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Renedo Illarregi, Erika; Alexiou, Katerina and Zamenopoulos, Theodore (2022). Co-design as healing: A multi-level analysis based on a project with people facing mental health problems. In: DRS 2022 (Lockton, D; Lenzi, S; Hekkert, P; Oak, A; Sabada, J and Lloyd, P eds.), 25 Jun - 3 Jul, Bilbao, Spain.

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Version: Version of Record

Link(s) to article on publisher's website:  
<http://dx.doi.org/doi:10.21606/drs.2022.427>  
<https://www.drs2022.org/>

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Jun 25th, 9:00 AM

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### Citation

Renedo-Illarregi, E., Alexiou, K., and Zamenopoulos, T. (2022) Co-design as healing: A multi-level analysis based on a project with people facing mental health problems, in Lockton, D., Lenzi, S., Hekkert, P., Oak, A., Sádaba, J., Lloyd, P. (eds.), *DRS2022: Bilbao*, 25 June - 3 July, Bilbao, Spain. <https://doi.org/10.21606/drs.2022.427>

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# Co-design as healing: A multi-level analysis based on a project with people facing mental health problems

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doi.org/10.21606/drs.2022.427

**Abstract:** The present paper explores the notion of co-design as healing by focusing on a project with participants facing mental health problems, who met once a week, guided by open design processes. Reflecting on semi structured interview data, as well as relevant literature from different disciplines, the paper offers a conceptual framing of how co-design can be considered as a healing practice, at a systems, social and individual level. At a systems level, co-design allows working with complexity, and approaching mental health problems holistically. At a social level, co-design empowers collectives to negotiate what realities to change and how. At an individual level, co-design affects people's wellbeing, by enhancing their sense of agency and connection, stimulating thinking and essentially providing a grounding embodied experience. The paper offers a lens through which to reflect and expand on what we do as designers, and supports the notion of co-design as healing with initial evidence from one project.

**Keywords:** mental health; healing; empowerment; wellbeing

## 1. Introduction

'I do think we should have design groups in a design group is just as (...) important as we have art, when art is one of the number one isn't it, to help people (...) we should have design groups (...) is this the first?' Amara

This paper frames co-design as healing, drawing on the first-hand experiences of people with mental health problems who engaged in a co-design project. In the quote above, participant Amara suggests that more design groups should be offered alongside art for helping people with mental health problems. Indeed, although art therapies are widely recognized and commonly offered as mental health services, the same cannot be said about design, hence Amara's proposition.

Nonetheless, co-design cannot be effortlessly framed as a helping profession, before discussing the nuances of such definition, outlining the underlying paradigm and situating it within the wider picture. Helping professions, are defined by the APA Dictionary of Psychology (2021) as those 'providing health and education services to individuals'. These are usually one directional: there is someone who is the helper, and someone who is helped. Co-design



practices do not conform to such duality. Within a participatory collaboration (e.g. participatory design or co-design), reciprocity often occurs, a sort of exchange (of ideas, opinions, reflection) where all involved meet on equal grounds and validate the views and visions of others (Dreessen et al. 2020). In this paper, the terminology of healing is chosen with reference to the reciprocal nature of such relationships and includes the non-animate landscape which might be the object of design. In other words, co-design as healing refers to a process where participants are acting as healers whilst being healed.

Healing, as defined by Merriam-Webster dictionary (2021) could mean ‘to make well again’, ‘restore to health’, ‘free from injury’, ‘to overcome’, ‘mend’, ‘to restore to original purity or integrity’, or ‘to make sound or whole’. Upon conducting a concept analysis, Wendler (1996) defines it as an experiential, energy-requiring process in which space is created through a caring relationship in a process of expanding consciousness and results in a sense of wholeness, integration, balance and transformation and which can never be fully known. The term healing is also often associated to alternative practices to improve health which may not see body and mind as separate. It is associated to holistic practices, including those which consider human and non-human entities as part of the same whole, and may recognize seeking balance with environment as key part in achieving health. This potential for reciprocity (Dreessen et al. 2020) and for a co-designerly distribution of power, is what makes co-design as healing contrast with other approaches to care, constituting an innovation within mental health.

Indeed, it is time to look at mental healthcare creatively and find new ways to care for our wellbeing. In the UK, where this project took place, there is a requirement of participatory research and development of new ways to improve the services’ productivity, as mental health problems represent the largest cause of disability (Mental Health Taskforce 2017). They represent the highest burden of disease in many other high-income Western European countries and come fourth or fifth in some low-income countries (World Health Organization Regional Office for Europe 2015), imposing a major burden on individuals, society, and the economy (“European Framework for Action on Mental Health and Wellbeing” 2016). Furthermore, the mental health effects of the coronavirus disease (COVID-19) pandemic may shape population health for many years to come (Zhang and Lange 2021). Considering this critical situation and responding to the call for new ways to improve services’ productivity, this paper considers co-designs’ healing properties and illustrates it with empirical data.

Most co-design studies in mental health focus on the design process or the outcomes of design (Kettley, Sadkowska, and Lucas 2016; Glazzard et al. 2015; Nakarada-Kordic et al. 2017; Kaasgaard and Lauritsen 1997; Mužina 2020; Wadley et al. 2013; Blake et al. 2016; Orlowski et al. 2019), and not much attention is given to how the process itself may enhance wellbeing of co-designer participants, with a few exceptions (Tseklevs 2020; Warwick et al. 2018; Amiri, Wagenfeld, and Reynolds 2017; Craig 2017).

Extending the search to co-designing with different target groups - not necessarily mental health clients - few studies do illustrate a relationship between participation in co-design

and wellbeing. Tseklevs (2020) reports that although the original aim of their project was to co-design one or more models to inspire digital–physical technologies that foster wellbeing and motility for people living with dementia, their surprising finding was that more than an artefact, the subjective wellbeing and mood of people with early signs of dementia benefit from the collaborative creative space that the workshops created. Myerson and Ramster (2017) advocate co-design as a way to improve employee belonging and wellbeing, making a link between participatory design activities and improved levels of mental wellbeing. De Couvreur et al. (2013) conceptualize a creative process where disabled people and their carers become conscious actors in providing collaborative maintenance of their own physical, mental and social well-being, showing how collaborative designing, making and using artifacts fosters several elements of subject well-being in itself.

Responding to the lack of understanding around how mental health clients experience co-design and the potential this process may have for recovery, this project placed emphasis on understanding participants' perspectives. There was no prior agenda other than designing - anything or nothing- and understanding their experiences. Although the concept of co-design as healing emerged from the data analysis, the author's (ERI) previous experiences facilitating workshops did suggest that impact on participants was likely. Prior notions around how and why such interventions could affect mental health were described in earlier publications (Renedo-Illarregi 2018; Renedo-Illarregi, Alexiou, and Zamenopoulos 2019, 2020). One hypothesis was that by engaging with the inherently uncertain process of co-design in a supportive environment, new patterns of thinking, feeling and behaving may begin to emerge, often resulting in some progress in the participants' recovery (Renedo-Illarregi, 2018). In addition, theoretical associations between the experiences of designing and psychosis were explored around agency and embodiment, hypothesizing that designing may help integrate fragmented dimensions of experience (Renedo-Illarregi, Alexiou, and Zamenopoulos 2019). A further publication described a shorter and more structured project (Renedo-Illarregi, Alexiou, and Zamenopoulos 2020), similar to most other unpublished projects the author facilitated in the past (See Bidean.co.uk).

This paper presents one way of looking at data. It is a proposal based on, but abstracted from, empirical data. It should be read with caution, as an idea which may help inform further research and as a lens to reflect on co-design practice at large. These insights are supported by data from the project, yet the concept intends to be further reaching in scope, opening up a discussion on the subject of what co-design as healing might be in different contexts.

In summary, we envision that co-design as healing, or designerly healing, has certain unique qualities that manifest at different levels of analysis. Approached holistically, it includes healing a person, healing mental health problems, healing the environments within which these emerge and so on.

More specifically, the concept is explored through three levels of analysis or lenses. We start exploring co-design as healing at an abstract, systemic level, then move to the social level, exploring how it affects and manifests through the collective, and finally look at how it affects each person as an individual. Although the analysis is organized in these three levels, these are not independent categories, but parts of the same phenomenon.

## **2. The background: co-design within mental health services**

The study was part of a larger PhD project which explored the experiences of participants with mental health problems who engaged in co-designing. This paper proposes a conceptual understanding of co-design as healing based on reflections grounded in empirical data in relation to the literature. In this sense, the focus of the paper is not an in-depth reporting of empirical findings. It is rather a conceptual framing of the proposition that (co)design is a form of healing, illustrated by data which supports this claim. Although the project data does suggest that co-design had a beneficial impact on participants mental health, the paper goes a step further in unpacking the analytical perspective of co-design as healing more broadly, which is one of many interpretations after all. The project is briefly introduced before we proceed to discuss co-design as healing.

### *2.1 Co-design at Psychosis Therapy Program*

#### **2.1.1 Project Overview**

The project was organized with clients from Psychosis Therapy Project (Psychosis Therapy Project 2021). It was a ‘collaborative’ project where participants worked together on a common project (Zamenopoulos and Alexiou 2018), with the particularity that the goal emerged from the process.

After obtaining Open University Human Research and Ethics Committee approval (REF 3050), nine participants signed up and provided informed consent. All the quotes in this paper are anonymised except from Anthony’s, who chose to be referred by his name. Participants regularly attend the Psychosis service for one to one talking therapy and their engagement with co-design varied from intense to peripheral. During the day, light lunch is provided, and other drop-in activities are available (e.g. art therapy). The co-design workshops were embedded in this context. Meeting with the manager beforehand helped ensure that the research was appropriate and make adaptations. For six months, weekly design workshops were delivered, loosely structured in three stages: Understanding design, finding and mapping situations and creating design(s).

- The first stage aimed to help participants familiarize with each other and with design. It consisted in activities such as bringing objects that were meaningful and discussing their design process in relation to a collective timeline; or prototyping design solutions to respond to each other’s improvised design problems (any). In that way, participants were introduced to design in a flexible, semi-







Figure 2. The co-designed boardgame

### 2.1.2 Data and analysis

Data for this study were collected through semi-structured interviews, photographs and a reflective journal. Six participants were interviewed following the project, and five were interviewed again six months later. Data reported in this paper were analyzed through Interpretative phenomenological analysis (IPA), taking a bottom up approach in line with (Smith, Flowers, and Larkin 2009), and exploring their experiences openly.

### 2.1.3 Key insights

The data gathered portrayed helping intentions and healing consequences throughout the design process. On one hand, the experience appeared worthwhile, meaningful and positive for participants in various ways. On the other, the design process itself led to outcomes that related to well-being more broadly.

Through the Interpretative Phenomenological Analysis, the themes below were identified as reflecting the key experiences of participants. Although a detailed reporting of this data is beyond the scope of this paper, a few quotes are used to illustrate the themes and the breadth of experiences that participants associated to designing.

*Contributing* refers to notions of counting, having validity, mattering, which participants associated to the project, often explicitly, and other times implicitly (e.g. acknowledging and recognizing the value of what they designed).

I felt good in myself, better and just, I don't know, contributing towards something or just not being dismissed (Anthony, 1<sup>st</sup> interview)

[the design project] made me feel that what I think is counting ... that I can think creatively (...) I mean I can create something new, something really exciting... (Nealy, 1st interview)



It gave me confidence the project, that my idea counts, yes (Nealy, 1<sup>st</sup> interview)  
you are achieving something else, but you are achieving something other than to  
better your mind or to better your mental health (Amara, 2<sup>nd</sup> interview)

The theme of connecting was also prominent, referring to initiating or deepening of connections, developing different ways to relate, connecting over other things than usual worries or connecting unselfconsciously.

it was good, it was socializing life people better in that group, understand people better, yes that was nice (Nealy, 1<sup>st</sup> interview)

but it was a good excuse for other people to have a chance to interact and talk about such stuff rather than their problems (Jack, 1<sup>st</sup> interview)

The concept of *intentioning* threads together different dimensions of experience such as being stretched toward, feeling directed, focused, grounded etc. The term was devised in reference to intentionality, which The Oxford Dictionary (2021) defines as the quality of mental states (e.g. thoughts, beliefs, desires, hopes) which consists in their being directed towards some object or state of affairs.

I think I stretch it just stretches you towards designing. (Amara, 2<sup>nd</sup> interview)

I was just thinking of the word... it was ... yes it was grounding I think and...it [the design process] seemed grounded and spiritual as well at the same time to me (Amara, 1<sup>st</sup> interview)

With the design project I am in the world. I kind of interact with the world (...) [it] is a more in-the-world sort of thing. (Anthony, 1<sup>st</sup> interview)

but design is rooted in the world because it is function and you know you are designing things, things, objects I suppose, whereas creative writing you can go off in flights of fancy (Anthony, 1<sup>st</sup> interview)

The theme of thinking emerged from participants reports that the project 'got them thinking, or thinking differently, or made them realize that they can think. They also referred to thinking through alternatives, which helped to open their mind, which as one participant suggested could lead to better therapy.

it [the design project] gives that feeling (...) we create [a] new game, and all together and everybody start to think. Before we didn't think, but later after this project, we start to think, yes that is it (Nealy, 2<sup>nd</sup> interview)

The theme of *bettering*, referred to participants explicit references to how designing affects wellbeing or mental health.

you remember that when I said to you 'I wish I had your brain' and you said 'we all contribute' and I thought about it afterwards and what I really meant was 'I wish I had your mental health' because I think you are very mentally healthy. I wish I had that but now I feel I have, I have actually got that! (Amara, 1<sup>st</sup> interview)

Participants experienced design as a collective and holistic approach, which brought them closer together, grounding them within the world they inhabit. In reflecting on these qualities of experience and the project as a whole, co-design as healing was conceptualized.

### 3. Co-design as healing

In this section a conceptual understanding of co-design as healing is proposed through an analysis that is akin to abductive research strategies: it builds on the empirical data whilst positioning these in relation to broader concepts that stem from the literature. The central aim is to conceptualize the co-design process as it is manifested in this project, in order to respond to the broader question of why and in what ways co-design can be considered as healing. The systems, social and individual levels of analysis provide different lenses to look at the same, whole phenomenon.

#### 3.1 *Co-design as healing at systems level*

well... I think maybe it was like a brainstorm in our brains met you know, like the (...) universal mind I think must have been at work and got together and did a good creation a design (laughs) (Amara, 1<sup>st</sup> interview)

Throughout the twentieth century, much of psychiatry aspired to reductionist simplicity; whether in the Freudian unconscious, the human genome, or dysfunctional neurobiology, researchers sought to identify the underlying cause of the troubles faced by their patients (Fried and Robinaugh 2020). However, as Fried and Robinaugh (2020) review, far from uncovering simple etiologies, the past century of psychiatric research has revealed systematic complexity (Kendler 2012).

Yet, despite this growing recognition of this systematic complexity, there has been little change in how psychopathology is studied, and most research remains rooted in the mono-causal framework (Fried and Robinaugh 2020). Monocausal frameworks on why phenomena such as psychosis manifest may also limit the diversity in healing approaches, and risk creating firm boundaries regarding the source of the problem, for instance by assuming the illness is 'inside' the person only. According to Fried and Robinaugh (2020), to make genuine progress in explaining, predicting, and treating mental illness, we must embrace the complexity inherent in these disorders in theories, methods, and empirical research. Design healing has a further proposal, which is embracing the complexity in the treatments of the issues themselves.

Through a design lens, we can approach mental health as a wicked problem, which defies singular definitions or solutions, and is indeed by nature indeterminate (see Buchanan 1992; Rittel and Webber 1973). We propose that (co-)design as a healing approach does not assume that there is an underlying determinism operating behind the emergence of mental health problems and it is only our lack of knowledge that makes them unpredictable or unexplainable. Even with sufficient research it might not be possible to unravel the mechanisms behind such phenomena and find any ultimate solutions. It includes the possibility of

indeterminism, and within it, celebrates pluralism, the crafting of explanations based on personal experiences. Within the proposed scenario, designing, acting and constructing new meanings and new explanations, becomes in itself the act of healing. This approach, so familiar within design, has a lot to offer to mental healthcare. By working through complexity and not against it, designing gives leeway to the collectives and individuals who are part of these systems to navigate the complexity themselves. It no longer frames the problem inside individuals; what needs healing, is a whole system, not a person. When healing occurs, is through a systemic change of a whole.

### *3.2 Co-design as healing at social level*

it push us to think big (...) [The] project gave us that idea to think big, and whatever we think it counts, I mean I didn't have that thought before (Nealy, 2<sup>nd</sup> interview)

Mental illness, mental health and what has been coined as the medicalization of human distress and its social implications have been analysed in depth. Foucault discussed how the concept emerged within a particular historical point, and is bound to the political concerns and values of that culture and society (Foucault 1973). According to him (1991) psychiatric practice is linked with a whole range of institutions, economic requirements, and political issues of social regulation after all.

People with mental problems have historically suffered considerable disempowerment and stigma, and the concepts of recovery and co-production emerged to counteract this. From a service user and survivor perspective, negative uses of power and control remain defining features of mainstream mental health services and yet co-production is explicitly about progressing 'a transformation of power and control' (Carr 2016). Although the expectation among mental health service users and survivors is that their expertise be regarded as an asset and decision making is equally shared (Rose et al. 2003), in reality, they have also expressed dissatisfaction with participation in mainstream community and inpatient services (Bee et al. 2015). Power over the types of discussion that are held is maintained through 'the rules of the game, rules of engagement and agenda-setting' (Lewis 2014, 1).

Based on these perspectives, co-design provides ways to reconfigure 'the rules of the game', increasing the chances for genuine social empowerment. In this project, participants crafted what was to be designed, or it emerged from interactions. In projects where a clear agenda is set by an institution, design as healing could remain sensitive to participants by navigating these rules of the game and making them accessible to every stakeholder. Also, facilitators can open up the brief or negotiate the agenda when necessary.

Furthermore, most activism within mental health, claim power over matters directly related to services, without demanding power over other issues besides mental healthcare. 'Service user and survivor collectives that adopt a challenging approach and campaign on broader social justice issues can, and often do, find themselves side-lined by the very mental health services and organisations they are trying to change.' (Carr 2016, 19). Yet Cahn's original conception of co-production is radical and has values rooted in social justice. Its demands and

challenges reach beyond services and pose a challenge to society itself and the wider values placed on different people, contributions and achievements (Carr 2016).

Engaging in purposeful activities and generating concepts to respond to participants matters of concern are part of design as healing at a social level. Co-design may present itself as an empowering way of healing, as a form of practising power over other issues- beyond individuals' mental health. Participants' experiences suggest processes of empowerment manifested in different ways throughout the project, showing relevance with the framework presented by Zamenopoulos et al. (2019). Their work draws from other theorists to spell out four manifestations of power in co-design. 'Power over' refers to that which involves the other or is relational, power over something, and 'power to' refers to power to do something (Göhler 2009). After, Gaventa and Cornwall (2008) distinguish two other forms of power: 'power with' that is developed through collaboration, mutual support and solidarity, and 'power within' that is developed by self-knowledge and the ability to recognise and mobilize our own assets.

Of particular relevance to designerly healing at a social level is the notion of 'power over', especially because it is often compromised within marginalized collectives. In the project, the focus of participants changed from solely improving one's mind, to something else, 'achieving something other than bettering one's mind', as Amara would put it. Co-design is socially empowering as it enables the transgression of concepts that confine problems within the minds of certain people. Participants recognised the contributions they made to the world, with some thinking about how to market it, counting the number of people who had used it and reflecting how it will help users.

'Power with', was also experienced by participants. Design enables people to connecting around a purpose, and start developing a better understanding of each other's thinking. Participants felt safe to connect with others and some were able to share their psychotic experiences in ways they hadn't done before.

'Power to', the capacity to make sense of one's matters of concern, frame design problems and develop design solutions was also observed in the projects. This notion acquires additional significance when participants' sense of agency is diminished, something which can happen with psychosis. One participant, Anthony, attested to becoming more driven and remarked that while his more artistic activity (e.g. collage) happens by gods direction, it was himself who designed. Hence, the subject of empowerment, also relates to healing at the individual level. The notion of 'power within' is also explored in the next session, individual level.

### *3.3 Co-design as healing at individual level*

you know, I have been well for years, you know, for a good while, but I feel better in myself more (..) you know, sort of more (...) like driven (Anthony, 1<sup>st</sup> interview)

The project data suggest that co-design may help participants, justifying the need to develop, as Warwick et al. (2018) put it, the dialogue around co-designs impact on participants

and clarify its role in affecting wellbeing. Vink et al. (2016) describe how there is not yet a clear analysis of how the design process influences wellbeing across levels, entities, types, outcomes, intentions and transformation, including any negative impacts.

Warwick et al. (2018) report that there are aspects of the design process, such as the 'wicked' nature of what it addresses, that might feel challenging to non-designers, and the multiple directional changes in the 'fuzzy front-end' could also feel alien to them. According to the authors, the uncertainty within these problems can impact stakeholders, who may be uncomfortable with ambiguity and open-endedness. On the other hand, this wickedness is possibly a positive characteristic of co-design as healing, as described in section 3.1, and navigating ambiguity may be beneficial to healing at an individual level. However, it is also important to consider, as Steen, Manschot, and De Koning (2011) suggest, "whether the intended benefits are indeed realized", and the "risks of co-design." Although negative impacts were not observed in this project, further research is needed to identify possible risks of co-design as healing, and how to mitigate these. In this particular case, the co-design project was embedded in a long-term ongoing service, which is believed to function as a safety net, and gives continuity of activities and support beyond the ending of the project.

More broadly, the participants first-hand accounts provided a very rich picture, expanding far beyond the dichotomy of whether or not wellbeing was improved, and providing insights into the nature of designing and its potential for healing. Some key concepts were those of contributing, connecting, thinking, intentioning and bettering, which are briefly exposed below.

The notion of contributing links the individual with social and systems healing levels. People with mental health problems have often experienced traumatic events which may involve loss of control. In fact, according to Slade et al. (2014), one of the seven abuses of the concept of recovery is that contributing to society only happens after a person has recovered. This perception, in turn, may hinder recovery, as giving back to society was found a key element for recovery (Williams, Almeida, and Knyahnytska 2015). Hence opportunities to contribute to society through co-design can help participants heal in this respect.

The notion of connecting, links to the social level, but it can be healing at the individual level too. Participants shared unusual experiences spontaneously in relation to design activities, often through humour, motivated by, whilst also informing, the design situation. This demonstrated what Akama proposes (2018), that 'uncanny' encounters of 'perplexing alterity' can become a generative methodology. In this case, it also acquires a healing dimension, encouraging a positive attitude toward unusual beliefs, a celebratory attitude toward difference.

Another important aspect was that of thinking, thinking more, and thinking differently. Nealy in particular, reported that she was still thinking in what we could consider designerly

ways, months later. Considering that people with mental health problems often suffer cognitive decline, whether linked to medication (Husa et al. 2017) or generally (Fett et al. 2020), stimulating thinking through designing might be helpful.

Other aspects of the individual level healing have to do with participants' experiences as they relate to intentionality. As Fuchs (2007) describes, when the automatic constitution of reality is dismantled, it needs to be replaced by active or rational reconstruction, a task which overburdens the patients' adaptive intentional capacity. Amara's references to being 'stretched towards designing', or the notion of design directedness that is brought up by Anthony, seem to coalesce into the idea of intentionality manifesting in healthy -or healing- ways through designing. In a design process, there is no need for a particular goal to be preestablished, but a sense of purpose emerges through the process (Dorst and Cross 2001; Cross 2001). This aligns with Merleau-Ponty's claim that there can be intentional acts which are not of or about anything specific (Reuter 1999). Design is goal-oriented, yet these goals are not given beforehand. In this sense, designing might promote the re-emergence of agency in an embodied way, restoring individuals' intentional capacity. This has its implications in relation to empowerment, too. Participants in these projects unlocked and transformed their knowledge and resources to carry out design tasks, which can be associated with 'power within' from Zamenopoulos et al. (2019) framework. Framing the process like therapeutic, acquiring mental health, becoming more confident or feeling better within oneself are descriptions which appear to manifest 'power within'.

Finally, Amara referred to design as grounding, and Anthony talked about design being more rooted in reality because of function. Specially in contrast to Art Therapy, designing may have a particularly grounding effect due to the practical purpose and context of use, demanding some reference to a shared reality. Design threads the person who uses something, with that thing, and the reason for using it, into a coherent event. For someone who has diminished connection with the shared notion of reality, engaging with generating function might have an embodying, grounding effect.

#### **4. Summary and conclusions**

This paper presents the concept of co-design as healing and supports it with findings from a co-design project, focusing on multi-level analysis - systems, social and individual. Notions of contributing, connecting, *intentioning*, thinking and *bettering* were explored by participants in the interviews. By looking at these projects from the systems perspective, we discussed co-design's unique approach to mental health, which places emphasis on the system as a whole, not just the individual in isolation. Looking at the co-design project from a social perspective, we found that it facilitated the development of connections and interpersonal relations and nurtured a feeling of being part of society. Furthermore, co-design can empower marginalized collectives to find their voice and influence change. Finally, various experiences point to co-designs healing potential for individuals, who might feel an enhanced sense of agency and connectedness, experiencing the process as grounding or embodied.

Considering the small sample, these findings cannot be generalized. Nonetheless, the implications of co-design as healing are potentially far reaching and transferable, and therefore this proposal can be reflected upon a variety of existing projects, and used to organize other projects and inform further research.

**Acknowledgements:** Our most sincere gratitude to the research participants, co-designers, without whom this project would not have happened. Thanks to Dorothee Bonnigal-Katz for her guidance and other staff at Psychosis Therapy Project. This project has been funded by Design Star, Arts and Humanities Research Council.

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