women felt that this was also key to maintaining their wellbeing during the process as they prevented them from becoming overwhelmed and helped them to feel valued, again providing a vital social resource.

Although both the Mums Matter facilitators and co-design facilitator played key roles in maintaining and improving the wellbeing of the women they supported, only the mental health facilitator worked with that primary aim. The co-design facilitation team considered the wellbeing of the women in relation to the activities they were asked to complete, but it was no one person’s main responsibility or focus.

5.4 Structure

In both cases, the co-designers and service users talked about valuing the structure provided by the service or co-design project.

In the case of the Mums Matter service, this was not surprising as it had been designed to take the women through important topics in a logical order. None of the service users interviewed felt any content should be removed, or moved to a different part of the course. They all talked about the content being critical to help them to progress in their recovery and provide the resources required to rebalance their wellbeing.

Although the structure of the co-design activity wasn't focused around improving wellbeing, nevertheless, it was an important factor that helped the co-designers to maintain their wellbeing during the process. Understanding what was going to be achieved overall, and within each session, was incredibly important to help them feel confident about their tasks. One co-designer noted that:

"[The facilitator] recapped and said 'this is what we have done in this section, we've finished this bit and this is how we are going to do the next bit', so it was really structured. It certainly really helped me feel confident in the process because you knew you were making progress and achieving what needed to be achieved".

This was particularly important in relation to the activity between sessions. Having activities clearly explained with examples and frameworks to support them, helped the tasks to become a positive experience, rather than a focus of their anxiety.

Several co-designers did discuss the difficult timing of one activity, as they were asked to generate ideas over the Christmas period, and it became difficult to manage this around other commitments. Although they had been reassured about how much work they needed to do, they all felt a responsibility to achieve as much as possible, which had the potential to result in a negative impact on their wellbeing. Similarly, the service users in the first cohort of Mums Matter were given activities to do at home that were part of their continued learning about their mental health and wellbeing. These were rarely completed, mainly to do with the pressures of life at home. Service users described feeling 'guilty' about not having completed 'homework'. As the facilitator detected this issue during the sessions, this aspect of the service had been changed for cohorts two and three. However, this correlation does demonstrate the need to share and manage expectations of activity between co-design sessions to reduce this potential point of anxiety.

For both co-designers and service users, the perceived flexibility within the structure was equally important. Despite the focused timeframe, the co-designers described feeling that they had time to contribute, and they felt listened to, which was very important to their wellbeing. One co-designer remarked that despite the structure, sessions were not 'formal' and so "it made you feel really comfortable to be able to say whatever you thought". In a similar vein, the service users found that they had the opportunity and space to share their feelings, and they were not rushed onto the next topic.

Designers therefore need to consider the project structure not just from the point of view of achieving the desired outcome, but also in relation to mitigate negative impacts on co-designer's wellbeing.

5.5 Management of the beginning and the end

As well as the importance of structure, the beginning and the end of both the service and the co-design project provided opportunity to considerably impact on the women's wellbeing.

In both cases, the beginning of the service and co-design project commenced with a one-to-one meeting between the mum and the facilitator. For the co-design project, this was a formal one-to-one interview process to select the co-designers, but it proved to be an important stage in setting expectations of the project and forming relationships with the facilitator.

For Mums Matter, the facilitator met with the potential service user in order to assess her suitability and readiness for the course. However, it also proved to be important to gain an understanding of their mental health and wellbeing, and potential triggers that might impact on the mum during the service. Conversely, the co-designers shared some of their mental health experiences as motivation for participation in the project, but there was no discussion around how the co-design activity might impact on their wellbeing.

Data shows that meeting the facilitator before Mums Matter began helped the service users to feel more comfortable with the idea of attending: "because I had already met [the facilitator]... she was

like, well done for coming”. Many of the service users still talked about feeling anxious before attending the service for the first time: “because I suffer from anxiety everything goes to my head so at first I was thinking am I going to look stupid?” The co-designers expressed similar emotions in relation to this stage of the projects; they said that they felt excited about the co-design project, but they were still anxious about meeting the other co-designers for the first time.

Likewise, the ending of the co-design project and service delivery was a factor that could have a detrimental impact on the wellbeing of the women involved. The participants in both the co-design project and Mums Matter service were in regular contact and had a purpose for meeting. In both cases, when this ended, the women described a sense of loss. For the service users, this had been predicted, and the end of the formal service model was followed by two additional sessions that took place in the community.

In the case of the co-designers, the impact of the end of the project was not predicted or managed. The co-designers said they felt “sad it was over”, and wanted to continue to have a way to contribute to the project. Unlike many co-design projects, the service, and co-designers, were not local to a particular area, and such an opportunity was not possible. However, it proved important to the co-designers that they had an application for their new ‘resources’.

Managing both the beginning and the end of contact are key to maintaining wellbeing, to ensure that a sense of balance is retained or attained during and post-project. Further research would help us to understand the impact of the pre- and post-project phases in detail, to provide guidance as to how this might be achieved.

6 Conclusion

This research has found that being involved in co-design projects may have an unplanned impact on co-designers’ wellbeing. Furthermore, there are clear similarities between the factors that had impact on the co-designers’ wellbeing, and those that had an impact on mental health service users’ wellbeing, outside of their simple involvement in the project or service.

By drawing comparisons between a service focused on improving wellbeing, and a co-design project that unintentionally impacted on wellbeing, it is hoped that readers can gain insight into the factors that influence wellbeing within the co-design project. Also, how negative factors might be mitigated or managed in the future based on how these factors are managed in a mental health setting. This directly builds on one particular aspect of Vink et al.’s (2016) earlier findings, which stated the importance of understanding negative outcomes and how these might be reduced. A summary of the factors found through this study to impact on a co-designer, and how these could be managed, is presented below (Table 1):

Table 1 How to mitigate against factors that negatively impact on a co-designer's wellbeing

Commonality of experience	<ul style="list-style-type: none"> • Allow opportunities to share their experiences in a non-judgemental space.
Group dynamics	<ul style="list-style-type: none"> • Create opportunities for the community to ‘bond’ on a personal level. • Allow everyone to contribute and be listened to. • Ensure no one dominates the group.
Facilitation	<ul style="list-style-type: none"> • Create relationships with each co-designer to establish lines of communication and possible triggers for their wellbeing. • Recognise the importance of your inter-personal skills, over your design skills. • Gain co-designers’ trust in your ability to deliver outcomes. • Gain co-designers’ trust that you understand and empathise with their experiences.

	<ul style="list-style-type: none"> • Check-in between workshops to establish co-designers' general wellbeing, as well as the progress of the design work. • Ensure one member of the team has a responsibility to consider and monitor the wellbeing of the co-designers.
Structure	<ul style="list-style-type: none"> • Explicitly outline and re-cap on activities to provide reassurance about achievements. • Build in regular opportunities for people to share their thoughts and opinions. • Negotiate the timing of co-design activities so they don't have unintended impacts for the co-designers • Manage co-designers' expectations in relation to each activity.
Management of the beginning and the end	<ul style="list-style-type: none"> • Meet co-designers in advance to establish general wellbeing, triggers etc., as well as set expectations for the project. • Consider ways to keep the community involved post-project. • Keep lines of communication open post-project so co-designers remain informed.

Some of these factors have been discussed in literature in relation to successful co-design projects, for example, the importance of facilitation (Burns, Cottam, Vanstone & Winhall, 2006; Tan, 2012; Light and Akama, 2012), the impact of sharing experience (Battarbee, 2003), and the dynamics of group behaviour (Light and Akama, 2012; Van Mechelen, Zaman, Vanden Abeele & Laenen, 2013). However, none of these have been found to relate specifically to a co-designer's wellbeing before, or correlated with mental health practice.

This paper does not suggest that people with lived experience of sensitive issues should be excluded from co-design teams; on the contrary, it is crucial that those with expertise and skills to offer continue to be involved in the co-design process. However, it suggests that designers need to be more explicit in their management of wellbeing during such co-design projects. Moreover, as current statistics suggest that one in four people will suffer from a mental health problem during their lifetime (McManus, Bebbington, Jenkins, & Brugha, 2016), it becomes even more vital that designers are aware of the impact the process can have and how they can manage both these intended and unintended impacts, regardless of the focus of the work.

Just as recent research has called on the design profession to change and adapt the roles it plays to maximise user input (Yee, Jefferies, & Tan, 2013; Tan, 2012; Burns et al., 2006), this paper suggests that designers also need to extend their responsibility, to simultaneously enable and protect the co-designer during the process. This prefigures a new duty of care for the co-design process. Practitioners need to plan and craft their project, including co-design group composition, design activities and project structure, in relation to the 'co-designer's experience', as much as the desired outcomes.

Although further research is required to extend the knowledge of these wellbeing impacts and the best ways for these to be managed, these findings are presented as a starting point for designers working in this context. Also, the research is presented as a call for the design profession to recognise their potential impacts and to learn from other sectors who have expertise in managing mental health and wellbeing in a composite and integrated caring manner.

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