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What are the effects of co-designing on participants' mental health and does uncertainty play a role in this change process?

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ABSTRACT The purpose of this paper is to present the initial theoretical work undertaken in a PhD project which aims to understand co-design in the context of mental health, in particular the effects that designing has on participants with mental health problems, and the role that uncertainty may have on facilitating change in this context. The project was motivated by a series of co-design workshops that the author had facilitated in the past (2014-2017) with people with mental health problems who had reported some benefits. This experience suggested that by engaging with the inherently uncertain process of co-design in a calm and creative environment, new patterns of thinking, feeling and behaving may begin to emerge, often resulting on some progress in participants' recovery. In this paper, an interdisciplinary review of relevant literature is presented alongside a speculative discussion of how and why designing may have an impact on mental health, specifically looking at the potential role of uncertainty in this process. We propose that uncertainty could be a key concept both as a potential explanatory factor of why change may occur in participants, and as a generative tool when drafting design activities for this target group. This review and discussion will inform the design activities that will take place in the collaborating mental health organization following successful ethics approval. Following an abductive approach, analysis will be oriented towards explaining what is observed in the co-design workshops, to generate an initial theoretical understanding of the mechanisms at play. The outcomes of the research should shed some light on the effects that designing could have in facilitating psychological change, and our understanding of uncertainty both in relation to design and psychology.

Keywords: co-design, mental health, mental illness, uncertainty, psychology, recovery, theory



Background

The purpose of this PhD project is to better understand the effects that the process of co-design may have on participants who have mental health problems and construct theory as to why this could be the case.

A few projects had been published recently that describe the use of co-design principles within mental health, often facilitated by guidelines such as the Experience-based Co-design, which encourages the use of design methods by other professionals, for instance: (Larkin, Boden, and Newton 2015; Cooper, Gillmore, and Hogg 2016). Among the projects led by designers specifically within the mental health context, focus relied on developing appropriate design methods or describing the design outcomes (Kettley, Sadkowska, and Lucas 2016; Glazzard et al. 2015; Nakarada-Kordic et al. 2017; Kaasgaard and Lauritsen 1997), leaving the effects of participation on mental health users -aside general feedback- yet to be explored. We can nevertheless find some examples that investigate the psychological effects of participation among members of the general public (Corcoran, Marshall, and Walsh 2017) or those with physical conditions such as diabetes, (Hendriks, Dreessen, and Schoffelen 2016) or spinal cord injury, (Macdonald 2013; Langley et al. 2013). Most often, these collaborative design projects answer to a relatively specific brief, perhaps responding to a particular need or problem: for instance co-creation of an online resource with young people experiencing psychosis (Nakarada-Kordic et al., 2017). In the projects I facilitated in the past (image 1), the project began with a process of problem identification, an exploration of 'matters of concern' fuelled by the experiences of participants themselves, similar to what Sanders and Stappers (2012) describe as societal-value co-creation, mostly occurring very early in the process. Designing in general, but even more so at these earlier stages, requires a very peculiar relationship with not knowing, which makes uncertainty a paramount concept to consider as a start. As Dorst and Cross (2001) described, problems and solutions co-evolve, and not only designers are often unaware of how to solve problems but these may also be unknown beforehand.

In relation to psychopathology, the implications of this concept seem all the more profound, as indeed much of uncertainty research has been undertaken in relation to mental health (Tracey and Hutchinson 2016), with research ranging from existential psychology to psychiatry following a wide variety of methodological and epistemological approaches.

Unfruitful efforts to situate observations on how people engage and experience open goal designing within existing narratives inspired me to consider the relevance of uncertainty and its associations to change in this context, especially considering that reflections from participants also seemed to portray periods of confusion preceding change. As May (1950) described, a shift in one's attitude toward uncertainty will indicate a break with past scripts and patterns of behaviour.

Acknowledging the intuitive nature of these initial ideas, a further analysis of these subjects led to some common themes across disciplines. Although someone could criticise the overly diffused complexion of this brief review, it is important to note that theoretical breadth is encouraged to

enrich the abductive possibilities of research (Henwood and Pidgeon 2003), and help inform alternative theorizations.

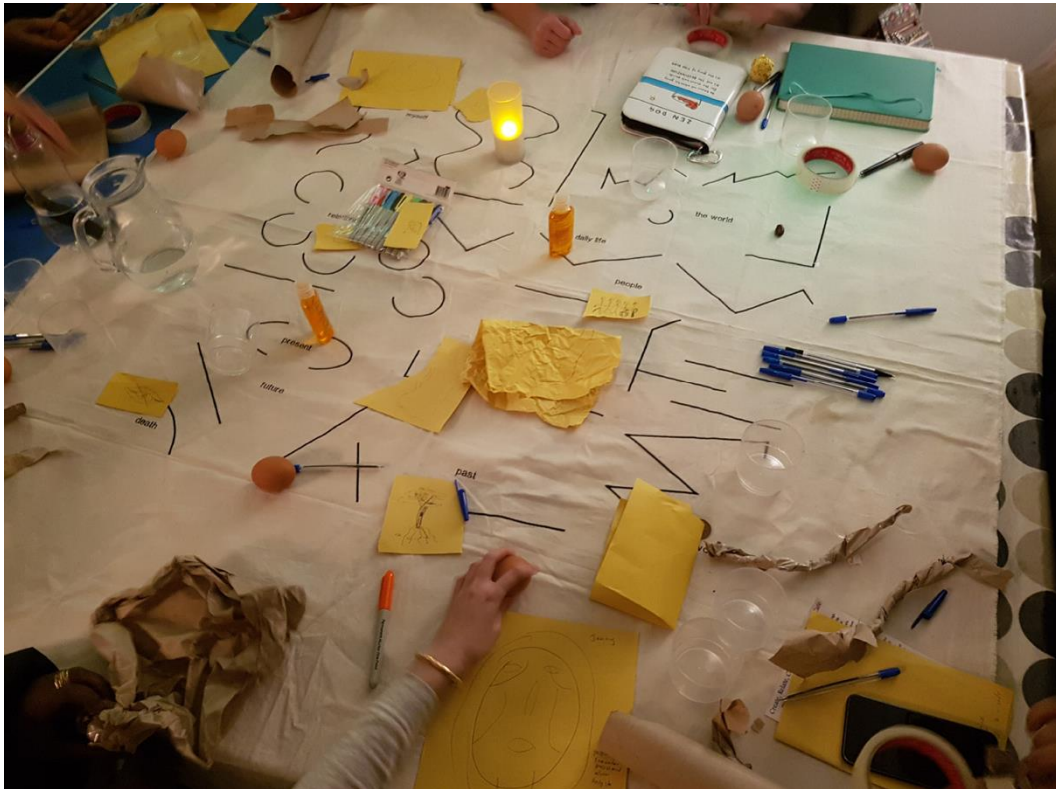


Image 1: co-design workshops at a previous project.

Uncertainty and change:

Uncertainty has been studied in a variety of ways both within Psychology and Design. Taking an interdisciplinary approach, literature has been revisited through the lenses of whether it is concerned with uncertainty as an experience or as a tool. This strategy is oriented towards later stages of the project. Hence, when having to code and analyse participants' data alongside literature, it is unlikely that a disciplinary matrix will prove as advantageous as a phenomenological one. What is the existing knowledge about how uncertainty is experienced (uncertainty as experience) or how uncertainty is used (uncertainty as tool)?

If we were to discuss with someone their personal experiences of uncertainty, we would likely encounter value statements in their narratives, sometimes embedded in the language used– e.g. *dealing with uncertainty*. In fact, not only do different people experience uncertainty differently, but the same individual may relate to it in various ways depending on the context (Durrheim and Foster 1997). Bar-Anan et al. (2009) found that with increased uncertainty, subjects showed stronger



affective reactions, both negative and positive, thus the more uncertain someone feels, the stronger their emotional response.

On the other hand, although context may play a role in how uncertainty is experienced, some individuals appear to struggle particularly in the face of the unknown, so much so that psychopathology is sometimes measured by reference to the nature of someone's relationship with uncertainty. For instance, pathology, according to Gordon (2003), arises from the avoidance of uncertainty, and trying to create certainty where there is none. From a completely different epistemological and methodological standpoint, Mcevoy and Erceg-Hurna (2016) have found the construct of 'intolerance to uncertainty' to be a characteristic across various diagnoses of mental illness, and White and Gumley (2010) associated higher uncertainty intolerance in individuals with psychosis with more negative perceptions about their experiences.

Nevertheless, not all experience of mental illness has been associated with intolerance of uncertainty. Often mental illness and creativity had been associated with a high tolerance for ambiguity. (Abraham, 2014).

Gabora (2016) argues that arousal-provoking uncertainty can be experienced negatively as anxiety or positively as a wellspring for creativity (or both), and articulates how this phenomenon explains creativity. Indeed, Cash and Kreye (2018) have pointed out that designers respond to fluctuations in uncertainty perception by progressing within and across design actions. The study findings evidence uncertainty perception as a potential causal mechanism driving the progression of design activity and Tseng and Ball (2011) suggest this ability to use ambiguity as a generative element increases with practice. Interestingly, a changing relationship with uncertainty has been studied in relation to the development of designer identity in students (Tracey and Hutchinson 2016). Participants demonstrated increased positive orientation rates as the course went along, from (67% positive or mixed) to (79% positive or mixed), although the authors do warn that this could also be a result of unconscious bias, as students try to align themselves with perceived qualities of what makes a good designer. This research is poignant as it depicts how uncertainty as an experience is transformed into a tool by designers.

Many of the common design tools make use of uncertainty some way or other. For instance, Inoue *et al.* (2017) describe how the uncertainty of visual information presented externally can facilitate design reasoning, as designers are able to find semantic meanings and develop designs from meaningless geometric forms.

When engaging non-designers, they may or not be able to experience uncertainty in such ways to spontaneously drive the design progression. In the context of co-design, the design process is facilitated via the use of tools and methods, which help participants orchestrate their skills in such way to perform in a designerly way. Along these principles, tools used in earlier projects in mental health had been revisited against the concept of uncertainty. For instance, *bodystorming* activities may generate a sensation of embedded uncertainty, but their playful nature reduces epistemological uncertainty (awareness of lack of knowledge on a subject). Hence, whilst designers



may engage with uncertainty in ways that drive design activity spontaneously, participants could be encouraged to do so through design tools, and it is possible that this process enables some form of change on them as a result.

Usually, we tend to think of the designer as the subject rather than the object of change, hence Simon's famous definition. "Everyone designs who devises courses of action aimed at changing existing situations into preferred ones." (Simon 1969). Nevertheless, the transformative impact of immersion in the creative process can bring about sweeping changes to that second (psychological) level of complex, adaptive structure that alter one's self-concept and view of the world, extending far beyond the 'problem domain' (Gabora 2016). Whilst designers are used to engage in these processes and may not report changes in themselves, when non designers are engaged in co-design via toolkits that enable non verbal communication, the transformation that takes place is been described as remarkable, invariably positive and often therapeutic (Sanders 2000).

Although, as described by Higginson and Mansell (2008), the why people change psychologically, whether that is result of therapy, a result of psychotherapeutic intervention or during natural recovery, remains unknown, thematic analysis across diverse strategies helped draw some parallels with design and inform theoretical insights. Across the literature, perhaps the most salient theme figuring as important for psychological change is meaning making. Meaning making was identified key for psychological change in studies in art therapy (Forgeard et al. 2014) in posttraumatic growth and stress related growth (Linley and Joseph 2011; Helgeson et al 2006), participatory design (Hendriks et al, 2016), psychological change as a result of everyday life (Gianakis and Carey 2011; Higginson and Mansell 2008). Most interestingly, is that literature on psychological change (Linley & Joseph, 2011) specifies that searching for meaning by itself is not associated with positive change, and the person must engage in more complex reflexive processing that will allow new meanings to emerge.

Here is the key element. As for emergence to happen (e.g emerging new meanings) it follows that no full conscious control or awareness is assumed by the subject, or -in the case of a group – by any given subject alone. It is likely, that those that engage in complex, reflective processing experience uncertainty, when old patterns of thought, affect and behaviour are disrupted, and new ones emerge, when certain meanings are challenged and new ones emerge. It is also possible, that designing is a particularly effective way to navigate this process, due to the generative relationship with uncertainty and its fundamental purpose of generating change.

A tentative conceptualization

It is clear from the review that there is high variability on how uncertainty is experienced, which has been associated to context, affect, psychopathology and creativity in different ways, but how do these variables relate to one another? In which ways can uncertainty (its presence, its variability or its transformation) be used as a tool, and could this be reflected on people's experiences, perhaps even facilitating some form of change and recovery as a result?



People with mental health problems may show unhealthy patterns of thought, affect or behaviour which are often resistant to change via treatment and/or therapy. Rather than addressing these problems directly, design may provide an opportunity that encourages participants to engage in new patterns of thinking, feeling and behaving that are driven by the design process, which makes generative use of uncertainty perception. Arousal provoking Uncertainty is no longer experienced as anxiety, but as a driver for design activity. Participants are now less resistant to complex reflective patterns which are associated with the emergence of new meanings. Change in participants is no longer the objective of engaging with design activity, but the side effect of their efforts to change something else – ‘existing situations into preferred ones’.

Next steps

Many more conceptualizations can be articulated to understand why participants with mental health may be affected as a result of engaging with design.

This review is meant to introduce one original theoretical framework based on a thematic literature review and inspired on personal experiences as workshop facilitator in mental health. The intention, nevertheless, is to continue this research process by gathering data which will include theories of participants themselves. By encouraging participants to reflect on their own experiences, they will likely articulate their own associations and reasons to explain any effects. As Tavory and Timmermans (2014) outline, the theoretical frameworks of the people under study can prove more illuminating and inspiring than academic theorizing.

In the following months, design workshops will be organized with clients of the collaborating charity. Via a variety of mixed methods such as standardized questionnaires, participant observation and interviews, data will be gathered about their experiences. This will be analysed to generate tentative explanations about the phenomenon, aiming at construction of theory. The results of this project may inform strategies to aid recovery, and may contribute to the wider area of co-design for health by providing some evidence of how engagement on design projects affects participants, and how facilitators can use tools to enhance their experiences.

References

- Cash Philip, and Melanie Kreye. 2018. "Exploring Uncertainty Perception as a Driver of Design Activity." <https://doi.org/10.1016/j.destud.2017.10.004>.
- Cooper, Kate, Chris Gillmore, and Lorna Hogg. 2016. "Experience-Based Co-Design in an Adult Psychological Therapies Service." *Journal of Mental Health* 25 (1):36–40. <https://doi.org/10.3109/09638237.2015.1101423>.
- Corcoran, Rhiannon, Graham Marshall, and Erin Walsh. 2017. "The Psychological Benefits of Cooperative Place-Making: A Mixed Methods Analyses of Co-Design Workshops." *CoDesign*, June. Taylor & Francis, 1–15. <https://doi.org/10.1080/15710882.2017.1340484>.
- Dorst, Kees, and Nigel Cross. 2001. "Creativity in the Design Process: Co-Evolution of Problem–solution." *Design Studies* 22 (5):425–37. [https://doi.org/https://doi.org/10.1016/S0142-694X\(01\)00009-6](https://doi.org/https://doi.org/10.1016/S0142-694X(01)00009-6).
- Durrheim, Kevin, and Don Foster. 1997. "Tolerance of Ambiguity as a Content Specific Construct." *Personality and Individual Differences* 22 (5). Pergamon:741–50.
- Forgeard, Marie J. C., Anne C. Mecklenburg, Justin J. Lacasse, and Eranda Jayawickreme. 2014. "Bringing the Whole Universe to Order: Creativity, Healing, and Posttraumatic Growth." In *Creativity and Mental Illness*, edited by James C. Kaufman, 321–42. Cambridge: Cambridge University Press. <https://doi.org/10.1017/CBO9781139128902.021>.
- Gabora, Liane. 2016. *Honing Theory: A Complex Systems Framework for Creativity. Nonlinear Dynamics, Psychology, and Life Sciences*. Vol. 21.
- Gianakis, Mary, and Timothy A Carey. 2011. "An Interview Study Investigating Experiences of Psychological Change without Psychotherapy." *Psychology and Psychotherapy: Theory, Research and Practice* 84 (4). Wiley Online Library:442–57.
- Glazzard, Martha, Richard Kettleby, Sarah Kettleby, Sarah Walker, Rachel Lucas, and Matthew Bates. 2015. "Facilitating a 'Non-Judgmental' Skills-Based Co-Design Environment," 13–16. http://research.shu.ac.uk/design4health/wp-content/uploads/2015/07/D4H_Glazzard_et_al.pdf.
- Gordon, Kerry. 2003. "The Impermanence Of Being: Toward A Psychology Of Uncertainty." *Journal of Humanistic Psychology* 43 (2). Sage Publications Thousand Oaks, CA:96–117. <https://doi.org/10.1177/0022167802250731>.
- Helgeson, Vicki S, Kerry A Reynolds, and Patricia L Tomich. 2006. "A Meta-Analytic Review of Benefit Finding and Growth." *Journal of Consulting and Clinical Psychology* 74 (5):797–816. <https://doi.org/10.1037/0022-006X.74.5.797>.
- Hendriks, Niels, Katrien Dreessen, and Jessica Schoffelen. 2016. "Anchoring and Transcendence: PD As an 'Enabler' in Quality of Life." *Proceedings of the 14th Participatory Design Conference: Short Papers, Interactive Exhibitions, Workshops - Volume 2*. <https://doi.org/10.1145/2948076.2948077>.
- Higginson, Sally, and Warren Mansell. 2008. "What Is the Mechanism of Psychological Change? A Qualitative Analysis of Six Individuals Who Experienced Personal Change

- and Recovery." <https://doi.org/10.1348/147608308X320125>.
- Kaasgaard, K, and P Lauritsen. 1997. "Participatory Design at a Psychiatric Daycenter: Potentials and Problems." *Studies in Health Technology and Informatics* 43 Pt B:816–20. <http://www.ncbi.nlm.nih.gov/pubmed/10179781>.
- Kettley, Sarah, Ania Sadkowska, and Rachel Lucas. 2016. *Tangibility in E-Textile Participatory Service Design with Mental Health Participants*.
- Langley, J., Craig, C., Gwilt, I., Chamberlain, P., Bateman, R., Partridge, R. 2013. "Applying Inclusive Design Principles to Improve Self Management in Spinal Cord Injury." In . http://research.shu.ac.uk/design4health/wp-content/uploads/2014/09/D4H13_Vol2_web.pdf.
- Larkin, Michael, Zoë V.R. Boden, and Elizabeth Newton. 2015. "On the Brink of Genuinely Collaborative Care." *Qualitative Health Research*. <https://doi.org/10.1177/1049732315576494>.
- Linley, P. Alex, and Stephen Joseph. 2011. "Meaning in Life and Posttraumatic Growth." *Journal of Loss and Trauma* 16 (2). Taylor & Francis Group :150–59. <https://doi.org/10.1080/15325024.2010.519287>.
- Macdonald, A.S. 2013. "Exploring Design's Potential Agency in Changing Roles and Responsibilities in SCI Rehabilitation." In .
- May, Rollo. 1950. *The Meaning of Anxiety*. Literary Licensing.
- Nakarada-Kordic, Ivana, Nick Hayes, Stephen D. Reay, Carla Corbet, and Amy Chan. 2017. "Co-Designing for Mental Health: Creative Methods to Engage Young People Experiencing Psychosis." *Design for Health* 1 (2). Routledge:229–44. <https://doi.org/10.1080/24735132.2017.1386954>.
- Sanders, E B.-N. 2000. "Generative Tools for Co-Designing BT - Collaborative Design." In , edited by Stephen A R Scrivener, Linden J Ball, and Andrée Woodcock, 3–12. London: Springer London.
- Sanders, Elizabeth B.-N., and Pieter Jan. Stappers. 2012. *Convivial Design Toolbox : Generative Research for the Front End of Design. Orbis Litterarum: International Review of Literary Studies*. Vol. 61.
- Simon, Herbert A. 1969. *The Sciences of the Artificial*,. [M.I.T. Press].
- Tavory, Iddo, and Stefan Timmermans. 2014. *Abductive Analysis: Theorizing Qualitative Research*.
- Tracey, Monica W, and Alisa Hutchinson. 2016. "Uncertainty, Reflection, and Designer Identity Development."
- Tseng, Winger S.W., and Linden J. Ball. 2011. "How Uncertainty Helps Sketch Interpretation in a Design Task." In *Design Creativity 2010*, 257–64. London: Springer London. https://doi.org/10.1007/978-0-85729-224-7_33.
- White, R. G., and A. Gumley. 2010. "Intolerance of Uncertainty and Distress Associated with the Experience of Psychosis." *Psychology and Psychotherapy: Theory, Research and Practice* 83 (3):317–24. <https://doi.org/10.1348/147608309X477572>.