Co-design as healing:
exploring the experiences of participants facing
mental health problems

A Doctoral Thesis submitted in partial fulfilment of the
requirements for the award of Doctor of Philosophy

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The Open University

June 2021
Abstract

This thesis is an exploration of the healing role of co-design in mental health. Although co-design projects conducted within mental health settings are rising, existing literature tends to focus on the object of design and its outcomes while the experiences of participants per se remain largely unexplored. The guiding research question of this study is not how we design things that improve mental health, but how co-designing, as an act, might do so.

The thesis presents two projects that were organized in collaboration with the mental health charity Islington Mind and the Psychosis Therapy Project (PTP) in London.

The project at Islington Mind used a structured design process inviting participants to design for wellbeing. A case study analysis provides insights on how participants were impacted, summarizing key challenges and opportunities.

The design at PTP worked towards creating a collective brief in an emergent fashion, finally culminating in a board game. The experiences of participants were explored through Interpretative Phenomenological Analysis (IPA), using semi-structured interview data. The analysis served to identify key themes characterising the experience of co-design such as contributing, connecting, thinking and intentioning. In addition, a mixed-methods analysis of questionnaires and interview data exploring participants’ wellbeing, showed that all participants who engaged fairly consistently in the project improved after the project ended, although some participants’ scores returned to baseline six months later.

Reflecting on both projects, an approach to facilitation within mental health is outlined, detailing how the dimensions of weaving and layered participation, nurturing mattering and facilitating attitudes interlace. This contribution raises awareness of tacit dimensions in the practice of facilitation, articulating the nuances of how to encourage
and sustain meaningful and ethical engagement and offering insights into a range of tools. It highlights the importance of remaining reflexive in relation to attitudes and emotions and discusses practical methodological and ethical challenges and ways to resolve them which can be of benefit to researchers embarking on a similar journey.

The thesis also offers detailed insights on how methodologies from different fields were integrated into a whole, arguing for transparency and reflexivity about epistemological assumptions, and how underlying paradigms shift in an interdisciplinary context.

Based on the overall findings, the thesis makes a case for considering design as healing (or a designerly way of healing), highlighting implications at a systems, social and individual level. It makes an original contribution to our understanding of design, highlighting its healing character, and proposes a new way to support mental health. The participants in this study not only had increased their own wellbeing through co-designing, but were also empowered and contributed towards healing the world. Hence, the thesis argues for a unique, holistic perspective of design and mental health, recognizing the interconnectedness of the individual, social and systemic dimensions of the healing processes that are ignited.
To Uriel,

Who left this world having us imagine so much of what may lie beyond, you will be missed.
Acknowledgements

Without research participants, co-designers, this project would not have been possible. I will always be profoundly grateful to participants at the Psychosis Therapy Project - Nealey, David, Anthony Heavin, Nestor, Amara, Baris, Ellaria, Uriel and Jack (some names changed for anonymity) - for they catapulted me out of my world into a wide sea of possibilities of being and believing. I have felt their care, trust and encouragement, and I can only hope that our experiences together were meaningful for them too. They taught me what sense-making may be like beyond language, shown me worldviews without the limits of space and time, and welcomed me with unprecedented courage to create together. The mutual acceptance and appreciation I have found in that group and the knowledge we co-created goes beyond what can be portrayed in this text.

Thanks to participants in the Islington Mind drop-in who engaged in co-design for wellbeing. Raymond Black, Bea, Damian, Liam and Louisa (some names changed). I did not have a chance to get to know them over a long time, so I have immense appreciation for granting me such trust from the beginning.

My sincere appreciation to earlier participants within the mental health community whose insights informed this PhD.

Dorothee Bonnigal-Katz, founder and clinical director of the Psychosis Therapy Project, your guidance and references were key before, during and after the project. Thanks to Dr Peter Nevins who, as director of Islington Mind, helped me plan the projects. I am grateful to the staff and volunteers at both organizations, especially Jessica Clayton, Pietro Denaro, Martin Reyes, Vasiliki Simoreli, and Barry Watt.

Dr Katerina Alexiou and Dr Theodore Zamenopoulos, you have made my experience of doing a PhD one of continuous joy, and that, I hear, is a rare occurrence. You have been
nurturing in praise and critique alike. You have made me feel capable from start to end, and you have transmitted to me your authentic curiosity toward the world.

My sincere appreciation to The Open University for giving me this opportunity, and the funding provided by Design Star (AHRC). Thanks to Dr. Gudela Grote and ETH Zürich for inviting and funding me to join the Uncertainty Conference in Monte Verità, Ascona.

Dr Nicole Lotz and Dr Sarah Vicary, thank you for reading my progress report and for your valuable feedback. Thank you Dr Sarah Vicary for reading and advising in the IPA chapter, and thanks to Dr Gina DiMalta, it has been a pleasure to collaborate with you.

Dr Stephen Hayward helped me channel my curiosity in an academic form for the first time, teaching me to research and showing me the pleasure that is writing and encountering difficult questions.

Thank you, Ryan Brown, my dear friend, you know me, and understand me, you care. I remember your encouragement when I first formulated the idea of working within mental health ‘is genius, is as if we are all in a train that is heading to a broken bridge, and you speak the language of those at the back who know the solution, and bring it to the driver’. Thanks, Ahmed Makia, for being my international soulmate and reading through me to articulate ideas whenever we find each other in the same place. Thank you, Emelia, you are sincere and honest, so ready to have a laugh and engage with the utterly absurd and the deadly serious as if it was in essence the same thing.

Thanks to Carla, German, Cameron, Maxim and Vincent for being my home, and for trying the board game that we co-designed for hours on end. Thanks to Dr Jacopo Amidei for sharing the start of this journey, and for continuing to give me advice to date. Carla, Cameron, and German, thank you for taking care of me when I most needed it. My friends Ane, Beñat, Elle, Maddalen, and Manex, thank you for reaching out and sharing your perspectives.
My family back home, Laxia, Eluska, amatxo eta aita, thanks for welcoming me when Covid hit and I fell physically and mentally poorly, making me feel safe until I recovered health and hope. Eluska and Unai, I will not forget your warmth, your wise advice Eluska, your intelligent questions Unai. Uxue catching flies, Unax spaghetti making, Ximun dancing, and hugs at a distance with Alberto, Oier, Katixa and Eluxka, are memories that will last. Our weeks of total lockdown together were an important part of this journey.

During this project, I received counselling from two therapists. Thanks to my analyst Alan Taylor in London, whom I went to during my fieldwork, for working with me through past and present and exploring the subconscious through dreams in such transformational times. Thanks to my therapist thereafter Jaspreet Tehara, in Stony Stratford, for helping me grow and find insights at the best and worst times.

Thank you Josh for making me laugh and dance, and for introducing me to a nurturing universe. Meir, I am so grateful for your generous attitude, and delicious vegetable meals while I was writing up. Thank you, Alex, Mora, Miriam and Oda for imparting me your witch power. Polo, thanks for your insights on Deleuze and our moments of *detrimentalization*. David, I will not forget your encouraging words ‘I love the things you say’, even when we were both feverish and locked, we did not lose our queer sense of humour. Thank you Ian Mihajlovic for your timely show-up and for filling the house with work energy toward the most tedious part of the journey.

I am very thankful for the people that I encountered in my travels and conferences throughout this journey. My sincere appreciation to Dr Yoko Akama, who gifted me a copy of their book ‘Uncertainty and Possibility’ at the PDC conference dinner. Thanks to Pablo Ochoa, Daria Loi and Emily Crompton for helping build a virtual exhibition at the PDC 2020. Special thanks to Kaspar Raats who showed me the beauty in small things with his way of video recording. Dr Spyros Bofylatos, your unconditional welcome in Greece was unprecedented, thank you. I am grateful to my peers there, Alexis, Efi, Giulia, Jaouen, Juan, Juanma, Margarita, and Nicolas, for reminding me that in a way, everything is possible. Finally, Alyona and Yuri, thank you for welcoming me to the world of healing.
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The meaning of the terms we use to communicate became a poignant matter throughout this thesis, especially during the fieldwork. I often wondered whether we perhaps had the feeling of understanding one another, yet were assuming entirely different interpretations after all. As I record in my reflective diary and discuss in section (7.4.1), I concluded that as long as we had an orientation toward one another, this ambiguity of language and communication did not need to be a barrier. There is hardly ever a clear-cut or universally agreed definition of any term, and the ones I employ in this thesis are no exception.

Notwithstanding, readers from different backgrounds might be unfamiliar with some of the terms that I will be using. Furthermore, some terms are similar to one another, or function as umbrella terms, manifesting in particular ways throughout the thesis. Consequently, indicative descriptions about various terms that will be regularly employed are outlined below.

**Mental health:** A state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community. (World Health Organization 2021)

**Mental health problem:** In the context of this PhD, what constitutes a mental health problem is first and foremost framed by the participants themselves, and it is often what brought them to contact the charities which I collaborated with. In the Mind website, they argue for using the phrase ‘mental health problems’ as many people have told them it feels helpful for them. However, they also recognise other related terms such as ‘poor emotional health’, ‘overloaded’, ‘burnt out’ or ‘overwhelmed’.

**Wellbeing:** While most contemporary research claims wellbeing is multidimensional in character and associated with how well we feel we are doing as individuals, communities and societies, there is no single agreed definition (Mansfield, Daykin, and Kay 2020). On the other hand, it is a term that most of us can relate to at a personal level. The Warwick Medical School, which was involved in the development of the wellbeing questionnaire that is used in this thesis, defines mental wellbeing as the positive aspect of mental health. As they state, it is more than the absence of disease, and people with mental wellbeing feel
good and function well. Some people call this positive mental health, others call it flourishing. (Warwick Medical School 2021)

**Co-design:** As Zamenopoulos and Alexiou (2018) describe, the prefix ‘co’ signals the collaborative, cooperative, collective or connective nature of engagement in design. So, co-design means that people come together to conceptually develop and create things/Things that respond to certain matters of concern and create a (better) future reality.

**Co-creation and Co-production:** Any process in which different parties come together in order to create a mutually beneficial outcome. In design research and practice, co-creation often refers to the collaboration between experts and non-experts (users) who bring their creativity together to develop a solution (Zamenopoulos and Alexiou 2018). It is a familiar term within mental health, where the related term of co-production is also heard.

Indeed, Voorberg, Bekkers, and Tummers (2014) compare the record definitions of co-creation/co-production in a systematic literature review consisting of 122 papers (1987-2013), observing that – to a large extent – both are defined similarly. Empirically, they remark, co-creation and co-production are used as interchangeable concepts, and raise the question of whether this supports conceptual clarity. They lastly appeal to reserve the term ‘co-creation’ for involvement of citizens in the (co-)initiator or co-design level, whilst Co-production is considered as the involvement of citizens in the (co-)implementation of public services (Voorberg, Bekkers, and Tummers 2014)

**Therapy and therapeutic:** The term therapy is defined by the Oxford Dictionary (2021) as treatment intended to relieve or heal a disorder (e.g. a course of antibiotic therapy) or the treatment of mental conditions by verbal communication and interaction. In the context of this PhD, therapy is understood more generally, including treatments which might not be limited to verbal communication (e.g. art therapies). All these therapies share the purpose of improving the wellbeing or health of those who receive them. This distinguishes therapy from co-design. Co-design practices do not necessarily hold the purpose of treating participants, and may not conform to the duality of giver and receiver, as it often happens in therapy. The notion of therapeutic, on the other hand, can be associated to anything as long as someone finds it to be the case. Hence, besides not being framed as a therapy, co-design could be therapeutic, as cooking or running might be.

**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’. The term healing is also often associated to a variety of alternative practices to improve health which may not see body and mind as separate. It is often 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. The terminology of healing here is used
with reference to the nature of this interrelatedness among co-designer participants, including the non-animate landscape which might be the object of design, and how this entire system may move towards restoring health, mending or ‘making sound or whole’.

**Recovery:** According to the Mental Health Foundation (2018), when it comes to mental illness, recovery can mean different things. For some people, it will mean no longer having symptoms of their mental health condition, whilst for others, it will mean managing their symptoms, regaining control of their life and learning new ways to live the life they want. The Mental Health Foundation make reference to recovery being described as a process. The recovery movement broadly focuses on restoring functioning above and beyond symptom reduction and recognizes the ability of people with mental health problems to participate in society (Davidson 2016)

**Psychosis:** Psychosis is an umbrella term to describe an experience that may be associated with a variety of mental and physical problems. The mental health charity Mind (2021) describes it as when you perceive or interpret reality in a very different way from people around you. The website lists the most common types of psychotic experiences as hallucinations, delusions and disorganised thinking and speech. It affects people in different ways. It might be experienced once, have short episodes throughout one’s life, or live with it most of the time (Mind 2021).

**Agency:** In very general terms, the Stanford Encyclopedia of Philosophy (2021) describes an agent as a being with the capacity to act, and ‘agency’ as denoting the exercise or manifestation of this capacity. There is ample discussion on the sense of agency, and how this might be experienced in relation to psychosis. Overall, there might be a diminished sense of agency, and some people may feel their thoughts or actions are controlled by others.

**Embodiment:** In the context of this thesis, this notion might refer to the phenomenon of how one’s relatedness to the world occurs through a habitual grounding of a person’s self within their body, which to some extent is taken for granted in the every day. A case of the extreme opposite, being disembodied, might mean seeing one’s body as a puppet, for instance; having to reflect consciously and continuously on every action made (such as reaching a cup of tea) as if there was something else (including our conscious self) mediating every single step. As Fuchs (2010b) explains, insofar as mental illnesses disturb or interrupt the unhindered conduct of one’s life, they also exacerbate the tension within embodiment that holds between being-body and having-a-body. According to the author, in mental illnesses, there is a failure of tacit mediations upon which one’s bodily being-toward-the-world is based, and instead of serving as a medium of relating to the world, the body makes itself noticeable as disturbing or resistant.

**Unusual experiences and beliefs:** These are experiences or beliefs that are not shared by other people. The terminology is commonly used within mental health to refer to experiences such as hearing voices, or strongly held beliefs that others do not share.
**Mattering**: It is the extent to which we make a difference in the world around us (Elliott, Kao, and Grant 2010). Perceiving that we are noticed by and are important to others is known as the experience of mattering to others (Rosenberg 1985).

**Uncanny**: Defined by the Merriam-Webster (2021) as strange or unusual in a way that is surprising or difficult to understand, or seeming to have a supernatural character or origin. The uncanny is not simply an experience of strangeness or alienation, it is a peculiar commingling of the familiar and unfamiliar (Royle 2002). As Royle (2002) describes, it can take the form of something familiar unexpectedly arising in a strange and unfamiliar context, or of something strange and unfamiliar unexpectedly arising in a familiar context.
1 Introduction

This thesis is an investigation of the healing potential of co-design in the context of mental health. Based on previous experiences of using co-design with marginalized groups such as people with mental health problems and inmates, the study set out to explore the questions ‘how is co-design experienced by people with mental health problems?’ ‘does it affect wellbeing?’ ‘what is the potential of co-design as a healing practice?’. On the way, it became a much bigger exploration driven by our experiences together, a journey through designing where we shared -and build from- our curiosities, worldviews, unusual experiences, and philosophical questions. Below, I delve into the background and motivation of this study, before introducing research questions and objectives, methodology and contributions in more detail.

1.1 Background and motivation

Healing and inventing are probably the terms that best portray how this journey began. It was when I was studying design as an undergraduate, and possibly questioning my decisions, that I remembered there was one time, as a child, when I wanted to be an inventor. It was much later, during my master’s degree when the opportunity for a self-directed project brought me to look into the experiences of dreams and troubled minds.

I designed a series of objects that through their uncanny nature facilitated empathy among people within the mental health community (Figure 1). Through handling these objects which we otherwise take for granted, participants found ways to communicate things that would usually be kept to themselves or not articulated at all. It was through testing these artefacts that I asked myself ‘why not design together?’ I had learned about co-design at the university, and I was eager to know more.
Co-design is a process where designers work alongside potential users to develop products, services, ideas...etc. Sanders (2000) reported the veering away from a reductionistic, product-focused world, where designers think of people as ‘consumers’ or ‘customers’, heading into a new space where relationships between people matter more than products and human experience matters most of all. Co-designing is becoming central within the changing landscape of design research (Sanders and Stappers 2008). Often synonymously treated notions of co-creation and co-design have been growing within the wider landscape of Participatory design (PD) (Sanders and Stappers 2008), which originated in the Scandinavian labour model, focusing on empowering trade unions and workers (Basballe, Halskov, and Hansen 2016).

If we define participatory design as a form of practice embedded in specific contexts and working with particular constituencies to envision viable and desirable alternatives to the status quo (Brown et al. 2012), participatory design and co-design in mental health is
particularly interesting, where we can observe very diverse, often conflictive views of what constitutes a mental health problem, and what causes it in the first place.

Following graduation, I began exploring the possibilities of co-designing within mental health. Around that time, I also had an opportunity to travel to India, invited initially for a stay in the Cochin art biennale. During my trip around the country, I came across various ways of caring for mental distress, including places of pilgrimage where healing rituals were performed. I felt profoundly welcomed, despite being the only foreigner. Screams, dances, multiple forms of human expression enabled moments of catharsis among the pilgrims. Their beliefs, their particularities, were all entangled within rituals that brought them together, for different reasons, through different means and for the same purpose. These are solely my interpretations, as I am, after all, a stranger to these traditions, but these touching experiences informed the principles that would manifest throughout my work thereafter.

My approach toward mental health problems was influenced by the multiplicity of beliefs that can inform recovery. Although often limiting and requiring caution, I began to appreciate the benefits of not having had any formal education in psychology. I could not negotiate particular ways to help participants, simply because I did not know any. A similar reflection was shared with me by a mental health client in one of the workshops run through Bidean, which I co-founded with my colleague Pras Gunasekera. It was Islington Mind, the collaborator of this PhD project, that welcomed us to co-design with their clients. We received some training on mental health first aid (to manage crisis) whilst we explored the potential of our methods. Sometime later, they employed us as consultants to facilitate the evaluation and re-design of their services. Even before national Mind created the Service Design Toolkit (published only as an internal resource), Islington Mind had welcomed us as design researchers, an innovative attitude that demonstrated their commitment to a collaborative approach. I will always be thankful for their trust. When the possibility for a collaborative PhD emerged years later, I was confident we could work together again, this time to explore clients’ designing experiences.
In the intervening years between the work at Islington Mind and the PhD, I had the opportunity to run few other projects within mental health, and work with inmates within a prison, all of which informed research questions that culminated in this work.

The co-design workshops I facilitated began by identifying adversities, which led to the development of some design concepts. For instance, in a project organized in partnership with the V&A and Depression Alliance, many participants were interested in the subject of panic attacks, and how these affected everyday life, resulting in different design outcomes, such as a ring that integrated therapeutic coping techniques, or brown breathing bags that raised awareness about attacks in public spaces. In prison, I tried a similar method, this time starting from encouraging inmates to identify ad hoc products that improved everyday life. I was acquainted with the weapons, tattoo machines, and other artefacts that were confiscated, and I wondered whether the same creativity was being used for less conflictive purposes. We conducted collaborative research and designed a variety of solutions.

Through these experiences, I noticed some participants reported profound changes and often begun behaving differently. Others did not seem to feel anything so abrupt, but most found the engagement worthwhile.

Their accounts raised questions that could not be answered by existing literature. Despite being of paramount importance, not much focus had gone into understanding how participants experience co-design. As Bowen et al. (2013) describe, in a service design project developing ‘Better Outpatient Services for Older People’, improving co-design methods requires not only understanding those methods and their effect on design outcomes but also how methods affect the people involved.

In my practice, I also noticed that involvement in design appeared different from standard therapeutic interventions offered to people with mental health problems, and must be studied in its own right. In contrast to available therapies, I noticed that the principles guiding the workshops were not participants’ investment in their recovery, but their focus
and effort to reimagine and change the realities through which their mental health problems emerged in the first place. Through design, recovery manifested as a distributed process.

Throughout my involvement within mental health, many people would ask “is it like art therapy?” being perhaps the only thing they could associate it to. I have been cautious with this, for a few reasons. While design is associated with art schools in the UK, it is part of the engineering schools in Spain and associated to architecture in Italy, for instance. Whether design belongs here or there, art or science or a separate thing altogether is an ample debate. Furthermore, I had never been trained as a therapist. Creative art therapies and occupational therapy are established practices and have rich histories, often intertwined with theoretical frameworks from other disciplines. Feedback from participants indicated novelty too, one commented, ‘this was nothing like what I have done before’. I wished what emerged from the project to be a fair representation of what participants experienced. This presented methodological benefits and challenges. By not firmly situating the project within existing paradigms, I hoped participants would be free to create their own meanings as the experiences unfold. I wanted to draft design’s possible role in mental health from within this ground understanding of their experiences.

It is a timely moment for such a project. Mental health represents the highest burden of disease in many high-income Western European countries and comes fourth or fifth in some low-income countries (World Health Organization Regional Office for Europe 2015). Mental health problems represent the largest cause of disability in the UK, and there is a requirement for participatory research and development of new ways to improve the services’ productivity (Mental Health Taskforce 2017). Furthermore, the mental health effects of the coronavirus disease 2019 (COVID-19) pandemic may shape population health for many years to come (Zhang and Lange 2021). Judging from my own experience, the impact on people with and without pre-existing conditions is unprecedented, from severe struggles with isolation, fear and loss, to existentially enlightening experiences, everyone’s journey has been unique. The way mental health
problems are approached was already moving towards more participatory approaches, and the need is now imminent.

The recovery movement, which broadly focuses on restoring functioning above and beyond symptom reduction and recognizes the ability of people with mental health problems to participate in society (Davidson 2016), and the patient-oriented treatment plans that acknowledge experiential knowledge, opened up doors to imagine new ways to support recovery. Mental health services are increasingly encouraged to use co-design methodologies to engage individuals and families affected by mental health problems in service design and improvement (O’Brien, Fossey, and Palmer 2021).

According to the World Health Organisation, mental health problems, such as psychosis, can cause serious and disabling changes to the thoughts, emotions, perceptions and behaviour of people, who also face a significant risk of violation of human rights (World Health Organization 2019). Individuals can experience stigma and discrimination resulting in reduced access to health and social services (Tee and Üzar Özcetin 2016). Negative stigma and discrimination continue to socially exclude service users (Hamer, Finlayson, and Warren 2014), who disclose continuous suffering mainly arising from stigma, loss of credibility and identity, isolation, powerlessness and hopelessness (Kaite et al. 2015).

Through co-design, participants are respected as experts in their experience and their contribution makes them key actors (Sanders 2000). This suggests that a project which encourages participants to design based on their experiential knowledge is a timely development for the changing landscape both in design and in mental health.

A collaborative PhD provided the opportunity to situate the research within the mental health community. Islington Mind offers mental health services to residents and further aids recovery by encouraging the participation of service users in decisions that affect their daily life. The community support currently operates across three different sites, Despard Road, Ashley Road and Isledon road. This includes training, education and
employment opportunities together with social activities that enable service users to live a full and enriching life (Islington Mind 2021).

Psychosis Therapy Project (PTP) is an organization that provides specialist individual, group and art psychotherapy for people who experience psychosis, currently operating in Islington Mind, Mind in Haringey and Lambeth and Southwark Mind. Therapy and long term support are offered by psychoanalytically trained practitioners and trainees, giving socially and economically excluded clients time and space to articulate distressing experiences and cultivate robust and enduring solutions (Psychosis Therapy Project 2021).

In response to the pandemic, both Islington Mind and Psychosis Therapy Project migrated services to online and via telephone and continued to offer support to clients who are facing unprecedented circumstances. Services have started with limited face to face work again and will continue opening up in line with the government road map. The fieldwork for this research project was concluded shortly before the Covid-19 lockdown happened in 2020 in the UK, and thus data were collected entirely face to face, although communication and journal paper developments thereafter continued remotely.

Many recovery-focused initiatives within mental health charities such as Islington Mind are often organized according to clients experiences, rarely using diagnosis in the way they organize and offer services.

Psychiatric research and treatment initiatives are also moving away from traditional diagnostic categories and focus on transdiagnostic phenomena (Pienkos et al. 2019). Most recently, changes that relate to cognition, perception, selfhood and reality, temporality, interpersonal experience, and embodiment were reviewed across the psychiatry literature from a phenomenological point of view (Pienkos et al. 2019), providing an opportunity to build an interdisciplinary framework to understand the experience of designing in this context.

Summing up, this PhD project has given me the opportunity to bring together interests that have rarely been explored together – perhaps being confined by their disciplinary
boundaries- concluding in times of a pandemic, when most of us have been challenged one way or another.

1.2 Research questions and objectives

Like many other nascent areas of research, this project was ruled by both top-down and bottom-up research questions, which is characteristic of abductive reasoning.

My intuition is that we are too often elusive about the messiness of research questions that are typical of design projects. Research questions were not set in stone from the start. In social sciences, drafting research questions with participants is often thoughtfully defended as part of the constructivist agenda, for instance in participatory action research. In this project, some questions helped me set the project, articulating and disclosing my intention before approaching participants. New questions emerged from our interactions, and finally, a set of questions has been crafted for analysis that ultimately structured this thesis, which are the following:

Question 1: How is it like for people with psychosis to engage with designing? How is it similar or different to other experiences that relate to recovery?

Question 2: How does co-design affect wellbeing?

Question 3: What can we learn from conducting a short co-design project with mental health participants about their experiences? What are the challenges and opportunities?

Question 4: How do we facilitate co-design projects within mental health?

Question 5: How do we imagine design’s role in healing?
1.3 Methodology

The interdisciplinary nature of this inquiry called for the integration of various methodological strategies. The project aims to study a phenomenon that exists only as a result of it. Co-design is both the method of research, research through design, delving into the world of participants, and is also the subject of study, research about design.

Epistemologically, I describe insights from pragmatism and phenomenology and how they contribute to the project, before outlining how my philosophical assumptions were challenged by working with participants and drawing parallels with Akama's (2018) proposal of welcoming the uncanny in design research.

Two projects were organized, one embedded in Psychosis Therapy Project (design at PTP), and the other in the regular drop-in service at Islington Mind (co-design for wellbeing). Different kinds of data were gathered, through semi-structured interviews, questionnaires, a reflective diary and photographs, which were analysed following different methods. An Interpretative Phenomenological Analysis (IPA) study was conducted with semi-structured interviews of six participants of the Psychosis Therapy Project to explore their experiences inductively. Another analysis, convergent mixed methods, was applied to five of these cases in combination with questionnaire data to investigate how participation may affect wellbeing. A case study analysis was applied to data from the co-design for wellbeing project at the drop in. Finally, I derived insights about facilitation and co-design principles, by reflecting on data across projects.

Hence, the research questions outlined in the previous section are approach by different methodologies:

Question 1: Interpretative phenomenological analysis (IPA).

Question 2: Convergent mixed methods.
1.4 Originality and contribution

Co-design has been around for many years, often involving marginalized communities, yet the experiences of participants have often remained unexplored. Similarly, although some authors may have hinted at its psychological effects, design practice has never been studied as a tool for recovery, and its healing potential remains generally unknown.

The PhD project was informed by a practice that aimed at making use of co-design for the benefit of people with mental health problems, an enterprise which I began in 2012 when I thought of the idea somewhat serendipitously upon approaching a charity to test my designs. The contribution of this thesis is threefold. First, it provides a substantial analysis of participants’ experiences of co-design, which can be used in a wide variety of settings where similar tools and strategies are employed. This includes service design and co-design projects in the health sector, co-creation projects which are often critiqued for resulting in further alienation, or commercial design projects where collectives deemed vulnerable are involved in one way or other.

The thesis contributes to helping prevent design’s involvement in certain areas causing more harm than good, which is the most urgent priority. This is the somewhat ‘corrective’ contribution of this thesis. Furthermore, by describing a framework for facilitation in detail, and raising awareness of the tacit dimensions of co-designing, the thesis responds to an urgent need to discuss our involvement within mental health, whilst providing guidelines to do so.

Secondly, it makes a proposition to the world to use designing activity for healing. This is a contribution based on opportunity. It is an invitation to our design community to
significantly extend their role once again. Rather than focusing on co-designing things for healing, the thesis proposes the very act of design as a form of healing.

Thirdly, as research through design, the thesis provides insights and questions about mental health, particularly around psychosis.

In addition, the way that the study wrestles with a variety of epistemologies and methods from different fields and responds to these challenges, integrating and threading them all into an interdisciplinary whole, constitutes a methodological contribution.

1.5 Summary of the thesis

The thesis is organized into eight chapters.

Following this introduction, the literature review examines relevant literature organized under various themes, purposefully drawing together knowledge across various fields, this includes co-design and participatory design particularly in the context of mental health and wellbeing but also literature focussed on recovery, empowerment and the survivor movement. Current therapeutic practices are explored, creative art therapies and occupational therapy, psychotherapy and how design may align and differ from these. Finally, literature on experiences of mental health problems is reviewed, including how these problems are conceptualized, and insights from phenomenology which are relevant to this project, such as psychosis, agency and embodiment.

The third chapter, on methodology, begins with the epistemological approach, before laying down the co-design method and detailing the data collection and analysis processes.

The next chapters correspond to three different studies. Chapter four is a case study analysis of the ‘co-design for wellbeing’ project. Chapter five presents the Interpretative Phenomenological Analysis (IPA) of the Psychosis Therapy Project (PTP) based on
participants’ interviews. Chapter six sets up to answer the question of whether co-design affects wellbeing using a mixed-methods approach.

The seventh chapter presents insights about facilitation, examining key principles and attitudes whilst reporting on emotions and ethics.

The final chapter focuses on discussing the project as a whole, especially laying out the case for designerly healing by integrating findings and insights across projects at various levels of analysis—systems, social and individual. The thesis concludes with a summary of contributions, limitations and ideas for future work.
2 Literature review

As a nascent area of research, besides responding to a knowledge gap, this thesis is responding to a knowledge opportunity, driven by earlier experiences. Consequently, an exploratory literature review was considered most appropriate. Exploratory literature reviews seek to find out what actually exists in the academic literature in terms of theory, empirical evidence and research methods as they pertain to a specific research topic and its related wider subject area (Adams 2007). As the author remarks, this kind of approach is deemed appropriate for emergent areas where there may not be an existing body of knowledge. As no studies were found which set a direct precedence to this project, an exploratory review focused on the breath, rather than the depth, of what is already known that may offer some insight.

The process can be loosely conceptualized in three stages: The first helped prepare the fieldwork, and focused around the interdisciplinary areas of uncertainty and psychological change, besides reviewing projects that related to co-design and mental health. Studies pertaining to the much wider area of design for wellbeing were excluded when the potential users of such designs were not involved in the process – for instance how designers or architects create products or environments that aim at improving wellbeing. Design in relation to ageing and wellbeing, an area which is also significantly wider in scope, was not reviewed in-depth, and such studies were not included unless their relevance to this project was particularly salient. Similarly, participatory and co-design projects with other groups (e.g. people with dementia) were not included unless there was a contribution which related closely to this project, such as a particular focus on effects on participants or a relatively similar methodological approach. The area of creative practices, craft making and participatory art, as well as the area of therapy, including art and occupational therapies, were also purposefully excluded from this initial
review for methodological reasons, to preserve a sense of intentional naivety in order to favour interpretations based on participants’ accounts rather than preestablished notions.

The second stage of literature search, during fieldwork, had the aim to inform a more empathetic understanding of participants and provide insights into their worldview. Much of the area of phenomenology of psychopathology, including other subjects such as psychosis and spirituality, were explored while working with participants.

The final stage of the review, following the data analysis, is reflected in the format delineated in this thesis, and consolidates the literature reviewed prior to the fieldwork, literature that became relevant during fieldwork, and that which helps situate and contextualize the findings. The published studies around co-design and mental health were searched again, which evidenced a relative increase in publications since the start of the project. Furthermore, literature on creative therapies was reviewed at this stage to provide a general introduction, without delving into an exhaustive review, in line with Adams’ (2007) guidelines on exploratory approaches.

There were no filters in terms of date or geography. However, literature searches were conducted in English, which may have resulted in missing relevant works written in other languages, especially outside the geographical areas of Europe, Australia and the US where most publications reviewed here originated from. Although this debate is beyond the scope of this thesis, it is a limitation that should be kept in mind.

The resulting literature review presented is thus organised in various thematic areas. First, the research is positioned within its wider context, reviewing existing co-design projects within mental health. Second, I delve into the concept of recovery and psychological change to distil current trends. Subsequently, I explore the subject of empowerment alongside literature from the survivor movement. Next, I review more broadly how mental health problems are approached by therapeutic practices, reflecting on similarities and differences with design. Finally, I examine the literature on the experience of mental health problems, present insights from phenomenology and provide an overall summary.
2.1 Co-design and Mental Health

In the last few years, the popularity of co-design to develop mental health services and products seemed to have boomed significantly. Nevertheless, participants’ experiences are largely neglected, with most studies focusing on the design process or outcomes.

The recent cultural and political changes prompted a philosophical shift in promoting shared decision-making in healthcare design, treatment and quality improvement (Palmer et al. 2019). In response, co-design methodologies have been adopted within service design, quality improvement initiatives and research to ensure end-user participation (O’Brien, Fossey, and Palmer 2021). As Carr et al. (2011) conclude, integrating Experience-based design approaches within the healthcare system moved consultation to a new level of co-design and co-production, building a sense of community and ownership around a project, and ensuring that lived experience is the best evidence for the effectiveness of the process. Co-design has become an accepted means of making ongoing improvements to healthcare provision (Robert et al. 2015).

Within service design, a few projects have 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 (EBCD), an interdisciplinary methodology that is being increasingly used in service enhancement (Larkin, Boden, and Newton 2015; Cooper, Gillmore, and Hogg 2016). Larkin, Boden, and Newton (2015) took three qualitative research studies about hospitalization in early psychosis (exploring the perspectives of service-users, parents, and staff) and translated them into service improvements via a collaborative process. In this sense, they used (EBCD) to “scale up” findings from earlier projects into a consensus from a much larger group rather than designing in collaboration from an early stage of the project. Cooper, Gillmore, and Hogg (2016), on the other hand, begin with the collaborative design of the project itself, starting with interviews with service users where they identified key parts of the service-user journey. Both Cooper,
Gillmore, and Hogg (2016) and Larkin, Boden and Newton (2015) remark that EBCD can be a helpful methodology to use in mental health settings. Also, both studies suggest that resource limitations within the settings meant meaningful changes were difficult, thus it was unlikely for them to lead to effectively ‘bottom-up’ service developments (Larkin, Boden and Newton, 2015) or truly co-designed services (Cooper, Gillmore and Hogg, 2016).

Indeed, in a review of 13 papers that use EBCD, A. Mulvale et al. (2016) analysed the alignment of methods used with EBCD methodology, and how power imbalances among participants were addressed. Their objective was to identify methods used to involve patients, family and service providers in child and youth mental health service improvement research. A systematic review of the English-language peer-review literature since 2004 was carried out. Many participatory research studies in child and youth mental health were consistent with core elements of the EBCD methodology, but few focused on experiences and incorporated the perspectives of all participants throughout the research process. Storytelling and visual media, employing youth as researcher partners, establishing equal status among participants, offering counselling support, paying particular attention to confidentiality, scheduling frequent breaks, and having skilled interviewers and facilitators were suggested methods to address power imbalances for this population.

This argument resonates with findings from a study that looked at the experiences of participants on a UK healthcare participatory project, in this case, focused on outpatient services for older people: participants did not think to be ‘doing’ the designing, and had doubts about the effectiveness of the intervention (Bowen et al. 2013). Others have also pointed out the challenges in establishing participatory approaches in the healthcare context due to differing epistemological, cultural and methodological assumptions (Rothmann et al. 2016). An interesting approach that appears to tackle these diverse paradigms between service design and the healthcare context is presented by Szücs Johansson, Vink, and Wetter-Edman (2017). The authors describe A Trojan horse approach to changing mental health care for young people through service design.
Changes were brought in by the clinical team based on the explicit agenda of developing new digital mental health services for young people, yet it held a hidden agenda of supporting new ways of working within mental healthcare.

Arguably, another way to address power imbalances could be to include service users not only in the co-design of these services but also in delivery. Martin, Stevens, and Arbour (2017) describe the implementation of a recovery-oriented program to support users to co-design and co-deliver wellness groups, making every effort to include participants who wanted to run a group despite their psychiatric symptoms. Again, nevertheless, the authors got the impression that staff were on board with recovery-oriented ideas “in theory” but not on a practical level.

Power differentials were indeed themes identified as important by research on co-design with vulnerable populations in an international research collaboration (G. Mulvale et al. 2019) and in a review of co-design methods with Culturally and Linguistically Diverse (CALD) communities in mental health services (O’Brien, Fossey, and Palmer 2021). G. Mulvale et al. (2019), in reviewing eight cases drawn upon the knowledge of the research team with experiences of co-design in public services, conclude facilitators must consider how meaningful engagement will be achieved and how power differentials will be managed. Similarly, in O’Brien, Fossey, and Palmer’s (2021) review comprising 9 papers, the quality of the relationship between researchers and CALD communities was the most frequently reported consideration, including power differentials.

The issue of power has been a key concern for co-design and participatory design from the start. In the co-design projects I facilitated in the past, the projects began with an exploration of matters of concern fuelled by the experiences of participants themselves, similar to what Sanders and Stappers (2012) described as societal-value cocreation, mostly occurring very early in the process. In this regard, these projects share the approach described by researchers facilitating the participatory design projects at Malmö town in Sweden: ‘Starting point is not the search for yet another ‘killer application’ but everyday activities and challenges in people’s lives’ (Ehn, Nilsson and Topgaard, 2014). Also
contrasting with solution-focussed projects, Whitham et al. (2019) describe an approach where there was no expectation for the co-design process to result directly in change, instead this had to be enacted by practitioners and their organisations. In their case, the purpose of the co-design process was to unlock future creative and transformative potential, and they used co-design to engage participants in creating practical, reusable tools, rather than developing solutions to existing problems. Usually, nevertheless, collaborative design projects in mental health are informed by a relatively specific brief, perhaps following an institutional agenda. In studies looking at mental health patients, the scope of this initial brief can have particular significance: As Bjerknes and Bratteteig (1994) put it, people have the right to maintain a different opinion than those in power and build knowledge on a different basis. However, collaborative design approaches can struggle to fulfil the explicit and implicit promises they make to meaningfully empower participants despite the wealth of professional and personal experience they may have from interacting with services (Whitham et al. 2019).

Another way to work on power differentials and ensure a positive experience for participants is to learn about their experiences. Within service design, Warwick et al. (2018) analyse how the design process impacted the wellbeing of co-designers of a new perinatal mental health service, who had drawn on their personal experiences to create a new offer, ‘Mums Matter’. The authors then compared and contrasted these impacts with interviews conducted with the eventual service users of the co-designed service. 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. 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 and using an existing resource to meet a new challenge; while the service users felt that the skills and knowledge they acquired during the course resulted in improved wellbeing outcomes, hence new resources to meet an existing challenge (Warwick et al. 2018). By 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).

If we look at co-design within mental health beyond the service design area, the majority of projects involve the co-design of technological solutions, most often for young people with mental health problems.

Bevan Jones et al. (2020) identified 25 original articles and 30 digital mental health technologies that were developed with children and young people. The themes identified were as follows: principles of co-design (including potential stakeholders and stages of involvement), methods of involving and engaging the range of users, co-designing the prototype and the challenges of co-design. Only five articles (19%) of twenty-five reviewed by Bevan Jones et al. (2020) described a process evaluation. The mixed-methods acceptability evaluations found that participants affirmed the value of collaboration, described the experience as ‘enjoyable’ and ‘rewarding’, stated they had gained knowledge and skills and felt more able to talk about mental health issues and support others (Robinson et al. 2017). Negative comments reported that collaborative meetings were at times bureaucratic and dry (Huggett et al. 2017). Wiljer et al. (2017) noted how it had been a challenge to keep participants engaged as the project progressed and they had less ‘ownership’ if they did not have clearly defined roles (reviewed at Bevan Jones et al. 2020).

One particular comment, reported in Hodson et al. (2019), is especially relevant to this PhD, concerning the notion of focusing on something other than their personal circumstances. It appears that the youth (participants) were able to identify with the personas, which encouraged a feeling of belonging while at the same time it allowed the youth to focus on helping someone else.

Thorn et al. (2020) aimed to document key elements of the co-design process, including an evaluation of young people’s experiences of the co-design process, who made recommendations for the #chatsafe suicide prevention social media campaign. The fact
that young people felt better able to safely communicate about suicide on the web, as a result of participation in the study, augurs well for youth engagement with the national campaign, which was rolled out across Australia. In total, 134 young people participated in the co-design workshops, of whom 131 (97.7%) completed an evaluation survey. The majority of young people indicated that they perceived participating in the workshops as a beneficial, acceptable, and safe experience. However, it is important to note that 8 young people reported that the workshop made them feel suicidal and 6 young people were unsure if participation caused them to feel suicidal, which demonstrates the importance of understanding participants’ experiences in more depth. My question – and provocation- is, whether participating in the co-design development may have benefited their recovery more profoundly than any app use would ever do, and what are the risks.

Some projects in the area of technological solutions in youth mental health appear to go beyond the idea of creating a tech solution to problems, and explore, through co-design, the real wishes and needs of the young people, which may not always align with the initial agenda. This process is reflected in Nakarada-Kordic et al. (2017) study, which describes the development and use of methods to engage young people experiencing psychosis in co-creation of an online resource to support their education and wellbeing.

Among other projects led by designers within the mental health context, focus mainly relied on developing appropriate design methods, or describing the design outcomes (Kaasgaard and Lauritsen 1997; Glazzard et al. 2015; Kettley, Sadkowska, and Lucas 2016; Nakarada-Kordic et al. 2017), leaving the effects of participation on mental health users aside from general feedback- yet to be explored. Kettley, Sadkowska, and Lucas (2016) investigate the Person-Centred Approach of Carl Rogers in psychology as a methodology and framework for design. They included three series of participatory workshops, intended to scaffold experiential learning around two near-future concepts: electronic or ‘e-textiles’, and the Internet of Things. Glazzard et al. (2015) emphasize how to facilitate a non-judgemental environment within a project of co-designing e-textiles with the Mind Network community of mental health and wellbeing service users, managers and volunteers. A decade earlier, Kaasgaard and Lauritsen (1997) discussed a system
development project following a participatory approach that engaged clients at a psychiatric centre. Interestingly, whilst Kaasgaard and Lauritsen (1997) discuss potential problems in establishing a common ground to engage psychiatric clients in design projects, Nakarada-Kordic et al. (2017) remark that the challenge to find common ground with the participants was based on them being young rather than having psychosis.

Although some reference to participants’ experiences in these papers is common, and sometimes include feedback from participants (see for instance in Glazzard et al. 2015), it is rarely their primary focus and the experiences of participating are not yet properly understood. There is therefore also a lack of studies exploring the potential benefits of participation in the design process per se, although some authors hint at it (Amiri, Wagenfeld, and Reynolds 2017; Craig 2017). As Vink et al. (2016) remark concerning service design, the total value created through co-design can be optimized by considering and managing not only the impacts of what is being designed but also the impacts of the design process.

Even within the wider area of design for health, studies focusing on the effects of co-design appear rare, with a few exceptions (Macdonald 2013; Langley et al. 2013; Tsekleves 2020; De Couvreur et al. 2013; Myerson and Ramster 2017). Some studies looked at the potential of design thinking among those affected by long-term physical conditions such as spinal cord injury (Macdonald 2013; Chamberlain et al. 2013). Macdonald, in particular, describes a process of problem identification and analysis facilitated in a designerly way, which resonates with this project. In this case, the aim is to enhance the rehabilitation pathway and self-management for Spinal Cord Injury (SCI) survivors. Tsekleves (2020) reports that although the original aim or 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, the surprising finding was the realisation that, more than an artefact, the subjective wellbeing and mood of people with early signs of dementia benefit significantly 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. Furthermore, as Esclante et al. (2017) remark, there is not discussion on how facilitators, who may find themselves undergoing rather emotional processes, are affected either, which according to Kettley and Lucas (2020) is an ethical issue. Albeit such studies involved different target groups - not necessarily mental health clients - they illustrate a relationship between participation in co-design and wellbeing, which must be further investigated.

Even fewer are the studies that speculate why these changes could occur in participants. Corcoran, Marshall, and Walsh (2017) suggest that cooperative place-making project workshops supported changes to psychological and community wellbeing by enhancing both a sense of personal growth and a collective sense of place-related optimism. Hendriks, Dreessen, and Schoffelen (2016) suggest how participatory design could ‘enable’ increase in perceived quality of life and secondary gains which - as Albrecht and Devlieger (1999) describe- occur when a person with a disability finds an enriched meaning secondary to the condition brought on by the disability. Their project focused on co-developing solutions for self-management of type 1 diabetes and studied how this process was experienced by participants. They specify a personal perspective should be the starting point for participatory design that aims at acquiring secondary gains, whilst Macdonald actively seeks to change the users’ narrative from the self as the user to the other.

Finally, based on previous experiences, during the course of this PhD, I had the opportunity to publish some ideas about why changes may occur in participants, before collecting any data. This theoretical work (Renedo-Illarregi 2018) conceptualized uncertainty as a potential explanation for changes that could be expected in people with
mental health problems who partake in design. It suggests 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. Together with supervisors, we (Renedo-Illarregi, Alexiou, and Zamenopoulos 2019) also drew some theoretical links between the experience of designing and that of psychosis around the themes of agency and embodiment. We hypothesised that the experience of designing may pose a continuous force towards the coupling, or pulling together, of dimensions of experience which in psychosis are sometimes experienced as particularly fragmented. A further publication focused on the ‘co-design for wellbeing’ case study, which is described in chapter 4 (Renedo-Illarregi, Alexiou, and Zamenopoulos 2020).

Another important aspect of the intersection between co-design and mental health is the way dominant medical paradigms may translate inadvertently to our design process and outcomes. In discussing research at the intersection of design and mental health, (Kettley and Lucas (2020) observe that there is a general lack of explicit theoretical framing or modality, which is concerning. For instance, technological developments and the design of assistive digital devices for mental health - which represented the largest category of papers they reviewed by the authors- followed a predominantly user-centred and problem-based approach, which effectively asks for a medical or disease model by engaging in design for a diagnostic label or disorder (a needs-based, or lack-based approach). These insights are in line with Neretti’s (2020, page 13) recent observation ‘Considering design research affordances, the current design interventions for mental disorders limit themselves in provoking change by materially translating current paradigms of mental health. Such interventions miss the chance to learn more about the conditions that produced the disorder and its experience and miss the opportunity to provide alternatives to ways of caring, preventing us to learn more about the way we conduct our everyday life.’

This project resists adopting such medical paradigms by taking a step back and engaging with participants’ experiences and insights much beyond their involvement with mental
health services. If participatory design has the potential ‘to arrest the escalating problems of the man-made world’ as Cross (1972) described, when we co-design within mental health we could commit to explore these escalating problems and creative ways to tackle and prevent them, whilst understanding how this engagement helps participants in return.

2.2 Recovery and psychological change

The term recovery is a broad concept that has become increasingly popular in the mental health community and acknowledges a wide variety of experiences regarding what it means to be unwell and get better. Recovery-oriented approaches are those which focus on individual definitions of wellness and the processes which promote those (Leonhardt et al. 2017). As I understand it, the term does not always imply an illness, to begin with, or cure.

It is often associated with therapy or treatment, but the concept of recovery can be understood more widely and include self-directed care or natural recovery, which is reflected in initiatives such as the introduction of Personal Budgets, agreed amounts of money allocated to someone to direct their recovery (Disability Rights UK 2018).

According to The Mental Health Foundation, the recovery model aims to help people with mental health problems to look beyond mere survival and existence, encouraging them to move forward, set new goals, do things and develop relationships that give their lives meaning. ‘Recovery can be a voyage of self-discovery and personal growth. ‘Experiences of mental illness can provide opportunities for change, reflection and discovery of new values, skills and interests’ (Mental Health Foundation 2018).

Meaning-making processes are indeed a major theme presented across the literature of psychological change, a concept which relates to recovery. Forgeard et al. (2014), in their literature review on artistic creativity and benefits to wellbeing, discuss the theme of
meaning-making as possibly leading to posttraumatic growth and being key in the recovery process, among other elements such as engagement and flow, catharsis, distraction and positive emotion.

Research on posttraumatic growth and stress-related growth also points out that these events challenge people’s underlying assumptions about themselves and the world and compels them to search for new meanings (Helgeson, Reynolds, and Tomich 2006; Linley and Joseph 2011).

More specifically, Linley and Joseph (2011) point out 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.

Higginson and Mansell (2008) and Gianakis and Carey (2011) have studied psychological change as a result of everyday life, describing it as a consequence of reflexive processes characterized by increased insight and meaning reorganization specifically related to critical experiences associated with strong emotional arousal. Both research studies were based on semi-structured interviews of a small sample group and used Interpretive Phenomenological Analysis (IPA). Gianakis & Carey (2011) point out themes: identity, connection, threshold, desire to change, gradual process and sudden moment and finally thinking process. Higginson and Mansell’s (2008) research highlight the following themes: hopelessness and issues of control, the change process, new self vs old self, and putting the problem into perspective. Higginson and Mansells (2008) suggest that common processes may underlie the maintenance, and relief from various forms of psychological distress and the various paths to recovery taken by participants.

Some parallels arise from the investigation of experiences of psychological change without psychotherapy and the observations within co-design workshops. A thinking process seemed to be associated with enacting the change with a gradual process (Gianakis and Carey, 2011). As Gianakis and Carey (2011) describe, this contrasts with cognitive therapy, which presupposes that changing one’s thinking is what leads to
change (Beck et al. 1979). In design, this thinking and meaning reorganization is often emergent, forming after a particular insight or design solution is reached.

2.3 Empowerment and the survivor movement

Historically, people with mental health problems have lacked a voice, neither they nor their families were involved in decision-making on mental health services, and they continue to be at risk of social exclusion and discrimination in all facets of life (WHO Regional Office for Europe, 2010). Those who embrace the designation of “psychiatric survivor” are those who have experienced abuse and/or oppression in the mental health system (Adame 2013). Adame (2013) summarizes the psychiatric survivor movement is an international political activist movement primarily made up of organizations dedicated to fighting for human rights in the mental system.

As defined by the World Health Organization, in a mental health context, empowerment refers to the level of choice, influence and control that those who use mental health services can exercise over events in their lives, although I would argue for including the significance of influencing what is beyond their lives, too.

Empowerment is one of the central pillars of mental health recovery (Leamy et al. 2011). It has been identified as an important focus in occupational therapy practice (Hammell 2016) and art therapy (Secker et al. 2007), although it has been remarked that there may be differences in how clients and practitioners understand empowerment (Kapitan 2014). According to Boehm and Staples (2004), for clients empowerment meant participation in society, social networks and supportive group processes, while practitioners conceived it as a personal process detached from the collective level, as an individual therapeutic change. Secker et al. (2007) indicate that some arts and mental health projects do empower participants at a social as well as individual level, and Morris and Willis-Rauch
(2014) develop Social Empowerment Art Therapy which encourages voluntary participation, facilitation rather than structured direction, group empowerment through collaborative decision making, and artistic practices that are chosen by members.

Notwithstanding, in a 15-month longitudinal study that collected data from 14-day centres, Sutton, Bejerholm, and Eklund (2019) found that participants’ rating of empowerment was surprisingly stable before and after the period, and question whether participation in day centre occupations should necessarily lead to greater empowerment. It may be that attendees in the study prioritized social support and refuge over goal-focused personal development, which is seen to prevent deterioration of mental wellbeing and enable the creation of enduring social networks. However, they argue, these outcomes by themselves do not necessarily lead to a greater sense of overall empowerment. Day centre programs should aim to develop attendees’ participation as citizens and capacity for self-determination in the broader community (Pelletier et al. 2015).

If we look at the literature published in co-creation, sometimes progressive participation is tokenistic and only involves consultation on predetermined decisions, where service users have no influence on defining what the problems are or what ought to be changed in the first place (Rose et al. 2003). As Carr (2016) remarks, service user and survivor participation strategies and forums are often led by services that determine the rules and procedures and retain ultimate decision-making power (S. Carr 2016). As the author describes, this service-oriented procedural and managerial, rather than relational, approach to mental health service user participation can often result in exclusion and disempowerment and does not offer the conditions for co-productive processes.

Overall, by increasing the use of consumer language and focusing entirely on people’s needs – rather than what they can contribute – public services have tended to disempower their users and have done little to prevent needs arising (Boyle and Harris 2009). As the authors summarize, since services largely ignore people’s abilities, their continuing need has often become their only asset in their battle for help.
Empowerment in co-design has been used to express a view that this process helps people to take control of their lives, develop critical awareness and knowledge about their situation, and long-lasting skills and capacities to participate and shape their environment beyond the confines of a particular project (Zamenopoulos and Alexiou 2018).

### 2.4 Therapeutic practices

Non-pharmacological interventions for people with mental health problems have been employed for decades. Besides the well-known talking therapies, art therapy and occupational therapy are also widespread practices. Art therapies are complex interventions that combine psychotherapeutic techniques with activities aimed at promoting creative expression (National Institute for Health and Clinical Excellence 2020). Occupational therapists use occupations (purposeful activities) to assist clients through the integration of the physical, psychological and social functions of human beings (Bryant, Fieldhouse, and Bannigan 2014).

The practices described in this section have been reviewed after the fieldwork took place, for methodological reasons, to try to explore design from participants experiences and not solely in relation to other practices.

**Creative art therapies**

Creative Arts Therapies is an umbrella term for healthcare professions that use the creative and expressive process of art-making to improve and enhance the psychological and social well-being of individuals of all ages and health conditions. The creative-expressive process engages physiological sensations, emotions, and cognition; facilitates verbal and non-verbal symbolization, narration, and expression of conscious or unconscious conflicts; and supports meaning-making through internal and external dialogue and communication between oneself and others (Shafir et al. 2020).
Art therapy is a very well known form of creative art therapy. As Malchiodi (2011) summarizes, a largely independent assortment of individuals, notably Margaret Naumburg, Edith Kramer, Hanna Kwiatkowska, and Elinor Ulman, began to use the term *art therapy* in their writings, defining a new discipline.

Art therapy is based on the idea that the creative process of art-making facilitates reparation and recovery, is a form of nonverbal communication of thoughts and feelings, used to encourage personal growth (Malchiodi 2011).

Since the early days of the profession, art therapy was permeated by a wide range of ideas from psychoanalysis (Killick and Schaverien 1997). During the past decades, a new form has also emerged from art studios, called Expressive art therapy (ExA), rooted in the phenomenological tradition, where the very process of artistic expression is regarded to be potentially healing (Hanevik et al. 2015).

As Malchiodi (2011) describes, Art therapy supports the belief that all individuals can express themselves creatively. Art therapy has often been employed to help people with psychotic experiences. Since the end of the Second World War, art therapists have had a consistent history of offering therapy to people who experience psychotic episodes (Wood 1997). As remarked on the Psychosis Therapy website, socially and economically excluded clients rarely receive support besides medication (Psychosis Therapy Project 2021). In this sense, Wood (1997) reports art therapists have been unusual in attempting to create the circumstances for this work within public sector services.

The National Institute for Health and Clinical Excellence guidelines for psychosis and schizophrenia suggest that arts therapies are considered to improve negative symptoms of psychosis (Attard and Larkin 2016). The authors examined the effectiveness of art therapy for people with psychosis by reviewing empirical papers published from 2007 onwards, concluding evidence for the effectiveness in symptom reduction and functioning for people with psychosis remains inconclusive: while High-quality quantitative articles provided inconclusive evidence, high-quality qualitative articles
indicated that therapists and clients considered art therapy a beneficial, meaningful, and acceptable intervention (Attard and Larkin 2016).

Montag et al. (2014) published one of the first randomised controlled trials on psychodynamic group art therapy for patients with acute psychotic episodes receiving hospital treatment. Fifty-eight inpatients with schizophrenia were randomised to either 12 twice-weekly sessions of psychodynamic group art therapy plus treatment as usual or standard treatment alone. The authors found that art therapy was associated with a significantly greater mean reduction of positive symptoms and improved psychosocial functioning at post-treatment and follow-up, and with a greater mean reduction of negative symptoms at follow-up compared to standard treatment. There were no group differences regarding depressive symptoms. Patients in the art therapy group showed a significant improvement in levels of emotional awareness (Montag et al. 2014).

Hanevik et al. (2015) describe the course of an art therapy group for five women suffering from a psychotic disorder and their statements of its usefulness. Two of the participants described how they, by the help of art therapy, were able to control their psychosis. The rest reported an improvement in mastering their psychosis. One of the participants described that the exploratory artistic work had opened a new ability for her to distinguish between her helpful spiritual experiences and her hallucinations or religious delusions connected to her psychotic experience.

Art therapy techniques have been employed by helping professionals, and as Malchiodi (2011) describes, even the simplest drawing task offers unique possibilities for expression, often helping a child or adult to communicate what words cannot.

Other forms of creative art therapies include drama and play therapy, music therapy, dance-movement therapy, drama therapy, psychodrama, and poetry therapy (Shafir et al. 2020).

The British Association of Dramatherapists (2020) describes drama therapy's main focus the intentional use of healing aspects of drama and theatre as the therapeutic process. It is
a method of working and playing that uses action methods to facilitate creativity, imagination, learning, insight and growth.

According to the British association for music therapy, this form uses the different elements of music, such as components of rhythm, melody and tonality, to provide a means of relating within a therapeutic relationship. Clients are encouraged to explore instruments and the use of their voice to create a musical language that reflects their emotional and physical condition, enabling connection to the inner self and those around them (British Association for Music Therapy 2020).

**Occupational therapy**

Occupational therapists use occupations (purposeful activities) to assist clients fulfil their roles through integration of the physical, psychological and social functions of human beings (Bryant, Fieldhouse, and Bannigan 2014). As the authors review, although the concept of the therapeutic use of occupation dates back to antiquity, the term ‘occupational therapy’ was not coined until early in the 20th century. By 1988, occupational therapists in the UK were basing their treatment on much more clearly defined theoretical frameworks - psychoanalytic theory, behaviourism, humanistic approaches and developmental theories (Bryant, Fieldhouse, and Bannigan 2014). Currently, is summarized as a two-body practice that is concerned both with disorders of the body and with the experience of the person, and the profession has its theoretical frameworks that drive practice such as the European Conceptual Framework for Occupational Therapy (Bryant, Fieldhouse, and Bannigan 2014).

Kirsh et al. (2019) provide a literature review in search of evidence around occupational therapy (OT) interventions in mental health. They review 50 original articles, from which they derive a variety of themes: employment or education, occupational therapy involving psychoeducation, interventions using creative occupations and activity, addressing time use or occupational balance, in the area of -skills development, lifestyle modifications,
and occupational engagement, interventions using group or family approaches, and finally animal-assisted approaches.

Perhaps most relevant to the study of design within mental health is the importance of meaningful and productive occupation, such as education or employment, which is a core value of OT (Kirsh et al. 2019). Indeed, it appears that supported employment (SE), individual placement and support (IPS) in particular, which enables vocational skills and competitive employment for individuals with mental illness, are among the most successful interventions, with supported education also showing promising results (Kirsh et al. 2019). Supported employment programs typically provide individual placements in competitive employment, using jobs paying at least minimum wage, based on client choices and capabilities (Kirsh et al. 2019).

Also relevant to this PhD are interventions in the area of skills development, lifestyle modifications, and occupational engagement (Kirsh et al. 2019). The authors review ten studies located in the OT literature that address skills training, development of new habits or patterns of behaviour that promote lifestyle change and strategies that enable people living with mental illnesses to engage in meaningful occupations and live more active, independent, and fulfilling lives.

In a paper that proposes design thinking to be taught in occupational therapy schools, Mollo and Avery (2017) explore the similarities and differences between the processes. Nonetheless, the paper does not explore the possibilities of the design process for the actual treatment of their patients. It focuses on the benefits for the students and their future contributions in multi-disciplinary teams, with examples of how designers and occupational therapists can work together in developing services and products for clients. Hence, the focus lies on exploring the benefits of interdisciplinary collaboration for the development of products or services, rather than considering design’s potential as an occupation. However, the authors do acknowledge that the engagement of users in co-design could be an example of an activity that holds purpose and meaning through the process of participation as well.
In line with the approach adopted within this project, Bryant, Fieldhouse, and Bannigan’s (2014) new edition of Creek’s Occupational Therapy and Mental Health avoids chapters focused on diagnostic categories, acknowledging occupational therapy as being fundamentally about engaging with the person in their wider context and enabling them to respond positively to the challenges of living.

**Psychotherapy**

There are innumerable amount of approaches and schools of thought within talking therapies, and their analysis in relation to design is beyond the scope of this thesis. As with art therapies, talking therapies were not reviewed before the data collection.

However, while discussing participants’ interview data analysis, collaborator Dr Gina DiMalta suggested looking into person-centred or humanistic therapy, which emerged with Carl Rogers in the 1940s. Not surprisingly perhaps, the Person-Centred Approach of Carl Rogers is what Kettley, Sadkowska, and Lucas (2016) investigate concerning design. In their paper, they included three series of participatory workshops, intended to scaffold experiential learning around two near-future concepts: electronic or ‘e-textiles’, and the Internet of Things.

As Oberreiter (2021) describes, over the course of Rogers’ publications a change in access to psychotic phenomena can be observed in his work. While in early years, Rogers viewed psychosis as fundamentally different from neurotic conditions and emphasized the inability of psychotherapy to treat it, this perspective changes with the theoretical development of the person-centred approach, and the rejection of diagnostic labelling.

In a way, it is one of many talking therapies, and each approach may likely have something to offer to the practice of co-design within mental health and vice versa, yet humanistic therapies fundamental principles seem to align well with this project. As in participatory and co-design, embedded in humanistic therapies is a commitment to democratic principles in negotiating differences and solving problems when people are in conflict.
(Cain 2002). As Cain (2002) remarks, a fundamental value of humanistic therapists is their belief that people have the right, desire, and ability to determine what is best for them and how they will achieve it.

For Rogers, the essence of each human reality is distinct and exists in a continually changing world of experience (Rogers 1951). Roger’s (1942) idiographic emphasis is also evident in his critical stance toward diagnosis, preferring to view human beings as unique, individual organisms rather than as manifestations of trans-individual dysfunctional states (Cooper and McLeod 2011). In Levinas (1969) terms, this could be described as a fundamental ethical commitment to letting the Other be in all their Otherness: a ‘‘non-allergic reaction with alterity.’’

At the heart of a person-centred approach, then, is an understanding that human beings may want and need different things, and that an individual’s distinctive wants and needs should be given precedence over any generalized theories that another holds about them (Cooper and McLeod 2011).

As Cooper (2007) remark, at the heart of the existential and humanistic approaches, is a commitment to conceptualizing and engaging with people in a deeply valuing and respectful way. It is a commitment to engaging with all human beings in a way that is deeply valuing, regardless of their level of psychological distress.

Client-centred is unique in the arena of psychotherapies – it is distinctly not a directive therapy (Brodley 1990). Precisely perhaps because of this, there may be some parallels with the scenario that’s this PhD project created. In co-design, however, the purpose is not centred on participants’ mental health, there is not a priori therapeutic projects, which is a fundamental difference.

**In relation to the design approach.**

The discourse of how design differs from the therapeutic paradigms brings attention to the subject of designers’ and participants’ blurred roles in this co-design process. Whilst
in (Glazzard et al. 2015) designers and therapists are the helpers adopting a more therapeutic approach to support a non-judgmental environment, Hendriks, Dreessen, and Schoffelen (2016) conclude their paper questioning whether the designer should take a more or less therapeutic role. This is not an easy debate and there are valid arguments for varying approaches that one could take.

This PhD project tried to prevent being conceptualized as therapy for various reasons.

The first reason related to the notion of empowerment, as I was trying to stay away from interpersonal dynamics participants could associate with earlier therapeutic or educational contexts doctor-patient, teacher-learner, helper-helped. Within co-design, participants needs become their assets (Sanders 2000). The matters of concern are co-defined with participants, which could be their therapeutic benefit, but also anything else, such as religion, humanity, or caring for insects.

Other reasons to avoid any notion of therapy was to remain fairer to the perspectives of participants, adopting a wider philosophical stance and transparency in regards to my training.

2.5 Experiences of mental health and distress

2.5.1 A variety of conceptualizations of unusual experiences

There is a rich variety of different ways to understand experiences which are often associated with mental health problems. These may mean different things in different contexts and for different people, with conceptualizations varying significantly among cultures, through history, different schools of thought and from individual to individual.
For instance, cultural differences have been reported relevant in co-design projects within mental. Lwembe et al. (2017) indicated that, in many different cultures, people expect to be treated with their families and do not understand the typical individual approach to treatment.

Interestingly, some research found that it was more likely to recover from severe mental illness in developing countries than in Industrialized societies (World Health Organization 1973; Jablensky et al. 1992; Hopper and Wanderling 2000). These differences may have to do - among other reasons - with how illness is defined and what is expected from a specific situation. For instance, the U.S mental health system may incorporate a substantial list of psychosocial artefacts that create chronicity in patients where it could have been avoided (Harding, Zubin, and Strauss 1987). Meanwhile, other cultures may interpret the same experiences spiritually, where cultural sponsorship of healing practices and a commonly held belief in the ill person’s potential for cure can be more important than the specific practices or beliefs of the healer or patient (Turner 2006 as cited in Myers 2010).

Without necessarily approaching a cross-cultural analysis, within the UK, movements such as the Hearing Voices Network UK are examples of how what is considered a mental health problem can be redefined, challenging the status quo and offering those who have these experiences different ways to understand them. Although the first UK hearing group was formed in Manchester in 1988, now it is a national network with the aim of raising awareness of voice-hearing and other unusual experiences. It gives people an opportunity to talk freely about this, supporting them to understand, learn and grow from it in their own way (Hearing Voices Network 2018). In this situation, a new perspective develops, a change of beliefs regarding the experiences involved.

On this project, on one hand, I aimed to follow these recovery principles, acknowledging each person’s understanding and expertise. On the other, in my efforts to empathize with participants, I tried to learn about how such experiences might be, reaching out to literature on phenomenology. Hamm et al. (2018) integrate writings from these two
different perspectives which are concerned with the subjective experience of psychosis - phenomenology and recovery models.

Alternative conceptualizations more interested in the lived experience of psychosis (Hamm et al. 2018) respond to Increased awareness of the limitations of reductionist approaches that mostly rely on biologically oriented models. Indeed, as reviewed by (Hamm et al. 2018), both the philosophical phenomenological model of psychosis and the recovery model, focus on the first-hand experience of psychosis, and although they differ on methodology and epistemology, they are both interested in the alterations of subjectivity that occur, and both contribute to interventions that are responsive to these alterations.

Phenomenological writings have produced a conceptual model of schizophrenia referred to as the ipseity disturbance model, whereas the recovery writings generalize from common and diverse experiences of movements toward well-being (Hamm et al. 2018). The authors summarize that phenomenological writings focus on how lived experience in psychosis deviates from health whereas recovery writings concentrate on lived experience amid a return to health. Although these differences make it difficult to see how the two approaches might be integrated to inform treatment, the authors carefully examine major tenets in each body of literature and offer future roads for reconciliation among contributions.

It is important to acknowledge, therefore, in the context of this PhD, that what constitutes a mental health problem, psychosis, or recovery, is first and foremost framed by the participants themselves, recognizing everyone’s journey, and partly influenced by my readings in phenomenology.
2.5.2 Insights from phenomenology

*Psychosis*

Psychosis is an umbrella term to describe an experience that may be associated with a variety of mental and physical problems. Because one of the projects of this PhD was embedded in a service for people with psychosis, it is central to explore what this experience may mean, understanding, in the measure that is possible, how their first-hand experiences may be like.

The Ipseity Disturbance Model (IDM) is perhaps one of the most prominent associated with psychosis and schizophrenia, developed principally by Sass and Parnas, alongside many collaborators that incorporated the IDM into research (e.g. Fuchs and Röhricht 2017; Hamm et al. 2018). The IDM contends that a disturbance of, or instability in, basic or minimal senses of self (ipseity) contributes to the central disturbances involved in schizophrenia (Hamm et al. 2018). Ipseity refers to the foundational sense of selfhood, i.e. the tacit sense of “me-ness” that makes all experience self-experience (Sass and Parnas 2003). This basic disturbance alters the fundamental sense of self-sameness that influences normal self-world perceptions and boundaries; in other words, a core sense of “mine-ness” is corrupted. It is this core disturbance, rather than discrete symptoms such as delusions and hallucinations (viewed here as secondary to primary ipseity disturbance), that accounts for the lived experience and dysfunction involved in schizophrenia. For example, an individual might not experience certain thoughts emerging from the self, resulting in the experience of hearing voices (Hamm et al. 2018).

Understood as a disruption of “pre-reflective” consciousness, ipseity-disturbance involves three inter-related, trait-like phenomena: hyper-reflexivity, diminished self-affection, and disturbed grip (Hamm et al. 2018). Proponents of the model typically position hyper-reflexivity and diminished self-affection as the two central and complementary elements of ipseity disturbance (e.g. Sass 2014). Hyper-reflexivity refers
to a sort of exaggerated self-consciousness in which normally background or tacit phenomena become focal points of attention. Diminished self-affection complements hyper-reflexivity and refers to degradation in the experience of self as an agent or effective subject of awareness. These two complementary aspects of ipseity disturbance (primary or “operative” hyper-reflexivity and accompanying loss of agency) may then be further compounded in a secondary, defensive manner in what Sass has referred to as “hyperreflectivity” or morbid introspection (Sass 2014). In addition to the two primary elements, “disturbed grip,” also referred to as “loss of common sense,” has been proposed as the third element of ipseity disturbance (Sass 2014), referring to subjective disruptions in the field of awareness and reality in which objects and meanings have altered salience. The individual’s perceptual and cognitive field is experienced as unstable and volatile, resulting in the experience of fragmented thought and perceptual distortions concerning self and world (Hamm et al. 2018).

**Agency**

A diminished sense of agency is a common theme in research which deals with understanding the experience of psychosis.

On one hand, a diminished sense of agency may refer to the lesser ability to have an impact on the world around oneself. This feeling of disempowerment is something that most people can relate to and may experience at different points in their life. In many cases of psychosis, this particular sensation may indeed reflect the real situation accurately, as the power over the environment, others and even oneself can be extremely compromised by some events following breakdown such as being sectioned or treated compulsorily.

However, from the lived experience of the psychotic, a diminished sense of agency may not only refer to a lesser ability to impact on the environment or what is being done to them; in some cases, the lack of a sense of agency may extend to one’s inner world (e.g. thoughts, feelings, sense of will).
In situations where lack of agency extends to the sphere of one’s inner world, the person is not only unable to act upon things and events ‘out there’, but also experience inner existence as driven by foreign agency or subject to the agency of others.

These various cognitive phenomena have been framed as alterations of thought-agency and ownership (Humpston and Broome 2015). Examples portrayed in (Pienkos et al. 2019) include ‘thought insertion’, which is the inward projection of “other” thoughts into one’s mental space, and ‘audible thoughts’ referring to the vocalization of one’s thoughts into an external space.

One of the most characteristic experiences of psychosis, hallucinations, are considered as self-disturbances to the extent they are perceived as occurring independently from self, and this separation between self and its automatic processing is also often experienced as due to foreign agency (Pienkos et al. 2019).

Fuchs (2007) suggests that the inhibition of unintended thoughts or actions fails when the essential syntheses that relieve us of the task of actively connecting and building up the perceived objects, situations and habitual patterns of our lives are disturbed. Associations or even bodily movements appear ‘out of the blue’ and instead of serving as a medium for the patient’s intentional relation to the world, their thoughts, perceptions or movements may occur as single erratic blocks that stand in the way of their intentional effort (Fuchs 2007).

Hamm et al. (2018) conclude that treatments following paradigms reviewed earlier - phenomenology and recovery- need to address experiences of diminished agency and confused or fraught self-experience, by helping patients to name, reflect upon, and respond to their experience, as a basis for action.
**Embodiment**

As Hamm et al. (2018) summarize, if attending to subjective experience is addressed principally by promoting agency, treatment should attend to mental phenomena in the context of embodied experience.

The subject of embodiment is also one of the themes Pienkos et al (2019) use to organize their extensive review of the literature on hallucinations, suggesting it is central to the phenomenological study of psychosis.

A review of implications and applications of the subject of embodiment in schizophrenia is discussed in (Tschacher, Giersch, and Friston 2017). They remark how embodiment has become an influential concept in psychology and cognitive neuroscience, and that the embodiment of the mind constitutes the basis of social interaction and communication. Sensorimotor dysfunctions are closely associated with affective and psychotic psychopathology, leading to altered timing in the processing of stimuli and disordered appraisals of the environment.

Alterations of bodily self-representation have also been suggested to be a core component of schizophrenia, for example, changes in size and shape, alterations in body ownership or out of body experiences (Pienkos et al. 2019).

The idea of the disembodied self is central to the existential interpretation of psychosis presented in The divided self (Laing 1960). In Laing’s thesis, the schizoid person, who may or not develop psychosis, consists of an unembodied self, and a false self-system who deals with others and the world. He stresses that although most people regard the embodied position as healthy and the unembodied pathological, sometimes individuals may try to disentangle from their body, for instance, to achieve discarnate spirituality.
2.6 Summary

The exploratory literature review presented here aimed to lay down the interdisciplinary terrain within which the project is situated. First, I have reviewed the existing work within co-design and mental health, exceptionally including few works with other participant groups which were relevant for methodological reasons or their special focus on participants experiences and wellbeing. Overall, participants’ experiences have rarely been the focus of research, and there is a considerable knowledge gap on understanding people with mental health problems when engaged in co-design, which informed the core of this project. This also includes the experiences of facilitators, which are generally not discussed despite playing an important role to inform further practice.

The concepts of recovery and psychological change are distilled by providing some examples, and the subject of empowerment alongside literature from the survivor movement was introduced, as it will become key in interpreting project results.

The tenets of therapeutic practices differ in some fundamental ways with the design approach, as I summarize upon overviewing creative art therapies, occupational therapy, and psychotherapy.

Finally, the literature on the experience of mental health problems, especially insights from phenomenology, is summarized as it will enable us to interrogate the fieldwork data and interpret participants experiences in more depth.
3 Methodology

In this chapter, I first describe the epistemological approach of the thesis, drawing from various traditions to portray the philosophical underpinnings and journey undertaken throughout the project. Second, I describe the principles underlying the co-design approach and present the research design. Finally, under data collection and analysis, the ethical considerations of the thesis, the types of data collected and the different analytical projects with their respective methodologies and research questions are portrayed. The chapter is closed with a summary and some concluding remarks.

3.1 Epistemological approach

As Dixon (2020) describes, beyond defining a methodological orientation, design researchers do not often trace out their philosophic grounding. The precise reasons for this are unclear (Dixon 2020). As the author describes, the field of design might be far too pluralistic to ever align with any singular perspective, and given the value sometimes placed on this pluralism, alignment may not even be desirable. It is possible to argue that design research, especially design research involving practice, is simply too multivariate to be defined and framed in final terms (Dixon 2020). Dixon (2020) also argues that at a fundamental level those who engage in design research need to do more to properly investigate, contextualize and refine their philosophic commitments, allowing the field to better represent its positioning and value.

How is its knowledge generated? What are its tools and techniques? What are the assumptions backing these up? How do these link to design? These are some of the questions Dixon (2020) associates with this situation. In responding to the methodological challenges, he describes that designer-researchers will be better able to
examine a particular field’s offerings and identify value at the same time as appreciating its applicability: where it might fit and how it might be used, that is, put ‘into practice’. Linking to other knowledge domains, designer-researchers often choose to apply the methods of that domain alongside those of design (Dixon 2020).

I also concur with Cross (1999, 8) that ‘We do not want conversations that fail to connect across disciplines, that fail to reach a common understanding, and that fail to create new knowledge and perceptions of design. It is the paradoxical task of creating an interdisciplinary discipline’. Throughout the project, I engaged with philosophical commitments reflectively, in a continuous, iterative fashion, integrating methods most associated with health and social sciences within a design research approach.

To describe this research approach we must ask what designing is and what it means. Cross (2006) claimed that design ability is, in fact, one of the several forms or fundamental aspects of human intelligence. Indeed, when I had a chance to volunteer within an orphanage in Nepal, I use to think that design knowledge was continuously manifested in children’s play. Children were oriented to purpose, but they did not always know what it was, often framing it retroactively. This characteristic movement from the initial conception to the developed proposal through an iterative, open-ended design conversation, routinely employs strategies for reframing understandings and critically positioning possibilities, which is informed by the logic of abduction (Stewart 2014). As Servillo and Schreurs (2013) describe, abductive reasoning is an act to understand through logical inference which is associated with interpreting through possible logical assumptions but without being supported by certainty. Although the intention is for it to be plausible, the uncertainty of the assumption is at the core of abductive inference and accounts simultaneously for an intuitive, plausible, economical way of dealing with complex phenomena (Servillo and Schreurs 2013). Explaining research-by-design in terms of abductive reasoning, the authors show how hypotheses are generated from the interplay of different bodies of knowledge and contexts in (cyclical) processes, which are also interdisciplinary.
Accordingly, the project is characterized by my engagement with pragmatism and abductive reasoning, relying on intuition stemming from previous experiences within mental health. In line with Dixon (2020), who offers a statement on the potential value of Deweyan pragmatism as a philosophy for design research involving practice, I considered design as a special kind of knowing and reasoning which aligns with this tradition.

In addition, my emphasis on the experiences of the participants, which relate to co-design and participatory principles, brought me to engage with phenomenology, methodologically and theoretically. Indeed, at the fieldwork stage, engagement with theory from phenomenologists became essential as these authors explore psychopathology from an experiential viewpoint. It gave me insights as well as tools to understand participants throughout the process. Methodologically, a phenomenological approach is adopted to work with the semi-structured interview data from some participants, using Interpretative Phenomenological Analysis.

And finally, working with people facing mental health problems, and especially participants who have experience of psychosis, in itself raised and somehow elevated, questions about the very nature of knowledge and reality. I reflect upon these insights with regard to Akama's (2018) proposal of welcoming the uncanny within design research, interpreting how what emerged contrasts with insights from pragmatism and phenomenology.

### 3.1.1 Insights from pragmatism

“Drop the conception that knowledge is knowledge only when it is a disclosure and definition of the properties of fixed and antecedent reality; interpret the aim and test of knowing by what happens in the actual procedure of scientific inquiry” (Dewey 1960, 103).
Indeed, the commitment that pragmatists share is an emphasis on engagement with practices, an emphasis sufficiently widely held as to affirm it as a true hallmark of the view (Heney 2016). Pragmatism tells us to engage with persons and practices, with moral life, with the pressing problems of the day with the best conceptual equipment we can muster (Heney 2016).

Within pragmatism, ideas matter not because of their correspondence to an antecedent reality but because of what they allow people to do and to get done in the world (Wills and Lake 2020). This emphasis on usefulness enables flexibility. Indeed, at the beginning of the project, overall, the view was that what ultimately mattered most about assumptions and beliefs is how much use they are to us. Yet what was to be useful or not, is what we wanted to understand. A paradox not dissimilar to that of designing, where 1) philosophical reflections took place alongside the project and 2) these proofed to change and adapt as the design process proceeded. Indeed, the alignments between pragmatist philosopher Peirce’s notion of abductive reasoning and designerly logic have been explored before (Dorst 2011).

I adopted a pragmatic lens as part of departure, tempted by this malleability, and its embedment in practice. I was also responding to intuition, based on previous experiences, that the situations encountered in mental health services often illuminate or question fundamental aspects of the world, and constitute fertile grounds for philosophical reflection. As Wills and Lake (2020) summarize, the early pragmatists were resolutely anti-foundationalist, rejecting the grounding of truth on a priori principles, understanding any such ‘truth’ to be arbitrary, socially constructed and unverifiable. Instead of searching for metaphysical or immutable truths, pragmatists held ideas as practical tools that can be best understood in relation to their consequences (Wills and Lake 2020). Hence, it is within this epistemological framework, that the phenomenon of collaborative design within mental health is envisioned, in preparation for the fieldwork. Pragmatism’s emphasis on the experience of the researcher was also key, encouraging me to use my intuition and planning and approaching the fieldwork (co-design projects) with confidence. To understand co-design in mental health, such a phenomenon needed to be
first created, and I had to base my decisions on something. In line with abductive reasoning, besides reflecting on previous experiences and embracing intuition, I also drew from a wide range of literature from different fields while planning for fieldwork.

Pragmatism rejects the “passive spectator” view of knowledge and introduces the active, creative agents who through meanings helps structure the objects of knowledge and who thus cannot be separated from the world which they know (plural tense is added) (Rosenthal and Bourgeois 1980).

The pragmatic approach to ethics is also aligned with the predispositions that I was bringing to the project. As Dixon (2020) summarizes, Dewey argued in favour of the cultivation of what he termed a ‘reflective’ morality, a form of negotiated imaginative inquiry, undertaken in response to contextual concerns, and open-ended in direction. It was suggested that this presents design research involving practice with a vision of an ‘internalized ethics’ grounded in decision-making (Dixon 2020). Progress can be made by recognising the inherent uncertainty of moral problems, the complexities of moral experience and being willing to inquire anew in every moral context, drawing in data from a variety of scientific disciplines, to lay down new intelligent habits (Hildebrand 2008).

This project began by aligning with the ethical guidelines of Islington Mind, which were shared by the director, whilst also acknowledging that challenging situations may emerge which inform an embedded understanding of ethical principles and open new questions. Indeed, Dewey’s theory of moral understanding is social, imaginative and artful in character (Fesmire 2003). Fesmire (2003) explores the nature and function of imagination as it plays a role in moral conduct, which proofed relevant to the project as ethically complex situations arose.

As Rosenthal and Bourgeois (1980) describe, in grasping the systematic interconnections within the structure of pragmatism as a philosophic system, its assertions must be understood as arising from, yet going beyond - in the sense of making meaningful through
philosophic interpretation—the immediacies of lived experience. The test for the adequacy of such philosophic interpretation must be found in its continual verification of lived experience (Rosenthal and Bourgeois 1980).

It is not until the fieldwork takes place, in the project, that the concept of adequacy as dependent on the verification of lived experience is questioned. Lived experiences of participants in the project were unusual, and the idea of verifying by further experience can be, in a way, problematic.

Another limitation of the pragmatic view became evident, as it understands the pre-reflective modes of experience, as a type of "knowing" rooted in modes of behaviour, which ground and reflect the dynamics of the scientific method (Rosenthal and Bourgeois 1980). Yet within some phenomenological theories, this very pre-reflective mode of experience seems to be affected in people who have psychosis, see for instance (Hirjak et al. 2013; Pienkos et al. 2019; Sass and Parnas 2003).

### 3.1.2 Insights from phenomenology

According to the Standford encyclopedia of philosophy, phenomenology is the study of structures of consciousness as experienced from the first-person point of view (Stanford Encyclopedia of Philosophy 2013).

The difference in interest on emphasis, pragmatism with explanation and phenomenology with description, properly cast can be seen as a difference through which each movement offers something of value to the other (Rosenthal and Bourgeois 1980). Indeed, In the stage when the fieldwork was happening, these two strategies were offering valuable frameworks within the design process.

Frauenberger, Good, and Keay-Bright (2010) argue that phenomenology also plays a critical role in participatory design when it is undertaken as an interpretive and generative
process, mindful of end-user experience rather than directed toward the specification of outcomes.

During fieldwork, this tradition becomes relevant not only as a methodological approach but due to the subject of study of many phenomenologists, the lived experience of psychopathology. Their insights on experiences such as psychosis became important as I tried to understand participants. As the systematic project of investigating the structures of subjective experience, phenomenology may also be considered the foundational science for psychopathology (Fuchs 2010a). Though it methodically suspends any assumptions about causal explanation, it provides a rich framework for the analysis of subjectivity and its disturbances in mental disorders (Fuchs 2010a). As Fuchs concludes, from a phenomenological point of view, mental illness is not something merely “mental” but manifests itself in dimensions such as self-awareness, embodiment, temporality and intersubjectivity, or in short, in an alteration of the patient’s overall being-in-the-world. (see section 2.5.2)

Once the fieldwork is completed and data need to be analysed, bracketing helps put aside the ideas which helped inform the fieldwork in the first place, and interpretative phenomenological analysis (IPA) enabled me to engage with participants accounts in depth.

Summarizing, responding to and recognizing my limitations in understanding participants, phenomenology’s contribution to the project is two-fold. In terms of content, I could delve into the study of the experiences of psychosis, become accustomed to people’s stories and familiarize myself with the world from this point of view. On the other, I adopted it as a methodological approach through Interpretative Phenomenological Analysis.

Interestingly, furthermore, suspending ontological assumptions is both a method for phenomenological investigations and something that often occurs naturally in psychopathology. According to Laing’s (1960) conceptualization, ontological insecurity is
a characteristic of psychotic illness. In a way, participants are not only subjects of study and are in an insightful position to conduct phenomenological investigations, due to their experiences, which leads us to the next chapter, welcoming the uncanny and reflecting on previous assumptions.

3.1.3 Welcoming the uncanny: reflection on previous assumptions

Engaging with participants facing mental health problems, while reflecting on the aforementioned philosophical traditions, resulted in insights which I describe below alongside what I learned from participants. How did the project challenge my understanding of the world, and the tools I brought to this journey to analyse it?

I first reflect upon how understandings or questions that emerged from working with clients with psychosis contrasts with insights from pragmatism and phenomenology, and then situate this with respect to Akama’s (2018) proposal of welcoming the uncanny within design research. As she encourages, for design researchers who are already adept at anticipating the mess, errors, disruption, serendipity and uncertainty (Akama, Pink, and Sumartojo 2018; Schön 1983) ‘uncanny’ encounters of ‘perplexing alterity’ need not be ignored or analysed with suspicion but can become a generative methodology. In doing so, in including the uncanny, in this project, we find clashes among the lens I have brought to the workshops, from the insights from pragmatism and phenomenology, and the understanding that emerged from our interactions.

For instance, I realize, the lenses with which I engaged to understand what was happening, generally appear to rely heavily on an individual notion of creation and experience. Both pragmatism and phenomenology are western philosophical traditions and although there might be exceptions, the way language is used and analysis is performed frames the nature of knowledge and origin of creativity within an overall
individualistic paradigm. One such exception might be Mead (1934), who understood the mind in social as opposed to individual terms, portraying the individual mind and self as arising out of the social process.

Concepts introduced by participants, such as Amara’s universal mind, or the way Nestor does not seem to feel the need to differentiate between the impact of the experience of designing on him and the impact of his design on users, are examples of how certain assumptions were continuously challenged.

From our interactions, I came to understand knowledge and its creation as much more serendipitous than the way I had seen it portrayed in the paradigms described earlier. The meaning and creation of knowledge do not necessarily emerge from the lived experience of the knower as a coherent framework, nor is always followed by experience which will confirm it. In sharing experiences with others, others’ interpretations of perhaps bizarre stories clash with our own and generate novel ‘truths’ which are not based on previous, individual ‘truths’. The emergence of knowledge does not evolve coherently from the lived experience of that who knows but from a collection of knowers. One may not know something, and is suddenly part of the collective knowledge production, and can even reflect on having known all along, in retrospect.

Therefore knowledge, in this project, is what emerges from our individual and collective knowings. Collaborative design is arguably generative through the interplay of different kinds of knowledge, not only among various disciplines but among various participants. A positive attitude towards possibilities of what constitutes reality is what enabled creative ways to connect, as well as the philosophically open mindsets participants had, possibly due to their psychotic experiences and therapeutic journeys. As one of the participants, Anthony, described, he does not want people to lose their position but be tilted. This attitude towards unusual beliefs acknowledges Anthony’s experience as real for him and is methodologically fruitful. It makes design research an opportunity to explore the uncanny and stir epistemological and ontological assumptions.
Another clash between this emerging epistemology and initial assumptions relates to how knowledge is valued. What is the value of knowledge created? And what if that knowledge is only useful for participants themselves, say as it may be aligned with their unique, unusual worldview, does it make it less valuable? Within pragmatism, the research must offer transferable conclusions that are seen to hold warranted assertibility, which is Dewey’s alternative mechanism for evaluating knowledge (Dixon 2020). In other words, the author reports, these must offer conclusions based on sound evidence, valid in its context of inquiry and useable in others. In contrast, Akama (2018) reports on an entrenched legacy of research towards replicable and generalizable knowledge that dominates, reflected by how the conventions of design research, especially in PD, trend towards an emphasis of reporting on technology, processes and methods as interventions into the lives of others. On one hand, I had sometimes framed co-design as an intervention that might be transferable, on another, I realize the importance of being cautious with this approach, especially to avoid devaluing non-transferable and non-replicable knowledge. As Akama (2018) reports, many notable postcolonial and feminist scholars have already reminded us that this framing of ‘knowledge’ is just one of many worldviews (Chakrabarty 2000). For many ‘others’, words, ideas and knowledge cannot be detached from places, people and practices in which they are embedded in so they cannot be moved to another ‘context’ (Akama 2018).

I conclude that these are not necessarily contradictory approaches, knowledge has intrinsic value for the people and context in which it originally emerged –and part of it might also migrate to other contexts. In my view, what must be questioned and transgressed is the hierarchy that assumes that knowledge which is transferred is more valuable. Knowledge which is non-replicable, nor generalizable or transferable is also valuable. Transferability, the extent to which a body of knowledge can be used in another context, can have an important role to play in social change, yet it is not necessarily what justifies its value.

Therefore, I find myself considering these epistemological underpinnings as lenses, philosophical strategies, attitudes, that inform descriptions that must be framed one way
or other for transformation to take place in various landscapes. Akama learns to respect what her cultural wisdom can reveal that her design research training (in the West) has taught her to ignore, and such (silent and embodied) politics can manifest in different ways so that Kaze on Denwa, as a design and technology intervention for social outcomes, might be described differently – one that accommodates the spirit and plural worlds, and another that is centred upon the Anthropocene. The politics of this choice goes to the heart of PD, especially for a discipline that attempts to champion the participants’ worldviews (Akama 2018). For me, a choice among one or other may not be compulsory, or perhaps I do not see conflict in adopting plural epistemological positions. Although I acknowledge the limitations of the societal bias toward certain kind of knowledge, this project can be and will be, described in different ways, to respond to a variety of purposes. It may frame co-design as wellbeing intervention and ponder upon the transferability of findings, intending to encourage other people to embark on similar journeys, and serve them in doing so. On the other hand, the becoming of us who went through the process, manifest in a variety of realities and situated knowledge which have intrinsic value, no lesser than that which could be confirmed by further experiences or that hold what Dewey referred to as warranted assertibility. After all, this situated knowledge resulted, at least for me, in personal growth and transformation, and the value of this cannot be underestimated. One of my major struggles when I finished the fieldwork was realizing that part of these shared experiences would not make it into a thesis format, it simply could not. Learning to value this situated knowledge, and accepting its loss once the project was over, was part of the journey.

Hence, I propose an epistemologically and ontologically reflective, or playful attitude to those who engage with collaborative design with people facing mental health problems, and give a hint on the philosophically fertile encounters that may emerge from such work. Such attitude resonates with Akama’s (2018) *what if* proposition. She speculates ‘what if’ design research and PD could embrace plural worlds and acknowledge omitted (dismissed) phenomena? What if these ideas were recognised or even foregrounded as a welcome addition towards an ontological ‘vocabulary’ that could begin to establish a
richer dialogue in design research, especially for cultures that have eroded ways to make sense of these? (Akama 2018). As she describes, the role played by such ‘uncanny’ phenomena is resonant with a Japanese anthropologist, Atsuro Morita, who describes ‘The innovation of method resides in the encounter with a perplexing alterity that refuses to fit the given framework but rather anticipates a new understanding presently beyond imagination.’ (Morita 2017, 246).

In this project, the uncanny is not only a result of a meeting of cultures but of unusual experiences happening among those who despite -or not- sharing similar cultural conditions, might have fundamentally different worldviews.

Inspired by the personal stories that Akama shares in her papers and to illustrate phenomenological bracketing in practice, I would like to finish this section with an instance of the uncanny recorded in my reflective diary. A day when telepathy became possible (Figure 2).

Amara mentioned about telepathy (...) [proposing] telepathy learning in the actual game [that we were designing] as part of spirituality [section]... At some point in the workshop she mentioned that her aunty was a clairvoyant and stuff like that and even her sister worked in churches doing these kinds of messages from loved ones (...) so I said ok and then I remembered (...) the game from the 70s where you have four cards and you have to guess (...) Amara was like ok go on (...) let’s try it and I was like... should we try it? (...) as part of a card [for the game that we are designing], (...) go on then so I made four drawings and I said ok you have to think about which one I am thinking and you have to draw it and so I looked somewhere else, (...) I decided that I wanted to think the spiral (...) and they draw the spiral, they draw it (...) I don’t know if they tell each other but I draw it, and I asked Uriel think about what I am thinking out of these four cards and then Uriel said ouh... (...) the donkey is jumping across the water, and then Amara was like (...) no Uriel it has to be (...) between the four options (...) I look at their drawings they showed me it was the spiral (...) and Uriel said (...) the spiral, and it was such a coincidence that we started laughing and obviously I don’t know if that feeds to their psychotic beliefs or delusional beliefs but the thing is that we started laughing and it was really tender moment where I said well, we are linked up aren’t we? and I think Amara said something very similar at the same time and we started laughing and
then Anthony said ok we are going to leave it at this high point we are not going to try again... (...) I was thinking how do we implement this as a card (...) little telepathy games erm... that kind of raise these questions of like spirits and connection, (...) I mean I told this to my own therapist and he had very interesting Jungian ideas about it (...) is almost like a very (...) primitive level of communicating and that jung had a name for it, that I don't know the name now he has told me twice but I forgot. Anyway, that is an interesting thing because it relates [to] (...) having a shared purpose all the time and how does this affect us psychically in a way (...) I thought they know my choices my my my sort of tastes. (...) they picked up on that by now maybe is a pure coincidence as well... but (...) is almost like a very tender unifying thing (...) the workshops are filling up with more and more moments that are this (...) sort of tender [moments]... (Reflective diary, 12.06.19)
3.1.4 Summary: a methodological journey

Summarizing, this research parted from a pragmatist position, journeying through phenomenology and concluded with a vision of its own that had emerged from the project itself and participant contributions, and aligns with Akama (2018) recent proposal to welcome the uncanny.

The thesis makes use of various forms of reasoning, at different stages. As Blaikie (2010) describes, different research strategies have a unique logic of inquiry and the abductive research strategy can answer both what and why questions, being used for exploration and description as well as for explanation. However, within an abductive approach of the research overall, there have been two analytical undertakings, that in view of appropriately responding to the research questions, were ruled by inductive and deductive modes of inquiry, using Interpretative Phenomenological Analysis, and convergent mixed methods respectively.

The continuous reflection on how these strategies integrate and come together to form a whole brings me to conceptualize this process as an epistemological journey.

This research is a great example that the value of investigating philosophical commitments during or even through design research is not necessarily positioning it in final terms, but enabling a reflection of how these philosophical groundings can indeed transform in the very process of designing, especially co-designing. By committing to the pluralistic approach of co-design yet maintaining a continuous close look into the philosophical underpinnings, the journey-like nature of such a process was revealed. This demonstrates that although design research is multivariate, there is some value in tracking the philosophical strategies adopted at each stage of the process, and wonder why these were challenged or transformed.
Hence, characterizing this chapter as an epistemological journey, I avoid making fabricated claims of sticking to specific assumptions on the nature of knowledge, being and reality, which would indeed undermine the transformative nature of the interactions that took place. From when the research questions were drafted, through the fieldwork when foundations of reality were up for discussion with participants, to the writing of this thesis which integrates knowledge belonging to different epistemological traditions, it was surely a bumpy road.

I propose to look at this journey-like nature of epistemology not merely as an inevitable methodological challenge of doing design research, but precisely its fundamental strength.

### 3.2 The co-design approach

In this subchapter I first describe the principles of co-design in general, my attitudes or orientation, followed by tools that are part of the practice of co-design, a portfolio of strategies that one can employ in response to the situations that are brought forward. Finally, I describe the project design, which functioned as a guide to aid timings and facilitation within which the aforementioned tools are employed.

#### 3.2.1 Co-design orientation

Overall, this thesis is investigating a phenomenon that is brought to existence only by the research itself, which is a common characteristic of design research with participatory action research, well known within the social sciences. Both design research and action research are concerned with bringing about change. Co-design in particular has been seen as a type of Participatory Action Research as it often draws from this methodology (Stewart 2014). The design researcher, nevertheless, embodies this process without being
reflectively aware of it as a process (Stewart 2014). In essence, Design processes both use knowledge and also produce personal knowing and collective knowledge which is different, with characteristics in common with other knowledge and distinct character of being embodied in the process of designing itself (Downton 2003).

Akama (2015) draws on the Japanese philosophy of Ma as ‘between-ness’ to explore the transformative potential of designing together. She describes co-designing as an activity based on emergence, where constituents are mutually changing towards purposeful outcomes. Referring to some of her experiences as a co-design workshop facilitator, she uses the concept of ‘between-ness’ as the vehicle (or tool) for the emergence of possibilities, present for instance when various participants are unsure about each other’s thoughts and actions and yet work together towards defining common goals. Her examples resonate with my experience of co-design workshops.

As Akama and Light (2018) ask, How do we ready ourselves to intervene responsively in the contingent situations that arise in co-designing for change? Hence, the way I situate myself within the co-designing environment, how I intervene or hold myself back, is important for how emergence manifests.

Akama and Light (2018) describe the act of readying ourselves for contingent Participatory Design. What readiness are we practising within the flexible and evolving conditions that are an inherent part of collaborative design work? They present ‘readiness’, and the need for attunement (Akama and Light 2018). As the authors describe, designer-researchers practice is widely recognized as configuring participation. They argue that in order to understand and work with tensions inherent in such practices, we require readiness: on the micro-scale, to respond to small moments of intersubjective nuance and to feel a way through; and at a macro-scale, to be dexterous and willing to work on turbulent, shifting sands.

Designers’ embodied knowing shifts from moment to moment, often in response to the intersubjective nuances of the group (Akama and Light 2018). The concept of ‘attuning’
has been developed in their previous work where they describe how, as: ‘the unexpected, divergent situation emerges, practitioners have to reassess and modify their systems of knowing-in-practice, allow adjustment to a course of action, change previously held views and build new understanding in the situation that is unfolding’ (Light and Akama 2012, 69). They explore sensitivity to relations and ways of ‘attuning’ to invisible, subtle and complex dynamics, and how these are shaped and conditioned by our upbringing, culture and society. This sensitivity is not taught in formal design training, though, arguably, it is a skill central to design facilitation and essential when negotiating ‘matters of concern’ (Akama and Light 2018).

Indeed, Light (2015) further suggests that it is more important to be attuned to relations and ready for anything in these flexible and evolving circumstances than it is to have an action plan. Thus, one skill is to make an appropriate judgment call on what might and could happen next and decide whether to intervene: to disrupt or to preserve (Light 2015). In co-design, therefore, first of all, we are attuned to relations, then we hold a portfolio of tools (section 3.2.2), or ways with which to be able to intervene, and finally, we may hold a general action plan, an overall idea of how the project may unfold, or a project design (section 3.2.3).

### 3.2.2 Tools

The designers often use commonly found, playful, everyday objects to access, interpret, visualise, articulate and communicate implicit knowledge through facilitated conversations (Light and Akama 2012).

The projects I organized made use of design tools that aim to emphasize what Sanders and Stappers (2012) described as societal-value co-creation, which mostly occurs very early in the design process and is linked to discovery.
Generally speaking, this method of using a set of tools to facilitate the design process aligns with what Sanders (2000) refer to as Generative tools, which describe a participatory design language that can be used by non-designers and can be combined in an infinite variety of meaningful ways. Activities based on chance, which focus on how to get out of habits and experiencing new things, are particularly relevant to this project due to their generative use of randomness.

Some tools were adapted from those I had used on earlier occasions when I worked with mental health participants through Bidean. Others were created from researching psychosis and brainstorming ways to engage participants. I also made use of an adapted version of cultural probes (Gaver, Dunne, and Pacenti 1999), which a participant later referred to as Cultural Specimens. Finally, tools, or activities, were also created ad hoc, in response to a particular situation.

Different participants are likely to feel more comfortable performing some types of activities than others. Therefore, in a group workshop, tools form different constellations to drive the overall project forward and encourage different kinds of engagement. Tools can be combined in different ways along a timeline to fit the different projects.

Whilst an experienced designer may usually drive design activity spontaneously by tuning into the requirements of the context or project needs, when facilitating projects with non-designers, this shift can be encouraged by introducing various tools or activities through a timeline. Therefore, these transformations are encouraged by managing tools in relation to our attunement and readiness (3.2.1) and the overall project timeline or design (3.2.3).
3.2.3 Project design

3.2.2.1 Design projects in collaboration with Islington Mind and Psychosis Therapy Project

Three design projects were envisioned, of which two finally took place. The design of these projects was based on an initial understanding of the services available at Mind, and the clients who usually attend them. Three different personas were developed that represented different types of clients and discussed with the director of the charity alongside their services.

The development of these projects was done based on previous experiences on co-designing with mental health clients, and by researching the charity, with whom I had worked on a previous occasion in evaluating and redesigning their services.

Additional meetings were organized with the managers of different services: the general charity drop-in, the enablement service, and the Psychosis Therapy Project, an organization that operates in various local Minds.

The enablement service is an 8-week program where clients specify a problem they want to work on, and they are paired with a volunteer that helps them articulate and resolve this problem, who meets them once a week at an arranged place. It is very popular, and there is usually a waiting list. Volunteers are usually psychotherapy students, or other individuals with an interest in mental health, who are trained for mental health first aid and other aspects such as safeguarding. The idea was to include volunteers with a design background, for instance, design students, that would be assisting the client in this process in a designerly way, thus using some design tools and techniques. The lead staff, design volunteer and the client would have been interviewed. Unfortunately, although some design students were interested in participating, this project could not take place
due to difficulties in coordinating timings between the training that is necessary to volunteer - happening every few weeks - and students’ course schedule.

One of the projects, ‘design at PTP’ was to be embedded in the Psychosis Therapy Project. It was organized to take place in the psychosis group drop-in area, where clients usually wait for psychoanalysis and engage with other activities from time to time. This project was approximately six months long and started without a fully articulated program, just by talking to clients and asking them if they would be interested in designing. The format had to be flexible as it is not likely that participants will always be there at the same times. It had a very loose framework for the workshops, and a general timeline. It was somehow more ethnographic in nature, with me starting to spend time in the space once a week and recruit participants by word of mouth.

The other project, ‘co-design for wellbeing’ was much shorter and more structured (once a week for 8 weeks). The idea is to explore a design project of short duration, which can be relatively easy to implement across different charities and even delivered by professionals who aren’t designers. It will not begin with a particular brief, but rather a process of identifying matters of concern. This makes the project slightly more challenging, and recruitment was by self-referral. The general framework for the project was based on a five-stage design process I had used in my social enterprise. Because the rationale for this PhD proposal emerged from this practice and participants feedback, I considered it important to undertake a similar project. It was organized to take place at the Islington Mind drop-in at the HUB.

**Design at Psychosis Therapy Project (PTP)**

The structure of ‘Design at PTP’ was designed to respond promptly to participants, and most activities were created or adapted while the project was happening. Therefore, it is difficult to separate the story of this project in two, that of methodology and that of research findings, since are both parts of the same whole.
However, for clarity, this section describes the process the way it was designed, whether that was before -in the planning stage before the project-or during -while the project was happening. To support the transferability of this method to other contexts, any detailed data on what participants did is excluded from this chapter and is presented in section (5.1).

Nine participants signed up to the project, three females, one Turkish (age 58), one white British (59) and another who marked ‘any other ethnic background’ (60), and six males, one who marked ‘any other ethnic background’ (43), another white Irish (57), one black British (44), one Turkish (56), and two white British (ages 71 and 58). These details were gathered anonymously after the project, to create a sense of the group demographics, and were not part of the questionnaires nor analysis.

The design project was conceptualized as composed of three phases, titled Understanding design, Finding and mapping situations, and Creating our design(s). The first stage Understanding design consisted of simple exercises to understand and define the groups’ notions around design. The second phase, Finding and mapping situations, aimed to share and map participants’ interests with the intention of co-creating a brief. For that purpose, participants were asked to create and use their own Cultural probes (Gaver, Dunne, and Pacenti 1999). Finally, the third stage Creating our design(s) centred on the creation of designs proposals which aimed to respond to the emerging brief(s). At the very beginning, participants were given a set of diaries corresponding to each stage, which could be used as they saw fit (Figure 3)

These phases were a way for the designer to structure the process, but apart from the diaries distributed at the start which contained an outline, it was not something that was presented again or tracked. In general, I continuously placed materials created in previous weeks on the table and would aim to weave together the ideas and insights that people were coming up with and include them in the following week, making use of the distribution and display of artefacts and questions across the table to coordinate this process.
Figure 3. Photos of diaries ‘understanding design’, ‘finding and mapping situations’ and ‘creating our design(s)’

**Understanding design**

At the beginning of the project, participants were encouraged to bring an object or more and comment on their significance and meaning.

A time-like mural was made to represent the histories of these objects and discuss how their design processes interrelated.

The objective was to begin formulating a shared sense of key notions, commencing from individuals’ relationship with certain objects and slowly extrapolating towards general definitions. Simple small templates were used to facilitate the creation of these definitions.

During this initial stage, I identified the need to complement these reflective processes with some hands-on design activities to be completed in single sessions.

*Swapping design briefs* consisted of writing a short brief and passing it to another participant, who would need to respond to it. *Making banana cases* was a short project to design and prototype a product in one single session.

**Finding and mapping situations**

This stage aimed to explore problems and opportunities that would help define a shared design brief, drawing from the participants’ situations and experiences. The makeup of participants’ everyday realities might be fundamentally different, which -despite
increasing the risk of the probes becoming irrelevant was an opportunity. To structure these cultural probes without overly prescribing the responses, and stay open to participants’ way of experiencing the world, general conceptual categories were discussed through an activity beforehand. What terms and categories would participants use to explore the world at the most abstract levels?

The exercise somehow illustrated different ways in which participants experienced and talked about their worlds but failed to inform a coherent inquisitive framework for the cultural probes. In the absence of any clear structure to guide the content that cultural probes should capture (e.g. what to capture), the structure was informed by the medium (how to capture) - a back to basics attitude. However differently, all participants could relate to the basic notions of taste, smell, sight, touch, and hearing, and these could also reflect the different ways in which information is captured. In conclusion, the cultural probes were finally designed in reference to the five senses, mostly reflecting the medium (e.g. photographs/sight) of the possible responses rather than the content.

Rather than giving a kit to each participant, probes or specimens (which were only partly made) were arranged over a table (disposable cameras, little containers for smell and taste, paper templates to make boxes for textures etc.) Participants were encouraged to build their own kit (Figure 4). The responses were spread out in the table, arranged thematically, and discussed. Storyboard templates were offered to encourage participants to expand from the materials in the table to interesting situations, and explore these alongside their potential to address interesting design brief(s). Although this exercise did not conclude with a clear brief, common themes emerged, as well as some notion of a shared purpose. The why of the design direction was established in very general terms (e.g. Stewardship).
Furthermore, participants were asked to think about whom they would like to design for, which did not emerge from the probes. Looking at these responses and reflecting on previous interactions with participants, I drafted 3 general groups we could design for, and three overarching functions. At this point, I decided to organize brainstorming sessions using these themes, the users that were mentioned by participants and the general sense of purpose determined.

There were three user groups, three functions and one overarching purpose, which I represented in different cards. Participants chose to couple the ‘user groups’ cards with the ‘function’ cards randomly, to form three combinations (e.g. user: Nature, function: to heal) that would guide three brainstorming sessions.

The purpose or principle overarching across all brainstorming sessions was determined as stewardship, or helping humanity.
Creating our design(s)

In the following week, one participant brought back a design concept which seemed to merge elements across two of the brainstorming sessions. The idea was shared with others within and beyond the group, and its originality and potential were reflected upon. Connections were made with the other themes from the cultural probes. The resonance of this idea with some of the other interests discussed and its potential regarding the collective purpose was used to drive the group’s efforts forward towards a collective project. The typology (e.g. a board game) had the potential to weave participants’ differing interests and skills into one single design concept with the overarching purpose of stewardship, increasing the likelihood of a sense of shared ownership, and allowing varying ways to participate in its further design.

In the final stage, participants design questions and ‘missing’ design decisions were given physical presence along the table to help participants navigate the process and contribute in various ways. (details in section 5.1.1)

The exhibition

The project concluded with an exhibition about the process and trying GAME with people who attended.

Co-design for wellbeing project

The research design was adapted from previous experiences developing a six-week co-design workshop (see bidean.co.uk). This co-design project focussed on cooperation in which participants find synergies across their different interests, but work independently on their respective goals (Zamenopoulos and Alexiou, 2018). Still, other forms of co-design emerged and were encouraged when it was considered favourable for engagement (e.g. when participants preferred to adopt a supporting role). I referred to such engagement as layered participation which aligns with the work of Kanstrup and Bertelsen (2018) who point to the designers’ obligation to legitimize a mixture of
investments in participation, including peripheral and low participation. Design opportunities are layered to encourage a variety of ways to engage.

The process was designed to accompany participants in exploring their interests and issues creatively, articulating a design challenge, and creating a prototype. They first expressed their challenges anonymously and explored them together as a way to inform design challenges. Next, they were encouraged to work on design solutions with some degree of cooperation. The intention was to create opportunities for participants to generate design ideas for projects that will help themselves as well as others, thus investigating indirect beneficial effects on their wellbeing. The process was guided by the 5 I’s - Identify, Ideate, Invent, Initiate and Implement (see bidean.co.uk).

Four participants took part consistently, although others joined informally at some points of the process. Another person joined briefly but was tired most times. The group demographics were: One female who ticked any other white background Spanish (age 50), another female black British Caribbean (47), another nonbinary English who preferred not to state their ethnicity (46), and two males, black British Caribbean (52) and white British (35).

Although some activities were created ad hoc or improvised to respond to participants, this project was shorter than the design at PTP one and much more structured.

*Identify*

At the beginning of the project, sessions helped participants familiarize themselves with design notions and identify issues, which are often informed by participants’ experiences. These are rearticulated as design challenges.

In one activity called “Infinite why’s”, participants sat in a circle, each wrote out an issue (often informed by personal experience) and placed it in a pot. The pot was stirred and each person took a note. They read their note aloud, and asked the person next in the
circle why? This person had to invent a reason, then ask why? to the next person. This process is repeated until the circle is completed, then another note is read.

Another activity made use of metaphors, like the tree. The main issue is written in the trunk with possible causes proposed as the roots, and consequences as the branches. Metaphors are a playful way to explore the complexity of some of the issues and involve an element of making which can be used as a strategy to encourage further participation.

Overall, the step Identify aimed to facilitate the externalisation of problems anonymously (e.g. Infinite why’s activity) and shift the focus from participants’ personal experiences to potential users’ experiences. This helped participants look at issues from a different perspective and become aware of how problems are often shared with others. Identify concluded by each participant selecting a design issue, although some preferred to take supportive roles. In this project, several challenges were chosen.

Ideate

In this stage, the focus was to facilitate the generation of ideas, through brainstorming. Different tactics were proposed to encourage participants, namely the use of performance and randomness. Performing can push participants outside their comfort zone, decreasing a judgemental attitude, and help generate more ideas. In one session, an issue was placed in the middle of the table. Using a box, each participant was encouraged to act out an imaginary solution in silence. Others had to express what they thought the person was representing, and each idea was transcribed onto post-it notes.

Otherwise, the use of random combinations of design elements was also particularly useful to stir the imagination.

Invent

Inventing something could be associated generally with parts coming to form a whole. Templates have great potential to guide this process for participants who may lack motivation or find making design decisions challenging. It can also help bring back
attention to the concept, and function as a communication tool between participant and facilitator.

*Initiate*

Finally, in *Initiate* prototypes were built using various mediums. They represented the designs created, culminated their efforts, and helped share the work with others.

*Implement (exhibition)*

This stage usually refers to the further development of ideas, in this case, the project culminates with an exhibition, where photos and descriptions of participants’ prototypes were put up on the walls at the mental health charity. The exhibition was open to other clients and staff of the charity and refreshments were served.

The exhibition is a great way to celebrate the group’s contributions and facilitate a sense of closure but is important to check if is something participants want to do.

### 3.3 Data collection and data analysis

In this chapter the ethical considerations, the types of data collected and the different methods of analysis are described.

For ethical reasons, all participants were given the option to opt-in or out participating in the different types of data collection, regardless of their engagement with design activities.

In the psychosis therapy project, nine people signed up and participated in the project engaging in different ways and with different intensities, out of which five completed questionnaires before, after and six months later, and conducted semi-structured interviews after the project ended, and again six months later. One additional participant
engaged in a semi-structured interview after the project, but did not complete questionnaires and was not possible to contact six months after for a second interview because he changed the arrangements with the services.

In the co-design for wellbeing project, seven participants signed up, of whom four participated throughout, three agreed to be interviewed, and one of them was also comfortable with being voice recorded and filling the questionnaire.

Photographs and a reflective diary, in written and audio format, were also kept for both projects.

Data collected within the Psychosis Therapy Project was analysed following two methodologies IPA, and convergent mixed methods, both of them further explained below. IPA was conducted from a phenomenological viewpoint, a bottom-up approach from the interview data on six participants. The convergent mixed method looked at the results of the questionnaires and then identified relevant data from the interviews to triangulate findings and look at how the project affected participants wellbeing.

All data from the co-design for wellbeing project was analysed through case study analysis.

Finally, data from both projects are used to contribute to the seventh chapter which looks at facilitation within mental health, where co-design strategies are reflected upon in relation to the experiences portrait by participants, alongside insights on ethics.

### 3.3.1 Ethical considerations

Here I describe ethical considerations as they hold relevance to methodology. Further reflections on ethics concerning the project are explored in section (7.4.2.2).
Unlike many scientific projects, where recruitment can be done to fit research design, this project prioritises principles of equal access as it was embedded within the services provided by a charity. This meant that a methodology such as IPA, which was first discarded because of the potential heterogeneity of participants, was later deemed most appropriate due to the small sample, common experience of psychosis (homogeneity) and richness of interview data. On the other hand, questionnaire data of a small sample had not much value to be analysed statistically yet could be triangulated with interview data to respond to the specific research question questionnaires intended to tackle. Other questionnaire data (IUS questionnaire see section 3.3.2) had to be excluded from the thesis because there was not enough evidence in the interviews to triangulate findings, and the sample was too small for statistical analysis.

This opportunistic approach to research design responds directly to ethical commitments of working in collaboration with a charity that has a past and a future to attend to, a culture, a set of principles and an existing relationship with clients.

For instance, in my view, once a project is offered to potential participants, one could not simple withdraw it or delay it for a long time because it did not recruit the number of people necessary for a certain type of analysis, or because the people who want to engage with the design project do not feel comfortable being recorded in the interviews. Ethical considerations for reliability and equal and flexible access were prioritised in this collaborative scenario, and its methodological implications cannot be underestimated.

Formal consent was the necessary condition to participate in the project, but questionnaires and interviews were voluntary. All participants were reassured that they could choose to participate in one way or other and that interviews and questionnaires were not necessary for them to engage in the project.
3.3.2 Data collection

Different kinds of data were gathered, semi-structured interviews, questionnaires, a reflective diary and photographs. The figure below visualizes the different types of data gathered from each participant at different times in the two projects (Figure 5). Intense and light engagement refers to the amount of involvement a participant had throughout the project, for instance if they were rarely joining the group at first and then begun attending regularly, the inner circle fraction corresponding to that participant will be pink and progress outwards towards turquoise gradients.

Figure 5. Visualization of data types and collection times.
Semi-structured interviews

Semi-structured interviews were organized with participants after the project concluded and approximately six months later. The flexible interview template used in the first interviews can be seen in (Table 1).

Table 1. First semi-structured interview template.

- How was your experience of this project?
- What do you think happened?
- Could you share any memorable moments, thoughts ...etc during this project?
- Did you notice any changes around you or within yourself as a result of taking part in the project?
  - Prompt any further reflection on details, the feelings, behaviours, thinking ...etc.
  - Are there any everyday life changes? (prompt with day in the life)
- What do you associate these changes to?
  - Would you say this project contributed to any of this process?
  - Why could these changes happen?
    - What aspects of the activity you think facilitated those changes?
    - How would you link the design processes with your experience of change?
  - How do you relate this to anything else that happened in the same period of time?
    - Either around this project or other things outside that may have affected this.
- What do you think worked?
- What would you change to make this activity/project more beneficial for participants?
  - Share about our aims when we designed the project and ask how this could be improved?
  - Share the research question (designs and mental health) and ask opinion and why.
- Any other feedback

Questionnaires

The WEMWBS 14-item wellbeing questionnaire (Warwick Medical School 2020), the short version of the IUS Intolerance to Uncertainty Scale (Carleton, Norton, and
Asmundson 2007), and three subscales of the Ryff’s wellbeing scales (Ryff 1989) were used.

The WEMWBS is widely used in evaluating diverse public health interventions, whilst being sensitive to change in psychiatric populations (Stewart-Brown et al. 2011). As discussed with the director of Mind, it is now used extensively throughout a wide variety of services in the UK, and I have used the test previously in the evaluation of co-design projects I organized at the V&A. As Stewart-Brown et al. (2011) describe, the questionnaire offers rigour for research and evaluation in public mental health, but also positive focus offers a developmental perspective which helps orient policymakers, participants and respondents towards mental wellbeing and identifying protective and promoting factors.

In the WEMWBS, item scores are summed to produce a total score ranging from a minimum of 14 to a maximum of 70, with higher scores representing higher levels of mental well-being. Most importantly, although the measure was not developed for monitoring a single person’s level of wellbeing, the WEMWBS scales have been shown to be responsive to change at the individual level and some practitioners are using them to help clients and patients think about ways in which their mental health is changing (Warwick Medical School 2020). Different statistical approaches give different results with regard to minimally important levels of change. For the 14-item scale WEMWBS, the methods give a minimum of 3 points and a maximum of 8 points (Warwick Medical School 2020). Therefore, considering Maheswaran et al. (2012), a change of 3 or more units (1 SEM) in an individual’s WEMWBS score was greater than the measurement error in the majority of the studies they analysed and thus could be interpreted as important.

Furthermore, the ‘purpose in life’, ‘personal growth’ and ‘self-acceptance’ subscales of the Ryff Scale of Psychological Wellbeing were used, employed also in the mixed methods approach adopted by Corcoran, Marshall, and Walsh (2017) in studying the psychological benefits of cooperative placemaking. Conducting this questionnaire was considered
important because of these earlier study findings - e.g. involvement in the sessions leading to personal growth, moderate effect (Corcoran, Marshall, and Walsh 2017) - but participants had difficulty understanding some of the questions due to the use of double negatives.

One of the insights developed before the fieldwork took place involved the notion of uncertainty. It was believed that participants relationship to uncertainty may change as a result of engaging with design. The test used was the short version of Intolerance to Uncertainty (Carleton, Norton, and Asmundson 2007). However, only one of the participants appears to touch upon this theme in the interviews, which is not enough to triangulate data from such a small sample, leading to their exclusion. Hence, qualitative insights around uncertainty are integrated into chapter seven, section (7.2.3).

**Reflective diary**

A reflective diary was kept in both written and voice format, which was later transcribed. The written notes could be taken during the workshops, but as I was immersed in our interactions this was kept to the minimum. After every session, as soon as it finished, I voice recorded everything I remembered happening and my reflections.

**Photographs and other materials**

Photographs were taken after every session – very rarely during, to avoid any distraction. The work done on that day was stored in an allocated space in the charity, often to be used again in the following week.

**3.3.3 Data analysis**

Different analytical approaches were used to respond to the various research questions, considering the type of data that were gathered in each project and the sample of
participants. Upon introducing them in relation to the chapters first, I reference and develop them further one by one.

A case study analysis was used with data on the short project, ‘co-design for wellbeing’, to look at the design process, how participants were impacted, and summarize key challenges and opportunities (results in Chapter 4).

IPA analysis was conducted with interview data of six participants from the Psychosis Therapy Project, to explore their experiences openly, understanding and interpreting how was it like for them (results in Chapter 5).

Mixed method analysis was conducted, using the semi-structured interview data from five of the participants at the Psychosis Therapy Project (same data as the IPA analysis) in combination with the questionnaire data, to understand changes in wellbeing (results in Chapter 6).

Finally, abductive analysis is characterized by both inductive and deductive reasoning, and was employed to look into how facilitation of the co-design project happened. It combines insights that emerged during the project and also from the interviews, with the strategies I made use of. In essence, I reflected on the process and my role in relation to the interview findings (results in Chapter 7).

3.3.3.1 Case study

For the co-design for wellbeing project at the drop-in area, as this research wanted to observe and better understand the experiences of a relatively small group, of whom only one participant was comfortable with interviews being recorded, a case study method was selected. The other two participants, whose responses were indeed much briefer, agreed to be interviewed with notes being taken.
The recorded interview was transcribed using the NVivo tool, and the notes from the other two interviews were also imported. Their responses were organized by general experience, impact and any effects on mental health reported.

Reflective diary entries were transcribed within NVivo for any observations I had made during the project, and pictures reviewed.

Finally, all data were integrated into the case study, focusing on the experiences of participants on one hand, and the project’s challenges and opportunities on the other.

### 3.3.3.2 Interpretative Phenomenological Analysis

How is it like for people with mental health problems to engage with designing? How is it similar or different from experiences with other activities? These are some of the questions that I was set to explore when choosing to use Interpretative Phenomenological Analysis.

Before the commencement of the project, I had anticipated that the group would be too heterogeneous and that there would be too many participants for such in-depth analysis, which made me discard IPA. Following completion, nevertheless, I realized the data I gathered lend itself most convenient for this type of analysis, and a retrospective evaluation was made to make sure the principles of IPA had been respected throughout the project. A phenomenological approach had been already taken, and the semi-structured interview questions were in line with the kinds of investigations that are often studied through IPA. I review details of the process in various sections. I start with reflexivity, the process that enables being aware of personal perspectives, as these influence participants and interpretations. Then, IPA characteristics are introduced concerning this project, laying out any methodological variation from a typical IPA study, and illustrating the process with images to delve into a detailed description of the analysis.


**Reflexivity**

The priority was to understand the worldviews of participants themselves. Previous notions were, to the possible extent set aside, yet they were also necessary to facilitate the workshops. Hence it is important to note that this is a special kind of IPA analysis, because I was not interrogating experiences they may have had before I intervened as a researcher, but about a phenomenon that was created as a result of our interactions.

Continuous reflexivity helped keep track of the evolution of my perspectives, what intention I may have brought to the group, the reflections on the design process as it was happening, my impressions about participants, and ongoing interpretations. A reflective diary was kept throughout the project, recording voice notes weekly while I embedded myself in the context, get to know participants, and create activities to engage them. After every workshop, as soon as I was on my own, a summary of what happened, and my thoughts and ideas would be reflected upon and voice recorded. These reflections would be used, in combination with the original co-design structure, to inform the consequent workshop. Often there would also be last-minute changes depending on what participants were present and what was brought back. These files were later transcribed and revisited.

In presenting the findings of the IPA project, one first section (5.1) is dedicated to spelling out the project summary, and an introduction to participants from my most personal point of view can be found in (appendix 2). The intention is to be transparent about my position and possible bias.

**IPA**

Interpretative Phenomenological Analysis, or IPA, is a qualitative research method used to look into how people make sense of their experiences, understanding their relationship to the world through interpreting their sense-making.

As Marczak and Postăvaru (2018) describe, IPA emphasizes the need to understand an individual’s lived experience through exploring their involvement in a specific event or
process. It is based on a model of a person able to reflect on and interpret what is happening around them to make sense of their experience (Marczak and Postăvaru 2018).

Although IPA is used in many areas, it can be seen to be working at its best with relatively new research topics for which not much is known or in areas that are inherently complex or ambiguous (Smith and Shinebourne 2012). It is thus highly appropriate to understand the experiences of participants of the design process, a new area of inquiry.

The focal point of an IPA study is guided by open and exploratory research questions (Smith and Shinebourne 2012), such as the semi-structured interview plan described in section (3.3.2).

IPA has three primary theoretical touchstones: phenomenology, hermeneutics, and idiography (Smith and Shinebourne 2012). As the authors summarize, the philosopher Edmund Husserl, founder of the school of phenomenology, argued for an approach that attended closely to human experience in its own terms, rather than according to a predetermined category. For the psychologist, this means bracketing one’s preconceptions as far as possible and allowing the phenomenon to speak for itself (Smith and Shinebourne 2012). As authors review, Heidegger (1962) was particularly concerned with how our experience always occurs and is made sense of within a situated context. For Merleau-Ponty (1962) a key factor was the importance of our bodies in enabling experience, and Sartre (1943) was primarily concerned with our relations with others. One can see how each of these thinkers is making their contribution to a holistic account of human experience, and IPA draws on this phenomenology as the underpinning for its approach (Smith and Shinebourne 2012).

Although IPA is concerned with experience and its meaning to people, it recognizes that this cannot be transparently extracted from people’s heads—rather, it involves a process of engagement and interpretation on the part of the researcher (Smith and Shinebourne 2012). The authors explain how IPA is also influenced by hermeneutics, the theory of interpretation. Smith and Osborn (2003) refer to double hermeneutic as the process
where a researcher is trying to make sense of the participant who is trying to make sense of what is happening to them.

Most commonly, an IPA study involves a small number of cases each analysed in turn and then moves to look for patterns across cases while trying to retain the individual nuances, presenting an analysis of convergence and divergence within the sample (Smith and Shinebourne 2012).

The aim then is to look in detail at similarities and differences within a group that has been defined as similar according to important variables (Smith and Shinebourne 2012), in this case, the experience of psychosis. Deciding on the extent of homogeneity is guided partly by interpretative concerns (degree of similarity or variation that can be contained in the analysis of the phenomenon) and partly by pragmatic considerations (ease or difficulty of contacting potential participants, the relative rarity of the phenomenon). In this project, pragmatic considerations included that project participants could choose to be interviewed or opt-out (and be audio recorded or not) and the rarity of the phenomenon- the first project of this kind. All participants of the IPA analysis had experiences of psychosis. The inclusion criteria were being a client of the Psychosis Therapy Project and having signed up for the design project. Furthermore, for this analysis, only those participants who opted for being interviewed and were happy to be recorded were selected, as IPA requires a verbatim record of the data collection event, for individual interviews usually audio recording (See Smith, Flowers, and Larkin 2009). However, to contextualize, all nine participants who signed up are introduced in (appendix 2). The detailed IPA analysis then focuses on those six who were interviewed and audio recorded.

In line with the theoretical underpinnings of IPA, participants are selected purposively because they can offer access to a particular perspective on the phenomena being studied (Smith and Shinebourne 2012). In this project, all participants in the group were invited to be interviewed, regardless of the intensity of their engagement with the project, because
every individual would have a particular perspective and for ethical considerations –
participants are offered the same options.

Once the first interviews were conducted, recordings were imported to NVivo II and
transcribed using their software (Figure 6). As Smith, Flowers, and Larkin (2009)
described, some of the existing computer software produced to assist with the
organization and coding of qualitative data allows the analyst to code directly to text,
images or digital recording.

In the first instance, every individual’s transcript was printed, and read several times,
making comments on the margin. Each case was thus analysed separately first, and the
comments, interpretations and questions were then inputted back into the software as
annotations. Within the program, any especially poignant phrases which were underlined
in the printed version were coded (assigned a node) titled ‘key’. Questions, notes, and
possible interpretations were noted with a view of trying to understand the unique
experience of each participant and what they may have meant in their descriptions and
comments. What is it like for each participant? In this first analysis, I was dubious of my
sense-making ‘But what did she really mean?’, an attitude which proofed to be
interpretatively fruitful.
Cases were automatically generated from the transcripts, assigning one case to each speaker. Each interview transcript was coded using software—called nodes in NVivo. These nodes—or themes—were mainly focused on what Smith, Flowers, and Larkin (2009) refer to as descriptive and conceptual comments. The language usage of participants was not analysed, although the sentiment of the interview was considered important—I often revisited the original audio to listen to the participants’ tone again. When transcriptions are done with the NVivo tool, all the text can be traced back to the corresponding recording fragment due to its tracking of time. In fact, participants repeated words very often (e.g. the, the, the…), which is possibly characteristic of their condition, but these were considered beyond the scope of this analysis. Curiously, while listening to my voice I noticed I was mirroring those kinds of repetitions, possibly an involuntary reflex for nourishing comfort. Using brackets, these repetitions are often omitted from the fragments reported in this thesis to facilitate reading.

As Smith and Shinebourne (2012) describe, often the analysis of the first case becomes part of the hermeneutic circle of understanding, inevitably influencing the analysis of the subsequent transcripts. However, following IPA’s idiographic commitment, it was important to keep an open mind to see if new themes emerged from each transcript (Smith and Shinebourne 2012). The naming of the codes at this stage often used participants terms. One limitation I found from conducting IPA with the NVivo software was the inability to create codes from the annotations themselves, hence code my own interpretations, to visualize the patterns that emerged from this.

Six months later, participants were invited again, when available, to discuss doubts arising from the original interviews, when I was not too sure if I was right in understanding them in one way or other. This revisiting is not perhaps typical of IPA, as it may lead to participants constructing retrospectively. However, having known participants for a while meant that I was also able to do interpretations (moving away from data) based on my understanding of them as a result of our interactions. The conceptual coding was particularly rich since the experiences under study were, to a degree, shared with me, too. On one hand, it had kept the idiographic focus, as each individual was asked questions
that arose from the analysis or their own initial account, clarifying doubts and seeking feedback for initial interpretations. On the other hand, an overall sense of themes from the group also enabled some prompting to participants in the second interview – only if it stayed somehow relevant to their case. Insight from one of the participant’s interviews, for instance, helped interpret the comment of another, which helped me prompt yet another to elaborate further on the subject. Therefore, the process was iterative, as transcripts were reviewed in light of new nodes. The first, the second, and in one case the third interviews, are categorically different in that sense, as the subsequent ones are inevitably more conversational, where I sought clarification and feedback, and we both constructed meaning together. For transparency, all data fragments specify if they are from the 1st, 2nd or 3rd interview.

Following Smith and Shinebourne (2012), at the final stage, some themes (nodes) were combined, making decisions on their pertinence and capacity to illuminate the account as a whole. Codes were thus grouped into superordinate themes, using NVivo (Figure 7).

Figure 7. Themes, or nodes, being grouped into superordinate themes
Some themes are relevant to all participants, whilst others might not be mentioned as often, but are considered superordinate nonetheless, by reason of their complexity and depth. Some visualization tools in NVivo are used to look at the structure of the themes (Figure 8).

![Visualization of nodes and how they merge to form themes.](image)

Figure 8. Visualization of nodes and how they merge to form themes.

The writing up of the study involves presenting the final general themes, illustrated with extracts from the participant and followed by analytic comments, referred to as narrative account, taking the themes established in the final table and writing them up one by one (Smith and Shinebourne 2012). In a typical IPA project, the narrative account is followed by a discussion section that considers the themes identified in the analysis in relation to existing literature (Smith and Shinebourne 2012). It is sometimes also possible to choose not to have a clear demarcation between these two sections and rather to relate themes to the extant literature as you are going along (Smith and Shinebourne 2012).

In this project, I opt for something in between. Due to the complexity of the phenomenon and the wide variety of literature relevant to the emergent themes, a separate discussion is added after each theme.

One theme, titled ‘change’ or ‘bettering’, based on explicit mentions of improvement and wellbeing, was omitted from the IPA narrative account due to considerable crossover with findings from the mixed-methods analysis.
3.3.3.3 Convergent mixed methods

To explore how co-design affects wellbeing, different surveys were conducted with participants who were comfortable undertaking them, before, after and 6 months past the conclusion of the project. Although three different surveys were conducted (Ryff’s wellbeing subscales, WEMWBS and IUS) only WEMWBS appears to be sensitive to changes at an individual level.

Although the project as a whole prioritizes qualitative research, for this particular question a mixed-methods approach was chosen. When a quantitative and qualitative element may help better respond to research questions, mixed methods designs are needed (Creswell 2011). The wellbeing questionnaire results were analysed case by case and then contrasted with the interviews.

Shared in all mixed methods designs is the collection of qualitative and quantitative data that is intentionally integrated (Bartholomew and Lockard 2018).

Convergent studies in particular include collecting qualitative and quantitative data concurrently, analysing data separately first and then integrating it (Creswell and Plano Clark 2018).

In line with Hanson et al.’s (2005) description of concurrent triangulation designs, interpretation involved discussing the extent to which the data triangulate or converge. Integration critically differentiates mixed methods from multiple-methods research; that is, mixed methods designs require intentional integration of the different data strands collected in the study (Bartholomew and Lockard 2018).

In this case, the qualitative analysis had already happened independently, inductively, through IPA. Separately, each individual’s scores were imported to SPSS. Finally, results from the wellbeing questionnaires were analysed case by case to see if there was any correspondence between their scores and what they expressed in the semi-structured interviews. The account was nevertheless limited to the areas covered by the
questionnaire and excludes more complex descriptions from the interviews -explored through IPA. A deductive process that triangulates the notions interrogated by the questionnaire with interview data.

Questionnaires

At the start of this project, it was unknown how many participants would sign up to participate in co-design, and from those how many would be comfortable doing questionnaires. Only five individuals at the design at PTP project and one participant at co-design for wellbeing completed these before, after and six months later. One participant from Design at PTP completed one before but left the service before the project finished. This presents considerable limitations in analysing this type of data.

While the WEMWBS questionnaire has been demonstrated to be sensitive to changes at an individual level, Ryff’s wellbeing questionnaire does not have such measure-reference to assess important changes in scores. Similar is the situation with the IUS score. It is not clear what amount of variation could be just noise. Furthermore, the IUS and Ryff questionnaires were relatively difficult to understand by participants, in comparison with the WEMWBS questionnaire. The double negatives in Ryff’s questionnaire were particularly challenging for participants, requiring me to repeat the sentence or change it to see if they understood it well. With the IUS questionnaire, several participants were struggling with the concept of uncertainty in itself. Furthermore, only Anthony’s interview has any evidence on the subject of uncertainty being relevant to wellbeing, thus these data have been excluded.

Furthermore, in comparison with Ryff’s questionnaire subscales, which focused on three aspects of wellbeing, self-growth, purpose in life and self-acceptance, the WEMWBS wellbeing questionnaire covers a wider area, lending itself more appropriate for the mixed-methods analysis. However, at the end of each case, the scores on Ryff’s scale are reported, with a short commentary on how it may or not be congruent with the results from WEMWBS. This should be interpreted with even further caution, due to the
significant limitations outlined above - difficulties with comprehension, and lack of evidence of what constitutes meaningful changes relative to one individual.

Summing up, earlier research in WEMWBS and its effortless uptake facilitated the integration of qualitative and quantitative data, whilst the Ryff and IUS results could not be integrated in this manner.

*Semi-structured interviews*

The same interview data analysed through IPA was used, excluding one participant’s interview who did not fill the questionnaires. On this occasion, rather than analysing data inductively, this was looked at through the lens of the items interrogated by the WEMWBS questionnaire. It is important to note that the IPA analysis took place before the mixed methods approach was applied.

**3.3.3.4 Abductive analysis**

Data from both projects were analysed abductively, reflecting in questions around the facilitation of the project and the proposal of design as healing.

Chapter seven combines my approach to facilitation, my intention and strategies, with insights that emerged from the interviews, as I reflect on the process and my role in the project.

How and why could design facilitate the experiences described by participants? How and why should design be considered as healing? Chapter eight discusses the phenomenon of co-designing with people facing mental health problems and integrates findings from the various studies into an overall narrative, resulting in a proposal, co-design as healing.
3.4 Summary and concluding remarks

As Dixon (2020) summarizes, in seeking to gain a handle on the problematic situation, designers likely draw connections to various otherwise unrelated fields, identifying value in specific (possibly alien) knowledge domains and attempting to draw this knowledge together in the context of their inquiry. Indeed, the interdisciplinary nature of the project and the lack of previous proposals of a similar kind required drawing theoretical knowledge and methodological tools from various fields, and their integration was not without its challenges.

Overall, a commitment to the principles of collaborative design, informed by previous experiences, guided the inquiry. By integrating various methodologies within the co-design project, and interrogating their contribution, my hope is to demonstrate the creative benefits of such methodological wrestle, when a project does not comfortably sit within the boundaries of any single tradition.

Through mixed methods, IPA and case study, I make use of the analytical tools that ultimately enable me to tackle each research question. Data collection and analysis were bounded by the context (working in a charity), availability of participants, and ethical considerations. Unlike other situations, where recruitment can be done to fit the research design, this project was collaborative, and first and foremost needed to respect basic principles of equal access for clients at the charity. Once a project is offered to potential participants, one may not simply withdraw it or delay it for a long time because it did not recruit the number of people necessary for quantitative analysis, or because the group was not homogeneous enough.

Epistemologically, this project challenges the notion of assumptions staying stable throughout the research process. While many fields do need this epistemological commitment as part of the rigour of their enterprise, design research’s rigour precisely relies on its philosophical versatility. By committing to the pluralistic approach of co-
design, yet continuously interrogating accompanying philosophical groundings, the journey-like nature of epistemology within co-design was revealed. This demonstrates that although design research is multivariate, there is some value in tracking the philosophical strategies adopted at each stage of the process, and reflecting on how these were challenged, transgressed or transformed along the way. An epistemological journey.
4 Case study: co-design for wellbeing short project

4.1 Introducing project and participants

The project used a five-stage design process borrowed from earlier experiences at my social enterprise Bidean (Identify, Ideate, Invent, Initiate and Implement), which commenced on the 16th of May 2019 and lasted 8 weeks. In this case, ‘implement’ which might refer to further developments, was considered the exhibition.

Unfortunately, not everyone attending the first day was comfortable with the formal process of consent forms, preventing them from joining. One of the important observations around recruitment was how Bea, a trusted participant, helped ease the concerns of another participant, Damian, who hesitated about paperwork. She assured him that he did not have to do the questionnaire if he did not want to, and explained what the consent form was for.

At this time, the charity was going through retendering, and staff had little time to mediate between participants and myself for recruitment. Other problems due to this exceptional circumstance included last-minute charity meetings (which included participants) which meant workshops becoming shorter without notice. All in all, four people attended the sessions fairly consistently throughout: Damian, Bea, Liam and Raymond. With regards to reflexivity, personal descriptions about participants can be found in (appendix 1).
Identify

Overall, the step *Identify* aimed to facilitate participants finding and thinking about ‘design problems’ that they may be interested to tackle, whilst introducing some general design principles too. The activities sought to facilitate a shift of focus from participants’ personal experiences to potential users’ experiences; or from *my* problems to *ours*. Some activities encouraged sharing issues anonymously with one another (e.g. put in a box) and others helped thinking through these and translating them to design challenges that refer to a user group—the externalization of problems.

*Identify* concluded by participants coming up with different design issues to tackle. In this project, several challenges were identified, namely (i) How to get help with grief?, (ii) How to feel more calm and relaxed?, (iii) How do we improve (our) understanding to improve inventions?, and (iv) How to feel self-love?

On the first day, we did an activity called ‘constant gaze portraits’, where participants were invited to draw one another without looking at their paper and without separating the pen from the paper.

Two further activities were focused on discussing design as meaning-making and problem-solving. For the meaning-making activity, the maze tablecloth (Figure 9) was placed in the middle and participants were invited to place objects that they brought or found around, associating them to different topics (e.g. home).

For the problem-solving activity, everyone was invited to make a device to help an egg fall to the floor whilst avoid breaking it (Figure 10).
Figure 9. The maze: A tablecloth embroidered with different sections related to different topics.

Figure 10. Egg protecting devices made by participants
We did an activity where participants design without talking which I had tried in the other project and we students. Then we reflected on what we have made, who was it for and why was it important (Figure 11).

Another activity called ‘The infinite whys’ was used to help participants delve deeper into perceived issues. The activity is inspired by the five whys (Serrat 2009) exercise. In this version, where each participant writes a problem and places it in a pot anonymously. In a circle, each participant draws a problem and asks the person next why? This person speculate for a reason behind the problem, and asks to the next, why? then the person next speculate a reason for the reason, and so on until everyone has taken a turn. Examples are shown below (Figure 12).
We also used metaphor to explore the interrelatedness and complexities of issues. Each individual was asked to make a tree to explore how a problem was interconnected, how experiences were networked: Fruits were used to describe things that helped, routes as causes, and branches as consequences (Figure 13).
As a final step, one collective tree was created to share and integrate people’s analysis into a whole, weaving the individual insights into one common creation (Figure 14).

Toward the end of this stage, participants choose one issue from those discussed or written in trees and turn it into design challenges or questions. Often participants chose what felt most relevant. Another activity involved working with these questions to generate sub-questions. In the reflective diary I record:

Damian didn’t say anything about the causes of mental illness (...) [he said] nothing comes to mind and then Bea spoke for him and she said well grief, for example, it was grief wasn’t it (...) he said yes grief, and so he said how do you write grief? and he wrote it down...so is like you know the companionship (...) how they know each other (...) somehow encouraged Bea to sort of speak for him (...) I guess knowingly that is something that he would be ok [with] (...)

(...) I asked them (...) to choose from the whole tree of issues and coping mechanisms etc. etc. to choose one and turn it into a challenge (...) (Reflective diary, 11.06.19)
Figure 14. ‘Tree’ group activity to analyze how problems relate to one another.

(... from that central, how to cope with grief question, for example, (...) come up with different subquestions, and that was really really good, so Bea went for it directly and Damian had a bit of difficulty at the beginning but then (...) we give him a couple of examples and then he continued, finished it, same with Liam (...) they just filled it all up (...) I had time to do one for me and then we shared a little bit (...) Damian, he said no I don’t want to share it and that it’s fine (...) (Reflective diary, 11.06.19)

Finally, we explored ways to research the challenges. I talked about contemplating or observation, talking to people or interviewing, or looking it up or desktop research. Participants were encouraged to consider using one way to find out more about the challenge. We also talked about how first-hand experiences help inform the design challenges.

I asked Damian what research he wanted (...) interviewing and I said (...) we can practice that here now, and he said can I interview you? (...) and Liam wanted to do the contemplating (...) [yet] he was struggling what to choose [I asked] what are you most curious [about]...and he was like (...) I am not sure (...) don’t worry just have a
thought and you know you can choose more than one... and so he started (...) to write down staying social (...) [I said] ok is there any places where you can observe how people do this already (...) anywhere you can go this week (Reflective diary, 11.06.19)

**Ideate**

In this stage, the aim was to come up with design ideas, brainstorming in response to the challenges chosen.

A brainstorming activity was used: a design challenge was put in the centre of the table, and participants passed around a box. Whoever held it had to act pretending the box represented the solution to the challenge, and others had to guess what that could be (Figure 15 and Figure 16). All the guesses are written in post-it notes, and constitute ideas, which sometimes were also formed in interaction. For instance, in response to ‘how to help with grief’:

[it was] Damian’s turn (...) and then Bea said, if you open the box I know what to say, and he opened it and she said ‘Pandora’s box! because I read it not long ago’ (...) Damian had to mix these things together with others and he ended up saying well you kind of put memories in, then you shake them, or instead of memories, he said, they are things to do, so I said ‘so activities?’ he said ‘yes kind of...’ so we created this box that was for encouraging activities randomly (Reflective diary, 18.06.19)

Damian, for instance, did not respond well to generating ideas. In such cases, the aim was to make participants feel at ease. Others can help by beginning to generate ideas themselves or by reframing. For instance, in response to how to cope with Grief, which was relevant to Damian, one response was watching TV, to what I inquired how is a TV different that specifically helps with grief? Damian responded that it was colour TV? and laughed (being aware that colour is not particularly special nowadays) and I continue this thread by asking whether we were travelling in time. This kind of humorous play and bodystorming stimulated the generation of ideas, as I record in my diary:
Figure 15. The box: Responding How to feel more calm and relaxed?

Figure 16. The box: responding to how to feel self-love?
... there was a lot of jokes even things like why is this tv different that helps cope with grief? or whatever, and Damian said is colour! I said oh we are travelling (...) in time he laughed so loud, is always so liberating(...) to come up with services (...) we said ok we are going to act out (...) I started ringing someone to kind of bodystorm (...) and nobody was [answering] (...) very funny moment where I was like ...well is not going to work is it? and Damian was laughing Bea said well you are not a very good (...) [Damian] took the phone hello? and I said hello? are you ok? I said no... and then Bea said well you are not supposed to ask are you ok you are supposed to ask how are you? (...) I was like well I am not very well (...) he ended up mixing this situation (...) mixing like tele-transportation with walkie talkies with flight tickets (...) they said well your walkie talkie flight ticket is in the way so don’t worry (Reflective diary, 18.06.19)

Another way to facilitate the generation of ideas is randomly combining elements to see what emerges. For instance, post-it notes that were written in response to the box exercise were mixed randomly to try to create concepts (Figure 17).

Figure 17. A participant combines chamomile with jewellery and a wheel of emotion in one concept
now ... because all the things that were said that were normal coping mechanisms, some may be negative like hoarding, I decided that after each of them, basically to do the other exercise which was planned for later, but instead of choosing an idea and developing it, (...) I asked them to mix three things, let’s say eating, hoarding, music and try to visualize and think about something that combines those things (Reflective diary, 18.06.19)

**Invent**

Templates were used to help participants develop their ideas further, interrogate who were the users and what were the purposes of the designs. This was useful in stimulating thinking and creativity, but it also helped structure interactions. For example, I found it challenging to follow one participant’s thinking and creativity, and the templates were a useful reference point for our interaction, to imagine together, arriving at some common understanding (Figure 18).

![Figure 18. One of the participant’s (Raymond) first draft of his concept in a template](image-url)
Some other times, the making helped frame and think through concepts that were emerging in response to the design challenges. The stage or inventing and initiating (making), therefore, were intertwined.

...he is there doing the aeroplane (...) I circulated around the different people I could feel the total energy of the room going down a lot, and I think is the temperature, even one of the participants Bea said is about temperature and not sleeping much... I joked about (...) Liam fall asleep at some point (...) he did some jewellery out of them (...) camomiles I did (...) asked him [to try] to reflect back in the brief (...) do the different variations (...) he said elderly and I said ok why? and then he said because they are likely to have camomile (...) I just challenged it ok where do you buy this (...) explore a little bit about the context of this designs (...)

(...) aeroplane is done (...) pandora box aeroplane and then (...) I challenged them to think how to cope with grief (...) I basically tried to just play with these prototypes (...) put myself in the context (...) ok now I need help with grief and I encounter this object how do I encounter it? (...) Uriel was like it comes from the window (...) reimagine the sort of ways in which this play will help me (...) then Damian quite bluntly said we should through it! (...) I really I appreciate this kind of simply just do this and that (...) Uriel was like (...) oh there is a wasp in the hope box (...) in the plane (...) we kind of questioned (...) all the time with whatever was happening, we tried to (...) imagine (...) make sense really of what was going on. And then I said ok so let’s put it in a context (...) where would you get this? and he said (...) you would get it in a shop (...) Uriel said (...) he made a call to AGE UK to ask what time the death cafe was in Angel (...) I was like ok death cafe I arrive and we have this thing (...) (Reflective diary, 09.07.19)

Initiate

In this stage, the focus was on developing prototypes to further explore the form and function of the proposed ideas. One of the participants designed jewellery made from calming eatable gums. Since he did not seem to have resources, I made some of the gums which he then turned into jewellery (Figure 19 and Figure 20). He made a storyboard to explain the concept (Figure 21).
Figure 19. Prototype of eatable jewellery for feeling calm

Figure 20. Prototype of jewellery made with clay.
Figure 21. Storyboard explaining the usage of relaxing eatable jewellery.

Figure 22. Damian’s prototypes and tests an aeroplane game to help with grief.
Damian developed another prototype from the concept of the aeroplane game which helps with grief (Figure 22). Finally, Bea made a spiral creation with a humorous message (Figure 23), while Raymond was focused on prototyping his artefact (Figure 24).
Exhibition

Finally, an exhibition was organized to showcase the designs of the participants (Figure 25). At first, Liam was not sure if he wanted an exhibition or not:

Liam said he wasn’t sure because he feels a little bit embarrassed, so I told him... I kind of asked why (...) he didn’t know how to explain it so I said to him (...) I asked him if we [could] do a few pictures (...) as a group (...) how you feel about that? he didn’t respond... he wasn’t sure, so I said ok look I will bring some prints next week, and then we think what to do, whether we put them up on the wall, or we look at them and discuss between ourselves (Reflective diary, 10.07.19)

On the day of the exhibition, Damian and Raymond put up the photos and shared refreshments with staff and other clients.
4.2 Analysis

This subchapter presents insights from drawing on the semi-structured interviews conducted with Damian, Liam and Raymond right after the project.

The semi-structured interviews focused on general questions, in order to see what was most significant to participants (see section 3.3.2).

The analysis focused on three main themes: the general experience of the workshop, the impact it had (if any), and if/how the activities affected the participants’ mental health.

My initial expectation was that participants would report positive experiences overall, as I had used a similar process on several occasions. A lot of the activities were devised to help participants feel safe in sharing issues, which may lead to connection, and to help them
use that information for informing designs for user groups, which may lead to feelings of worth and contribution.

Below I present and analyse participants’ responses and summarize observations about the project’s challenges and opportunities.

4.2 Analysis of participant responses

4.2.1 General account of their experience

When discussing their experience in general, all participants reported a positive experience. Damian added that he loved making. Raymond described the project as a quick process where everyone worked as one, which also raised questions about ownership of ideas.

It was rewarding in a sense that (...) you know processes would take place very quickly and you know it was just really interesting how people worked together (...) and I got a bit confused because I was wondering who would get credits at the end of it, that is what was going on at the back of my mind at the time (Raymond)

Following initial reactions, participants were prompted to elaborate on what happened. One participant described: ‘well... I think people managed to look back on things in the past, actually I thought it was a reflection. People having ideas (...) that they wanted to do and it was... I was... I would say like for their wellbeing in that sense, (...) references things from the past (...), findings so that is basically it really (Raymond)

Participants were also questioned about their most memorable moments in the process. While Liam reiterated the general impression ‘I remember there is a nice flow, there was a nice flow to it all, I thought…’, Damian mentioned one particular activity, where they had to create a system to avoid an egg breaking when falling from a particular height.

Raymond commented ‘it is to do with people’s problems basically, it is to do with, you
know, the desire (...) I mean still sorting the depression’. While Liam remembers the general sensation, the flow, Damian recalls a particular moment which he might have enjoyed, and Raymond provides an overall analysis of the project, as sorting out people’s problems, perhaps finding parallels between the design process and notions around depression or recovery.

Months later, when I saw Liam with a friend, he spoke fondly of the project, when I asked him to describe it briefly to his friend, he referred to it as a part interpersonal activity, a study governed through the rules or means of design.

4.2.1.2 Impact

Liam, after replying that he did not feel any changes in his every day that he associated to the project, specified that it did help with thinking: ‘I wouldn’t go that far [to say it had changed something], not really... but maybe... like I said with thinking, it has helped in some way. Maybe when you study design you think in design terms so maybe... I haven’t noticed but maybe it does’

Damian, when asked about changes, he suggested it was fun, and when asked about whether the project made a difference more specifically, he replied that it got him smiling.

Raymond describes design as having to do with grounding.

I mean basically is to do with grounding finding what grounds off things and then those grounds are being exposed as to what else is in front of a person that is in a in a worried or anxious state in one way or another so that things become crystal clear (Raymond)

Participants did not always find the impact of the project easy to articulate, beyond the immediate reward of being involved. Noteworthy that Liam describes the process helped with thinking, and Raymond remarked it had to do with grounding and making things clear.
4.2.2 Effects on mental health

When asked specifically about potential effects of the project on their mental health, Liam suggested ‘Yeah I thought is quite healthy is good when you... is like a new pathway (...) it may help think a bit differently, [so] it must be healthy.’

Damian referred to making as a parameter affecting wellbeing ‘Making things relaxes you and it makes you not think bad things.’

Finally, Raymond referred to a potentially negative effect of the project to induce a sense of stress: ‘erm... well it is interesting but what I am saying is... it may be chancing it because the person may have a hidden stress load. It’s like someone going to the laundry and a person is probably washing two items of clothes and that person is doing three items of clothes and someone comes in with a whole street load’. When asked if the project caused that in him, he elaborates ‘not exactly no no no I mean no I am saying that other people may feel stressed’. It is hard to interpret what he might have meant, but judging from the metaphor perhaps Raymond is tapping into how bringing experiences to the table could possibly trigger participants. Being in close contact with key staff, both to consult about activities or for prompt support may help mitigate any risks.

4.2.3 Challenges and opportunities

Through a first broad analysis of the participants’ responses, it seems that the project was a positive experience, although accounts differed among participants (e.g. a new frame of thinking or a relaxing activity). Either way, each varying perspective -held within unique insights, skills, health conditions, and preferences- seems to suggest that such co-design activities can support recovery as a grounding activity, helping with thinking, helping frame and clarify problems and preventing thinking bad things.
Still, some activities (e.g. exploring issues) could possibly trigger stress. Although it was not reported in this study, it is believed that having some alternative, simpler tasks at hand - such as making tree leaves - could work as contingencies if this was observed.

Through the project, I conceptualized the way each participant engaged in different ways as *layered* participation. For instance, one of the participants, Bea, often chose not to engage directly, carrying out some alternative art activity while in the session instead. However, she paid attention to what others were saying and often joined by either helping out other participants or by sharing opinions. She is participating in one layer, without preventing her engagement elsewhere. I record in the diary:

> I would get that as well in prison where they would say things like... I don't want to do it and then participate in an indirect way. It's almost as if they need to know that they don't know anything... they are not going to be [questioned] I don't know that is my interpretation, that is my feeling because she didn't participate, but she did all the time (Reflective diary, 18.06.19)

On the other spectrum of this layered participation, there was Raymond who is engaging with the project deeply and taking it to his territory, which may not be accessible to me. I do not necessarily understand his reflections, and we negotiate a layer where we can meet, I record in my diary:

> is really challenging and it’s interesting because it sort of goes in tangents all the time (...) ‘what I really mean, or what I really want to say’ and then he comes back, so it got some sort of central intention and it keeps drifting towards elsewhere, is this kind of circular thinking process that I was trying to follow (...) 

(...) when we were as a group and I asked him to do the same (...) he kind of had to, it was still unstructured, but he kind of put it down in the tree and then when we asked him to share it (...) he was bah don’t know if it makes sense and I was like... it doesn’t matter (...) he did and so yes the whole session was about using the tree metaphor to order (Reflective diary, 06.06.19)
There may also be a peripherical layer. Sometimes participants who may not engage with the project or join the group, such as Louisa, may choose to share personal stories and insights with me in the breaks, as I record in my diary:

> the consequence of that not having any work is that you are outside society outside the real world which she [Louisa] said (...) that is a struggle for her, she used the words ‘I sometimes don’t even feel as an entity I kind not feel like an entity’ and she laughed (Reflective diary, 06.06.19)

Layered participation enables continuous negotiation. A person is drawing her own work while she comments over our discussion, another has taken the design activity into the realm of their particular imagination and beliefs. The various layers and continuous negotiation acknowledge the different ways people may touchpoint with the project.

Another aspect of layered participation is not seeing different rhythms of work (or people missing sessions) as a hindrance. While some participants are doing an activity from the previous week, others are building what is needed for the next activity.

Participants’ diversity and differing responses to tasks are seen as beneficial. For instance, while one of the participants tended to strongly respond to any creative activity, another would often respond that ‘nothing came to mind’. The facilitator might encourage bringing attention to the task or help create collaborative links among participants. Challenging moments may arise when the facilitator is not able to understand a participant’s motivations or concepts. When this happened, the effort was to reframe the idea and communicate this back to the participant; but stating one’s limitations is also key to help create a sense of shared ownership and responsibility.

Participants were asked to share suggestions to improve the project. Two of the participants said they would not change anything, and the third suggested that he would want a part two. It would be worth exploring how such projects could be sustained long term.
Overall, the project suggests potential in using co-design to support recovery. The approach followed in this study favoured layered participation, offering opportunities to work individually and in a group and friendly to indirect, peripheral participation. Enabling participants to be in the space while doing another activity (e.g. art) and being appreciative helped build trust. The act of making in particular provided a layer for participation which was key for those who did not engage verbally in discussions. Each participant reported quite a different experience. Although the small group size may account for this heterogeneity, the flexibility of the process appears to have enabled participants to craft their engagement in ways that respond to their specific recovery journeys. Finally, externalizing the problems and then designing to address these may help participants look at issues from a different perspective. The use of personal issues to inform collective or societal challenges, and the subsequent focus on designing solutions, may constitute forms of empowerment specific to co-design, which could complement other services.
5 Co-designing with psychosis – an Interpretative Phenomenological Analysis

5.1 Reflexivity - Introducing the project and participants

In this subchapter, I summarize the design project at Psychosis Therapy Project or PTP. Furthermore, a description of participants (Nealy, David, Anthony, Nestor, Amara, Baris, Ellaria, Jack and Uriel) can be found in (appendix 2). I am giving an account of what happened as I remember it, which will help readers familiarize themselves with the project and participants before exploring their experiences in greater depth. Sharing my impressions can help increase transparency as it reveals what was most memorable and meaningful for me, which inevitably affects the analysis.

5.1.1 Design at PTP project summary

As discussed in the methodology, the project was organized in three phases, which were mostly a way for me to guide the process forward, not necessarily how the project was expressed to participants on an ongoing basis. In fact, the phases blended with one another.
**Understanding design**

Some activities began while recruitment was ongoing. The first one asked participants to bring along objects they found meaningful or liked. As some participants started bringing objects and discussing their choices in the drop-in area, others were able to ask questions about the project and sign up.

Each person engaged with this activity differently. For example, Anthony brought back - and wrote several pages about - his objects and shared them with other clients and therapists (Figure 26). Towards the beginning of the project, Anthony also shared collages which are based on his dreams - the green book - and gave me a copy of the one inspired by our conversations (Figure 27). Nestor preferred to talk privately with me about his chessboard, while Nealy taped the object (a flower) on the provided notebook and handed it back (Figure 28). Some other objects brought back can be seen in (Figure 29).

*Figure 26. Milking stools, brought by Anthony*
Figure 27. Photocopy of collage made by Anthony for his green book

Figure 28. Nealey brings a flower and writes about how they help
Once the group begun to form, a huge timeline was drawn on the table, inviting participants to discuss the objects they brought in relation to their design processes and their relationship with one another, leading to interesting philosophical discussions (Figure 30). For example, the flower raised questions like ‘Who is its designer?’ ‘Is it god?’ Etc.

Figure 29. Left: Photograph of iconic ‘Silla Barcelona’ brought by Jack. Right: Collection of hearts brought by Amara placed over the collective timeline

Figure 30. Timeline with the objects people brought back
Participants compared the design processes of various objects and discussed how some objects designed for one purpose (e.g. a milking stool) were used for another (stacking of CDs) (Figure 31). This same timeline was used to create definitions of design (Figure 32) and related terms such as ‘brief’. One of the participants, a former architect, created a drawing and questioned why briefs could not be geometrical (expressed in a visual way) (Figure 33)

![Figure 31. Anthony makes a timeline of the design of the milking stool and explains its current use](image)

We also discussed what we had designed before, considering it in the broadest form possible. Nealy, for instance, brought jewellery (Figure 34), and Baris talked about the ashtray he once made with the lathe.
Figure 32. Definitions of design discussed by participants

Figure 33. Uriel suggests briefs can also be geometric when asked about his drawing
During this initial stage, I identified the need to complement these reflective processes with some hands-on design activities to complete in single sessions, as I noticed some participants engaging in reflective discussions much more than others, and I wanted to promote everyone’s participation. I also noticed that it would be easier to understand the process of design from beginning to end by experiencing it in a single session – perhaps not everyone had the same memory.

These activities had to encourage engagement from participants whilst helping acquire a notion of the design process as a whole. The specifics of these activities were somewhat arbitrary -Designing banana cases and Swapping design briefs- yet were inspired by previous conversations.

Designing banana cases was influenced by the food-related conversations in the drop-in, although one of the participants made a more Freudian interpretation. Some examples are shown below (Figure 35, Figure 36 and Figure 37).
Figure 35. Banana case, the knife is the holder: brief by Anthony and design by Uriel
Figure 36. Banana case designed by Anthony

Figure 37. Banana case for two or three
The *swapping design briefs* activity was inspired by Laing’s (1960) depictions on the inner self of schizoid conditions (e.g. the need for control). Al Laing describes, the isolation of the self is a corollary, therefore, of the need to be in control, He prefers to *steal*, rather than to be given. I was reading this passage when I had this idea for swapping design briefs, give and be given a purpose.

Each participant created a brief, then handed it to a peer, who would have to interpret and design something in response (Figure 38).

In another occasion when we were trying to design quick concepts, Anthony designed a lead for six dogs for Baris who was sitting next to him (Figure 39).

*Figure 38. Swapping design briefs responses*
Another activity involved creating design briefs by using three makeshift pots labelled who, why and what. Often, physical artefacts, such as these pots, were made by participants themselves to facilitate design activities. Participants added possible users (e.g. who), possible reasons and possible things in each pot, combined them randomly and reflected and responded with a design proposal (Figure 40 and Figure 41).
Figure 40. Pots made by participants for randomly combining ‘who’, ‘why’ and ‘what’ prompts

Figure 41. Design response with random prompts, by Anthony
Finding and mapping situations

This stage consisted of exploring our curiosities and lives to form a design brief or find out what we could design as a group. For this purpose, the notion of cultural probes was introduced, as referred to in the methodology. However, I was not entirely sure how to prevent the probes from becoming too prescriptive. Our worldviews were different, and I wanted to make sure that by making these probes I wasn’t losing the chance for genuinely collaborative exploration. Therefore, an earlier activity was thought of to understand one another. Before the session began, I mentioned to Uriel about the tables that spin as it may help us with our exploratory activity, and he thought of using a CD and a vase to make a gyratory table (Figure 42).

The idea of the activity was to find out a little bit about our worldviews and help structure the cultural probes, finding a language for them that would not prescribe and limit participants’ responses.

The exercise somehow illustrated different ways in which participants conceptualized things, but failed to inform a framework for the cultural specimens.

Around this time, in one of the sessions, Uriel asked a question ‘I wonder how it is like to make with four hands?’. This struck me as a great coincidence, as I was separately working on a small experiment with Open University students, which required two people to
paper prototype together without talking to one another and without knowing in advance what they were about to make. The activity concluded when both participants thought to have agreed on the nature of their artefact. Hence when I heard Uriel ask that, I decided to do this activity with them. Baris and I both agreed that we made some kind of building, while Uriel or Anthony thought they made: the ‘holy ghost as a dove emerging from clouds’ or ‘ski off piste’ (Figure 43).

![Figure 43. Prototyping without talking to one another](image)

Alternatively, the cultural probes were made by participants themselves by choosing what to put in their kits and were based on the five senses. Because I could not think of a way to direct the content of what participants should bring back - due to concerns of being too prescriptive - I decided to make categories according to the type of information. Is it visual information, olfactory, tactile?

Participants could gather information in different ways, through various tools which corresponded to the five senses. Rather than giving them a made kit, participants had to choose what tools they wanted, complete them (e.g. put the tag or make a box),
customizing a tote bag. A participant, Anthony, much later, renamed this activity as *cultural specimens*. Participants brought back disposable cameras, and a few other items (e.g. books) or elements (e.g. holly water). These *specimens* were spread out in the table, arranged thematically, and discussed (Figures 44-52 and Figure 96).

*Figure 44. Anthony describes the things that he brought back as cultural specimens*
Figure 45. Cultural specimens, such as holly water, bog oak or heather

Figure 46. Anthony’s response to cultural probes, a map of what has been, what is now and what is to come
Figure 47. This was originally meant to be used with a phone to record. Anthony creatively responds by drawing a smile from the template.

Figure 48. Uriel’s drawing, based on the shape he often used.
Figure 49. Cultural response by Nestor, positive affirmations written by a friend

Figure 50. Cultural probes responses distributed over the table and organized thematically
Figure 51. Various pictures of tools and religious objects and games

Figure 52. Various cultural probes responses, photos of soft toys, boardgame, books...etc
Storyboard templates were offered to encourage participants to expand from the specimens in the table to interesting situations, and explore their potential to address interesting design brief(s) (Figure 54 and Figure 55).

From this exercise, various themes emerged, such as spirituality and nature. Intentions towards helping humanity appeared to be significant, perhaps promoting a sense of group identity. One participant formulated the ‘sine qua non’ of the design, a list of qualities without which design should not exist: green, energy, death, psychology (Figure 53). The why of the design direction was also determined to be Stewardship or taking care of humanity.

Figure 53. The ‘sine qua non’ of design, introduced by Uriel
Figure 54. Storyboarding situations, which describe the story of one of the objects photographed with the disposable camera, a religious item.

Figure 55. Nealy draws how a religious necklace helps someone.
I encouraged a discussion to see whom the group wanted to design for. Amara and Nealy thought of a person, but were struggling to formulate a description of a ‘user group’ (Figure 56). Another described two fictional characters helping each other across continents.

Figure 56. Amara writes about whom she would like to design for

Looking at the cultural specimens and reflecting on our discussions, I decided to organize brainstorming sessions using cards I could make from all the information – somehow bypassing the certainty of a fully formed brief. I wrote the three ‘user’ groups mentioned into different cards, and three overarching purposes in other cards. The groups were named: ‘The spiritual misfits’ (retitled by participants as ‘spiritual creatives’); ‘The wisening population’ (a linguistic twist on the ageing population); and ‘nature’. The
purposes were: To connect, To wonder, and To heal. Participants chose to couple the ‘user groups’ cards with the ‘purpose’ cards randomly. New combinations emerged and were used to inform brainstorming sessions: ‘To help Nature heal’; ‘To help spiritual creatives wonder’; and ‘To help the *wisening* population connect’ (Figure 57, Figure 58, Figure 59 and Figure 60).

![Image of brainstorming session notes]

*Figure 57. Brainstorming how to help nature heal*

Participants shared memories relating to some of the ideas generated. For instance, the ‘adopt an ant’ campaign to bring awareness of insects and learn altruism, was followed by one participant sharing a psychotic experience, where an ant helped him find the way back home, to which another participant asked, ‘what language did the ant speak?’.

In one of the sessions, one of the participants reframed the brief by stating that the question was not how to help spiritual people wonder, but how to help non-spiritual people wonder. The notion of a board game came forward when one participant added how wonderful would be to have something like ‘trivial pursuit’, in this same context.
Figure 58. Amara takes notes during the brainstorming session 'how to help nature save the world'

Figure 59. Amara’s notes during the brainstorming sessions ‘help nature heal’ and ‘help non spiritual people wonder’
In the following week, Anthony brought back a design concept which seemed to merged elements across two brainstorming sessions (Figure 61). It was a game that aimed to encourage people to be more green or sustainable. Rather than awarding the winners or punishing the losers, those who were identified as less green were given gifts or rewards (e.g. wildflower seeds) and were encouraged to act in response.

Anthony came ... and he was telling me about the idea he drafted in writing, as he usually does, for the ethical game and he decided [it] to be a green game. So what he did is he basically mixed up the two separate briefs (...) and he created this game (...) (Reflective diary, 5.6.19)

The idea was shared with others within and beyond the group, and its originality and potential were reflected upon. Connections were made with the other themes from the cultural specimens. The resonance of the concept with some of the other interests discussed and its potential with regards to the collective purpose of stewardship was used
to drive the group’s efforts forward towards a collective project. The concept had the potential to weave participants’ differing interests and skills into one single design concept with the overarching purpose of **stewardship**.

**Figure 6.1:** Anthony writes and sketches how his idea for a green game is used (its function)
Creating our design(s)

It can be argued that the development of this board game was emergent: it was the product of discussions on different experiences and ideas, and group and individual reflections through continuous play.

The group began playing some form of board game early on, inventing by playing as it went along, often making serendipitous use of objects (Figure 62 and Figure 63). As the board game involved questions that had no right or wrong answer, these began popping up as we moved forward designing (e.g. what is the colour of infinity?) (Figure 64).

Figure 62. Game prototyping while playing
Important notions were reiterated along with design questions, such as the focus on cooperation rather than competition, and on wonder rather than on factual knowledge.
acquisition. As Nestor was not there when the concept first emerged, he questioned the purpose of a game which has no winners. I brought him an article about types of games for us to reflect on it together (Figure 65). Nestor had very insightful questions about the nature and purpose of the game which helped us discuss and refine the concept.

Participants’ questions and pressing design decisions (e.g. how does the game end?) were given physical presence along the table to help navigate the process (Figure 66 and Figure 67). For instance, Amara began thinking about different rewards that related to the themes of the board game (e.g. wildflower seeds for the environmentally unfriendly), sitting in the area where this question was and making small signs representing rewards (Figure 68). She would share a reflection aloud ‘these rewards are too expensive’ which would lead to a group discussion (more in section 7.2.1).
Figure 66. Design questions are given physical presence, e.g. How does it end?

Figure 67. Design questions are given physical presence, e.g. How do rewards connect to ones’ failures? post it with green marker
Meanwhile, Nestor brought books and continued to write questions with a volunteer therapist (Figure 69 and Figure 70). Uriel continued to make more drawings for the game (Figure 71) and a logo, with feedback from the group.
Amara created the shapes and colours for the categories (Figure 72) discussions about possible rewards continued. She pointed out that the resources needed for buying them could depend on players’ finances. This made us generate various ideas until a guideline which would help users prepare rewards was conceptualized instead. We came up with a name for it, GAME. Anthony created paper prototypes and thought about dimensions (Figure 73).
Figure 71. Uriel creates drawings for the board game

Figure 72. Amara creates the shapes and colours for the categories or themes of the board game
Some paper models were made to decide the size and shape of the board, and I talked about the fast prototyping lab at The Open University lab that we could use for making.

Toward the end, Anthony and I sat in the drop-in area to write the guidelines and rewards, and discuss final design decisions (Figure 74). He had the idea of the tap becoming the place where the cards themselves would spin (Figure 75).

Following this session, I created the physical components of the game using laser cut and 2D printing resources at the Open University. I bought a round cutter online for the cards, which I illustrated based on Amara’s colour and shape choices and Nestors questions.
Figure 74. Anthony and I write the guidelines of the board game in the drop-in area

Figure 75. When they decided the box to be round, I printed examples online, which Anthony used to design and specify the parameters that would determine the size, sketching a double function for the box cover
At the end of the project, an exhibition was set up at the Islington Mind premises to showcase the process and achievements of the participants to charity staff and clients (Figure 79, Figure 80, Figure 81 and Figure 83). Everyone was invited to play the GAME (Figure 76 and Figure 77). The final prototype was made on the morning of that exhibition by Anthony who brought his sculpting tools (Figure 78). Amara gives closure to the project with a card (Figure 82), and participants, my supervisors and therapists meet, discuss the work and try the board game.
Figure 78. Anthony brings his tools and builds the prototype the morning of the exhibition

Figure 79. Participant Anthony, PhD supervisor Theodore and myself gather around the prototype
Figure 80. Volunteer Pietro and myself while we set up the exhibition

Figure 81. Therapists Psychosis Therapy Project look at participants work at the exhibition
Figure 82. Amara’s card given to me at the exhibition

Figure 83. PhD supervisor Katerina talks with Jess, trainee therapist at PTP
5.1.3 GAME: the design outcome.

In this section, I describe the design outcome, the board game, which following discussions with participants was licensed under a Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License.

*Game* is designed to encourage collaboration over competition and the exchange of ideas and perspectives in a non-judgmental way. It was played by other clients at Islington Mind, especially at the evening crisis café service, several PhD design students and supervisors at a AHRC Design Star retreat, and colleagues and friends of mine. Some players for instance commented ‘I have shared things I wouldn’t have done otherwise’ or ‘I didn’t know I was so self-conscious’. It helps participants wonder, get to know themselves and connect with one another and the environment. There are no winners or losers and interaction among participants is the main benefit. To achieve this, the board game involves players in addressing questions that relate to different themes, through different forms of interaction.

*Game* is composed of a set of cards with questions pertaining to the different themes in different colours, and a board offering 3 different ways to address the cards. There is also a set of empty cards where players can write their own questions.

The different themes are green, philosophical, spiritual, mind & body, creativity and ‘?’, which refers to any area not included in the main themes (Figure 84).

Randomly by using a spinning wheel, each question can be addressed in three different ways: Tell & share, Think & discuss, and Act & ask. (Figure 85 and Figure 86).

Through non-judgemental discussions with others, players may identify areas in which they may want to further reflect and develop themselves, individually or as a group.
Figure 84. Prototype of guidelines booklet (themes descriptions) and few cards

Figure 85. Prototype of guidelines booklets – ways to address questions and tokens
To keep track of these reflections, tokens corresponding to these themes are distributed among players.

Unlike most games, tokens are allocated subjectively. Throughout the game, when the player feels they need help with some area (e.g. spirituality), they can take a token as a reminder of this need (e.g. spirituality token) (Figure 87). Tokens can also be given by others - if the player accepts them. At the end of the game, the number of tokens of each type reflects what each player is most interested in - or in need of- developing. Rewards corresponding to each theme are given to those who have the most tokens belonging to that theme, to motivate them to develop that part of themselves. For instance, if you feel you are not very environmentally aware, fellow players could encourage you to take some green corresponding tokens. At the end of the game, if you have mostly green tokens, you may be given a reward that encourages you to become more environmentally friendly. These rewards could be created ad hoc by the group or selected from a booklet of ideas.
Figure 87. Tokens pertaining to different themes, in their box

GAME is featured in a video, made for the Participatory Design Conference, during the covid-19 pandemic lockdown (https://www.youtube.com/watch?v=0p5kvOZptu4). An embedded link can be found in (Figure 88).

Figure 88. Embedded link to video featuring GAME being played with flatmates during the first lockdown

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An online version was prototyped for the conference too, and an exhibition and situated action were set up in a virtual space with the assistance of conference organizers. An step by step example of how to play can be found in the Islington Mind website (https://www.islingtonmind.org.uk/game-a-board-game-co-designed-by-clients-at-the-psychosis-therapy-project/)

5.2 Analysis

Six of the nine participants who signed up were interviewed immediately following the completion of the design project: Nealy, David, Anthony, Nestor, Amara, and Jack. The former five were interviewed again 6 months later. Anthony was interviewed for a third time, due to the intricate descriptions of his experiences. Jack could not be contacted again because his arrangement with the service changed (meeting with his therapist elsewhere), so it was considered inappropriate by the manager. The semi-structured interview format can be found in the methodology section. As mentioned earlier, all data fragments specify if they are from the 1st, 2nd or 3rd interview. The second or third interviews were more conversational, where initial interpretations or doubts were shared with participants for feedback.

The analysis of the semi-structured interviews showed a high level of complexity, with emergent themes that are intertwined, and data fragments that simultaneously relate to more than one theme, too.

It is therefore of paramount importance to avoid considering these themes as mutually exclusive categories. The themes are best understood as dimensions of experience that interrelate with one another. Interpretations also take the function of lenses, as they consider data in one way or another.

Four themes emerged from this analysis: Contributing, Connecting, Intentioning, and Thinking. An additional theme, titled Bettering, is excluded as the results overlap considerably with the convergent mixed-methods study reported in Chapter 6.
Table 2. Superordinate themes alongside the pertaining themes or nodes and participants who made reference to these

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Themes or nodes</th>
<th>Participants who referred to them</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributing</td>
<td>Being of use, Bringing the best of people, Confidence, Counting, Credibility, I can contribute, Personal contributions, Solid stuff, Something out there, real, tangible, Tangible thing, Validity</td>
<td>Nealy, David, Anthony, Amara, Nestor</td>
</tr>
<tr>
<td>Connecting</td>
<td>Beyond chat, Body language, Different set of questions, Encouragement, Equal, Non-judgemental, Non-patronizing, Not dismissed, Other people asking, Recognize and share design knowledge, Sharing and helping others, Social thing, Talking something other than problems, Tilting in, Understanding belief</td>
<td>David, Nestor, Nealy, Jack, Amara, Anthony</td>
</tr>
<tr>
<td>Intentioning</td>
<td>Driven, Focus, Grounding, Rooted in the world, Motivation, Moved, Stretching</td>
<td>Amara, Anthony, Jack</td>
</tr>
<tr>
<td>Thinking</td>
<td>Alternativizing, Design for better therapy, Opens up mind, Thinking big, Various meanings</td>
<td>Nealy, Jack, Amara, Anthony</td>
</tr>
</tbody>
</table>
Each superordinate theme is a collection of nodes (or themes) from the interview transcriptions. As they encompass a collection of nodes, they vary considerably in length and complexity. Each individual case was analysed first, before considering the group as a whole. Therefore, some themes are relevant to all participants, and others are evident in some of the accounts only.

The table above (Table 2) shows superordinate themes alongside the pertaining themes or nodes. Few additional, miscellaneous nodes are excluded from the table below as they were not grouped - were reflected upon separately before write up. In the column at the right, participants who referred to that notion some way or another are named.

This table is a simplification, in that some of the interview fragments and nodes belong to more than one superordinate theme, which reveals how they relate to one another. Hence, throughout the chapter, after each theme, a section titled ‘interrelations with other themes’ is added. More details about the analytic process that led to these themes can be found in section (3.3.3.2).

5.2.1 Contributing: ‘you are achieving something other than to better your mind or to better your mental health’

5.2.1.1 Overview

In discussing their experiences of the design project, several participants referred to notions such as counting, contributing or having validity.

Often participants acknowledged that the project gave them the impression that what they did or thought counts, or had validity - such as when Nealy mentions that what they did ‘counts’.
In other cases, these impressions of contributing were not explicitly noted but were apparent in the way participants recognized and valued their contributions. For instance, Nestor talked about the board game which was created as something that ‘would make it’ in the market, while Anthony talked about the board game as something that will stay around. Furthermore, one participant, Amara, talked about their dreams for this game, expressing awareness on how grandiosity is common in people with psychosis, yet recognizing how entrepreneurs need also to have these dreams.

The way these notions were employed suggest recognition of significance beyond oneself. It is the notion that one has some form of value, meaning or purpose for others or the world.

This recognition takes many forms. For instance, Anthony described that contributing towards something with others had made him feel better in himself, and that his design work was less likely to be dismissed compared to his artistic creations. For Amara, recognition of her contributions was a process and seemed to crystalize with the final exhibition. Nestor’s emphasis lies with the final design outcome itself, the board game, which he described as a remarkable achievement, something that, in his words, ‘is not easy at all’. Nealy directly described how the project gave her the impression that what they do, counts. David, who only participated at the very beginning of the project, remarked that the design project can help clients to recognize that they can contribute something, helping them build their identity.

The notion of recognition of contributing, as used by David, is distinct from a sense of contribution, as it implies a commonly granted significance. Societal mattering is a concept I will also refer to when threading and interpreting the collection of notions around contributing, counting, having validity… etc.

From participants’ sentiments of surprise, it is suggested that counting and contributing is not something that they are habituated with, and was associated with the co-design experience.
Furthermore, Anthony shared experiences that relate to beliefs of having special powers, and Amara explicitly reflected on the notion of grandiosity in schizophrenia in reference to believing in the success of the game. This pointed to an interesting interplay between notions of being of special significance, as it happens in some forms of delusions or unusual beliefs, and recognizing contributions in the context of the design project—which are based on shared beliefs instead.

Below I unpick participant’s experiences in more detail.

### 5.2.1.2 Analysis

Firstly, the notion of contributing seems to be associated with an increase in qualities such as confidence.

For instance, Anthony associated feeling better in himself with not being dismissed and contributing towards a collective undertaking:

> I felt good in myself, better and just, I don’t know, contributing towards something or just not being dismissed, like (...) A lot of people like my green book [his collage work], but they dismiss it as well, as flights of fancy, but [in] this process things were not dismissed so readily (...) they were incorporated into something that we all contributed towards, so I felt better in myself (Anthony, 1st interview)

> it gives you confidence in yourself [the project] so I felt better over the past I don’t know is it 4-5 months is it longer (Anthony, 1st interview)

Nealy also talked about the sense of confidence that grew out of the process. She suggested that the project made her feel that what they created mattered, helping grow her confidence and ability ‘to think big’.

> [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, 1st interview)

[at the] design project, you already told us we can create anything (...) to think big... I mean even I can create - it gave me that confidence that I can even create, I can even think, and my thought is counting as well. Yes that is what I thought (Nealy, 2nd interview)

is 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, 2nd interview)

Both Anthony and Nealy seemed to associate this effect to the design project, in contrast to their experiences with art.

[the] design project makes [sic] more creativity, I mean because you have to create new things... But art projects ... it’s only doing art, how you feel it at that moment. You are not creating anything in art. (Nealy, 2nd interview)

It is different [from art] because it encourages just to create. Create new things and thinking big, you know big company or working, and think about what to create.... It was nice feeling (Nealy, 2nd interview)

Amara also mentioned how this project gives one confidence because it was achieving something other than to better one’s mind, recognizing the value of their participation beyond its benefits in terms of their own recovery.

I felt that I didn't come here to cry and to, to feel the ... support really for my mental health problems I felt that I was here to design rather than that (…)

yes so I mean in that respect that gives you confidence because you are achieving something else, but you are achieving something other than to better your mind or to better your mental health (Amara, 2nd interview)
Some of the recognition of contributing is implicit in the participants’ evaluation of the project outcome. Amara, Anthony and Nestor, for instance, talked about how the game helps people who play it, reflecting on the value of their contribution for others:

I mean it all helped us, each one was helped by each other (...) just being in the group and then doing the game. (...) I brought my energy to create those little things [for the game] and (...) if the game helped people in any way, which to me it does because it just brings joy... and education, so that is helping people. So just being a part of (...) saying I was in that group (...) I think that is a great thing (...) we all were responsible and we did [put] our energy (...) So (...) it will help anyone who plays the game really (laughs) hopefully... I think it will (Amara, 2nd interview)

Well I suppose what happened was what happens in the real world sort of, like you get together and you voice ideas (...) and something tangible came at the end of it: the board game which is good, it is a tangible thing so it will stay around (Anthony, 1st interview)

In addition, the design outcome is emphasized as real, which is perceived as adding credibility. Participants’ ideas for the further development of the game confirms the acknowledgement of its value.

With this ... with the design project I wrote out things I wrote out my feelings (...) on a subject (...) and once it was down on paper (...) and there is an actual game out there now. (...) that is that is something that you can see and touch’ (Anthony, 1st interview)

But I think you should try and market it. Get it out there as a game, put it in the mainstream in the shops. (Nestor, 1st interview)

The recognition of contributions is not only limited to the design work. In the case of Anthony, he also recognizes his contribution to the research community, in discussing a research paper portraying his case, he describes:

if a psychiatrist or psychologist or whoever read it [the paper], it may impact their view of someone else who has been lumped with all the schizophrenics [and] psychotics, but maybe elements of what they say is reality, or even if it’s not, it gives them an understanding of the thinking processes behind the psychotic (...) So
either way it may impact them (...) it may tilt them in certain way I think (...)

Although the project is not ongoing (...) you write things in a paper or periodical or magazine or whatever [then] someone sees it, a psychiatrist or a psychologist, and if elements of what I say relate to (or if elements of what you say that I say or said) relate to patients they have, (...) if there is some tangible proof of what I say (...) But even if there isn’t any tangible evidence to support what I say, it gives in the fact that I can live a fairly normal life. They may say well this bloke has weird... you know, Erika has written about this bloke and he has got weird, off the hand, ... out of this world ideas, but he can navigate his way through society to some degree and not wind too many people up. But there may be someone locked up on a nuthouse who has got the same ideas (...) kept on a long section, or indefinitely or whatever(...) They may say well someone with the same ideas (...) this bloke may be able to hack it in society with a little bit of help (...) I would like to think (...) that somebody’s dreams are in fact reality and (...) [but] even if some of my belief systems are not reality (...) it can influence other people in positions of authority, [it] can influence their ideas of things. Now hopefully they don’t just say well god they should have locked that bloke up years ago (laughs) (Anthony, 2nd interview)

Interestingly, the notion of contribution was also mentioned by David, who only engaged briefly, when speculating about what design could mean to participants:

I mean perhaps in a positive sense it [the design project] could help individuals to recognize that they can contribute something; because ... let’s say you have a psychosis patient who is quite ill, quite debilitated by that condition and not communicating very much, when they participate in your project they are given a voice and that is (...) really positive, so that helps to build their identity, whereas late capitalism is about building your identity through shopping (...) (David, 1st interview)

*The surprise element in contributing*

In participants’ narratives, it seems that they did not seem accustomed to contributing or mattering to society. They expressed sentiments of surprise, or the recognition happened progressively or in retrospect.

Amara, for instance, seemed to have increasingly recognized her contributions to the
project, for instance, evidencing how the recognition of the final product’s value to others relates to the explicit statements of achievement or confidence. Hence, in the exhibition, she first felt out of place, then she began looking at what was exhibited around and recognizing herself increasingly in the displayed work.

Although Nealy had earlier experience with creative activities, at the beginning of the project she expressed some concerns about her ability to be creative, mentioning a physical problem, a stroke. Yet by the end, she remarks that even they can create. Amara reflects on what she initially thought about design and the outcome, showing some sentiment of surprise. Anthony also expressed amazement with how what they created is going out into the world.

I mean our creativity is counting and we can create new things here even, whoever we are, whatever we are, we still can create new things (...) that project gives me that impression yes (Nealy, 2nd interview)

before I didn’t think about any invention (...) But now I am thinking: even me, I can invent, or I can give my idea to someone [and] they can invent, I can give at least some idea, and they can improve it, that is what I am thinking (Nealy, 2nd interview)

I thought design was something like that when you draw a bit of art you know, and I discovered, in the end, creating a game... I mean that is totally amazing to me it was such fun wasn’t it? (Amara, 1st interview)

[It] is amazing (...) you approaching this place in Archway and then sort of a few, 9 people (...) getting together and ... something else going out into the world (Anthony, 3rd interview)

This sentiment of surprise, of unexpected achievement, is reflected implicitly in Nestor’s account, who refers to the design outcome as something remarkable:

[making] your own board game: that is not easy, that is not easy at all, and [the fact it] is done, is I think really remarkable (Nestor, 1st interview)
Participants’ testimonies suggest an interesting intertwining between the concept of contributing and unusual beliefs, such as delusions of exceptionality, or what is also known as delusions of grandiosity.

Throughout the project, Amara and Anthony had both shared experiences that suggest these kinds of beliefs, often through humour. In one workshop, for instance, Anthony talked about when he believed that he could recognize the descendants of Jesus, who for a while he believed to be himself. Amara, laughing, replied ‘well that is interesting, I thought I was that person too!’.

Anthony’s beliefs, in particular, were shared in various ways, for instance through the cultural probes he brought back or the collages in his green book.

Anthony’s ‘dreamworld’ or ‘funny ideas’, which could be considered delusions of exceptionality, include beliefs on his ability to remotely impregnate women through dreams, which I learned about through a card he gave me (see section 7.4.2.2, ethical encounter 2). Both his delusions and the design outcomes seem to relate to the notion of contributing, and there is some correspondence among the general purpose of the designs with the vision of a better future he explores through his unusual beliefs. While societal mattering achieved through the exercise of design is shared with other people, his beliefs are personal and rarely recognized.

Anthony and I discussed how the different designs operate in their aim of changing the world, a humanitarian motive which is behind his delusions of exceptionality, too. Possibly, both his dreams and his designs are channels through which his will for changing the world is exercised.

this game can maybe contribute towards the decency of people [design contribution] my dream ideas [unusual beliefs] can maybe populate the world with easy-going natures who can lead people in these ethical ways. (Anthony, 3rd interview)
but also if you think you are by a process of spark (...) [impregnation] with an intelligent woman combine and you contribute towards the future peace and harmony of hundreds of thousands of millions of people (...) (Anthony, 2nd interview)

There are differences too, between the game he designed individually (Gods Green Gaia Game) and the collective one, which became evident when we reflected on how they fulfil their purpose. The Gods Green Gaia game, everyone would directly follow in their minds, whilst the collective board game was played through a physical board. Whilst it was easier for me to conceive the physical board game as influencing others (who play it), Anthony seemed to consider the alternative more impactful, which evidenced our differing notions around contributing. Much later in the interviews, Anthony compares:

It is almost, my Great Gods Great Green Gaia game was an intangible thing because you played it in your head...

(...) so I always wanted something solid at the end but I went up in the direction of something not solid (...) if everyone did that [play the intangible game in their heads], the world would be a better place (Anthony, 3rd interview)

In a way, Anthony is aware that perhaps the purposes of the two games are similar but the means are different.

(...) one directly changes your mindset but the other one almost through chat (...) having to address the issues (...) One is (...) an interior solitary affair that would affect everyone, whilst the other one (...) it’s a communal boardgame that involves other people (...) it’s not just left to your own interior conscience. Other people’s consciences and life experience (...) affects how you think, (...) maybe they come from two different points but the end result is almost the same (...)

(...) the (...) [boardgame] (...) it is been played by how many people played it so far? 10,20,30 people...

(...) you get insights into other people's minds which maybe affects yours so one is a solitary game the other is the... what is the opposite to solitary?

(...) what is the word erm... (...) social! It is a social... affair (Anthony, 3rd interview)
The board game, unlike his beliefs, is based on a shared understanding of reality. The ‘Gods Green Gaia Game’ was somewhere in between first, as it appeared to psychically affect people, yet when further questioned, Anthony addressed that gap:

No that is it but if it was pamphlet you stick it on a pamphlet and you put it out there then it would have a knock-on effect, people may... some people may (...) (Anthony, 3rd interview)

Although Anthony’s unusual beliefs seem to change with time, are held with a certain conviction. In contrast, he did not seem as firmly certain about the designs. By the end of the project, there is, however, a clear recognition of its potential impact.

say the game took off like in your scenario and everyone became more grounded and sorted and thought about philosophy and spiritual things and green issues (...) and become more grounded decent people (Anthony, 3rd interview)

Besides drawing on the different ways in which beliefs and designs operate, sometimes Anthony integrates them back within his worldview.

Then you never know we may happily be existing in a messianic era where everyone adopts the concepts and interacts decently (Anthony, 3rd interview)

[while] the game can maybe contribute towards the decency of people, my dream ideas can maybe populate the world with easy-going natures who can lead people in these ethical ways (Anthony, 3rd interview)

but just to finish that up, we may think it is our design or co-design whatever but what if there is some form of deity (...) who has a small smile in his or her face or their face thinking ‘oh yes they are going in the right direction (Anthony, 3rd interview)

As discussions developed, I also prompted him to reflect on this notion of contributions in the hypothetical absence of affirming deities.

even if there wasn’t a deity up there, the decency aspect is almost the prize of the game, isn’t it? The acting decently and understanding mindsets and the environment and nature (...) the changing mindsets (Anthony, 3rd interview)
existentialists (...) people are doing it for themselves so they are bettering themselves. (...) mankind bettering mankind... (Anthony, 3rd interview)

Summarizing, contributing, as a driver, can be understood to network across the impact that Anthony’s designs and unusual beliefs have in the world. By engaging in design, he explored efforts to change society through a dimension that is recognized by others, adopting forms that others could understand. It is also possible that his beliefs were influenced by the project since according to Anthony they were in continuous change.

It is not known whether other participants also had delusions of exceptionality while the project was happening, but both Amara and David made references to times where they had unusual beliefs, and Jack expressed persecutory beliefs.

Amara’s reflections on entrepreneurship, brilliance and grandiosity illuminate the fine boundary between these concepts. She talked about her dreams for the boardgame, whilst reflecting on Nestor’s comments about how people with psychosis deal with things like grandiosity. She concluded on how thinking about the idea brought her incredible joy.

I mean that is a bit like being an entrepreneur. I said to you I wanted [the game] to go (...) in Hamleys I want it worldwide, and you know it was going from greater to the greatest (...) and anticipating great things from this game; (...) Nestor has ideas (...) with schizophrenia that it’s something about like brilliance or something (...) that excites me because I think there is this spark, it brings a spark in me (...) I think I have seen something like that inside myself and you know some possibility (Amara, 2nd interview)

and then there is this idea of the game and then selling that worldwide and making loads of money (...) I don’t know where the money goes to you know, everyone that was involved I supposed, and some money could come to the HUB I mean the Psychosis Therapy Project in particular. (...) you know [in] mental illness where is all grandiose, and you think these amazing things, but you got to have that seed, even as a proper entrepreneur or (...) great person you got to have that seed (...) and so is possible! I believe in possibilities (...) But the idea is there, this gives me such an excitement, happiness and joy just to even think about something like that (Amara, 2nd interview)
David, on the other hand, shared what he referred to as a strange delusion he had which had to do with design, where he believed that the world was designed in reference to him. With my psychosis I actually often feel like things around me are designed for me (...) I didn’t feel threatened by it I felt significant, so that is that aspect of design, I really enjoyed design at school (...) (David, 1st interview)

people are with me not against me, that people are on my side in a kind of abstract sense you know (David, 2nd interview)

He affirmed that the activity of designing can only help to serve clients and that the achievements that you make are important, referring to how he tries to go to his studio quickly, even if he is psychotic.

(...) it could only serve to help them [designing]; because I think the things you do when you are stable, the achievements that you make [are important]. I mean for me, my artwork (...) in a sense could be imagined as an achievement, and so when I am sick I can’t work like that and I want to and I would start going to my studio [to work] quite quickly even when I am psychotic so that I can get back into the swing of it and be doing what I deem to be a purposeful life (David, 2nd Interview)

Although some participants may have had these beliefs of exceptionality, they also seemed surprised by what they have achieved through the project and how it mattered. This opens the question of how contributing through design and beliefs of exceptionality interact with one another, and whether designing alleviates any possible harms of delusions, which is further explored in the discussion (section 5.2.1.4).

5.2.1.3 Interrelations with other themes

The experience of contributing interrelates to intentioning (section 5.2.3) and is associated with willingness and motivation. Anthony, for instance, mentions wanting to contribute as a driver to design: In contrast, for Amara, it is the design project which stretches her towards designing.
I think you would leave us with an idea of things and I’d go away and I want to contribute so (...) I would think about something and I’d think about something so much that I write it down and I come back show you something the following week (...) (Anthony, 2nd interview)

(...) brought you more to stretch you more I suppose in that way, didn’t it, you know because I it I think I stretch it just stretches you towards designing (Amara, 2nd interview)

I would say it was I think it extracts ideas out of you that you wouldn’t have otherwise (Amara, 2nd interview)

Furthermore, the theme of contributing also interrelates with connecting. As Anthony reflects on the purpose of both his beliefs and the designs, he also comments on how others, due to his design contributions being more solid, are tilted towards commenting on his dreams too.

But is almost the project allows them to - even tho there is a conspiracy silence - to slightly veer towards outside their veering outside their silence to comment on dreams because they have been tilted in that direction by solid stuff written with regard to design ideas so does that makes sense so so (Anthony, 2nd interview)

5.2.1.4 Discussion

The importance of contributing and societal mattering

The way terms like counting, contributing, having validity were employed appear to all allude to forms of mattering, in the sense that they seem to recognize some notion of significance beyond oneself. As we saw, participants recognised and reflected on different ways in which they, their activity and their design mattered.

Among the various forms of mattering described in the literature, such as mattering to other people (interpersonal) or mattering to the world (societal), it is the latest which this theme most closely relates to. Interpersonal mattering is explored in the next theme connecting (5.2.2).
Societal mattering was differentiated from interpersonal mattering by Rosenberg (1985), who defined it as the feeling of making a difference in the broader scheme of sociopolitical events - of feeling that one's thoughts and actions have an impact, create ripples, are felt. This description resonates with participants’ experiences of recognizing their contributions.

Jung (2015) defends that although interpersonal mattering - which most literature focuses on - may play a role, perceived societal mattering may contribute more to one's psychological well-being within the work context. How people's work is perceived by society, as well as how they view their contribution to society may occupy a larger and potentially more powerful aspect of mattering (Jung 2015).

In psychosis studies, societal mattering is not been explored either, although there is some research on interpersonal mattering. Pernice et al. (2017) examine the role of mattering to others in mediating the relationship between social support and two separate variables: recovery and internalized stigma associated with living with a serious mental health condition. I suggest that while the notion of interpersonal mattering may be important and is also pronounced in participants accounts (see next subchapter connecting) the role of being significant to the wider public, to society at large, is also key. It is also what seemed to have surprised participants, suggesting contrasts with other services or projects, which may not provide such opportunities to contribute.

Although enabling people with mental health problems to make a positive contribution to a “big society” is part of the UK government strategy for mental health “No Health Without Mental Health” (HMG/DH 2011), many people within mental health services have been stigmatized and often may not hold a role or occupation. Indeed, in this project, contributing, creating something which is tangible and out there (in the world), or capable of going in the market, was described as something remarkable.

Stigma and (lack of) societal mattering are different but relate to each other. While stigma may be more associated with negative views, a lack of societal mattering refers to a form
of indifference, or marginalization. Unfortunately, there are large segments of society where marginalized groups of people have been made to feel insignificant (Pernice et al. 2017). Within this project, participants recognize their contributions in light of how they may make a difference. According to Pernice et al. (2017), at a collective level, people who feel as though they matter and that this is appreciated by other people will be an energized and engaged group of people who are capable of offering any things to their communities.

Arguably, whether or not lack of societal mattering contributes to the development of mental health problems, it often plays a role in exacerbating these or hindering recovery. The lack of purpose, goals, social roles or occupations is detrimental to mental health even without having any clinical symptoms.

Summarizing, within mental health, I suggest that societal significance may be difficult to achieve through the currently available mental health services, despite being part of the UK mental health strategy. The opportunities to contribute to the wider community are rare, often limited to activism or volunteering directly related to mental health.

In design, participants’ contributions count -by definition- for something other than to better their mental health, they matter to the world. The purpose of what is being designed is defined, and valued, for its societal impact, or in other words, the context of use. This situates the designing experience as particularly relevant to nurture a sense and recognition that participants can and did contribute to society, in Nealy’s terms, ‘whoever we are, whatever we are’.

**Design and delusions**

In my analysis above, I explore the relationship between social mattering and delusions of exceptionality. Amara discussed the notion of grandiosity in her reflection about her belief in the game. Anthony, on the other hand, reflects on his unusual beliefs’ purpose in comparison to that of the designs’.
Grandiose delusions (GD) are unfounded beliefs that one has special powers, wealth, mission, or identity (Leff, Fischer, and Bertelsen 1976), different from persecutory delusions. They are found across a wide range of conditions, including in around two-thirds of patients diagnosed with bipolar disorder, half of the patients diagnosed with schizophrenia, and in a substantial proportion of patients with substance abuse disorders (Knowles, Mccarthy-Jones, and Rowse 2011).

Delusions of exceptionality is a new term suggested by Isham et al. (2021) to replace delusions of grandiosity, which they consider to be an imprecise description of the experience. In their qualitative study, they determine that the meaning of these beliefs was not synonymous with extreme superiority or arrogance which is why they propose delusions of exceptionality as an alternative term. This was the case for Anthony and Amara, who despite having shared some experiences that may indicate some sense of exceptionality, never exhibited any sense of superiority. Indeed, my memory is that they were both quite remarkable individuals in regards to their appreciation towards others, embodying equality in practice.

According to Isham et al. (2021), these delusions are arguably the most neglected psychotic experience in research and have not been a specific focus of research and clinical practice. One apparent reason may be the perception that they may not be distressing or harmful, which Isham et al. (2021) argue might not always be the case. The authors investigate the possible harms directly from patients, as well as reasons why beliefs persist and what would they like from services. In a sample of 15 participants, harmful or potentially harmful situations were identified by all. Different kinds of harm, physical, sexual, occupational, emotional and social harm (such as being ridiculed by others) are listed. Harm was not solely caused by the belief per se, but sometimes due to the degree of preoccupation with it, or by others’ responses (Isham et al. 2021). In their study, disbelief by others was prominent and experienced negatively by most participants, especially those hospitalized.
Anthony did not report the disbelief on his delusions as a source of harm, but he did extensively describe how the design project, being more solid and not so readily dismissed, make it more likely for others to acknowledge his other work and ideas. Because of the designs, it was less likely to be dismissed in other important aspects of his life such as his unusual beliefs or dreamworld. He mentions this is noticeable in subtle ways like body language. Being ridiculed or dismissed, in light of the motives behind Anthony’s dreams - populating the world with decent and grounded people for the benefit of humanity, could also be indirectly undermining Anthony’s genuine goals to help the world.

Indeed, Beck and Rector (2005) argued that grandiose delusions may develop as a compensation for an underlying sense of loneliness, unworthiness, or powerlessness, noting from their clinical experience that many patients with GDs “have experienced prior life crises characterized by a sense of failure or worthlessness”. (Beck and Rector 2005 as in Knowles, Mccarthy-Jones, and Rowse 2011). A social role or rank may be determined to play an important role in some of the delusions of grandiosity, which emerge to defend ones “social self-esteem” (Heatherton and Polivy 1991).

Rhodes and Jakes (2000) explore the relationship between delusions and goals through a qualitative method. They suggest that if delusions relate to motives, it is also possible that general classes of delusion relate to general motives, noting the example of grandiose delusions with desire for achievement or power. They give some ideas about how the goals of life may converse with the contents of delusions, and suggest that this could illuminate ways to do psychotherapy work.

In (Isham et al. 2021), narratives emphasized that grandiose beliefs were ‘meaning-making’ experiences, and participants reported the beliefs as highly significant, providing a sense of purpose, belonging or self-identity. Furthermore, in a thesis exploring Grandiose delusions through a grounded theory approach, Grbic (2013) explored first-hand experiences of grandiose delusions, describing a process of moving from distressing to positive feelings. She summarizes that some individuals remembered making a
conscious decision that their life had to change and others talked about actively doing things to make themselves feel better. Indeed, the experience of GDs was viewed by some as a journey of recovery during which the individuals had the opportunity for healing.

It appears that these delusions may be experienced as purposeful on one hand, while also hold harmful consequences on another. Through design, this purposeful side of delusions can be used to illuminate and inform design activity, which in turn can make the participant less in need of delusional ideation, or prevent the associated social harm.

Hence, the purpose of Anthony’s beliefs and that of his designs have some commonalities. For Anthony, focusing on meaning-making through design might be a channel that could lead to fulfilment without having to rely as heavily on the delusional resort. Anthony’s case is particularly telling in this regard, as he mentions that he feels better in himself for contributing towards something together with other people. He is no longer the one person who can change the world through his beliefs, but part of a group that changes the world through commonly agreed means, in ways in which others recognize.

It is possible that the design project, giving Anthony the power to envision alternative ways to impact the world for good, for societal mattering, materializes his goals in a more shareable form, as well as insulating him from some of the social harm like being dismissed. Amara’s commentary on the further development of the board game, and the way she reflects her entrepreneurial dreams in relation to grandiosity are also an example of how the project provides an outlet to wishes for making an impact in society and mattering to the world. In a more general sense, David also talks about how recognizing their contributions and gaining a voice can inform participants’ identity beyond the label of mental illness.

Designing may offer possibilities for contributing to society in ways that other people confirm and understand, which has a different quality than delusions, which are often, although respected and acknowledged in best of cases, mocked or dismissed in the worst.
Participants could link their goals with designs through a process of continuous negotiation with others, within a shared reality. Beliefs systems, including delusional or unusual ones, are part of these explorations of design’s purpose, they are networked in the process. The created outcomes constitute contributions that -as participants put it- *count*, driving the recognition of mattering which often takes participants by surprise.

**How did participants beliefs affect design?**

Another interesting question for discussion is the way unusual beliefs affected the contributions and the purpose of the designs.

In studying grandiose delusions through grounded theory, Grbic (2013) develops a theory around the Expanding sense of Self. One of the four related categories is Higher consciousness, among the others titled: search for healing, regaining control and element of truth and validation. Grbic (2013) describes that most participants described a higher state of consciousness, which was characterised by heightened perception and moving from a focus on materialism to increased spirituality. During the state of higher consciousness, the participants experienced spiritual connections with other people, nature and supreme beings such as god and Christ (Grbic 2013). The state of higher consciousness and heightened perceptions also led the individuals to experience their world as highly significant and meaningful, feeling that they had a purpose in life or destiny (Grbic 2013).

It is not clear if participants in this project experienced anything alike, but many interactions through the process, the cultural probes responses and their accounts seem to align, to a certain extent, with Grbic’s (2013) analysis. I often thought about how their worldview transcended the mainstream socio-political, economical agenda and questioned what was, in fact, important.

Arguably, nevertheless, if grandiose delusions are considered in this light, not only the design project may provide a channel for societal mattering for participants but what
matters to them may be in line with worldviews that challenge the motives which have traditionally driven design activity (e.g. profit).

In line with what Sanders and Stappers (2012) describe as societal value co-creation, in this design project matters of concern were explored openly. The nature of these matters of concern was humanitarian and spiritually oriented, a philosophy where caring for each other and the planet seemed to be paramount. In essence, what I noticed in working with this group was a conscience that considered more carefully and seriously alternatives to what matters in life, which then informed the board game accordingly. I suspect that this spiritually and philosophically invigorating attitude may have been related to participants’ experiences of psychosis, and had an important impact on the design.

**Conclusion and summary**

Contributing and societal mattering, although a key part of the UK mental health strategy, is not something participants seemed accustomed to, and opportunities for such societal roles are rarely available, or inaccessible, for people with psychosis, often due to stigma.

On one hand, the design process enables an already existing willingness to contribute, and responds to the lack of opportunity to do so. It might alleviate the need for delusions of exceptionality or its associated harms. The design process may motivate the generation of ideas in ways that support participants societal mattering specifically, because these ideas 1) are situated in a reality that is collectively negotiated 2) their imagined use in context involves the world. On the other, matters of concern emerging from designing with participants align with Grbic’s (2013) participants’ accounts of moving from a focus on materialism to increased spirituality. The design project may have interesting things to offer, to people who have delusions of exceptionality. People who have these delusions, on the other hand, may offer great contributions to the world through design.
5.2.2 Connecting: ‘have a chance to interact and talk about such stuff rather than their problems’, ‘it helped me understand people’s thinking processes’.

5.2.2.1 Overview

Another theme that emerged from participants’ narratives was that of connecting, with terms describing the quality of those relationships too, such as being acknowledged, understood, asked, not dismissed, not judged.

It seems that the design project meant initiating interaction among some participants, and getting to know each other. Anthony further describes understanding other’s thinking processes better and overcoming communication barriers with Baris, who spoke another language. They reported that they got to talk and know people with whom they did not interact before.

Jack remarked how the project meant connecting over something other than problems or worries, and Anthony speaks about how the interaction was something other than the chat which often happens in the drop in. On the other hand, the existing connection around mental health, and the ethos of the HUB was also recognized as playing a role, as described by Amara and David. On the other hand, sharing belief systems and psychotic experiences, which were recognized by Amara as not having been shared with peers before, had its challenges, but was also associated with building stronger connections (Amara) or reflecting on them (Anthony).

It can be argued that the project seems to offer alternative ways to connect. Some participants’ experiences suggest connection happening through the project, such as being asked questions about drawings done in the group, or having people at the charity
react in different ways or show curiosity for the project. Nestor talked about sharing experiences and hobbies, and learning about people. Showing interest or curiosity towards one another seemed to be favoured by the project.

Doing things, creating, and playing all together appeared important for connection, as explicitly remarked by Nealy.

Various sentiments are associated with these connections, or to put it another way, these relationships had certain qualities. Specially Amara and Nealy seemed to have noticed the nature of these connections being non-hierarchical and non-judgemental, forging a sense of equality between all participants, including myself as a facilitator. Amara further described the connections in spiritual terms and made associations between the connection among us participant co-designers, with the way the board game makes people (users) connect.

5.2.2.2 Analysis

Initiating and forging connections.

Some participants talked about how they connected through the project, for instance how they got to know people who -although they had seen around the drop in every week- they did not know beforehand. For instance, Anthony talked about how he hardly talked to Uriel beforehand, and how he could chat with Baris because of the design group, despite the language limitations. Nealy and Amara also remarked that they did not know, or did not even talk to some of the other participants before the project, although they knew each other from a hospital stay years ago.

(...) I found that we were relating well (...) because before the design group I felt I don't think Anthony said anything to me for all the time I have been here (...) and then I got to know him (Amara, 2nd interview)

I hadn’t talked to Uriel hardly at all until your group, and other people, Baris we chatted a little bit because of your group, even though his English is not great we
could chat you know a good bit (...) (Anthony, 2nd interview)

I mean as a group I didn’t know Uriel very much (...) I knew him but [I didn’t know that] he was also creative, he was good making pictures and everything [so] yes I started to know people better (Nealy, 1st interview)

Some participants mentioned that the project helped them understand each other better.

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

it [the design project] helped me understand people’s thinking processes (...) a bit more (Anthony, 2nd interview)

**Ways to connect**

Participants often referred to what they shared or talked about, what they connected over, or ways of interacting beyond the ‘usual chat’.

On one hand, the design project seemed to provide opportunities to connect over something other than the usual worries or helped transcend over-identifying with mental health problems. On the other, it seemed to have provided also an opportunity to connect over more detailed experiences and beliefs such as those related to psychosis.

Hence, participants appreciated talking about something other than problems or doing something different, referring to the content of conversations, and the ways they interacted.

I know what design is all about, so it was interesting to be able to talk about it and show some items of design (...) it was nice to chat to other people, (...) it was a good excuse for some people, I mean I don’t need an excuse, but it was a good excuse for other people to have a chance to interact and talk about such stuff rather than their problems, because they are used to just come in here and talking about their problems you know... (Jack, 1st interview)

E I can see how it [the design project] would help bring out some people who needed to be brought out and to talk about things you know, to take their minds off
the worry or the depression or the stresses of whatever other people are going through, and even for me, it was a welcome relief to be talking about something else other than what they did to me last night, how upset I was, how upset I always am, about why they keep doing this thing to me and I just keep beating myself head against a brick wall for so long with one problem, that is just a welcomed relief to have someone say: by the way what is your opinion in design? So it is good to have had someone just pose a different set of questions. That is what the design project means, means to me (Jack, 1st interview)

people would say, oh you know is Erika here today? Is she in this week? Is she coming later on? And, what are you doing in your project? (…) and rather than coming here and chat you know, and I am not saying that chat for an hour wasn’t good, but to do something else as well (Anthony, 2nd interview)

It appears that the connecting subject of mental health might have its benefits, but not so much if it becomes the only focus or the only way in which people identify and connect. While Amara recognized the value of having a common ground around mental health, David talked about how often clients would overidentify with the diagnosis and how the project provided a break from that.

Well… we have that mental health connection anyway don’t we (Amara, 2nd interview)

a lot of sufferers probably are overidentifying to be honest and don’t recognize that it is part of them, not all of them (…) I think some PTP participants do sadly overidentify, which is a consequence of the illness, and if it is particularly disabling and they are isolated they then ruminate on the illness and their problems with it, and the trauma of it, and don’t see themselves as people who (…) say have bipolar not are bipolar. (unclear) I have bipolar, (…) is not I am bipolar, which is the whole of my personality and identity is bipolar (David, 1st interview)

Besides opportunities to talk about something other than worries, there were also chances to share experiences to a certain depth, such as psychotic experiences, perhaps in a different light.

Both Amara and Anthony talked about sharing their psychosis or unusual beliefs with one another. They both seemed to have felt uncomfortable first, and then reached different
reflections. Amara mentioned how she had never shared this with peers before, and that it did make her shortly paranoid to see how they could be similar, but that it was amazing and felt a great connection. Anthony, also, remarked how getting to know Amara through the project had meant learning about some of her unusual beliefs. Although this made him uncomfortable at first, he decided to act normal, feeling able to ‘deal’ with a different belief system. He comments on the challenges of this deeper connection, yet reflects how others may have that reaction to his unusual beliefs too.

(…) sometimes even part of me felt paranoid because it was so similar I thought this is got to be made up this can’t be real you know but and I but I do I do think is a real person with real problems…(Amara, 2nd interview)

Because otherwise I wouldn’t have learned for example about Uriel’s thing about recycling…(…) and the way that that me and Anthony had had such a connection mentally you know, in our mental experience. I found I thought that was amazing I never met anyone [who] had had same similar thoughts (…) we got the same beliefs (…) we had almost the same psychotic belief me and him and I found that amazing because usually I don’t talk about anyone’s, they don’t speak about their psychotic beliefs. I found that when I met people normally even people you do know [has] got problems (…) they may not tell you about their psychotic experiences and beliefs and I was amazed to hear about his (…) I felt like great connection there and that is why I think we have got this bond, partly because of that, because of the group and because of that (Amara, 2nd interview)

(…) well I thought I … the following week I thought will I step away from her, not engage with her, because she told me this [her belief] and it freaked me out (…) but I thought no, the way is to be normal with her (…) and even though I am a bit freaked out (…) I chat to her as normal and didn’t mentioned it and just (unclear) I think I walked home part of the way with her (…) like I got to know people more (Anthony, 2nd interview)

(…)

maybe people said the same about me if you get to know me… I come up with my weird ideas and I put weird ideas all over other people and people [they] may say oh… keep [him] on an arms-length (Anthony, 2nd interview)
Furthermore, for Anthony, sharing design things with others led to an increased sense of acceptance and interest from others toward his unusual beliefs.

(…) people would, you know, just in the common room, they would ask questions about what was going on, and they [would] read stuff that came out of me because of the project, and maybe it changed their mindset about me, so that they viewed other things I said with a little more, not just understanding, a little more (…) belief (Anthony, 2nd interview)

When I asked Amara whether the context of designing has any impact on how relationships develop, she agreed and pointed to the fact that the game they designed embodies the common themes upon which the participants connected over. Hence their connection forged around the themes that built the purpose of the design, which all go with the game as well. The process of purpose finding and the purpose-driven action which follows (creation of the game) seem part of the process of connecting. Amara and Nestor did not seem to demarcate clear boundaries between what was conceptualized as the design process or outcome.

(…) we seem to connect in ways of bits of nature and religion and spirituality and you know it all went with the game, didn’t it? and is all part of the game (…) (Amara, 2nd interview)

Yes because a lot of help is needed (…) and this new this new ideas of of of helping you know (…) really I am thinking god is love god is a creator, creator is designers and to bring that energy into helping the world yes (Amara, 1st interview)

Participants reported various kinds of interactions that appeared concomitant to how designing encouraged working or collaborating, including doing things together, or people reacting to things they created. The activities in the project, are recognized as enablers to getting to know one another.

once I get people reading and looking at little diagrams, it was Uriel who liked my diagrams of the stools, and the joints and the milking stools, and stuff he liked he said oh I like your diagrams (…) you know like funny little cards, I am not much good at cartoons, but we did quite a few of them …– (Anthony, 1st interview)
I [brought] loads of stools (…) CDs, books, and (…) drawing in little doodles (…) little diagrams (…) showing this to people and stuff (…) people you know were amused by that (…) in a good muse, a good way (Anthony, 1st interview)

I liked working towards the board game (…) showing other people, sharing work experiences, their hobbies and interests as well, it was nice. (Nestor, 1st interview)

So that was good, yes, bringing the books in and engaging in people learning about these people. (…) it is a good bunch of people, very intelligent people. Nice talking to them. (Nestor, 1st interview)

It was a social thing, but it was social with other people who weren’t involved in the project who asked questions about it as well. So you know it was a good (…) you know I will be sorry [when it ends] (…) like I will have to find something else to do, I will have to annoy them all with my whistle (smiles) (Anthony, 1st interview)

Nealy appears to invoke a notion of being brought together through thinking, playing and creating new ideas as a group, and Amara referred to a universal mind, a collective brainstorm.

it was nice to be play all together and [create] new ideas all together as a group yes I enjoyed that yes (Nealy, 1st interview)

I think maybe it was like a brainstorm in our brains (…) what did I say earlier the universal mind I think must have been at work and got together and did a good creation a design (laughs) (Amara, 1st interview)

When prompted to reflect on any changes during the project, Nealy replies that they were brought together as a group:

yes I mean it changes about bringing us together as a group and thinking all together as a group playing games and laughing yes it was change I mean we laugh a lot yes (Nealy, 1st interview)

yes no I think it bring us together generally and then I mean yes I mean is change generally yes. (Nealy, 1st interview)
Qualities of connections

Participants also made several references to the qualities or characteristics of connections made through the design project, such as feeling everyone is equal, being able to understand one another and not judging one another.

Amara experienced her ideas to be equal to anybody else’s, and Nealy mentioned how I was just one of them, an equal.

I feel like I did achieve something you know, it was my idea to have a game wasn’t it? I think it was my idea really and I feel really proud of that. Somehow I think it made me feel equal, the ideas that I did have (...) they were just as equal (...) they were good ideas I think I had some good ideas... yes... makes me cry you know [Amara, 1st interview]

I mean we can trust you straight away, and you were happily explaining very nicely and you didn’t make it like a classroom or something, you were friend with us and that affects us as well. The person is important also as much as [the] project, you explained us everything very clearly and you make it more easy for us and very little challenge. You appreciate it and you encourage, that skill is important (Nealy, 2nd interview)

You were so friendly, so close; one of us, you behaved like one of us. (Nealy, 2nd interview)

Being non-judgemental seemed to be an important element of the group, too.

Here we don’t judge each other we accept the way we are, yes, but outside we have to be careful what we say, what we do, how we talk, everything, but here inside the group, we are ok. (Nealy, 1st)

[here] we are thinking of something and we are safe (...) I mean in the outside, if I get this kind of project I can think oh I can’t do it, I can’t do it, it is so difficult for me, people are so creative and they are going to laugh at me or something (Nealy, 1st)

This sense of equality seems to extend to sharing experiences and belief systems too, where different worldviews were exchanged, acknowledged, and respected. Anthony
referred to how people were less likely to dismiss his ideas, and when prompted, reflected on how the experiences of others are legitimimized as equally valid, too.

Erika: do you think that the designing project for example enabled you to do that in return in terms of considering or legitimizing that experience of the other as...

Anthony: is equally valid

(Anthony, 2\textsuperscript{nd} interview)

Amara talks about how with designing, she is relating better, more with the heart, which makes her feel happier.

It just really makes me feel connected and (...) with love and that makes me relate better and be happier (...) that makes me feel happier, relating more with my heart

(...) you know that is what I am doing with designing (Amara, 2\textsuperscript{nd} interview)

Connections were not always smooth. One participant mentioned not connecting with someone, although she also framed this as leading to learning from one another too.

I don’t really connect with Uriel really I didn’t connect much with him, I think there was more like a disconnect with him (laughs) (Amara, 2\textsuperscript{nd} interview)

but maybe that has pressed my buttons and for me to learn ... learn from feeling angry or upset (...) there is things to learn isn’t there (...) maybe we had something to learn from each other... (Amara, 2\textsuperscript{nd} interview)

Finally, David and Amara mentioned the positive effect of how the HUB is set up, which provided favourable conditions. Amara expressed how the ethos of the HUB is for people to be equal. Furthermore, David talked about how the HUB is an appropriate place for researchers to negotiate with participants.

Well the Hub isn’t it. Yes... very important because, I suppose you know, I have been here like two years now actually and like getting used to being around therapists and just as human beings (...) I think the idea is for us all to be equal (...) because I was here a while before you came, and so I think I was used to doing that, so with you and the project that was easier because of the hub (...) (Amara, 1\textsuperscript{st}
I mean I think you did it well in that you got to know us over the lunch, that is why I think the lunch is quite a successful way of negotiating with surveyors and researchers and PhD students [and] with the service users (David, 2nd interview).

The connection is also expressed by Paula in spiritual terms, especially referring to the depth of connections towards the end.

(... it connects I think from the universal mind (...) I think has to do with love, as well as universal, physical body, or you know mind body and spirit and... I have ... we are all connected (...) I know is supposed to be a spiritual thing but (...) is all very literal to me when I think about it and so...(Amara, 2nd interview)

(... this group of people to do this creation of this game (...) it was deeper and I think it was on like spiritual level really and emotional and mental (...) I think we did connect in those ways especially at the end ... I am not sure about the beginning too much because I wasn't there so much (...) with my unwellness sometimes I feel that I can see the spiritual side of what is happening, and well I didn't see it this time, but I think you have just brought it [up?] (...)(Amara, 2nd interview)

5.2.2.3 Interrelations with other themes

The theme of connecting seems to relate to contributing and intentioning, as it appears to nurture a sense of togetherness through shared action.

Anthony and Paula discussed design as interacting with the world and being stretched, intertwining the notion of connecting with focus, direction, grounding, which are explored in intentioning (section 5.2.3).

[when collaging] I am focused and calm and relaxed on one way, if I was left to my own devices I I could be like that (...) but you have to interact with the world (...) for the duration of the time that I am doing the green book I am out of the world I am just in my own situation which is good in one way but bad in another, when I am doing the carving I am even more out of the world (...) dusty from head to foot and my nails I can’t go out people wouldn’t understand (...) will think you have dirt
I would say it was I think it extracts ideas out of you that you wouldn’t have otherwise and yes definitely and bring yes you are connect you do connect with the people (...) you can make strong connections with some you know in the group and erm... erm... what else... well everything that a group (...) you are creating these ideas (...) it just makes you feel better and and it gives you a sense of (...) accomplishment, achievement and stretch you, stretches you in different ways and you can have a lot of fun and... fun group. (Amara, 2nd interview)

As mentioned earlier, the theme of connection also relates to contributing (5.2.1), as there is a shift in how Anthony perceived his contributions being received by others, altering the nature of those relationships. As a result of the designs not being dismissed as his ‘wilder’ ideas were, he felt that people would not be able to dismiss him for them - wilder ideas- quite in the same way either. Furthermore, Nealy remarks that if I was like a teacher or if I patronized them, they were not going to create, pointing toward the importance of the qualities of connections for contributing.

if is like a teacher or if you were [to] patronize us, we were not going to create, we were not going to, we would [be] scared to tell you something, but it didn't happen we were so encouraging so friendly that helps importantly yes (Nealy, 2nd interview)

I don’t know contributing towards something or you know just not being dismissed like my green book (...) a lot of people like my green book but they dismiss it as well as flights of fancy, or but this this process you know things were not dismissed so readily (...) or at all, they were incorporated (...) into something that we all contributed towards so I felt better in myself (Anthony, 1st interview)
5.2.2.2 Discussion

Participants of this research project signed up voluntarily and were already attending a day centre, which indicates their ongoing involvement within a service designed to reduce social isolation.

Feeling connected to others is potentially an important aspect of the project and research shows a significant positive relationship between loneliness and psychosis (Michalska da Rocha et al. 2018).

Gayer-Anderson and Morgan (2013) suggest that a vicious cycle of exclusion may develop, whereby the disorder limits connections and support, which then leads to a removal of important buffers, thereby increasing the risk of relapse and causing an escalation of psychotic episodes, further social disengagement, and so forth.

It seems that most participants had been seeing one another in the drop-in, yet through the project they reported developing relationships and deeper connections, interacting with people with whom they did not before. They seemed to invoke increased connectedness, by getting to understand others thinking processes, feeling safe within a group, or sharing psychotic experiences with peers for the first time, for instance. We also discussed philosophical, religious, and unusual beliefs without judgement, thinking or playing together, and building a shared purpose.

Attending a regular drop-in may provide the opportunity for additional interventions to be possible, yet it may not always be enough to develop a sense of connection, build a sense of mattering to one another.

Indeed, Michalska da Rocha et al. (2018) raise the possibility that the strategies which are often applied to reduce loneliness in people with psychotic disorders might not be very effective, based on the results of the Adult Psychiatric Morbidity Survey in England (Meltzer et al. 2013), which suggest traditional approaches to reducing loneliness, such as increased social support and participation had only a limited effect on subjective
loneliness. Just increasing possibilities for social interaction might not always be effective (Meltzer et al. 2013).

Well-known drop-in services are one example, which increase possibilities for social interaction, but to what extent these relationships develop? Clients may not feel as if they ‘know’ one another.

According to Lim and Gleeson (2014), pre-existing social networks may be a useful starting point to improving the quality of those relationships. It may be more feasible for those with high avoidance tendencies (e.g., comorbid social anxiety or schizotypy) to improve current relationships rather than develop new relationships.

The Psychosis Therapy Project at the Hub provided a great context in which to facilitate the design project, as people were familiar with one another, even if they did not ‘know’ one another, which might have nurtured a sense of deepening connections or them becoming more meaningful. The development of these deeper interactions focuses on something other than, to quote participants, their worries, which may differentiate it from group therapies which focus on what is being treated, or artistic approaches that focus on personal exploration or expression. In this project, the various approaches seemed to complement very well.

Meltzer et al. (2013) ponder upon the importance of the quality of interaction rather than the quantity. Connections made through the experience of designing together seemed to have certain qualities, which are portrayed by participants as non-judgemental and equal. Some participants expressed such interactions happening despite challenges such as language barriers, or having earlier difficulties with groups.

Theorists and researchers conceptualize the sense of mattering to others as the perception that one is valued, recognized by others, along with the feeling that others are concerned about their well-being (Pernice et al. 2017). The way relationships are portrayed by participants arguably invoke the notion of mattering. Participants talk about various actions that indicate a recognition of mattering, such as people asking questions, in the
case of Anthony, or bringing books to show others, in the case of Nestor. Also, the way participants expressed the qualities of the connections build through the project, such as equality or non-judgemental behaviours, or spiritually meaningful connections in the case of Amara, appear beneficial for building a sense that one is accepted, is seen, and matters to others.

According to Lim and Gleeson (2014) the specific dynamics of relationships, such as reciprocity, where individuals seek support from one another, can further moderate distress associated with delusional ideation, often present in psychosis. In their study, participants with psychosis who reported higher relationship reciprocity were significantly less distressed than those who reported lower relationship reciprocity. The authors provide a possible explanation that more balanced relationships may promote positive bonds between individuals, whereas less balanced (or one-sided) relationships may confer feelings of burden on the helper and guilt on the recipient. To facilitate the development of more balanced relationships, individuals with psychosis may benefit not just from receiving social support but also from opportunities to in turn provide constructive social support in ways that improve their self-esteem (Lim and Gleeson 2014).

Here is where the contributing, explored in 5.2.1 and this theme interrelate, through the concepts of reciprocity and mattering that emerge among peers, but also in relation to the community and society. A sense of mattering to others is implicitly recognized in many early recovery narratives and testimonials describing the importance of feeling valued, acknowledged by others, and engaged in reciprocal supportive relationships (Deegan 1988; Ridgway 2001). Stigma, lack of social support, isolation, and inadequate resources may exacerbate a serious mental health condition and impede recovery, and contribute to feelings that we are alone, irrelevant, or do not matter (Pernice et al. 2017). Participants exchanges among themselves, and exchanges with others outside the group appeared balanced, transcend those distinctions of helper and helped, which is inevitably intertwined with the concept explored in the subchapter on contributing, too. Furthermore, Anthony suggested that the design project was social also with people
outside the group. During the lunch, some of the tasks would be shared with others, raising curiosity and discussion, and mobilizing interaction beyond the boundaries of the activity itself.

Furthermore, in the co-design project, the participants worked together towards contributing to something (see section 5.2.1), they negotiate values, interests, dreams and build a shared purpose for their creativity and design which arguably can be experienced as a meaningful bond. Acceptance into a group of individuals who hold similar values is likely to generate feelings of connectedness and increase the chance of having a confidant from whom one can seek support (Lim and Gleeson 2014). In this context, an exploration of common values was used to inform collective action. Furthermore, the process does not assume values or take them for granted, there is a development and negotiation which occurs through design. I believe the openness and readiness towards wonder and discussion lead to an appreciation of those who might not share the same values. Letting a common purpose emerge might create a sense of belonging, and be favourable to instil a sense of mattering among participants.

As Lim and Gleeson (2014) conclude, the aversive experience of loneliness, together with well-known physical and mental health risks, justify the development of specific interventions targeting the reduction of loneliness. The authors report that in people with psychosis, the ability to connect is challenged by various factors, and a well-designed intervention may reduce the risk of developing psychosis, alleviate the distressing experience of symptoms, and reduce the risk of relapse. Participants of this study have made several references to experiences of connectedness, specifying how the project related to the development of relationships, which suggests that designing may be considered to reduce loneliness.
5.2.3 *Intentioning: ‘it just stretches you towards designing’*

5.2.3.1 *Overview*

In describing the designing experience, several participants made use of terms that evoked a form of force produced by, or associated with, the design situation. Terms used included being stretched toward designing, as remarked by Amara, or feeling more focused and driven, more directed, as expressed by Anthony.

In comparing the designing experience to other activities, Anthony brought the notion of direction. He remarked that he needed a little bit of direction to start, which design gave him. However, he experienced that while when he was doing collage he was directed by holly spirits, it was him who designed. This is particularly relevant because when he engaged in making collage, if God did not place the appropriate words or paper scraps in front of him, it was not meant to be, and he would stop the activity.

Anthony remarked that designing was more rooted in reality because of function, and Amara described the experience as grounding.

Nealy talked about the relationship of his voices with concentration, focus, but also being in a group or alone, which relates also to the previous subchapter (5.2.2)

Feeling driven, stretched toward designing, and grounded all imply some form of force felt that relate to the embodiment of certain experience. What is designing about at its most essential? These remarks can be associated with the phenomenon of intentionality, which is reflected upon in relation to participants’ experiences at the discussion (5.2.3.4).
5.2.3.2 Analysis

Anthony described that the project made him feel directed, focused, driven, and went on to suggest that this sense of directedness associated with designing also extended to other elements of his life through other’s recognition. When prompted to elaborate on ‘getting more well’, he described becoming more ‘driven’

...you know I have been well for years you know, for a good while but I feel better in myself more (...) sort of more you know like driven, sort of like driven in a 2CV you know like Bridget Bardoux (laughs) no, no, driven. (Anthony, 1st interview)

...if you are sensible and sane and directed in certain elements in your life then (...) people can maybe find it hard to put you down in other elements or other parts of your life which aren't quite as clear cut (Anthony, 1st interview)

Some participants mentioned the notion of focus. Furthermore, Anthony gained knowledge that he was able to focus when he wanted, after a long period, since being medicated, during which he did not put his mind into anything.

(...) in some ways, I feel like it is playing, in therapy, because (...) playing with the mind, and ideas as well, I am just realising maybe that is playing as well, but I mean I also go there for (...) what is the opposite of playing? I think working, yes, and things like design don’t feel like work (...) is work and play (...) was for playing, wasn’t it, in a way, (...) it was work [too] because we have to focus I suppose and think or feel (...) I think feeling somehow is connected to my feelings or joyful maybe... very joyful anyway (Amara, 2nd interview)

things may be going around my head but they are not (...) collages going around in my head but I very seldomly concise anything... my dreams are scraps of paper, Jessica asked me have I got (...) a chronological thing, is like paperback diary stuffed with bits of paper (...) so this [design] it focused my mind (...)

(...) sometimes they got me on such high doses of drugs I could barely focus and sometimes I couldn’t watch telly for more than 10 minutes, not that I watch a lot of telly but I couldn’t read a book for more than 10 minutes my attention span ... but since they take me off the drugs (...) I haven’t really put my mind to concentrate in,
for very long (...) apart from collages I don’t put my mind to much else. (...) since they low the dose of the drug or put me on a different drug, [not] that I am on a very high dose at the moment, but still it does affect you (...) I used to do (...) [investigations at work] and still got the ability to focus, and get to a certain point, and so it gives me the confidence (...) or it gave me the knowledge that I I still got the ability to focus when I want to (...) and argue a case with others (...) or discuss aspects (Anthony, 1st interview)

Directed, stretched toward

Amara used the term being stretched, which may also appeal to a sense of being mobilized towards designing. It appears that design provided a form of direction that favoured focus.

well... well... it was a bit different yes because I mean I think with my therapy I can I think with my therapy I can go there to cry for an hour if I want whereas I didn’t feel like I was free to sit there crying with you I felt it was more about (...) we had to do the designing the I felt like (...) kind of said to me just certain way you know is more about the designing (...) than sitting there crying or so. I mean (...) so that brought you more, to stretch you more I suppose, in that way didn’t it, you know because (...) I think I stretch it just stretches you towards designing. I don’t know... (Amara, 2nd interview)

Amara talked about ideas as being brought out by the project or by me, a sense of being mobilized that extended beyond the design project and stimulated ideas in other areas. The association seemed to be sustained over time, as speaking on the phone with me after some months sparked many ideas.

... I think (...) you bring out something in me that is like my ideas and because oh ! you know what! you know when I was on the phone last (Amara, 2nd interview)

(...) I spoke to you on the phone about the design, or wanting to do the book, the game, but yes affected (...) all my ideas (...) getting me to sit there and write about them which (...) I don’t remember doing before, so really (...) it does affect, (...) it does stretch over everything else (...) other projects... (Amara, 2nd interview)
I was unwell (...) it may have been the first or second week (...) I was very unwell and then you rang, and then I was being I think positive about you making money from the game, us (...) I felt that you were a bit low or a bit negative about it all (...) but I felt very positive and I got off the phone and I and I started having ideas (...) I wrote them I didn't bring my book but I if I see you again I will (...) show you (...) I wrote about six pages and some was (...) just names of just some of my favourite songs that I happened to hear on the radio, which is a sign as well ...
(Amara, 2nd interview)

While being directed and stretched seemed to refer to the immediate experience of designing, motivation is associated with the project more generally.

well... I don't know if I have already said it but I think like well I mean to say it gives me such joy and that really moves me you know (...) like I wanted to come here and do the group, and I was motivated to get here and I don't know (...) the joy of it (...) that is partly what we are alive for, is to have peace, love and joy (Amara, 2nd interview)

(...) I am motivated I woke up that Monday morning, after speaking to the clairvoyant, that was as I said nearly two weeks ago, and I was motivated and I wanted to go to Iseledon road (centre with art therapy), rather than talking myself out of it, I talked myself getting into it... (Amara, 1st interview)

now I am more motivated and going out more (...) my diary always it was getting full up, but I would put crosses and crosses and ticks when I do it, but I have been having a lot of ticks, and busy (...) I have got three of my family coming over (Amara, 1st interview)

Anthony and Amaras’ accounts also reflected on how the designing experience is different from other things they had tried. Anthony commented that he needed some direction to start an activity, and compares it with occasions (in the writing group) where he would be advised to write on an open topic but this would get him blocked.

I think you did give us homework (...) sort of like camera things, (...) objects we liked and different things (...) it was never obligatory it was just if so (...) I tell you in creative writing, which is I gone on to since your design got me writing, sometimes [the facilitator], on occasion, once or twice said write whatever you want and (...) I never get... whereas I need some direction. If she says oh write about
the weather (...) then I can (...) sometimes [she] says write about anything you want (...) and I can’t think of anything, I need some [direction] (Anthony, 2nd interview)

once I got involved in your design group (...) you gave us little tasks to do, or things to think about and that was enough direction, or maybe it was just the right time for me to to start writing and doing things... (Anthony, 3rd interview)

(...) sometimes you have an art therapist or sometimes (...) you just go and work in your own (...) or there may be a worker, she may be in and out (...) but (...) you weren’t in and out of the room even, you were there and you were wanting the ideas weren’t you, you were wanting the design ideas and so that is what we were there to do (...) so that was exciting, or that was stretching, that was stretching me really because you know to think of myself as a designer, to do something to do with design really stretches me because is never been something I thought I was interested in, whereas really I am, really if I think more about it because even my art is some kind of design I have got some kind of style...(Amara, 2nd interview)

I was directed and something came out and it was a tangible... (Anthony, 2nd interview)

(...) so I like a bit of direction (Anthony, 3rd interview)

I suppose I will just be sitting around the room with them before (...) it would just have been what can we think of discussing, as opposed to direction (Anthony, 1st interview)

Anthony also commented that designing was different from other activities, in that it provided a different kind of focus. He described:

Erika: Do you think this focus is it different (...) [the] carving (...), the green book and design, is the type of focus different?

Anthony: when you are carving (...) [it] is calm a lot of the time, you have to cut this bit out, so it will take you 5-10 minutes, half an hour to cut that bit out and you can turn it over when you are doing it, but you have made the decision and then you’re calm for half an hour. But the design process, I know that carving is design as well, but [design] is more actively involved and under a little bit of pressure, but directed focused pressure
Reflecting on Agency

Anthony brought up notions about who is the one controlling the activities he engages with, in other words, who is perceived to be the agent behind the actions, contrasting the designing experience with other activities. Talking about his collages (on his green book), he invoked God and the holy spirit directing the activity:

The green book it comes so easy to me, because I have been doing it for so long. I can sit in the one spot and just reach my hands out and everything is there (...) it is directed by God and the holy spirit (...) and if I have to try too hard I don't put it in or I don't try. So if it comes easy [it is] because that is directed and god places the appropriate words and stuff next to me (Anthony, 1\textsuperscript{st} interview)

Anthony described that if the activity of collage does not come as directed by god or easily, it is not something he would carry on trying, which prompted further analysis - in subsequent interviews- about the designing experience. The picture Anthony portrayed reveals possible differences among the activities concerning his sense of agency. According to him, while collage is directed by God or the holy spirit, carving seems to be shared among god and himself. When he was asked about designing, he talked about a collaboration with materials, although it remained ambiguous whether he was still referring to carving. However, trying to understand what he meant by materials and elaborate on designing specifically, the interviewer showed him a specific extract from his 1\textsuperscript{st} interview where he talks about when he designed a lead for six dogs for Baris:

I came out from [from the therapy session] and I was trying to think about a design concept and you said I had to think of something. I couldn't think of anything and then [another participant] was sitting there between the two of us. I thought he walked 6 dogs so I thought oh he walks 6 dogs let's design a lead so he can walk them together (...) so what I am just saying was that was a little bit of pressure he was there and it came to so so (Anthony, 1\textsuperscript{st} interview)

When prompted to reflect on the direction or agency behind designing on that occasion (image 9). Anthony responds:
That was me! it was me that! because you know like [the other participant] was between me and you and I looked at him and I couldn’t think. I probably just come out of my session and my mind was all frazzled a bit from talking too much (...) and then I just thought a walker for six dogs you know, but you remember it was little leads on the end of plastic tubes that were joined to separate them so the leads wouldn’t get twisted. But that was me in there that was me (...) (Anthony, 3rd interview)

Furthermore, on another occasion, Anthony talked about the game needing some direction, implicitly showing his involvement and agency within the project.

the game was totally totally just the idea of the game had been voiced etc but it was but it was maybe it needed a certain amount of direction (Anthony, 3rd interview)

but then later on when the game had coalesced it needed even more... (Anthony, 3rd interview)

sorting out just fine hone it fine-tune it (unclear) even though I know is open so you can play it how you want and whatever so but you know just some direction (Anthony, 3rd interview)

It is possible to suggest that designing contributes to an enhancement of his sense of agency. By contrast, there seemed to be a barrier for the artistic activity to contribute to the emergence of agency in quite the same way, as the motivation to carry on the activity diminishes when not directed by god. When Anthony was engaged in artistic creation, he was experiencing flow, in a way he is directed by an external force, in this case, god. If he did not feel to be directed by God, he would not continue the effort, activity will cease, minimizing the chance for a sense of agency to materialize.

I am directed [in collage] and it is almost like if something isn’t at arms reach, is not meant to be (Anthony, 3rd interview)

Anthony seems to attribute the agent differently to the activities of collage, carving and designing. Considering that diminished sense of agency is one of the important alterations associated with psychosis, these insights hold profound implications for the role of design as healing.
Grounding

Being rooted in reality or grounded is a quality that Anthony and Amara referred to. Furthermore, Nealy experiences with voices, and in what situations these cease arguably also relates to this notion. It appears that focus or concentration may be associated with grounding, which Anthony explains through the concept of function.

Anthony defined design as more rooted in reality, in contrast to the other activities (collage, carving or creative writing), which may reflect the context in which design took place, as well as how design activity is generally driven by a purpose determined by the real world, or an outside, external need. In terms of the context, Anthony describes that when he does the green book or carving, he is out of the world for hours, until the artwork is completed. Furthermore, carving or creative writing often explore more personal imaginaries, what he calls dream world or funny ideas.

(...) for the duration of the time that I am doing the green book I am out of the world. I am just in my own situation, which is good in one way, but bad in another. When I am doing the carving I am even more out of the world because I am black, you know dusty, from head to foot (...) so I remove myself from the world. 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. But the creative writing is as well, but you can go off in flights of fancy. You can with design as well, but design is rooted in the world because it is function and you know you are designing things, things, objects I suppose (Anthony, 1st interview)

According to Anthony, design is rooted in the world ‘because it is function’. This idea of function seemed to refer to the purpose of what is created (what the object is for), implying the world out there. Anthony constantly reflected on his designs’ functions, and how they are used. In contrast to artistic expression, this grounding quality of designing may facilitate a particularly embodied experience.

Anthony made also references the real world when asked about what happened in the design project, in general.
Well I supposed what happened was what happens in the real world, sort of like you get together and you voice ideas and (...) (Anthony, 1st interview)

When prompted to talk about what he thinks the effects of the project had on mental health and psychosis, Anthony responded that when he is focused he is less likely to ponder wilder ideas, a characteristic shared with other activities such as carving. He also mentioned how focusing may make him less self-absorbed.

when I am doing a task I am focused on that, so I am less inclined to think psychotic ideas or ponder my situation and just focus on the task in hand and I know my mum has said that to me as well (Anthony, 1st interview)

so that by focusing in on something you are less self-... I don’t know (...) you are less full of your own psychotic ideas you know, you are thinking other things (Anthony, 1st interview)

Nealy mentioned that although she suffers from voices, in the design group she did not experience them, elaborating that these tend to stop when she concentrated on something.

I hear voices and when I was doing the project they didn’t insult me a lot, they didn’t insult me. I feel safe in the Islington Mind HUB. I like everybody who is here and this project was nice also. I am sure it is going to help lots of mental health people (...) and a lot of people is [sic] going to create nice things (Nealy, 1st interview)

if I concentrate to do design and doing things together, they stop (Nealy, 2nd interview)

Interestingly, Amara mentioned the experienced as grounding as well as spiritual:

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, 1st interview)

Designing may have the potential to direct the focus of attention to the context, or purpose of use, which is experienced as externally driven, and somehow helps engage the
person towards it. Designing therefore may provide a direction and focus which is rooted in the world, yet constantly engages participants in making decisions and driving action.

5.2.3.3 Interrelation with other themes

The notion of intentioning relates to contribution, as well as connecting. Anthony’s following passage portrays how these themes interlace.

if you are acknowledged to be of some use or [have] some validity in certain things, you know the project gave me direction (…) if you change people’s mindsets about you, yourself in one way, then it will affect how they view you in another way (Anthony, 2nd interview)

In comparing the likelihood of voices in different contexts and activities -in art and design activity, Nealy confirmed that it depends both on whether she is by herself or in a group and the level of concentration required, which interrelates the notion of intentioning with connection. This seems to relate to Jack’s comments on minds being taken off their worry, too.

[in a group] they stop. But if you are with a problem in your head and you are not concentrating much just doing the art they carry on (unclear) (Nealy, 2nd interview)

(...) I can see how it [the design project] would help bring out some people who needed to be brought out and to talk about things you know, to take their minds off the worry or the depression or the stresses of whatever other people are going through… (Jack, 1st interview)

When she is prompt about doing design activity by herself, she explains that voices did not insult her because she was thinking:

because I was thinking what to do that is why they didn’t insult me I was thinking oh I can do this I can do that and (unclear) listening the others and no they didn’t… because I was concentrating (Nealy, 2nd interview)
5.2.3.4 Discussion

Participants made reference to a form of force associated with design, which they expressed as feeling more driven, stretched towards or being directed or grounded. Their detailed descriptions, such as the sense of rootedness in reality through function, could be interpreted to correspond to a heightening sense of agency and embodiment through design, experiences that relate to the concept of intentionality.

The Oxford Lexico Dictionary (2021) defines intentionality 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. As Krueger (2020) describes, in its technical phenomenological usage, “intentionality”—from the Latin verb intendo (“aim,” “hold out,” or “stretch”)—refers to the way that consciousness can be about things, that is, the way it can stretch out or be directed toward objects both internal (mental images, memories, fictional objects) and external (things, relations, and events in the world).

The concept of intentionality has been understood in philosophy in a variety of ways. As Reuter (1999) describes, ever since Brentano’s introduction of the concept of intentionality into contemporary discussions, intentionality and intentional acts have been described by two metaphors, as directed towards something and as of or about something. As Reuter (1999) interprets, Merleau-Ponty seems to claim that there can be intentional acts which are not of or about anything specific. He defines intentionality by its “directedness”, which is described as a bodily, concrete spatial motility. It appears that the expressions of participants most coherently allude to Merleau-Ponty’s notion of the concept. Merleau-Ponty reacts to what he sees as Husserl’s excessive cognitivism by foregrounding the bodily dimension of intentionality: a “motor intentionality,” or form of bodily understanding, that allows us to remain spontaneously open and responsive to the people and things around us (Krueger 2020). Watsuji’s definition of intentionality is also interesting when interpreting participants accounts in light of the concept of intentionality. As Krueger (2020) summarizes, instead of characterizing intentionality as
an intrinsic feature of individual mental states, Watsuji prefers to speak of “practical act-
connections”: ongoing patterns of worldly engagements in which individuals enter into
“relationships of reciprocal activity” with their environment (Watsuji 1996 as in Krueger
2020). Amara’s references to the universal mind and being stretch towards designing, or
the way Anthony talks about directedness in contrast with other activities, all seem to
coalesce into the idea of intentionality emerging from these interactions rather than being
a quality solely located in individual minds.

Psychopathology, and psychosis, has often be interpreted as a disturbance of
intentionality. As Hirjak et al. (2013) summarize, after the introduction of
phenomenology at the beginning of the 20th century, many psychopathologists analyzed
essential phenomena of schizophrenia by means of Husserlian concepts and employed the
term intentionality. Mundt, for instance, postulated that the term intentionality means
“the ability to build up and maintain a coherent subjective world of patterns of meanings
and purposes” (Mundt 1990). According to Wundt, a breakdown of the patient’s
intentionality results in both positive and negative symptoms in schizophrenia. In line
with his theory, the development of systematic delusions means a re-establishment of
meaning after the collapse of intentional performances (Mundt 1990).

Phenomenology distinguishes between a thematic, explicit, or reflective intentionality
(e.g., when I look at this chair to the left from me) and a more basic, non-reflective or
tacit sensibility—called “operative intentionality” (Merleau-Ponty 1962)—that constitutes
our primary presence to the world. Operative or pre-reflective intentionality is the mode
in which habits and dispositions come to be sedimented; it furnishes the background
texture or organization of the field of experience and thus serves as a necessary
foundation for more explicit acts of judgment, perception, and the like (Sass and Parnas
2003). The authors describe that from a phenomenological standpoint, we can
distinguish two interdependent aspects of the intentional act: a pre-reflective embedded-
ness in the world along with a tacit or pre-reflective self-awareness or ipseity. We may
speak of a pre-reflective self-awareness whenever we are directly, non inferentially, or
non reflectively conscious of our own occurring thoughts, perceptions, feelings, or pains,
appearing always in a first-person mode which immediately reveals them as our own (Sass and Parnas 2003).

Sass and Parnas (2003) argue that although the major symptoms and signs of schizophrenia are heterogeneous in many respects, they can be understood in a fairly unified way, as a self-disorder or an ipseity disturbance involving characteristic distortions of the act of awareness.

Hirjak et al. (2013) further articulate that the subjective experience of schizophrenia patients with body-affecting first-rank symptoms, which include phenomena such as made actions and replaced control of one’s will, is rooted in the disturbance of intentionality and a diminished sense of agency.

As discussed, Anthony appeared to attribute more self-agency to the activity of designing. While artistic inspiration (e.g. collage) is often perceived to be directed by God, it is himself who designs, manifesting a willingness to respond to the demands of the situation, some goal-directedness. Interpreting these claims, which I first found surprising, through the lens of intentionality, points towards the directedness of design, as creating favourable conditions for the emergence of agency. A healthy form of intentionality may emerge from designing, which aligns with Hamm et al.’s (2018) remark that treatments -based on phenomenology and recovery paradigms- need to address a diminished sense of agency by helping name, reflect upon, and respond to experience as a basis for action.

Sass and Parnas (2003) discuss that in psychopathological conditions such as schizophrenia, there can be no clear sense of goal-directedness, or associated differentiation of means from goal, no strong reason for certain objects to occupy the focus of awareness over others, no reason for attention to wend outward toward the world, rather than inward toward a reflexive awareness of one’s own body or processes of thinking. Sass and Parnas (2003) further specify that the mechanisms via which the things that one should attend to and those one should ignore to be able to drive action in a way
that feels autonomous and coherent, seem to be disrupted. Design behaviour is precisely characterized by this ability to iteratively frame the things and the context that are relevant in a particular situation (Cross, 2001), and designers are trained to navigate this goal-directedness in attending to the needs and desires of the users, their contexts and the resources available.

Often, in a design process, there is no need for a particular, specific goal to be preestablished, but a sense of purpose emerges through the process (Dorst and Cross 2001; Cross 2001). This emergent property may be especially interesting if we consider Merleau-Ponty’s notion that intentionality emerges from the interactions because it suggests that design’s emergent purpose may hold some structural correspondence with consciousness’s emergent intentionality. Being stretch towards designing, being grounded or the notion of design directedness seem to coalesce into the idea of intentionality emerging from the enactment of design. It is possible to imagine the emergence -or attuning- of intentionality under these conditions, or through, the designing situation. Design has indeed that peculiar characteristic, that is a goal-directed activity, but towards a goal that is not well-defined, which aligns with Merleau-Ponty's claim that there can be intentional acts which are not of or about anything specific (Reuter 1999).

As Smithers (2002) describe, we design things when there is a need or a desire for some part or aspect of our world to be different, and we cannot immediately specify how it should or could be changed. What makes designing a particular kind of activity, distinct from problem-solving, planning and other human activities, is that it starts with something that neither specifies what is required nor defines a problem to be solved, yet it must arrive at a design—a specification—for something that, when realised or implemented, will satisfy the motivating needs or desires (Smithers 2002). Therefore, designing must finish with designs, without starting with anything that can be properly understood as a problem for which the final design is a solution (Smithers 2002). This apparent paradox—arriving at a kind of solution without starting with a problem—is what makes designing different from other activities (Smithers 2002). Schön (1983) describes that design emerges from the reflective activity at the interplay of a designer and
the environment. As Zamenopoulos (2012) reviews, this view essentially conveys the idea that cognitive functions are not simply the product of an information processing system (an isolated mind); they are instead formed from the coupling between the mind, the body, and its environment.

The directedness and grounding nature of designing that participants pointed towards, alongside these paradoxical conditions - goalless yet goal-oriented - opens up the possibility that the experience of agency could be remanufactured, or trained, by the designing situation, and so the sense of embodiment healed, too.

In schizophrenia, the loss of the vital embodied contact with reality may be expressed in complaints about a certain opacity of consciousness, like feeling in a fog, or a general existential feeling of being alien to the world (Fuchs and Röhricht 2017). According to Fuchs (2010) instead of serving as a medium of relating to the world, the body makes itself noticeable as disturbing or resistant and what was implicit becomes explicit and enters the focus of attention. Fuchs (2007) suggests that associations or even bodily movements no longer serve as a medium for the patient’s intentional relation to the world, standing in the way of their intentional effort instead. In schizophrenia, the transparency of the body is so reduced that it can no longer function as a medium of turning to the world (Fuchs 2010).

A grounding or embodying experience is arguably beneficial for people experiencing such challenges. Indeed, as Hamm et al. (2018) summarize, if attending to subjective experience is addressed principally by promoting agency, treatment should attend to mental phenomena in the context of embodied experience.

Fuchs and Röhricht (2017) outline psychotherapeutic approaches based on body awareness and movement techniques that are suited to foster self-management and enable patients to re-establish a more stable and coherent sense of self. Phenomenological approaches consider schizophrenia as fundamental disembodiment, including a weakening of the basic sense of self, a disruption of implicit bodily functioning, and a
disconnection from the inter corporeality with others, resulting in the loss of the pre-reflective, practical immersion in the shared world. (Fuchs and Röhricht 2017)

Anthony talked about design being more rooted in reality because of function. The rootedness in the world because of function implies a relation, an interaction, a coordination of parts into a whole which often includes a thing (an artefact, a design), a user or a context. Threads the person who may use something, with that thing and the reason for using it, into a coherent event. For someone who has lost that coherent or collectively agreed connection with reality, engaging with generating function can be seen as artificially manufacturing this groundedness, which can indeed have an embodying effect. Watsuji’s example of intentionality as constitutively social is illuminating to understand Anthony’s claims of how function makes design rooted in reality. As Krueger (2020) summarizes, Watsuji tells us that, just in a simple experience of seeing a wall as a wall, “social consciousness has already intervened” (Watsuji 1996). As he summarizes, intentional objects like walls show up, experientially, as already saturated with meaning, as embedded in shared contexts that specify their salience and significance. Watsuji’s point is that the form these tools take—the “how” by which they manifest as meaning-saturated intentional objects—is not the product of an individual consciousness but exhibits a meaning common to all those who are concerned with this tool (Krueger 2020).

In this project’s case, the designing experience involves an engagement with not only considering things impregnated with function and as embedded in a shared context, but it involves the creation of them. For people with psychosis, who may have an altered experience of intentionality, this engagement and creation of function may place a particular kind of demand that grounds them.

From a phenomenological perspective, Poulsen and Thøgersen (2011) argue that embodied engagement of the designers plays a fundamental role both in understanding the problem at hand and in opening up new ideas leading to a new design solution. According to their study, the verbal interaction constantly finds its meaning in reference to a tacit level of embodiment, which remains unspoken. The verbal interaction is also
integrated into the designer’s tacit use of items in the surroundings and design thinking relies on a more complex and multidimensional interaction, which is based on the pre-linguistic engaged perspective of the lived body (Poulsen and Thøgersen 2011).

Designing’s *groundedness* and rootedness in the world through function may have an impact on these processes and constitute a helpful embodied and grounding experience for participants. Designing as rooted in reality, as grounding, may have helped participants turning towards the world.

Watsuji develops a stronger critique of individualist approaches to intentionality than either Heidegger or Merleau-Ponty, ultimately arguing that thinking of schizophrenia exclusively as a self disorder may be too narrow a perspective, bringing to light the irreducibly relational character of such self-disturbances—losing touch with others is, simultaneously, to lose touch with the resources that give us a world of experience in the first place (Krueger 2020). Simply put, Watsuji argues that consciousness and intentionality are constitutively social. The “deep structure” of intentionality, as Krueger (2020) refers to it, is constitutively regulated by features of the betweenness within which that intentional activity first arises. Designing is a particular kind of betweenness which appears beneficial or *healing* for the phenomenon of intentionality.

This chapter conceptually threads together dimensions of experience that participants referred to such as being stretched toward, feeling directed, focused, grounded etc, which did not initially show a clear connection. I proposed the title of this subchapter making use of a new word *intentioning*, which I understand as the act of manifesting, performing or exhibiting intentionality. Arguably, all consciousness has this quality of intentionality. However, from people with psychosis we learn that it is something that can perhaps be experienced in significantly altered ways. This thus opens the possibility of *intentioning* as something that can be nurtured, rebalanced. A healthy, embodied experience of intentionality cannot be taken for granted, and designing presents itself as an activity that may help address this.
5.2.4 Thinking: ‘oh this could happen like that, this could happen like this, is better to look that way I start to think that way yes’

5.2.4.1 Overview

Some participants discussed that the project ‘got them thinking, or thinking differently, or made them realize that they can think. In relation to thinking differently, participants referred to a form of agility of thinking achieved through exploration of different alternatives or taking various perspectives during the design process, which helped to open their mind. In comparing designing to other creative activities like carving and writing, Anthony also introduced a notion of rhythm ‘fast and slow’ which seems to relate to thinking processes.

5.2.4.2 Analysis

Get thinking

Some participants refer to the designing experience as getting them thinking. Nealy remarks that they didn’t think before, and the notion is shared with Jack, who participated only at the beginning.

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, 2nd interview)

I am always you know open. I think I am not shy but other people are, and I can recognize that it is a good thing to have them coming and you know [saying] ‘why don’t you write down, draw something’, you know design gets them thinking (Jack, 1st interview)
Amara seemed to have expressed, during the project, a similar process of intensified thinking which surprised her and had an impact beyond the workshop. As I recorded in my reflective diary:

Yesterday Amara in the drop in said to me, oh it is a shame we do a (unclear) the movie maybe we should watch it (...) and I suggested maybe (...) talk to Barry about it, and then she (Amara) looked at me and was like ‘that is what is happening, I keep thinking what other good ideas can I have’ and laughed (Reflective diary, 25.07.19)

Also, there seems to be increased confidence in the ability to think as a result of the project. This appears relevant in the case of Nealy.

Thinking wise, yes it [the project] give me [the idea that] I can think wise all the time, I don’t have ideas now but in the life I might have (Nealy, 1st interview)

In the second interview, she expanded more on this notion, and how she realised, through the project, that she can still think, despite having lost creative thinking abilities due to a past comma.

After the comma my creative thinking is just blocked, I cannot create anything but I am still thinking what could be needed? (...) I couldn’t think of new things yet, but it reminded me (...) and I am still thinking: what could be done, new things sometimes (...) I start to think yes... (Nealy, 2nd interview)

Nealy: Yes I can tell that that project gave me [the] idea to create something, and my brain is a bit slow but still, I am thinking I could create. Yes, I am thinking that way, I haven’t yet [created something] but at least I am thinking

Erika: So basically you have learned your potential?

Nealy: Yes

(Nealy, 2nd interview)

Nealy: I am thinking ‘’oh my god who thought this is good invention, is really good something like that, or for every information in the google you know, every kind of information about hospital, transport, city map you know, oh my god is good
invention. I started thinking big you know, people inventing these things; what else could be, which kind of thing could help people to make life easier, I start to think that way yes.

Erika: and you engage in this yourself?

Nealy: yes yes

Erika: like you kind of try and engage your mind as to thinking how the world could be improved or things like that?

Nealy: yes yes yes yes

(Nealy, 2nd interview)

**Thinking differently: possibilities and openness**

Some participants expressed a change in thinking to do with considering possibilities or alternatives. Nealy remarked how she started to think about how things could happen this or that way.

Because you gave us opportunities and you gave us all the ideas we need... and you explained the project and we put all the pictures we took to show people what we did and things like that. But I am not a hundred per cent sure that I could be more creative, that is what I was thinking I (unclear) could have been more creative, but it is going to affect my (unclear) life, and I was at home oh we can do this or we can do that idea ah... we can, I mean I can create at home also, think about something in life, what I mean some (unclear) oh this could happen like that this could happen like this is better to look that way I start to think that way yes. (Nealy, 1st interview)

Furthermore, Jack suggested that this way of thinking, acquired through design, could lead to better therapy, as you get accustomed to considering different possibilities which opens your mind. He gave the example of a therapist giving different explanations for certain experiences (e.g. paranoia), and the client being more likely to consider them because designing encourages that kind of thinking.

I think if you’re sitting around and having what they call a brainstorming... By brainstorming a problem you bounce ideas off of each other, it makes you
understanding of someone else’s, other people’s perspective. It means that you are open to receive different ideas. So (...) if someone was talking to a therapist [and he/she] was saying to the client ‘your problem is not as big as you think’ ‘look at it this way’, ‘open your mind to receive other people’s’. By talking about, brainstorming a design problem, it is in a way opening people’s mind to the idea that their opinion of it is not always set in stone and that they have got to be able to listen to other people’s ideas and implement [them] because they can come at something from a completely different angle and end up with one [opinion] that you may think is wrong, but (...) something that you never even saw, you never knew, but it exists (Jack, 1st interview)

It is good to have them sit around the design thing because you know they will come up with ideas that people never thought about, so that would then lead them to think ‘well it is a good thing to keep an open mind about certain things’ and would then internally lead to better therapy. Because if the therapist said ‘look I would like you to see it another way, what if so and so, you wasn’t being followed down the street’, or ‘stop being paranoid’ etc it’s trying to get people out of the psychological problem they are in. (Jack, 1st interview)

Anthony expressed how he was never fixed to anything during the process. It is interesting that in his case, he first appeared more resistant to uncertainty, for instance not being comfortable with the rules of the game being ambiguous, and slowly became more comfortable with it.

(...) but once we honed - honed is a good word – [the rules of the game] (...) it was good I and I enjoyed making the box. (Anthony, 1st interview)

I never stuck rigidly to anything. Even the lid of the game board: you did it two fonts and one font was nearer one of the fonts I did (...) but the other one stood out more (...) so I let my font go - so I was I was never rigid to anything (Anthony, 1st interview)

I am open to just like, not quite the belief system, but I am open to people explaining situations that I maybe have a [different] explanation of that (Anthony, 1st interview)

Amara also talked about the design project as opening a different mind.

Design well, that is a creative thing isn’t it? and getting better I think is create[ing]
a different mind, maybe (Amara, 1st interview)

When prompted to elaborate on how design allows changing the mind in a second interview, Amara specified it opens it up to different stories and ideas.

Opened up, opens it up (Amara, 2nd interview)

(...) maybe like the spirit world (...) maybe it opens up and all the different stories (...) open up your mind to many (...) different ideas (Amara, 2nd interview)

I think because I think being relaxed really let my mind erm... erm... what is that word... let my mind run free yes (Amara, 2nd interview)

Thinking differently and having different perspectives is something that constantly happened in the design process and is described by Anthony as good-humoured.

I think you have to when there is different ideas, different people having different ideas, you have to discuss them all and you maybe need to let go of some of yours, or fight for some of yours, they have to let go of some of theirs, or fight for some of theirs, but it was fairly good-humoured most of the time, wasn’t it? So yes it was good-humoured all the time I think, it is all right I think. (Anthony, 1st interview)

**Sense of rhythm and thinking**

When Anthony was encouraged to reflect on his experiences, he contrasted design with other activities by referring to concepts of rhythm. This illuminates the type of thinking that happens specifically in design.

He described that designing was ‘fast and slow’, while creative writing was ‘fast and fast’, and carving and collage were ‘slow and slow’.

... design is sometimes quick-fire ideas [initially] but then is developed so it is fast and slow, whereas the creative writing is fast; the carving is thought about slowly and then you turn things slow (...) So creative writing is fast; this [design] is fast and slow (Anthony, 1st interview)
The experience of rhythm may be intertwined with other qualities of experience. Fast seems associated with the quality of coming up with ideas without much analysis and slow when ideas are more carefully developed. Designing seems to shift constantly from freely generating ideas and developing them carefully.

creative writing is very quick and it is in 2 or 3 minutes you have to write something down (...), now the design process maybe you can [be quick] if you are shouting out things, it is initial ideas and stuff and that, but [design] it's developed.

(Anthony, 1st interview)

Anthony also seemed to refer to conditions enabled by the various activities, such as pressure, and the feelings associated with these. For instance, slow was associated with feeling calm, while fast was associated with being under a little bit of directed focused pressure, which was reviewed in the section of intentioning (5.2.3). Having some pressure or being busy seemed to prevent him from thinking ‘funny or wild ideas’, specifying that it was a positive kind of being busy and that it wouldn’t send him over the edge.

I supposed we did design (...) you know I enjoyed being busy but it was good busy (...) I didn't have much time to think about wild ideas (...) I can hack it I can hack being busy (...) I can be busy again and not send me over the edge. (Anthony, 1st interview)

Finally, Anthony also reflected on how thinking about design could be ceased to do something else and resumed later on, which contrasts with other activities which he would not interrupt.

I can be doing the green book for 18 hours 20 hours at a time (...) is slow slow but sometimes it can be done in one sit down session. (Anthony, 1st interview)

I can’t go out to the shop in the middle of doing either of them [collage or carving] whereas say I am thinking about design at home or writing something at home, I can take time out and go out to the shop come back... (Anthony, 1st interview)
5.2.4.3 Interrelation with other themes

This theme interlaces significantly with the notion of intentioning (5.2.3). For instance, Anthony’s reflections about focus and concentration, arguably relate to thinking, which he remarks had not been mobilized much since being affected by drugs.

[The project] give me the confidence (...) the knowledge that I still got the ability to focus (Anthony, 1st interview)

Nealy referred to thinking together as a group, which relates to the theme of connecting (5.2.2), as well as being able to create and think, which reveals how thinking and contributing interrelate (5.2.1).

I mean it [design] changes about bringing us together as a group and thinking all together as a group, playing games and laughing, yes it was change, I mean we laugh a lot yes. (Nealy, 1st interview)

I mean even I can create it gave me that confidence that I can even create, I can even think, and my thought is counting as well yes that is what I thought (unclear) (Nealy, 2nd interview)

Furthermore, It seems that thinking all together, in a safe environment, positively affects the mind.

yes... I mean to in the mind to make us think all together is making mental positive way affected positive way, because we are thinking of something and we are safe we are in the safe environment am... (Nealy, 1st interview)

Thinking differently also might relate to the quality of the connections made, as participants become more open-minded or likely to consider other peoples views and think through alternatives. In relation to Anthony’s comments about people being more open to his unusual beliefs, I asked if the design project enabled the reversal, him considering other peoples experiences as... - he finished my sentence ‘equally valid’.
5.2.4.4 Discussion

Some participants talked about how the project made them think, with expressions such as ‘at least I am thinking’ or ‘it gets them thinking’. This sensation of thinking more, or at least thinking, is important if we consider the complaints that people with psychosis often have, for instance when Anthony and David talk about medication and the effects on the ability to focus or work. Nealy also talks about how the comma affected her thinking, and seems to suggest that through the project she learned she could think.

Indeed, Husa et al. (2017) published the first report of an association between cumulative lifetime antipsychotic dose and global cognition in midlife schizophrenia. Based on these data, higher lifetime antipsychotic dose-years may be associated with poorer cognitive performance at age 43 years.

More generally, in individuals with psychotic disorders, most cognitive functions declined over 2 decades after the first hospitalization, declines which were clinically significant (Fett et al. 2020). The authors describe that some declines were larger than expected due to normal ageing, suggesting that cognitive ageing in some domains may be accelerated in this population. If confirmed, Fett et al.’s (2020) findings would highlight cognition as an important target for research and treatment during later phases of psychotic illness.

In this sense, the design activity can be understood as stimulating thinking. The designing situation is a demanding one, cognitively. It welcomes and makes use of shifting modes of thinking, too. After periods of antipsychotic medication or other health events which affect cognition, designing appears to have helped realize the capacity for thinking, focus and creativity. After an important event, such as a psychotic episode or a comma, whether due to the medication or the event itself, participants may have significantly changed habits, for instance by being hospitalized, and may not have needed to think or focus intensely. The project may have stimulated thinking, promoting engagement with tasks that demand cognitive effort, and thus supporting recovery.
On one hand, it appears that it stimulated participants thinking, which is reflected in some of their comments such as it getting them thinking. In this sense, participants refer to thinking more or beginning to think. On the other, it appears to have helped them think differently, through alternatives, be more open-minded. Some participants referred to thinking differently. Specifically, it seems that design helps one think through different alternatives and opens the mind. The concept of uncertainty and how it plays a role in the designing situation is relevant as it may lead to participants feeling more at ease with ambiguity and consider different perspectives, which one participant remarked may lead to better therapy.

The capacity to look at alternatives and make use of that ambiguity relates to the unique relationship between design thinking and uncertainty. Indeed, design reasoning research has demonstrated that effective designers are not only at ease with uncertainty, but thrive in relation to the opportunities it affords (Alcaide-Marzal et al. 2013; McDonnell 2015; Schön 1983; Christensen, Bo Thomas & Ball 2017). In the design literature, it is thought possible that epistemic uncertainty triggers a ‘metacognitive switch’ that is highly bounded by the prevailing context (Christensen, Bo Thomas & Ball, 2017). I cannot assume these mechanisms are at play behind participants experiences, as there are many aspects of the design situation which can lead to participants feeling it opens their minds and think through possibilities with more agility, but I think this aspect warrants attention. I further elaborate on this notion in section (7.2.3), under ‘Navigating uncertainty’.

Furthermore, perhaps this continuous shifting between what Anthony refers to as fast and slow is driven by the designing context. In creativity research, the capacity to shift between modes of thought had been referred to as contextual focus (CF) (Gabora 2003). As the author explains, whilst the term associative thought refers to creative thinking that involves defocused attention to context, and is conducive to detecting relationships of correlation, analytic thought refers to creative thinking that involves focused attention and executive processes conducive to detecting relationships of causation.
For Anthony, rhythm or dynamic is different in collage and carving, creative writing, and design. While it is difficult to interpret precisely what Anthony may mean when referring to design as slow and fast, in contrast with the other activities it seems that designing may entail something which makes the experience dynamic, providing ways, perhaps through the interaction with the design situations, to shift from one particular mode of feeling and thinking to another. This resonates with recent research by Kannengiesser & Gero (2019) who present an ontological model of fast and slow design thinking based on Daniel Kahneman’s model of human cognition, which incorporates a fast and intuitive thinking system and a slow and tedious one. Kahneman (2011), made this dual-system theory accessible to people outside cognitive psychology in his book Thinking Fast and Slow. As summarized by Kannengiesser and Gero (2019), what is common to all accounts of dual-system theory is that human cognition is described to be governed by two systems: system 1 for fast, intuitive and effortless thinking, and system 2 for slower, analytic thinking that requires greater cognitive effort. System 1 is assumed to govern much of our daily behaviour and it is only when the fast responses generated by system 1 do not produce the results expected that system 2 comes into play (Kannengiesser and Gero 2019). Anthony’s account of design as fast and slow points toward a cyclical pattern involving different forms of thinking. The way design threads different modes of thinking could hold some correspondence with the notions of thinking fast and slow.

Designing might be an interesting exercise to respond to the decline of cognitive functions that may be associated with mental health problems, whether as a result of psychosis itself, a physical illness such as in the case of Nealy or medication as reported by David and Anthony.
6 Does ‘Designing’ increase wellbeing? A mixed-methods analysis

6.1 Introduction

From the nine participants recruited for design at Psychosis Therapy Project, six were comfortable to fill the questionnaires in addition to the interviews. Data from one of them is excluded because he left the country and did not fill the second and third questionnaires. One individual from the other project ‘Co-design for wellbeing’, did the questionnaires but his data was excluded as it was challenging to interpret. Most questions were ticked in the same number, and I had observed that he filled it very quickly, probably not having the chance to read it.

In this chapter, I explore whether (co-)design may have affected participants wellbeing through a mixed-methods analysis. Participants completed the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) questionnaire (Warwick Medical School 2020) and three of the Ryff’s wellbeing subscales (1989), before, immediately after and approximately six months after the project ended (two weeks margin). They engaged in one semi-structured interview immediately after and another one (or two in the case of Anthony) six months after the project. The results from the questionnaires and the interviews are analysed at an individual level, due to the small sample size.

The coding of qualitative data from the semi-structured interviews was conducted first within the IPA study, inductively. Separately, individuals’ wellbeing scores were summarized. Finally, results were analysed case by case to see if there was any correspondence between their (WEMWBS) wellbeing score changes and the themes
from the semi-structured interviews. In this study, the focus lies in the areas of wellbeing covered by the questionnaire and excludes more complex descriptions of their experiences from the interviews (see chapter 5 in this thesis).

Any data from the questionnaires which is not discussed in the interviews - or evident in my reflective diary - is reported without interpretation as it cannot be triangulated. Similarly, The Ryff scales results and a brief commentary are added after each case, but the data is not easily integrated with interviews, due to the limitations with this questionnaire described in the methodology chapter (see section 3.3.3.3).

In the WEMWBS, item scores are summed to produce a total score ranging from a minimum of 14 to a maximum of 70, with higher scores representing higher levels of mental well-being. The results from the WEMWBS questionnaire are interpreted following Maheswaran et al. (2012), who suggest that a change of 3 or more units in an individual’s WEMWBS score was greater than the measurement error in the majority of the studies, and thus could be interpreted as important. As there is no gold standard for measuring high mental wellbeing, all cut points are by definition arbitrary (Warwick Medical School 2020), yet Bianco (2012) settle a cut-off point of 40 and below to indicate probable depression and a score of 41-44 to possible depression.

The items from WEMWBS can be found in (Table 3). In the right column, there is a corresponding abbreviation that will be used in the subsequent data graphs.

The purpose in life, personal growth and self-acceptance subscales of Ryff’s scale of Psychological wellbeing (Ryff 1989) add up to be 21 items. Here they are organized according to the category, whilst it was presented in a different order to participants (Table 4).

244
Table 3. WEMWBS questionnaire, the column to the right are the abbreviations that will be used in the graphs.

<table>
<thead>
<tr>
<th></th>
<th>None of the time</th>
<th>Rarely of the time</th>
<th>Some of the time</th>
<th>Often of the time</th>
<th>All of the time</th>
<th>Shorten</th>
</tr>
</thead>
<tbody>
<tr>
<td>I’ve been feeling optimistic about the future</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Optimistic</td>
</tr>
<tr>
<td>I’ve been feeling useful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Useful</td>
</tr>
<tr>
<td>I’ve been feeling relaxed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Relaxed</td>
</tr>
<tr>
<td>I’ve been feeling interested in other people</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>people</td>
</tr>
<tr>
<td>I’ve had energy to spare</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>energy</td>
</tr>
<tr>
<td>I’ve been dealing with problems well</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>dealing</td>
</tr>
<tr>
<td>I’ve been thinking clearly</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Thinking</td>
</tr>
<tr>
<td>I’ve been feeling good about myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>good</td>
</tr>
<tr>
<td>I’ve been feeling close to other people</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>close</td>
</tr>
<tr>
<td>I’ve been feeling confident</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>confident</td>
</tr>
<tr>
<td>I’ve been able to make up my own mind about things</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>ownmind</td>
</tr>
<tr>
<td>I’ve been feeling loved</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>loved</td>
</tr>
<tr>
<td>I’ve been interested in new things</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>interest</td>
</tr>
<tr>
<td>I’ve been feeling cheerful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>cheerful</td>
</tr>
</tbody>
</table>
Table 4. Ryff’s subscales purpose in life, personal growth and self-acceptance.

<table>
<thead>
<tr>
<th>Purpose in life</th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I live life one day at a time and don’t really think about the future</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>I have a sense of direction and purpose in life.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>My daily activities often seem trivial and unimportant to me.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>I don’t have a good sense of what it is I’m trying to accomplish in life.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>I enjoy making plans for the future and working to make them a reality.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>Some people wander aimlessly through life, but I am not one of them.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>I sometimes feel as if I’ve done all there is to do in life.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Personal Growth</th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am not interested in activities that will expand my horizons.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>I think it is important to have new experiences that challenge how you think about yourself and the world.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>When I think about it, I haven’t really improved much as a person over the years.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
</tbody>
</table>
I have a sense that I have developed a lot as a person over time. 1 2 3 4 5 6

I do not enjoy being in new situations that require me to change my old familiar ways of doing things. 1 2 3 4 5 6

For me, life has been a continuous process of learning, changing and growth. 1 2 3 4 5 6

I gave up trying to make big improvements or changes in my life a long time ago. 1 2 3 4 5 6

<table>
<thead>
<tr>
<th>Self-acceptance</th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>When I look at the story of my life, I am pleased with how things have turned out.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>In general, I feel confident and positive about myself.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>I feel like many of the people I know have gotten more out of life than I have.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>I like most aspects of my personality.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>In many ways, I feel disappointed about my achievements in life.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>My attitude about myself is probably not as positive as most people feel about themselves.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>When I compare myself to friends and acquaintances, it makes me feel good about who I am.</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
</tbody>
</table>

The five individuals from the Psychosis Therapy Project group who completed the wellbeing questionnaires and the semi-structured interviews were: Nealy, David, Anthony, Nestor and Amara.
Both Amara and Nestor had resistance to be part of a group setting at first, and their engagement increased progressively.

It was like...I was a bit resistant at first, at first I was a bit resistant I don’t really want to do this and as time went on (unclear) once every three weeks or something and it turned out once a week I would be for 30 minutes (unclear) half an hour... (Nestor, 2nd interview)

... it was a very positive experience for me the group I know I started off I was having difficulty I think joining in the group but I think by mid group (...) or certainly by the end I think I had felt better (Amara, 2nd interview)

Nealy, on the other hand, reported becoming busy with external issues toward the end of the project, which prevented her from coming to some sessions.

yes I had appointment often and I couldn’t come some of the days, so that affected me, I really wanted to come, but I couldn’t come (Nealy, 1st interview)

David participated in the first activity of the project, but never joined the group. His reasons were a little more complex, in his own words:

Well I just didn’t I didn’t have time to really get into it, so I wasn’t there very much during the group... (David, 1st interview)

I do find it difficult to be around people who are in who are affected in such a way (...) to be around people who are really struck down by psychosis is a way of underlining my own psychosis to myself, which is something I want to wash away and not identify with (David, 2nd interview)

although I need to also be aware of it and identify with it in order to manage it (David, 2nd interview)

Anthony’s participation was intense from beginning to end and included some individual work in between sessions. He usually arrived a little late, due to his therapy sessions.

I was never there for the full session (...) it always started near enough when I would come out from [the therapist]. I didn’t know when you [had] started (Anthony, 1st interview)
6.2 Case by case analysis

6.2.1 Nealy’s Wellbeing

Overall, results from the WEMWBS questionnaire show that Nealy’s wellbeing score increased throughout. More specifically, her wellbeing score was 32 before the project started, 37 after it ended and 46 on the follow-up survey 6 months later, interpreted as important considering (Maheswaran et al. 2012). The graph (Figure 89) below shows a breakdown of the 14 indicators of wellbeing, before (e.g. Optimistic - plain colour), immediately after (e.g. Optimistic - lines) and 6 months after (e.g. Optimistic - dots). Each item will be the same colour across time, with different patterns to indicate time. Abbreviations and respective questions can be found in (Table 3).

![Nealy’s Wellbeing graph.](image)

Figure 89. Nealy’s Wellbeing graph.
In Nealy’s interview, the theme of thinking is very prominent, as well as the theme of connecting with others (see sections 5.2.2 and 5.2.4), which are the steepest improvements in the questionnaire, alongside energy levels.

As discussed in chapter five, Nealy’s perception about her capacities changed as she learnt that she could, if she wanted to, be creative, invent things. These notions, of thinking differently and having hope for the future, are intertwined in the case of Nealy. In the wellbeing questionnaire, she increased the frequency of how optimistic she feels about the future from ‘none of the time’ before the project started, to ‘rarely’ immediately after it, to ‘some of the time’ 6 months after. A similar pattern is observed, in the case of confidence: which increased from ‘none of the time’ to ‘rarely’, to ‘often’ 6 months later. In the interview, she associates an increase of confidence to the project too.

... it happened lot of things in my life, (...) I paid some of my debt yes in my life, and also positive things happened at the same time, in here with the project, also I enjoyed doing it and it gave me confidence the project, that my idea counts (Nealy, 1st interview)

In some cases, there was a drop in her scores immediately after the project which increased again in six months. For example, there was a decrease in how often she felt good about herself, from ‘some of the time’ before the project started, to ‘rarely’ immediately after, but then spiked to ‘often’ after six months. She reported no change in feeling useful before and immediately after the project ‘none of the time’, but again recorded an increase to rarely in the six months follow up. In the interview, nevertheless, she did use the notion of use in a collective sense:

... you ask us to think big, we felt that we are working, it was useful, we created something and it counts. It was a nice feeling (Nealy, 1st interview).

She regularly reiterated that although she was not yet creative, she acquired a new sense that she could, in the future, which resonates with the questionnaire results. In the project, Nealy mostly engaged at the beginning of the project, missing a lot of the sessions where the final board game, the collective design, was being developed, perhaps missing
the opportunity to develop and conclude ideas. The question about ‘feeling good about one self’ could reflect her feeling about these last weeks, when, unfortunately, she may not have been as engaged, although it could be unrelated too. Her results may suggest a new sense of hope and confidence for the future, although her sense of achievements in the two weeks prior was not as strong:

I don’t have ideas now, but in the life, I might have, yes. (Nealy, 1st interview)

I can tell that that project gave me idea to create something, and my brain is a bit slow, but still I am thinking I could create yes (…) I haven’t yet, but at least I am thinking (Nealy, 2nd interview)

In the questionnaires, she reports being interested in new things ‘some of the time’ at the start of the project, then ‘rarely’ and ‘some of the time’ again after six months.

In the interviews, Nealy continuously refers to the notion of thinking, resonating with the steep improvement in the questionnaire. Nealy reported being able to think clearly ‘none of the time’ before the project, ‘some of the time’ after, and ‘often’ after 6 months. There is also a gradual increase in being able to make up her own mind about things, and her ability to deal with problems well is stable throughout the project (‘none of the time’) then spikes to ‘some of the time’ by the follow-up.

In the interviews, thinking is also expressed in relation to togetherness, or associated with the sense of connectedness. In the questionnaire, Nealy reports being interested in other people and feeling loved ‘all of the time’ before and after the project, which decreased to ‘some of the time’ and ‘often’ respectively after six months. However, she indicated that she feels close to people, ‘some of the time’ at the start, changing to ‘all of the time’ at the end of the project, which then decreased to ‘often’ six months after. Again, in the interviews, this closeness may be intertwined with the notion of thinking, playing, laughing together, which she refers to when prompted to talk about the project’s impact.

(…) make us think all together is making mental positive way, affected positive way because we are thinking of something and we are safe (Nealy, 1st interview)
The safety of the environment, the reassurance that others would not laugh at her, that her idea counted, and the very act of creating together had a positive effect.

... it is affecting positive way to talk mental illnesses, yes we were all together and we were trying to do something different, nobody was going to laugh nobody was going to make us small, it was everybody like us all together creating, yes it was good it affects mental health positive way yes (Nealy, 2 \textsuperscript{nd} interview)

I hear voices and and when I was doing the project or they didn't insult me a lot, (...) I feel safe in the Islington Mind HUB (...) I am sure it is going to help lots of mental health people ... (Nealy, 1 \textsuperscript{st} interview)

Finally, in the questionnaires, she reported a decrease in how relaxed and cheerful she felt before and after the project, from ‘some of the time’ to ‘rarely’, which returned to ‘some of the time’ after 6 months. On the other hand, she perceived a great spike in terms of her energy levels, from ‘none of the time’ to ‘some of the time’, which stays stable thereafter.

These results seem to be relatively congruent with results from Ryff’s wellbeing questionnaire. Nealy’s personal growth score subscale was 24.00 before the project 29.00 after and 25.00 six months later. In terms of purpose in life subscale, one of the data entry points was missing from the baseline questionnaire before the project, and the score was 18.00 after it concluded and 24.00 after six months. Finally, the self-acceptance score was 28.00 before the project, 21.00 after it ended, and 25.00 after six months. Although comparisons are precarious, this does seem to hold some coherence with the results of the WEMWBS questionnaire: While personal growth may be associated with Nealy’s sense of a bright future and different view on her possibilities, perhaps not being able to participate in the project in the final weeks -among other things probably happening to her- affected self-acceptance.
6.2.2 David’s wellbeing

David was a regular client at the Psychosis Therapy Project, but he did not participate in the design project often. In the interviews he described his experience of the activity he engaged with, gave insights on what prevented him from participating more, and described the reasons why he thought design could benefit clients from an external point of view.

His wellbeing score did not change before and after the project, staying at 38, and increased to 42 after six months (Figure 90).

<table>
<thead>
<tr>
<th></th>
<th>Before project</th>
<th>After project</th>
<th>Six months later</th>
</tr>
</thead>
<tbody>
<tr>
<td>All of the time</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some of the time</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None of the time</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

![Figure 90. David's Wellbeing graph.](image)

In his interview, he reflected that since he did not participate in the group, any improvement would have to be associated with his work with the therapist and not necessarily the project.
I think because I had less involved than any participants (...) and I also have been seeing [his therapist] for two and a half years now approximately (...) so maybe the improvement that I see was more from my sessions with him rather than your project (David, 1st interview).

He reports a good experience with the activity he did engage with:

When I wrote the text in January it was the one object that I inherited from my father who died 18 months earlier and it felt such a symbolic [thing] that I inherited his pill organizer (...) The exercise of writing about that object was helpful for me and therapeutic (...) organized my thoughts about the object (David, 1st interview).

David also described, from his point of view, the benefits he believes designing might have for mental health.

well, first of all, I think it would be good if they could do that, (...) when they are in good health and they are stable, they can engage in that activity because it could only serve to help them, (...) the things you do when you are stable the achievements that you make, I mean for me is my artwork... (David, 2nd interview).

Although there were slight changes in the scores of individual items, as the interviews focus on an external perspective it is not possible to comment on scores’ association to interviews. Additionally, following Maheswaran et al., 2012, the changes before and after the project cannot be interpreted as important as they did not exceed 3 units.

The results from Ryff’s scales show that the Personal growth scores decreased from 36.00 to 34.00 after the project and 32.00 six months after. The Purpose in life subscale was relatively constant, increasing one point from before to after the project and staying stable thereafter (34.00, 35.00, 35.00) and the self-acceptance score increased from 27.00 to 30.00, then decreased one point after six months to 29.00.
6.2.3 Anthony’s wellbeing

Overall, Anthony’s wellbeing score increased following the project and decreased to the initial score when it was measured six months later. It was 51 before the project began, 55 after it ended and 51 at follow up (Figure 91).

Anthony seemed to have a healthy level of wellbeing, higher than the 40-44 range associated by Bianco (2012) with possible depression. Indeed in the interview, he recognized that he had been well for many years and that the project had made him somehow more driven and feeling better in himself. However, when prompt about changes in the everyday associated to the project, he briefly also mentioned not having been confident before.

Yes that is it well, I have been well for years you know, for a good while, but I feel better in myself, more like driven (Anthony, 1st interview)
I just wasn’t confident and I haven’t been in... the only the only time maybe if I had the cold or something one week (Anthony, 1st interview)

Looking at the scores, what changed most during the project is how often Anthony’s felt able to make up his own mind about things. Before the project, he reported ‘some of the time’, which spiked to ‘all of the time’ immediately after, and decreased to ‘often’ after. Being able to make one’s mind resonates with Anthony’s interviews, which revealed a strong sense of having experienced a sense of direction and focus, of having become more driven, whilst learning that he could focus again. He remarked that design is more rooted in reality (than other activities) due to its function. Furthermore, Anthony reported thinking clearly ‘often’ both before and after the project, which decreased to ‘some of the time’ after six months. In the interviews, Anthony gives an account of the way his ideas and other people’s interact in the group situation, being proud of not getting fixated.

[without the design project] it would just have been what can we think of discussing as opposed to direction, that we think on our feet about how... to... about certain situ[ations] (Anthony, 1st interview)

These aspects of perspective-taking and arguing, as well as the sense of agency held while designing, may have some relation to how often he felt he could make up his own mind and think clearly.

Many of the aspects captured by the questionnaire stayed stable throughout. He reported feeling positive about the future ‘often’, dealing with problems well ‘often’ and interested in new things ‘often’, among other stable aspects described further down. This was apparent throughout the project, with Anthony showing interest in the project and engaging intensely. He would present the design project to others as something that ‘got him started’, as something without which he would not have joined the writing group, although he also wondered if it might have been the right time.

I was like the creative writing (...) followed on from this so if it hadn’t been for the writing and thinking and writing again and thinking again week after week [in the
design project], then I wouldn’t have got involved in that [in the writing group] as I said earlier, or I was unlikely to get involved in that because I didn’t do it in the past when it was available here … (Anthony, 1st interview)

...that [design tasks] was enough direction, or maybe it was just the right time for me to start writing and doing things, but you see the creative writing and the poetry groups sort of are as a follow on from the design group (Anthony, 3rd interview)

The recognition of how the design outcome affects the world, and his unusual beliefs may arguably relate to how useful he felt. Before the project, he reported feeling useful ‘some of the time’, which increased to ‘often’, but returned to ‘some of the time’ at follow up. Although the recognition of this contribution remains intact after six months (e.g. 3rd interview extract below), the scores show him feeling useful less often than right after the project. Considering this, it would be sensible to argue that once this activity ceased, his sense of usefulness returned to what he is used to – yet the sense of achievement lasts.

is amazing just from a you know like a you know you approaching this place in Archway (…) and sort of like the something else gone out into the world … (Anthony, 3rd interview)

Anthony also reflects on how what the group created contributes toward the world, as well as his dream world (e.g. unusual beliefs) does.

(…) this game can maybe contribute towards the decency of people [design contribution] my dream ideas [unusual beliefs] can maybe populate the world with easy-going natures who can lead people in these ethical ways. (Anthony, 3rd interview)

The notion of being useful is intertwined with relationships with others and feeling better.

(…) a lot of people like my green book (collage) but they dismiss it as well as flights of fancy (…) this process (…) things were not dismissed so readily (…) or at all, they were incorporated into something (…) that we all contributed towards so I felt better in myself (Anthony, 1st interview)
In the questionnaire, however, none of the items around relationships - such as feeling interested in other people, feeling loved and feeling close to others- seem to have changed. According to the interview, the design project had tangible results, which cannot be easily dismissed by others like his other work. The project gave him the sense that if people could take him seriously in the design project, they could also do so in other less straightforward areas of his life. He made use of concepts of credibility and validity. The questions in WEMWBS may not capture this specific aspect of interrelationships: being respected and acknowledged, being accepted.

His level of confidence and how often he felt good about himself also remained unchanged in the wellbeing questionnaire, (responding ‘often’ in all three stages).

It [the design project] gives you confidence in yourself, so I felt better over the past, I don’t know, is it 4-5 months is it longer? (Anthony, 1st interview)

The questionnaire results show slight changes in the way he feels, which return to the same levels after six months. For instance, he reported feeling cheerful ‘often’ before the project, which went up to ‘all of the time’ right after finishing, and back to ‘often’ after six months. Although there is no mention of feeling cheerful in Anthony’s interviews, he made several references to humour and banter concerning the project.

There was a good bit of banter and sometimes there was jokes (Anthony, 1st interview)

His energy levels followed a similar pattern, from feeling he has the energy to spare ‘some of the time’ before, to ‘often’ immediately after, to ‘some of the time’ at follow up. On the other hand, he reported feeling relaxed ‘often’ before the project, which decreased to ‘some of the time’ and back to ‘often’ at follow up. In the two weeks before the project finishing, Anthony helped prepare the final prototype and exhibition which could correspond to his feeling less relaxed and with higher energy levels, especially since the scores went back to the baseline after six months. Anthony made some reference to how he felt specifically around the final exhibition and mentioned that the project helped him gain the knowledge that he could be busy again without it sending him over the edge.
(...) I think Erika will bring it all together at the end (...) when I said hopefully, (...) a big thought bubble came out of my head (...) but it came together enough for the party and the exhibition. (Anthony, 1st interview)

(...) you know I have heard of someone went out for a cigarette, the stress got so much for them (laughs) (Anthony, 1st interview)

(...) I can still manage being busy rather than it send me over the edge and then it becoming too much, no this was pleasant I enjoyed it (Anthony, 1st interview)

Anthony’s personal growth score remained stable before and after the project (remaining at 39), while purpose in life decreased by four points (from 40.00 to 36.00) and self-acceptance decreased by six points (from 35.00 to 29.00) immediately after the project. After six months, purpose in life remained stable (at 36) and the other two subscales increased slightly (personal growth to 41 and self-acceptance to 32). This is incongruent with the wellbeing questionnaire, where generally the score improved during the project and then returned to the same level. It is difficult to interpret these results. If we triangulate with the interview data, in most likelihood Anthony’s wellbeing improved, and he continued to reflect in the project as a helpful experience months later. As described in the methodology, some participants struggled with the double negatives of Ryff’s scale questions, which might have affected the results. It is also possible that differently framed questions made Anthony reflect on his wellbeing in different ways. The wellbeing questionnaire is framed positively and asks how often he might have felt in the previous two weeks, rather than presenting statements to agree or disagree with.

### 6.2.4 Nestor’s wellbeing

Nestors wellbeing scores increased from 50 before the project, to 56 after it finished, and then decreased to 45 six months later (Figure 92). These changes can be considered important. In the interviews, overall, Nestor seemed to refer both to the process of
working toward making the board game (the design process), as well as to the board game itself, as therapeutic, and I often struggled to know what he was referring to.

Yes I mean I suppose that it will [be therapeutic], everybody is got on board and helped. Doing such a thing is therapeutic, and is a therapeutic boardgame: we talk about spirituality body and mind (…) (Nestor, 1st interview)

I can’t answer that (how is it therapeutic) is is just… it is just therapeutic working towards (unclear) making the boardgame together that is all I can say really. (…) I don’t really know how to answer that (Nestor, 1st interview)

![Figure 92. Nestor’s Wellbeing graph.](image)

Nestor recognized that his life has improved recently and refeed to various things that were happening at the same time.

Just for me personally my mood stabilizers kicked in. I have started taking them in March and I am much better now, much happier now than I was before. I have got a good friend to join the gym with, so we are going to help each other lose weight. (…) That is about it really… I have [been] enjoying my time off university (…) I am reading as well (…) I am at a better place, but
this counselling thing starting to kick in as well. I have been here about one year and three months or something. (Nestor, 1st interview)

(...) The sun is out every day which helps yes (Nestor, 1st interview)

When he was asked about whether he sees any differences between design and how other activities are therapeutic, he replied:

They all do, they all have their own benefits (Nestor, 1st interview)

Nestor reported feeling optimistic about the future ‘some of the time’ before, which increased to ‘often’ after the project concluded, and returning to ‘some of the time’ after six months, he details in his comments:

So inner peace, knowledge, weight loss (...) for me at the moment. If I achieve that, that would be nice. So yes I am happy, much more optimistic actually to be honest. But it is something we may need to work on, it may take many years until I may not need therapy any more ... (Nestor, 1st interview)

The interview with Nestor also revolves around his interaction with others. In the questionnaire, he reported being interested in other people ‘often’ at all stages. He did seem to feel closer to people after the project, from ‘some of the time’ to ‘all of the time’, but reverted to ‘some of the time’ after six months. He felt loved ‘all of the time’ both before and after the project, decreasing to ‘often’ at follow up. During the project, Nestor’s interaction with other people significantly increased.

catching up and talking to people there were loads of very intelligent people here (...) We were talking about the link between intelligence and mental illness [she] agreed that a lot of people with mental illness had a high IQ, which was nice, it was nice talking to her about that. [participant] seems pretty clued up (...)it was nice talking to people you know, sharing our ideas and beliefs (Nestor, 1st interview)

His interactions with others and his contributions, the sense of usefulness and his role within the project, seem to be interrelated.
Yes bringing my books (...) and picking up the subjects, spirituality, body & mind, I refer them like four fibres [unclear] of these perspectives (...) the books that I brought in. the Dalai Lama book was very good, the Buddhism book (...) The Jung book... (Nestor, 1st interview)

So that was good yes bringing the books in and engaging in people (...) You were saying you didn't know much about Jung. I think Amara was saying she didn't know much about Freud. (Nestor, 1st interview)

In the questionnaires, Nestor reported being useful ‘often’ both before and after the project, which decreased to ‘some of the time’ six months later. In the interviews, Nestor recognized his contributions to the design, and show interest in its further development:

I found quite a lot of the flaws (...) and I managed to correct them and how to turn it into a better perspective so I think it can be therapeutic ... (Nestor, 2nd interview)

He reported feeling good about himself ‘some of the time’ across all three time points, and feeling confident ‘often’ also throughout the project and thereafter.

The statements that relate to dealing with problems well and thinking clearly follow the same pattern. From ‘some of the time’ at the beginning, increased to ‘often’ after concluding the project, and again ‘some of the time’ after six months. He reported being able to make up his own mind about things ‘often’ both before and after the project, which then decreased to ‘some of the time’. As Nestor mostly focuses on talking about the work done, clues on these parameters (e.g. thinking clearly) are perhaps more implicit in the overall discourse and not reflected upon directly.

How often he felt relaxed and cheerful follow the same pattern. From ‘some of the time’, increasing to ‘often’ by the second questionnaire and decreasing back to ‘some of the time’. There is a decrease in how often he feels he has the energy to spare, from ‘often’ before the project, to ‘some of the time’ thereafter.

He reported being interested in new things ‘some of the time’, then ‘often’, returning to ‘some of the time’. From the interview, it seems that his interest in the design project itself seemed to have increased throughout.
I just got more engaged, at first I was quite resistant to it that’s all (…) I didn’t really want to do it, but as time … say I once talk to you once a fortnight, remember that? (…) I don’t know suddenly I had more interest (unclear) and started coming every week instead of every fortnight. So yes, there has been an interest on my behalf. (Nestor, 1st interview)

Nestor’s personal growth score in the Ryffs scale, remained relatively stable before and immediately after the project, decreasing a little from 29.00 to 28.00, but increased to 39.00 six months after (11 point increase). In the self-acceptance subscale, there was a change from 27.00 to 29.00 after the project, which increased further to 32.00 after six months. The purpose in life score increased from 30.00 to 36.00 (6 points increase) after the project, and then decreased back to 31.00. The data seems to be congruent with his account of improvement during the project, when various other parameters affected him too (e.g. medication, socialising), with purpose in life showing the steepest increase. However, while the WEMWBS questionnaire shows a decrease from after the project to follow up (below baseline), only the purpose in life Ryff subscale decreases to baseline.

6.2.5 Amara’s wellbeing

Amara’s wellbeing scores increased from 50 before the project, to 59 once it concluded, and returned to a similar score, 51, six months later (Figure 93). These changes can be considered important, and there is some relevance with what she described in the interviews. Indeed, Amara made a poignant statement about her mental health in a card she gave me once the project concluded, which she later on also described in the interviews.

It was all part of my process of getting better (…) I think I wrote it to you in your card (…) 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! Even though like I
said in the card, even though I struggle some, I struggled this morning … (Amara, 1st interview)

As with all participants, change in scores cannot be solely explained by the project. Indeed, she considered the design group to be part of the process, and she did not seem to feel the need to consider it separately - a particularly holistic way of looking at her recovery. Various other changes during the project included discontinuing - to her regret - talking therapy (therapist changed roles), and signing up to creative writing. In the interview, she mentioned what was said by a clairvoyant, to which she associates some reflections, too.

(...) this clairvoyant Tracy, what she said to me like eh... you have been trapped within yourself so that’s what it has affected all my life and I haven’t had my family, I wanted a family. My mental health, being trapped within myself has affected me till now and with the closure of the group [design group concluded in an exhibition] and I suppose the writing group still going, and other things are
started to happen, and like closure of that problem and is all happening and this group is part of it, good part of it. You know because you thought I could speak up in a design group. I I never thought I could do it. (Amara, 1st interview)

One of the most important changes according to the wellbeing questionnaire is how often she had been feeling optimistic about the future. Before the project, she reported feeling optimistic ‘often’, which spiked to ‘all the time’ when it concluded, and decreased to ‘often’ again after six months.

Indeed, in the interviews, Amara appeared optimistic not only about the changes she had felt taking place but also those she expected in the future:

Yes a total life change, and such an important change (...) my life will be different now, my life is different now (Amara, 1st interview)

The present is very interesting because is I think (...) I am changing, things are changing for me. (Amara, 1st interview)

It is just it is a different part of me that is coming out it really is my life, is the rest of my life. Because I have been told (...) this was going to happen, and I was told that the depression was going to be a feel of the past, and I was told that the rest of my life was going be make up for all that I had in my life previously, all that depression, since I was 18 I have been depressed and is all over. I said to Sara the other week in the art group, is over I feel like crying, I really do (Amara, 1st interview)

You rang and then I was being I think positive about you making money from the game, us making from the game. I felt that you were a bit low or a bit negative about it all but I felt very positive and I got off the phone and I started having ideas and I wrote them (Amara, 2nd interview)

The theme of connection is prominent in Amara’s interviews. In the wellbeing questionnaires, she reported that she felt interested in other people ‘often’ both before and after the project, which increased to ‘all of the time’ six months later. She reported an increase in how often she felt close to other people, from ‘often’ at first, to ‘all the time’
when the project concluded, which decreased to baseline at follow up. Finally, she ‘often’ felt loved both before and after the project, decreasing to ‘some of the time’ after six months. In the interview, she discussed how she got to relate to other people through the design process and how building a relationship with me was important. She also expressed her philosophy around connectedness. Amara’s notion of creation and that of connectedness seem often to be part of the same phenomenon.

Well I think it was important having a relationship with you (...) because you would hope that the person running the group will be mentally healthy and I think that does rub off on people... and also then I think I get on (not for the last week or so) with Anthony, but I was getting on much better with Anthony, and having this laugh as well with him (...) so you know relationships within the group (...) (Amara, 1st interview)

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

Amara associated how the design process enabled connections, and the function of the design they created, the board game, also supported relating to one another at different levels.

(...) how to articulate something that (...) you cant [articulate] that it has no words for it (...) we seem to connect in ways of bits of nature and religion and spirituality and (...) it all went with the game didn’t it ... (Amara, 1st interview)

Amara remarks feeling useful ‘some of the time’ first, which increased to ‘often’ after the project, and returned to ‘some of the time’ six months later. There is a sharper increase in how often she felt good about herself, from ‘some of the time’ to ‘all the time’, and then back to the initial frequency, which seems to resonate with her comments:

I feel like I did so well (...) especially after looking around at the end of the party and I feel like I did achieve something you know, it was my idea to have a game wasn’t it, I think it was my idea, really and I feel really proud of that somehow. (Amara, 1st interview)
She reported feeling confident ‘often’ which did not change over time. In the interview, she did nevertheless talk about confidence and associated it with humour and banter, the ability to speak up, and her contribution. Most interestingly, she also talked about how the design project gives one confidence because you are achieving something other than bettering the mind, referring to making contributions through design.

I got confidence and I had lots of fun, I have lots of fun, with lots of laughter ... banter, I discover that I can do banter, (laughs) (Amara, 1st interview)

It did make me very confident, with making that game because it is a brilliant game, is such fun and when we played it. I know I didn’t have the confidence that day [in the exhibition] to play it (...) but... I played it another day and it was such fun (Amara, 2nd interview)

Her answers to the questions how often you feel relaxed and how often you feel having energy to spare follow the same pattern, starting from ‘some of the time’ at the beginning, moving to ‘often’ after the project, and back to ‘some of the time’ six months later. She reported feeling cheerful ‘often’ both before and after the project, and ‘some of the time’ six months later. Humour and laughter, and happiness are notions she talked about often in relation to the project.

you do you always make us laugh, you do, I mean you are so good at laughing, you are so good with people and, you know, made me feel really really good (Amara, 1st interview)

I ended up having such a great time at the end (...) by the end I think I was more happy (Amara, 1st interview)

There were no changes in how often she had been dealing with problems well or were able to make up her own mind about things, reporting ‘often’ throughout. Similarly, she reported being interested in new things often at all three time points.

She reported being able to think clearly ‘often’ following the conclusion of the project and thereafter, which is an improvement from before when she felt this way ‘some of the time’.

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In her interviews, although not a lot of emphasis was given to the idea of thinking clearly specifically, Amara reported that the project was stretching her, toward designing, and she kept thinking about what other good ideas she could have.

…(your phone call] was getting me to sit there and write about them [ideas] which (...) I don't remember doing before so really (...) it does affect (...) it does stretch over everything else...(Amara, 2nd interview)

Amara’s purpose in life and personal growth scores increased during the project (from 30.00 to 37.00 and from 31.00 to 39.00 respectively), and then remained relatively stable (staying at 37.00 for purpose in life and increasing one point to 40.00 in personal growth). Self-acceptance, on the other hand, while it increased by 8 points during the project (from 30.00 to 38.00), it decreased by 11 points six months after (27.00). This is not too dissimilar to the pattern in the WEMWBS wellbeing scores, showing improvement while the project happens and returning to baseline level.

6.3 Discussion

Overall, the wellbeing score of the 4 participants that engaged most consistently increased from before to after the project, and their responses hold some correspondence with their interviews. Their accounts revolve around notions of confidence, hope, connection with others, thinking and mood. The levels of three of them decreased after 6 months from the completion of the project. The fifth participant, whose engagement was peripheral, did not have an improvement during the project, yet his score increased after 6 months. The
means of wellbeing scores of the five participants can be seen in (Figure 94).

![Figure 94. WEMWBS Wellbeing scores by individual, before, after and six months later](image)

The interviews helped facilitate a more reflective assessment and understand nuances that were not captured with the questionnaires, while these, in turn, assess dimensions which participants may have not brought to the discussion if they weren’t prompted. In combination, they provide a richer picture.

Unlike the IPA analysis, this mixed-methods study looks specifically into effects on wellbeing. However, one of the key insights from IPA was precisely that co-designing focused on something other than participants’ own mental health. Their involvement was not framed as a therapeutic intervention, and that is possibly part of its unique benefit, it being an indirect consequence rather than a target. Notwithstanding, some participants did also frame the process as therapeutic.
7 Facilitating co-design within mental health

7.1 Introduction

This chapter presents some reflections on the process of co-designing with people facing health problems, linking what I learned from participants about the co-design process and my role in it, to how I facilitated and experienced the process. To do this, I look at the two projects together (the co-design for wellbeing case study and the design at PTP project), using examples from data and my reflective diary to generate a hypothesis about some key characteristics of the co-design process. I hope that this helps frame my (co-)design approach, the design strategies, tactics and attitudes employed, and make it useful for anyone employing co-design, specially in the context of mental health. Indeed, the role of this chapter is to articulate what most co-designers have learned doing through practice, often intuitively. Such tacit skills remain generally neglected in design research and education. To call attention to these unspoken dimensions of our experiences as facilitators, I also offer a description of my emotional landscape and how it evolved throughout the process. As (Escalante et al., 2017) suggest, research on the impact of design research projects on the wellbeing of researchers who may find themselves undergoing rather emotional processes is lacking, and this chapter aims to contribute to this discussion.

I structure my reflection in three sub-sections, or levels: in the first section I discuss the concepts of weaving and layered participation, in the second I discuss the notion of nurturing mattering and in the third, I discuss facilitation attitudes relating to emotions and ethics. These notions emerge from reflecting on the different ways I tried to encourage or build participation in the two different projects. At the psychosis therapy
project, I came to see my role as a weaver. In contrast, at the co-design for wellbeing, I saw engagement was happening in layers instead. By weaving and layered participation, the aim is to ease participants into the situation and encourage each one to engage in a way that is natural and feels more meaningful to them. From within this participatory situation, a sense of mattering is already developing, but I find myself also in a position to nurture it further using certain strategies that help raise awareness of each person’s contribution to the design, to each other and the world. Finally, within a participatory situation where mattering is nurtured, certain attitudes and emotions emerge, which in turn are favourable to weaving and layered participation and mattering, closing the circle.

The ideas discussed in each sub-section are therefore not independent but connect to, and build on, one another conceptually as well as in practical, pragmatic terms.

![Conceptual illustration of co-design framework](image)

**Figure 95. Conceptual illustration of co-design framework**

The illustration above (Figure 95) portrays the interconnectedness of the notions discussed throughout the chapter. Each sub-section or level of the framework is represented by a different colour (orange, purple, and yellow). Each level builds upon the others. The vertical axis of the graphic represents how much control or intention the facilitator might be considered to have over the situations that unfold. For example, as a
facilitator, I have most control for weaving and layering participation (lower in the graph), but nurturing mattering may not be experienced as intentional. I have even less control over how my attitudes manifest and will affect participants as this much depends on them, or how our collective emotional landscape will emerge and unfold over time (top part of the graph). To the right of the image, the situated examples pertaining to each sub-section are summarized and organized by colour, which are developed throughout the chapter using data from both projects. The experiences of participants are represented by cylinders that cut across the illustration, as they inevitably interact with -and emerge from- all the levels.

I conclude this chapter with a discussion on these key characteristics, drawing on relevant literature.

7.2 Weaving and layered participation

7.2.1 Weaving participation

As discussed in Chapter 5, recruitment on the Psychosis Therapy Project happened informally and incrementally. I began interacting with some clients in the charity’s drop-in area, talking about the project, and organizing one to one meetings. I continued this while some participants began with the first activity, which was to bring an object. The weaving metaphor is appropriate because one thread of participation, e.g. Anthony bringing his objects and talking about them with me in the drop-in, would pull another thread, e.g. another participant inquiring and signing up.

This kind of dynamic continued throughout the project. I felt myself in the middle of an ecosystem where I would pull threads and weave them into the design project, which in turn would continue forming the ecosystem. As a designer, I was reading from and into
what was brought and used this to pull more threads, rearranging the situation constantly. What someone brought was used to raise interest from another, whose questions were in turn used to motivate yet another, and so on.

I sometimes introduced an interesting insight that one of the participants shared, to another individual who perhaps missed the session where this was shared. I remember for instance when the game idea came forward, Nestor was not in the meeting. When Anthony came up with a concept for a green game, I talked to Nestor about this in the drop-in area as I thought it would interest him as a chess player.

Anthony referred to another occasion:

I wasn’t there when she suggested the trivial pursuit type game but I was told the next session, or later that session or whatever, I was told that Amara had said [about that] so I went away and tried to think something that would incorporate some of what we talked about in the group ... (Anthony 3rd interview)

Sometimes I would do the weaving using materials. I asked both Nestor and David if I could add their object contribution to the collective mural, and they both agreed. However, concerning the exhibition, David did not feel it was coherent with the rest:

We looked at the panel that you had on the wall. you had my text typed up and I looked at them and I thought god this is so strange to see my writing here, (...) it looks discoordinate with the rest of the project, because it is quite detailed (...) I just think there needs to be made space made for people to do different things and I think (...) you are really good at it you know, you function as an encourager which is what any teacher -I know you are not a teacher you are a surveyor essentially- but you know, you need to encourage people (...) (David, 2nd interview)

Anthony used a religious analogy to describe my role in the process which I experienced as weaving. He called it the ‘coordinating force or mind’.

The story is, Mohamed... the carver, in Mecca [there] is a big square based around an old black meteorite, is set into the wall inside (...) and when they were setting it into the wall (...) the chiefs argued about who [should] pick up this holly [meteorite](...) it was a very old religious symbol (...) but who’d set the black
meteorite into the wall... so all the chiefs argued. One said I'll do it, I am bigger than you, I'll do it I am greater than you, and Mohamed (...) he took the meteorite and he put it in the middle of the rug, or the carpet (...) and they all stood around the carpet he said right, now all of you lift the carpet together (...) and they brought the carpet (unclear) over to the wall (...). That is why remembered the story, I read it a long time ago (...) so the idea is that you needed a coordinating force, a coordinating mind, not force, (...) to bring the different ideas (...) you were the coordinating element in bringing the co-designed elements together (...) and maybe none of us could remember who did what exactly (...) little bit here little bit there (...) I can remember who did a lot of the things like Uriel the diagrams, Nestor the questions, Amara the initial concept (...) Nealy we contributed towards (...) the scroll the big wall (...) other people were there at times (...) You were the coordinating element in bringing the elements together, like Mohamed was coordinating (...) The whole process of the game is the meteorite (...) you are the Mohamed in this situation the one who brings everyone together to bring, move something to a certain position, a position being the end result of the Game (Anthony, 2nd interview)

7.2.2 Layered participation

In the co-design for wellbeing case, the set of activities and number of sessions was more fixed than in the design at the PTP project. Rather than getting to know people progressively and weave their contributions into the fabric of designing, in this case, I set up a process that enabled various layers of engagement from the start.

Each individual could come up with their design, or choose to help others. There was less emphasis on coordination toward a unifying project, and the process of drawing links or connections was aimed at the mutual enhancement of different ideas instead, enabling each participant to find their comfortable form of participation.

As discussed in Chapter 4, for this project I created a set of activities, which aimed to facilitate moving through the design process: from identifying a problem to producing a series of prototypes. People could individually engage with these activities, and the key
was for these to be flexible enough to adapt to participants and welcome engagement at various layers.

What each layer is about may differ from project to project and depends on the participants. In this particular project, I came to understand the approach as layering when I noticed that someone could immerse imaginatively into the activities, bringing them to places that I did not understand, when another would engage somewhat peripherally, reflecting on what is going on, yet not formally performing the activities. Similarly, I noticed that in the same activity, while one of the participant’s imagination was going in tangents hard to follow, another would respond that ‘nothing came to mind’, which pushed me as a facilitator to craft, or improvise, new layers to allow and support different kinds of engagement.

7.2.3 Situated examples of weaving and layered participation

In this section, I present some examples from the activities that may belong to one or the other projects but together illustrate the variety of strategies or techniques that can be used to weave or layer participation.

*Interlacing designing with other activities/services*

This PhD project was embedded in an existing ecosystem of services for mental health, which created opportunities for participation.

For example, Bea regularly attended the art room every Thursday, where the co-design project was going to happen. She was very interested in the design workshops, yet in a way her art-making enabled her to attend the design sessions without feeling any commitment to engage with activities. Anthony had also been involved in various forms of craft before beginning the project. I learned about his carving skills when he brought an object he
made for his doctor. The knowledge he had of making helped us build the prototype. In turn, the project, gave him motivation for carving and collage. On the other hand, participating in design might be a way for people to become interested in other activities. For example, design motivated Anthony to join creative writing, a skill that he used back in the design project further down the line.

so I need motivation to do collage but I need extra, extra motivation to carve and so (...) it [the design project] gave me direction and inspiration... (Anthony, 1st interview)

the creative writing and the poetry groups sort of are as a follow on from the design group (Anthony, 3rd interview)

This interlacing of design with other activities could be problematic, for example, if I was to ‘measure’ the ‘efficiency’ of co-design against other activities, as I would need to isolate it. But this is difficult in collaborative contexts, and indeed a holistic way of working seemed to have been beneficial for participants.

**Adding activities to respond to disengagement**

An important reason for weaving and layering participation is to assure that no one is being left behind or excluded – unless it is their choice to do so. I was usually able to differentiate if someone did not want to engage or felt that could not.

Activities can be added or adapted to engage participants who seem to drift apart. One way is to add new activities. The following passage illustrates insights that led me to begin adding short design projects which did not relate to the project as a whole, as I planned it, but helped mitigate the risk of losing people who were not engaging in the discussions.

I talked to them about doing a small tiny design project, mini design project in the day (...) tried to explain what the brief was, (not everyone) got it at once (...) we had discussed what it means to us individually and tried to come up with our own definitions last week, but I realized that I had to do some making, some action to keep different people engaged... and I couldn't keep defining and defining especially because (...) some of the participants are more vocal than others (...), so
there needs to be, in every session, more or less a bit of action, even if (...) I think [it is] unrelated to the project as a whole, and so that everyone has got the chance to be active in different ways (Reflective diary, 20.03.19)

Splitting an activity into different tasks may be another way to respond to disengagement too.

For instance, in the co-design for wellbeing project, I used the metaphor of a collective tree to facilitate discussion about individual trees and how they related to one another –as described in chapter 4. Within this activity, if I saw someone who may not be discussing how our issues relate to one another, I might ask for their help to cut the cardboard for making the tree.

Another time, in the design at PTP project, we needed to group post-it notes for an activity, and I asked a participant who did not speak English very well, to help make the boxes (rather than use other materials that were available in the space, like empty boxes borrowed from the art room) thus keeping him engaged and contributing to the project (Figure 40).

On another occasion, at the design at PTP, Uriel helped me make a round structure, as a tool to do another exercise (Figure 42).

... he goes we can use cardboard (...) yes take a CD and we use it to cut a hole (...) the size of it was exactly the size of the pot, so I was like, how did you know (...) he goes I didn't know (...) I was like well is exactly the size (...) they may have used it to do the pot and so (laughs) (...) we actually do this turning wheel thing and Uriel is so impressed and is like this and I want to make it bigger but he is saying that it is so elegant like that (...) so we make this wheel [tool for the activity] and then we go on [to do the activity] and (...) he stops, and stares, and he says, yes I am really impressed (Reflective diary, 17.04.19)

Therefore, adding activities or splitting them into smaller tasks can enable people to keep connected to the project and take part in ways that make them feel comfortable.
**Responsiveness to participants’ comments**

If circumstances allow for it, not overcommitting to the plan may have its pluses, picking up on opportunities that participants themselves bring forward, even if they seem unrelated or uncanny.

As described in chapter 4, in the Psychosis Therapy Project, Uriel asked what would be like for four hands to work on something. As around that time I coincidently had set up a similar experiment elsewhere, I decided to drop what I had planned and try that activity instead which corresponded with Uriel’s curiosities.

Uriel philosophized about (...) how it is to work four hands in something instead of two hands (...) I said to him ok instead of doing the user journey things we are going to do these experiment today which [I did], (...) the silent prototyping [four hand exercise] (Reflective diary, 24.04.19)

**Sharing your own research challenges**

A ground level of participation can be achieved by sharing your challenges as a researcher and facilitator and inviting people to input in shaping the design process as well. By sharing the difficulties I encountered, participants may come up with ideas. Sharing one’s difficulties or doubts may motivate participants’ involvement as researchers, helping transcend the notions of participants as research subjects. For example, at some point in the design at PTP project, I was struggling to come up with a framework for cultural probes to avoid them being prescriptive. In the passage from my reflective diary below, I recorded how Anthony suggested a way to use the cultural probes, which Uriel augmented as well.

I am even trying to figure out a framework to sort of gather information (...) and then Anthony, articulated actually before me (...) ‘we bring these pictures and stuff and we see what is in common and we start building from there’ (...) (...)

(... Uriel said OK so you have come two levels up abstraction (...) to then figure out ... to then see (...) how is populated (...) (Reflective diary, 24.04.19)
Furthermore, sometimes I would be asked, especially by Nestor, questions that corresponded with the research questions of the project, such as how would the project help him. By replying that I did not know and that it was precisely what we were going to try to find out together, I invite him to take an active role in the reflective process, as a researcher.

This collaborative attitude towards research was then reflected in the interviews. Amara, reflecting on the creation of the game.

the pyramids [shapes of her design for the game cards] I think [come] from my experience actually, that is where they were coming from. Oh... and so what inspired the idea was yes! the game! it was from my experience because I said a game like trivial pursuit, we have lots of questions that is exactly where it came from... my experience! ouh... we have discovered something! (Amara, 2nd interview)

Throughout the thesis, I use participants to refer those who signed up and facilitator to define the person who proposes the project, like myself. In essence, weaving and layered participation by sharing our research challenges is an invitation for our roles to become more blurred, for participants to take a more active role as researchers and facilitators.

**Designing through use**

Designing through use was particularly prominent in the Psychosis Therapy project throughout the development of the board game. We started forming the board game by pretend playing it - it materialized through our use. Although it is not far from the concept of bodystorming, designing through use is different as it is not based on a prototype that we modify through feedback. Instead, in inventing our play, the board game formed in between. For instance, we played before any of the rules were set.

(...) we did almost one [way of picking up a card] each... actually Uriel took [one] randomly, I took the first one up (...) Anthony did the first on top (...) and then Amara chose [the card] ‘what colour is your soul?’ and she said ‘well it is lilac, and it is also the green, but is also changing ‘(...) [I say] ‘ok that is perfect (...) you get
five lilac points’ (laughs) which was the amount of points that she said [earlier] that I should have, so I gave her five points of lilac and we laughed, (...) Anthony was saying (..) ‘maybe we should have a master’, and then I said to him (laughing)’ no we don’t like masters... the master idea, right Amara?’ (...) Amara was like ‘yes! no everyone is equal’, so Anthony, everyone laughed, (...) I was like (...) we could think about facilitator? and then Anthony says... well the facilitator changes I guess with the round (...) and then Amara said yes (Reflective diary, 12.6.19)

This engagement in using a not yet formed product, happened much more easily in the co-design situation, than when I took the concept to my flatmates to try, who struggled to play at first. The passages below show how the board game spontaneously expanded in the design at PTP project through playing and storytelling and how in the process participants became more intimately engaged in the process, leading to design decisions about the game.

I said ‘oh should we start making it [the board game] (...) trying to prototype it’ (...) [and Anthony replied] ‘I want to draw it like sketch it, otherwise is just bits of paper...’ I said ‘ok let’s sketch it then’, and so he started asking Uriel more questions, (...) ‘are you vegetarian?’ (...) and then Uriel asked questions that were completely [original?] (...) [like] ‘how green you are’ but they are more philosophical... (...) [about] short term and long term memory (...) do you know from the beginning what memory you are going to use? so for instance (...) ‘I’m gonna know (...) about Erika in a year’ or ‘I’m gonna forget’ (...) constantly the conversation drifts away from the designing to the storytelling but is quite interesting because that is how we actually create some (...) very interesting crashes or frames (Reflective diary, 05.06.19)

Uriel said titles can be another category... for example (...) at the same time he started to draw a seagull so I thought ok what if some of the cards have images rather than letters (...) so Anthony was thinking that is (...) good if the idea merged to something else (Reflective diary, 05.06.19)

It was quite hard to follow what was going on first (...) there was a lot of levels of discussion first, I thought well we are playing for a little longer and (...) then we could try (...) the shape exploration (..)
We kept playing for a bit I mean then Anthony (...) explained the idea of the sort of bigger game (...) he said well we are thinking (unclear) small scale, (...) I kind of said to him (...) on one hand [is] an idea in its own right (...) [on the] other we could do [different things] with the same materials (...) use those [insights from his bigger game design] to address certain questions (...) 

[Anthony] was telling me (...) he was having a bath and he was thinking well I can’t really (...) think about all these green things while having a bath when there is a moth (...) that is going to die (...) curiously enough (...) I was thinking that as a reward because you were thinking (...) the idea that you care for the little animals (...) the rewards could be something that you use to save these little animals so (...) I don't know how would that look like really, but I think it is quite interesting (Reflective diary, 19.06.19)

Emergent briefs

Another situated example of weaving participation is how briefs emerge, often from interactions. This is as much a consequence of weaving participation, as it is an enabler. This is particularly relevant to the Design at PTP project. By leaving the design brief open, and it is emerging from our interactions, it enabled us to thread together a wide range of views and ideas, ultimately endorsing everyone’s contribution in one way or another. We put all the cultural probes responses (Figure 96), and we all tried to find a common ground among our responses. In a way, we were all looking for a pattern among our responses.

(...) I quite enjoyed us all contributing bits and pieces and sort of (...) finding (...) common themes I didn’t think (...) many common things would come up but apparently they did (Anthony, 1st interview)

Furthermore, in the passage below I describe how Uriel defined the function for our collective design from our interactions and the cultural probes responses.

I explained that to do a design brief, we can think of about these terms, who (...) very interestingly (...) Uriel mentioning actually that stewardship, so like taking care of the world, was what all the religious and spirituality have in common [within cultural probes], and that could be the function of our design (...) (Reflective diary, 22.5.19)
Weaving participation facilitates emergent briefs within the co-design situation, as inputs are constantly being reconfigured toward common goals.

Figure 96. Various responses to the cultural probes.
**The use of physical space and materials for encouraging participation**

Toward the end of co-designing the board game, different elements of the object needed to be designed, and various decisions to be made. I began to use the physical space to encourage engagement, by distributing the different materials and writing the design questions across the table (Figure 97). This helped distribute work among those present while enabling collective discussions to take place.

The use of physical space also extended participation informally to people from outside the group, that would go in the kitchen area for refreshments and ask a question or make comment. In fact, a couple of times we did some design work in the drop-in area (a living room next to the one in the picture) so that others could participate.
The following passages describe a particularly telling moment where we began designing informally in the drop-in area and I encouraged others to join.

So we started working actually on the last design decisions... the manual guidelines (...) in the very drop-in area, (...) we are all there chatting when Anthony and I started (...) in the meantime Nestor arrived at some point... ‘are you guys doing (...) the game?’ [and I said] ‘yes’ and so [he said] ‘are we there yet?’. He did expressions that were very nice... (...) he started talking about the questions, about mind and body [questions] that were missing, (...) at one point he said well this is what makes it that is not overwhelming... (...) kind of like each of us is contributing this and that (...)

[in the drop-in] we kind of are trying to make a map (...) Nestor got (...) a few in (...) and then David arrived and there was a few people (...) I encouraged people to (...) [I] open the questions about body and mind to everyone (Reflective diary, 10.07.19)

Sometimes, I would weave participation using participants’ materials in their absence with their permission. One participant, Ellaria, did not join the group. Informally, I would chat to her and update her on the project, and when the cultural probes were used, she was happy to take away the camera, take pictures, and bring it back. I was able to informally update her on the results and the themes that emerged and thank her for her contributions. On another occasion, I asked both Nestor and David if I could add their object contribution to the collective mural.

**Week to week**

Comments or ideas would be implemented into the design process from the previous week, helping weave participation, or sustain layered participation.

Anthony commented how what was said in one workshop became part of the following one, showing that what one says has a certain validity.

Not much went past you (...) like a throwaway comment you may hear and incorporate it (...) into the following [week] which is good in a way it shows you
what you say has a certain validity what (...) me or the others say has a certain validity to it and it is not dismissed at hand like my wilder ideas are (Anthony, 1st interview)

a record of things that are otherwise you know sort of I don't know what the word is what you call it what is if if if I don't know I don't know what ... I was going to say ephemeral I don't what that means I am not sure but here today gone tomorrow but the and it was it was good and you showed me pictures of things I have forgotten (Anthony, 1st interview)

Continuous reflection on my side meant that the weekly insights would help inform the following sessions and keep a sense of continuity for everyone even when they didn't participate very often, or with the same intensity.

Toward the end, this week to week integration of ideas became more literal, as I would integrate elements together (e.g. design of the cards with the latest questions...etc) (Figure 98 and Figure 99).

David, who only participated in the first task, suggested that continuity can help people with mental health challenges become more involved and more interested and when asked to reflect on what I could improve about the process, he suggested an alternative more regular version of the process, with sessions not spreading as much apart.

I'd probably [add] regularity you know if you had a group that met every day for five consecutive days people would really get into it and get involved in it and get interested in it. Doing it once a week and it being broken (...) changes peoples memory because I know from my own experience taking antipsychotic medication it makes you tired all the time (...) your memory is not as sharp as it should be (...) Regularity I think if it was five times a week or three times a week (David, 2nd interview)
Figure 98. Participant writes a question for the board game on a post it note.

Figure 99. The card colour and shapes designed by Amara, and the question, are integrated. Anthony thinks the card itself can spin and draws a pointer in it.
Navigating uncertainty

Originally, when I was thinking about the notion of design and its relevance to mental health, I hypothesised that the notion of uncertainty as embodied in design (and collaborative design more specifically) would have an important role to play in recovery. My effort was to acquaint participants with the notion of uncertainty, a choice which was incorporated for example in the choice of working with an open brief.

It seems that uncertainty or ambiguity as it manifests in design differs from art. Amara describes:

Design creation I mean is more (...) definite really (...) than doing my art because my art mostly is abstract but the design wasn’t abstract was it?, or maybe it kind of started abstract and then it had to be structured at the end, and come to a certain idea, it all had to be concrete (...) not like with my art really. (...) I think I want this design group again, [with art] it means something different for everyone (...) like we have got that within the game [as well] haven’t we, because [we are] exploring each person’s mind (Amara, 2nd interview)

Anthony gives his perspective on the design process, and when decisions (a movement toward certainty) are needed.

So (...) for a certain length of time is all right for things to be up in the air, because the thing can coalesce into a sort of coherent idea of things, but then at certain point you need to co-define, clarify the rules and get them down (...) and bring them forward (...) to a sort of conclusion (...) (Anthony 3rd interview)

I observed that sometimes, the uncertainty intrinsic in design, can be very fruitful, as it motivates reflection and action. As we were co-designing the game, Anthony found it difficult to deal with the fact that the rules of the game were not defined. Anthony dealt with the situation in various ways. I remember he brought other game ideas, one of them created with his mother. To me, these concepts were more uncertain because they were not grounded in a context of use, I could not imagine how people were using them. For him, these seemed clearer, perhaps precisely because they were not open to
interpretation or use by others. On another occasion, Anthony adopted a strategy that I later came to refer to as *bracketing of uncertainty* (Figure 100). Anthony reflected on it in his interview:

to get greater clarity on something so that the rules of the game was a bit hazy and (...) I wanted to bring that into something that could be understood by everyone (...) fair enough I wrote prototype (...) but that was just to cover [for myself], and once I had written that, I was happier, I was easier in myself then the game could be a bit fluid a bit lapped (...) until we sorted it out (...) once I had written that (...) it was a weight off my mind because it give (...) sense to the fact (...) that the game was unfinished (...) or haven't been figured out totally (...) whereas if I hadn't written prototype in a foot and a half bit of card then (...) I would have been unhappy (...) You were focused you knew you could bring it together (...) you were confident in yourself, but at that point I wasn't confident that we could bring it together but once I wrote prototype (...) once that big card was written it could just remain as it was, and no one was going to shoot it down (...) (Anthony, 1st interview)

![Figure 100. Anthony writes prototype to signify what we have created.](image)

In design situations, we can transform and bracket uncertainty. Anthony, by drawing the board to signify that what we were making was a prototype, bracketed and dealt with the
uncertainty whilst mitigating the fear of judgement. As the relationship with uncertainty is also an important aspect of mental health, the concept of bracketing (and unbracketing) might be helpful to facilitate co-design in this context.

Frustrations such as this one might have resulted in disrupted participation, yet the very process of bracketing uncertainty enabled Anthony not only to stay with it but to continue designing.

[the game] let to a discussion and another and another and another (...) but once we honed - honed is a good word - but but once it was (...) back to its basics (...) it was good I and I enjoyed making the box. (Anthony, 1st interview)

However, when he was asked about what he would change about the project, he mentioned, smiling:

if you honed (unclear) down the rules of the game a bit sooner I would have been happier, what else? (Anthony, 1st interview)

These situated examples demonstrate that the subject of uncertainty plays an important role in participation. On one hand, uncertainty, as it manifests in design, is a fundamental feature that enables weaving and layered participation. On the other, this weaving and layered participation might change participants response to situations and ability to deal with uncertainty.

I think the project does help with that [uncertainty] doesn’t it (Amara, 1st interview)

... I never stuck rigidly to anything, (...) even the lid of the game board you did it two fonts and one font was nearer the font I did (...) I could have kept that one but the other one stood out more (...) I picked the other one because I think it was deeper and darker .... (Anthony, 1st interview)

Months later, in the second and third interviews, I remember thinking that Anthony seemed to be more relaxed with ambiguity. I remember he was talking about how clients at the drop-in were once playing the board game differently, they weren’t doing it as it
was meant to be, which he did not seem to care about as much as I would have expected. Furthermore, in giving me feedback on a paper, and discussing a word that we invented, remarks:

Anthony: because in my in my book was the wising, remember I (unclear) the wisening the becoming wise or (unclear) while in this [your paper] is (...) wising

Erika so I suppose we need to make a decision because is and so

Anthony: Oh it doesn't matter it can be in flux (unclear) (laughs)

(Anthony, 3rd interview)

**The use of randomness and serendipity**

The use of randomness enabled both to deal with indecision, perhaps pushed by democratic or creative reasons, and to stimulate creativity, or even mitigate stagnation, hence ultimately encouraging participation.

For example, In the co-design for wellbeing case, I decided to use randomness to stimulate the creation of ideas, as I describe in chapter four (Figure 101).

On another occasion, in the Psychosis Therapy Project, when forming the brief out of cultural probe responses, participants decided to match the three different groups that we could design for (that I had summarized from their suggestions) and the three different possible purposes of the brief (to wonder, to heal and to connect) randomly with one another. On that occasion, I had made separate cards based on the information gathered from the cultural probes and our discussions on user groups, and they suggested combining them randomly to generate briefs for brainstorming. In (Figure 102), one result of this random combination is shown (matching the ‘spiritual creatives’ to the function of wonder).
Figure 101. Music radio, shaker and memory box are the terms randomly combined to stimulate idea generation in response to designing something for people in grief.

Figure 102. Random combination of user and function cards to inform a brainstorming.
Serendipity was also celebrated and enjoyed in the process. I remember Anthony happily telling other clients that the spinner we used for the game was the coffee tap that we borrowed from the refreshment area, which indeed helped generate the idea of the cards spinning instead when they coincidentally fit within the tap (Figure 103).

Figure 103. Anthony creates the first version of the board with the coffee tap and card

7.3 Nurture mattering

When we practice weaving or layered participation, we not only involve participants in the design process. The design process emerges from participants and their interactions. Participants are not only an asset for the process, the process exists because of them. As discussed in Chapter 5, particularly concerning the themes of connection and contributing, we, as a group, matter to one another. What we have designed together, is perceived to have had an impact beyond our group, and it matters to others, it matters to
the world. When we practice weaving or layered participation, we are hence nurturing mattering in many ways.

Yet there are certain additional strategies, within the co-design process, which can be argued to contribute towards nurturing mattering. In general terms, this involves processes of sharing personal stories or experiences and exploring those to inform design briefs, making sure participants are, or become aware, of others who may use these designs, promoting the understanding that design’s purpose ultimately involves other people or contexts.

In a therapy context, people may share their personal stories. One of the strengths of group therapy is precisely being able to share, openly and without judgement, difficult personal experiences with others who may identify with them. This is very valuable psychologically, but it was not the primary focus in this case.

In the projects reported, participants chose to give away stories, which often informed design. Anonymity was sometimes used, to avoid direct questions about the specifics. Whether the thoughts or ideas that participants shared were personal, or imaginary, or someone else’s, was not important, as their value and function were to inform collective concerns and support the purpose of designing.

In the two different projects, this happened in slightly different ways. I have titled the process at Psychosis Therapy Project ‘from personal sharing to societal mattering’, and the process at co-design for wellbeing ‘from problems that hurt to solutions that matter’. At the design at PTP, the interaction was initiated around something other than mental health, and experiences to do with psychosis were shared indirectly through designing, and sometimes used within the design process. In the co-design for wellbeing project, mental health was the central theme via which interaction was initiated, and anonymous stories were reframed progressively as challenges to design for.
7.3.1 From personal sharing to societal mattering

In the Psychosis Therapy Project, we started with participants’ personal contributions which were weaved towards the common contribution of the group, forming a thread which links personal giving to societal mattering. To provide a safe space for participants to share their ideas and thoughts, I structured participation initially around objects, by talking about objects, participants could choose how much of themselves they wanted to share with others.

In parallel, short design projects or experiments were introduced to help participants familiarize themselves with the notion of designing for others. At a later stage, through cultural probes, participants began looking at common themes emerging to inform a design brief.

These processes merged to create a collective sense of purpose, and a shared understanding that the impact was beyond one’s immediate sphere.

7.3.2 From problems that hurt to solutions that matter

In the co-design for wellbeing project, which was relatively short in comparison, specific activities were used to facilitate this process, allowing participants to share ideas about problems that people with mental health encounter quite early on. Participants first shared some challenges in an anonymous way, and they could choose to draw on their personal experiences if they wished to.

Using these individual challenges, group activities were organized, to explore how these relate to other issues and explore their complexity. In this way, the group started sharing or finding commonalities between concerns or challenges. In developing different ideas
from these challenges, the whole group participated, building a sense of companionship and shared concern. As each individual challenge was used for group brainstorming, it became transformed into a matter of concern that the whole group was trying to tackle.

The process marked a move from individual problems to solutions that mattered not only to the individuals but to someone other, and the group as a whole.

7.3.3 Situated examples of nurture mattering

Making space for lateral discussions

In a co-design project, we may have a particular plan or schedule to follow. I am conscious that this was a special kind of situation because I did not have the time restraints that are often part of co-design projects. However, to nurture mattering, I found that it is important to make some space, when possible and appropriate, for stories that may go on a tangent.

It is important that participants feel comfortable talking about their interests, and these may not unfold as expected. One of the particularities of design is that with some imagination, these lateral discussions can be thread back to the process in one way or another. On one occasion, I remember Uriel talking to me about how he would like to focus on things we do not understand, which I introduced to the group for further discussion. Although I was not sure what Uriel was referring to, I thought it was important to make space for this suggestion and bring it to the group, to nurture mattering.

Well I said what Uriel and I discussed in the drop-in (...) [Uriel said] we should focus on things we do not understand... because there is quite a bit of things that he doesn’t understand, for example photovoltaic energy (...) I said we would try to start putting these things into some form of a book so we keep track of... [for] when we need to do the whole design project, we keep track of ideas for
characteristics or things that are relevant (...)
and then Nealy asked so (...) what you mean not understand, and then [Uriel] started to describe (...) (Reflective diary, 27.03.19)

Making space may also mean finding ways to take note of these suggestions and insights for revisiting later. In the Psychosis Therapy Project, I did that by creating three different notebooks. Although they were not used much, having these available demonstrated that ideas and questions matter even when they are on a tangent.

**Appreciation, affirmation, and acknowledgement**

Continuous acknowledgement or appreciation of contributions along the process is key. It was noticed by participants and reported in the interviews. This also plays a part in how confident participants feel to voice what they think and engage with the design activities.

Very little challenge, you appreciate it and you encourage, that is skill is important also (Nealy 2nd interview)

...that project gave me that feeling...[that] everybody has some idea and everybody wanted to make this idea to come true. Yes I mean I found out that people are really creative yes I felt that way (Nealy, 2nd interview)

helps the world and it helps each person in the group (...) as well, yes because I think the attention you gave to each (...) of us (...) that is very important (...) for all of us yes... (...) affirming, you know affirming us (...) bringing, acknowledging the positive and or acknowledging us in some way (Amara, 2nd interview)

We all appreciated each other’s work. Whilst Anthony’s therapist mentioned his contributions were a reflection of his thinking processes, Anthony gave importance to how they created interactions.

he thought it [the initial design work] was an insight into my thinking processes (...) which I supposed it was so but I enjoyed doing it (...) doing them at home bringing them back interacting with people showing them to you talking through it with the others and the others talking through their ideas as well so (Anthony, 1st interview)
**Equalizing contributions**

It is also important to acknowledge every contribution equally throughout the process, not only to sustain participation but also to help participants develop their confidence in themselves and their ability to contribute. Unfortunately, we have a bias for valuing certain kinds of tasks more than others. This is challenged throughout the project, through continuous reflection, and by considering everyone as unique and irreplaceable.

Sometimes this also involves continuous reassurance. In the reflective diary, I recall:

‘I feel like I am not contributing very much’ [said Nestor]... and I said why... how you feel?... why is that? (...) they [participants] kind of create this (...) hierarchy (...) themselves so (...) how do you change that (...) make sure that everyone feels that the value of the participation is equal or (...) almost a philosophical shift, really very hard (Reflective diary, 19.06.19)

Amara said (...) I am not doing much again...[discredit her contribution] [yet] at some point she said again ‘oh no! yes the idea of the game was mine (...) There is something happening here, about not willing to take (...) a serious stake or serious sort of acknowledgement of oneself as part of a collective and I think I need to take an active role (...) [in] addressing it, in a sense (Reflective diary, 19.06.19)

Anthony said ‘feel’ [a category for the game], (...) and then today when he was readdressing [recalling] [he said] (...) yes Erika came up with this category (laughs) so I don’t know (Reflective diary, 19.06.19)

Sometimes the sense of ownership participants had over the design process and the design outcome would fluctuate. For instance, in the interview which happened 6 months later, Amara was confident that she came up with the concept of the game, whilst she had been resistant to recognize her contributions before. Yet she also believed that we are all connected and part of the same process. These notions do not seem to contradict each other. In reflecting on where the idea came from, in a eureka moment, she referred to her experience.
In the Psychosis therapy project, hence, especially nearing the end of the project, participants often acknowledged others’ inputs first, somehow downplaying their own, although in the interviews most participants acknowledged their contribution too. In a collective situation, it is possible that feelings of inferiority may manifest, and I felt the need to take an active role in correcting these skewed perceptions.

Attention should be given to those who participate less intensely in the project, too. What is the value of their unique contribution? David for instance would often ask ‘is that useful?’ immediately after giving a particular insight. In response to his apologetic statements around not having participated much, I would respond by acknowledging the unique value of his external perspective for the research.

In the co-design for wellbeing, on the other hand, the projects being individual, participants did not seem to give more importance to the other’s role in the creation. However, some participants may choose to help others, in which case their contribution should not be forgotten and must be considered equally valuable. For example, Bea, one of the participants, would often say that she would not join the workshop but then participated indirectly, by helping another participant, advocating for him, or by discussing from the background. In such a situation, an acknowledgement of the individual contribution may need to be informal so as not to interfere with or discredit their choice not to participate formally.

Equalizing contributions also involves being aware of the dynamics among participants and me as a facilitator, as our relationships are conditioned by earlier experiences or associations (e.g. teacher, researcher...etc). Therapeutic and learning environments may often imply a hierarchy, which is often intentional, sometimes necessary and some other times an unintended consequence of the associations that participants hold. To create a sense of equality, this project had to navigate these power dynamics that often occur in therapeutic or learning environments. From the beginning, I expressed the importance of the participants’ experiences for the research, without transmitting pressure,
either. I also tended to stay away from using educational or therapeutic concepts, such as project outcomes.

**Bridging**

I use the notion of bridging to refer to the process of encouraging reflection on how a personal problem or insight connects with a group of people who may have the same issue – the intended users or beneficiaries. Bridging nurtures mattering because it begins building a notion that designing most often involve serving others in some way -even if it stays solely at a conceptual level.

In the Psychosis Therapy Project for instance, right after we were discussing themes from the cultural probes, I asked participants to think about groups of people they would like to design for. Amara and Nealy both wrote about a particular person that they knew (Figure 56 and Figure 104). Asking questions about other people in similar situations might promote an awareness of design as potentially serving a collective.
In the co-design for wellbeing project, the externalization of problems was a way to bridge from what is personal towards a collective need, which as discussed happened in more determined stages.

**Reframing**

Similarly, these experiences are reframed throughout the process of design, for instance from being conceptualized as personal symptoms or beliefs to stories that matter in another capacity, as input for the design process.

In the co-design for wellbeing project, issues are turned into challenges. In the Psychosis Therapy Project, experiences such as delusions, beliefs and psychosis are shared in a new light, not as problems, but as stories in relation to the design process.

These experiences transcend beyond their definition as worries as they become part of collective purposeful activity. This may challenge the notion that experiences such as psychosis are solely problematic symptoms, which seems to align with the therapeutic approach at the PTP. Furthermore, it aims to invoke a notion that these experiences matter differently, as key insight, to inform design.

**Communicating impact**

I found that keeping participants informed about the developments of the research and the impact of their contributions outside the group, is an important part of nurturing mattering.

For instance, toward the end of the development of the board game in the psychosis therapy project, I took the prototype to my flatmates to try during the weekend. When I came back, I talked about the experience and the feedback given by the flatmates. Participants were excited about the fact that my friends had tried it.
I also kept participants informed about how my thinking evolved and the feedback I received from other academics. Participants were interested and able to engage critically with the research, make valuable comments about the PhD project, inquiring what my aim is, or who my client is.

they kind of really inquired about what I am doing in the PhD (...) he was talking about consultation and how they end up doing what they want anyway... and so there was a bit of quite intense discussion about who is my client in the PhD and they were really trying to understand what it is that I am doing and why, (...) they were like yes so your supervisors are your clients (...) Anthony said well there is the thesis outcome, the block of paper (Reflective diary, 24.04.19)

...be interesting to see what (...) whenever (...) if you come back [with something] (...) how you collate it... or put it all together (...) (Anthony, 1st interview)

well is great for you to do this research and find these things out from all the different people and see what you (unclear) come up with (laughs) (Amara, 2nd interview)

Amara: and then you do you go away and analyse it all?

Erika: yes that is what I am doing yes yes

Amara: So do we get to see what you write about it all?

Erika: yes! you will I will give you to read yes I will give you the thesis

(Amara, 2nd interview)

**Your own sense of mattering**

Not any less important for me was to feel that I mattered to the group and that my presence was welcomed and appreciated. Mattering is an important aspect of human experience, and I am no different in that I would like to use my experience in helping others somehow or at least prevent any harm. I believe that the process of nurturing mattering is often, in a way, reciprocal.
In the design at PTP, they made me feel like part of the group, I felt welcomed and comfortable. This was important for me, and it should not be underestimated. A particularly funny and touching passage from Anthony’s interview.

I don’t, wouldn’t change you, you are practically perfect in every way, like Mary Poppins, the Mary Poppins of the design project. (Anthony, 1st interview)

A similar experience happened with participants from co-design for wellbeing, although we did not have the chance to get to know each other as much.

Unfortunately, when I facilitated co-design for wellbeing, Islington Mind was going through the retendering process, which meant that most staff members were significantly busier than usual. These conditions, caused often by circumstances such as the renewal of contracts, affect staff severely (e.g. they had to reapply for jobs). In this case, although the staff were always accommodating and kind to me, I sometimes felt that what I was doing was taking resources (e.g. people’s time) that were scarce and needed elsewhere. Although I do not believe this affected my work with participants, we must acknowledge that a facilitator’s sense of mattering might impact the balance of the group overall, and addressing it may mitigate negative feelings about the project (e.g. being a hindrance).

### 7.4 Facilitation attitudes and emotions

In this sub-section, I discuss facilitation attitudes as they relate to emotions and ethics. I believe that our attitudes, the way we bring ourselves to the practice, make a difference when facilitating within mental health. There were certain attitudes or principles that I embedded in the process of facilitating participation and nurturing mattering, but these attitudes and emotions, as well as those of the participants, developed during the process as well. I found this journey one of important professional and personal growth. In my reflective diary, besides recording my insights on the design process and participants
wellbeing and engagement, I reflect on ethical questions, doubts, and my emotional landscape.

In the following, I start by discussing attitudes and emotions that were important or found to be particularly poignant in this study. Some were intentionally brought into the process based on my earlier co-design experiences with mental health clients or prisoners, but others, such as humour and banter which participants commented upon, emerged from the process spontaneously. I found that some of these findings, challenge certain assumptions around how we can or cannot express ourselves in response to unusual experiences or strange situations. In the second part of this section, I venture into a reflection on my emotional landscape as it evolved during the process and highlight some ethical issues by presenting a number of ethical encounters.

### 7.4.1 Attitudes

**No expectations**

Unlike many other projects, where there might be an agenda as to what needs to be co-designed, this project did not set out to fulfil a defined brief. As designers, we can fall into thinking that we should, just because we are used to doing it. I made it clear to myself and the participants, that we did not need to design anything.

Having no expectations about the design outcome does not mean that I did not encourage participants to engage in the design process. Keeping a balance between the two was what defined my stance. I would encourage participants and ask questions, but I would nurture acceptance and appreciation for any outcome, and try to consider all possibilities positive. When a participant did not engage in a particular way, it was an opportunity to find another way. Nealy describes the nuances of this encouragement in her interview.
You were so friendly, so close, one of us, you behaved like one of us, that affected us also very important (...) very little invention, you told us again and again is good thought, good thing to do it, and that helped us. (...) You would just explain [the] project, and you didn’t care much [if] we wouldn’t interact that much (Nealy, 2nd interview)

From the start, I told participants that I was interested to learn about the process and that it was up to them what to design, if anything. It was up to each participant to craft the extent of their engagement.

I believe that expectations of some kind are inevitable, but this continuous reassurance, that we had no pressure to do anything in particular or fit in any schedule played an important part.

Anthony, on making suggestions about what to change in the project, suggested creating a sign-up procedure so participants would attend more frequently, yet also reflected on the pressure that this might put on people.

... my mum went to a sort of cultural thing in the Irish centre a few months back (...) it was a cultural sort of thing for pensioners, Irish pensioners, to bring them back to their culture, but he made them sign something at the beginning saying that they would come every week (laughs) (...) I now I know that sounds a bit a bit hard but (...) I know from the initial thing [in the design project] was that you can drop in and out and you can go to your therapy, but I would make the bastards sign something (laughs) and turn up more more frequently (...) I know is a bit strict but but but you know if you get people’s signature maybe they would be... but maybe it would put pressure on them, and there wasn’t [pressure], and maybe you don’t need that, and the people that want to be there on a given day are there... rather than they signed the bit their name and they are they are just turning up and they don’t want to be there so maybe that is a bette (Anthony, 1st interview)

Sometimes expectations are formed from participants themselves. For instance, Nestor and David would often check themselves against my expectations. Nestor would often ask if he could do something for me, and David would also ask if his involvement, a particular insight or contribution was any useful. I would respond by appreciating all contributions, reassuring them of their value, yet expressing there is no expectation for specific things.
Flexibility

Flexibility refers to how much someone engages in the process, but also on what they decide to do. Although this notion is already implicitly part of weaving and layered participation, this section situates examples of nuanced moments where flexibility was also embodied through emotion.

For instance, in both projects, there was a stage when I encouraged some research during the week and gave participants various ways to do that, suggesting to them to think about the one they are most comfortable with. Participants thus could choose to do any of that or not, but also if they decided they wanted to do something, they decided what would that be.

Another poignant moment happened at a start of a session when only Uriel and I were present. That day, we were going to brainstorm ideas on how to help ‘wisening’ people (a play on words from ‘ageing population’ meaning those becoming wise) connect.

Although we were both sat in front of the materials for this, he seemed to be busy writing in his diary. I simply started brainstorming by myself, sat next to him.

And at the very beginning there was a few very silent moments where Uriel (...) so he was scheduling his own things and obviously he needed a space to do so and the time, so (...) I already mentioned the last brainstorming (...) but he needed to do this thing so I just started (...) throwing? ideas by myself whilst he was doing scheduling and it was quite.. it felt quite good, to have that kind of space (Reflective diary, 05.06.19)

Curiosity

Curiosity is contagious. I believe the way I could sustain a curious mindset was by being curious myself. The boundaries of that curiosity can be blurred, and include curiosity about each other’s background, lives and ideas, as well as our shared curiosities about the world.
I felt fascinated about participants’ stories and lives, and all the ideas and notions they would bring to me, which were often also strange, such as Uriel’s insights on spirituality, to give an example. Participants were also curious about me.

Unlike in therapeutic communities, co-design has not yet developed a policy on disclosure. The most important thing is to follow the policy of the organization that you work with. Myself, I shared part of my life that felt appropriate and safe when participants inquired. This was focused on any experiences that related to our project (e.g. playing the game with my friends), as well as things about my cultural background, which Anthony showed an interest in, and my career plans, which Nestor was interested in.

In the design at PTP project, we used the objects to begin learning about each other, and then inform a curious culture that grew outwards toward the world to form the concept of the board game. In the co-design for wellbeing project, at first, this disclosure was encouraged through anonymity. It was perhaps a less spontaneous process.

I also found that some participants were very curious while others’ curiosity was much more challenging to stimulate, perhaps affected by medication or mental health.

A particularly important insight from the Psychosis Therapy Project is that we seemed to share an orientation toward one another, which is a particular kind of curiosity, with no pressure in terms of sense-making. Often when I encountered certain ideas which I found difficult to follow, I would get a little apprehensive about my ability to determine if we were thinking about something along similar lines, or we were each talking about something completely different. I realized that the emotions we brought to it, the orientation toward one another in an accepting way, made understanding in intellectual terms secondary.

so... insight from today is that it doesn’t really matter if we understand each other or not as long as we are sharing the space, (...) it is fine if we don't understand, we are not sure if we are interpreting things in a similar way, it it is ok to be like that, (...) because we orient ourself towards one another nevertheless (Reflective diary, 17/4/19)
Humour

Most participants commented upon humour or banter when remembering the design project. This occurred spontaneously, and I never had considered it a factor when planning the workshops. I do have to acknowledge that perhaps my experience in working with people in mental health and prisons has indirectly influenced my attitude in this regard. Experience may help navigate the delicate boundaries of humour when it manifests in such settings, and a facilitator may be able to take more risks with more time spent with participants.

The use of humour was remarked by participants in various ways. Often participants remembered times of laughter, the use of banter during the project, and described the project as fun, or not being all work no play.

there was a good bit of banter and sometimes there was jokes and they were specifics (Anthony, 1st interview)

The use of humour is also interesting as it can lead to communicating unusual experiences whilst mitigating the risk of being patronized, transcending stigma. At the same time, humour can also be offensive in this same context, making the use of humour a delicate balance or a nuanced risk. Similarly to other attitudes and emotions, the safety of their presence comes from it not being the focus of attention, but a side effect, something that emerges from our co-designing. Humour happens to occur while we are creating, we are using the stories in humorous ways to inform designing, so it makes it more likely to become an empowering experience.

Overall, although experiences of psychosis or other experiences related to severe mental health problems are often distressing and very limiting, in this project there was a fair amount of humour emerging from sharing such memories.

One particularly humorous moment exemplifies this. In one of the brainstorming sessions at the design at PTP, we were discussing how to help the ‘caring nature heal’. We
were talking about insects and how an appreciation toward their role might benefit the world when Anthony mentioned the ‘adopt an ant’ campaign (Figure 105). We all burst into laughter, and he continued to tell us about his psychotic episode, where an ant led his way home once. The story was shared in humorous terms, in reference to what was being discussed at this particular moment and the design situation. Through humour, during the brainstorming, Anthony shared a psychotic episode in such a way that made us feel all connected, rather than estranged, from him and his experience.

Humour was mentioned by some participants when referring to how different ideas are negotiated among participants.

(…) people having different ideas you have to discuss them all (…) let go of some of yours or fight for some of yours, they have to let go of some of theirs or fight for some of theirs but it was it was it was fairly good-humoured most of the time.

Figure 105. Anthony’s ‘Adopt an ant’ idea responding to ‘how to help nature heal’ brainstorming.
wasn’t it so so yes it was good-humoured all the time I think... (Anthony, 1\textsuperscript{st} interview)

(...) thinking all together as a group playing games and laughing yes it was change I mean we laugh a lot yes (Nealy, 1\textsuperscript{st} interview)

you there to do that that group is you are there to do that and to me it was fun I mean even bringing my hearts in and people bringing their things in is all is all it was all very interesting and (Amara, 2\textsuperscript{nd} interview)

Banter was also present especially toward the end of the project and was appreciated by participants. In the interview, Anthony remembered this particular moment while we were trying the board game (Figure 106).

(...) Nealy said how can I lose weight? and (...) I wrote have Ramadan all year long (...) and you could read it upside down (...) she thought was funny (...) there seemed good banter (...) and joking (...) we were directed but (...) it was good-humoured it wasn’t all work and no play it was it was joking as well (Anthony, 1\textsuperscript{st} Interview)

\begin{figure}[h]
\centering
\includegraphics[width=0.5\textwidth]{image.png}
\caption{Anthony responds to Nealy as part of playing and designing the board game.}
\end{figure}
(...), by the end I think I had felt better and I know one day it was me you and Anthony I think and we were having a great laugh, banter (laughs) (Amara, 2nd interview)

I got confidence and I had lots of fun, I have lots of fun, with lots of laughter ... banter, I discover that I can do banter, (laughs) (Amara, 1st interview)

Sometimes banter included concepts of madness too, as I recall in my diary.

so I said should we play a game? and she really wanted to play [the game] (...) it was ok, tell and explain, and it was about blank cards, so it could be anything [I could say anything in response to the blank card] and I tell ok ‘I never have an umbrella because I always lose them’ and I ask them ‘why?’ and then they had to come up with different explanations, and she said well because your mind is very full of things, or absent-minded, I don’t know, and then Anthony said because you are off your brolly, (laughs) so instead of off your trolley or whatever expression they use in England to say mad, brolly (...) it was hilarious (Reflective diary, 19.06.19)

The notion of play seemed to be an important aspect too, relating to joy and laughter and recognised as an important distinguishing characteristic of the design approach.

Yes I think [design] is more to play, is about playing more, because not only we design a game, but to design I think it is to play more because with my art I play with the colours and here I was playing with the ideas maybe... (Amara, 2nd interview)

I choose to take difficult things and cry but erm.. you know the design group was for playing wasn’t it, in a way, it was work, it was work because we have to focus I suppose and think or feel (unclear) I think feeling somehow is connected to my feelings or joyful maybe very joyful anyway (Amara, 2nd interview)

**Navigating conflict**

One strategy I observed myself using when navigating tense situations or disagreements that take an uncomfortable tone, (although this happened rarely, I only recall 2 occasions), was to bring attention back to how these different, perhaps conflicting views relate to the design process or situation. Alternatively, if necessary, I would try to split participants’ individual attention to different tasks temporarily, and bring the group back together.
again later. Ideally, a change of tone may help de-escalate any potential conflict without necessarily repressing the actual content of the discussion.

So it was a bit of a challenge at the beginning but Nestor stayed there and then... Jack shared his tool he used for smoking weed, and Nestor was like so you smoke weed but you have mental problems, he yes but not because of weed, so he got a bit like ohh... (...) I was thinking what to do, what not to do, what to say, what not to say and... so I focused on the thing [the smoking tool] and we kind of talked about how (...) sometimes we see resources like magnets or something in one tool and then we can think of how it would be in another tool (Reflective diary, 20.03.19)

7.4.2 My emotional landscape and ethical encounters

7.4.2.1 My emotional landscape

This project has been an immensely meaningful journey for me. In my reflections during the facilitation, in my reflective diary entries, I also described my emotions. I believe that personal emotions are a too often silenced dimension of working within co-design. This neglected dimension, nevertheless, is of great importance. As designers, historically, we have not always been used to work in contexts which can be emotionally challenging, and therefore it is not in the tradition to discuss these personal aspects of our own experiences in research. However, most professions within mental health create spaces for practitioners to discuss emotions, which contributes to the health of everyone involved. For instance, a therapist will have a supervisor, and a volunteer often has supervised debriefing sessions, perhaps in groups.

By reporting this aspect of the project, I aim to give a sense of how getting involved in co-design in a mental health context is like, whilst being aware that everyone’s experience is different. I would like to advocate for putting systems in place so that the facilitators of co-design in marginalized, vulnerable or in any way troubled communities, are supported.
Throughout the project, I had the opportunity to discuss my feelings and experiences with a therapist, and I believe this had helped the research, as I was able to explore honestly how the project affected me, and also be reflective of how myself, my beliefs and my history, could also affect the people I was working with. I decided to start therapy for the first time, right before the fieldwork for the project started. I suspected that this reflective work not only could help prevent any harm but would also support growth. The experience became immensely enriching and transformational.

I hope that this account will be useful for other designers who may engage with similar projects, encouraging them to acknowledge their strengths and vulnerabilities, and seek or put in place systems that ensure a safe and enriching experience for participants and themselves.

In my reflective journal, I recall having felt blessed, confused, dreamy, interested, nostalgic, nervous... The fragments below portray the richness of this landscape.

Amara was like well (...) we don’t understand either, that is what she said, (...) we are kind of making it up now... and like she was so happy about saying that... (...) she was just laughing about it (...) I mean I felt so blessed, I felt really good (...) Reflection diary, 12.06.19)

It was very good to hear what Anthony did [wrote several pages about objects which was unexpected]...keep struggling about how to respond to it (...) how to make sense of it (Reflection diary, 13.02.19)

At that moment I was a bit overwhelmed of how to approach her erm...how to respond (...) keep that interest going and at the same time tell her ‘look we need to do the consent form because otherwise I cannot really note down anything about that’...and at the end I was quite frank (...) we chatted a little bit and then I said, you know, I think if you are happy to do the project (...) we need to do the consent form and go over the paperwork again and she said yes let’s do it (Reflection diary, 06.02.19)

So yes Nestor, there was Nestor there, was Uriel, Nealy, Amara and Anthony in the group today, but Nestor, as usual, he comes the first half of an hour he is very funny because he is always like ok what we are doing today (...) then he says I need
to go in twenty minutes, I need to go in fifteen, so today I started laughing and I said Nestor you are like a countdown, (...) and I said I am overwhelmed (Reflective diary, 15.05.19)

They affect you... I mean I dreamt with ...I think it was Anthony making like ... a kind of white (...) lamp which was an Angel, so like you move the lamp (...) like a wooden thing that goes into this lamp (...) this thing gets kind of stabbed by wood, but is like a nice stab, is like a stab that makes the wings light up (...) and I remember he brings it and to (...) the workshop and I think this was before he gave me this lauburu [basque symbol sculpture] (...) just the day before and I kind of asked him -in the dream- did you make this? (Reflective diary, 10.07.19)

We started to put down the objects that we brought together in a paper and which (...) he put the CV2 and he started to think about [its] design (...) as if there was a person that designed it (...) like a question why this thing exists in a way I felt a bit nervous because I thought like they may get bored wasn’t sure what to say, how to say it, I wanted to see what it emerged naturally so it was very interesting in that sense, to see how it flow (Reflective diary, 27.02.19)

I have had fun (...) there was a lot of sharing of experiences (...) somehow I felt enriched (...) psychologically it was a very enlightening, refreshing (...) sometimes it may be... but no (...) never felt stressed [in the design workshops], (...) The interviews instead, the one yesterday and today, I feel... it’s completely different, (...) there is some psychological stress that I am feeling and erm... which I can’t quite tell what it is, I think is just generally (...) the energy... just the feeling that you get. (...) so I don’t know if that tells something about the work that you do through in collaborative context through design and the work that therapists may do (...) (Reflective diary, 25.07.19)

There were some intense moments throughout the process. Possibly one of the most emotional was after the last session, before the exhibition, as I started to come to terms with the conclusion of the project.

That was the last session. I think I will be quite sad when this ends actually, very sad and at some point Anthony said to me could you, you know, could you let a message through when you finish your PhD (...) Amara asked me as well oh... she said you come back to give us (...) Anthony is funny (...) [he] said you know I would like to know if you managed, if you get your PhD and so yes I think is very important to like do that, do go back and ask for feedback (...) I am crying now
actually. (…) there is a lot happening in those conversations those interactions (…) where you are making something out of a lot of living experiences (…) somehow you go there you don't know what you are doing you kind of get things here get thing there (…) you have these beautiful moments I don't know if I have ever had so many sort of strange, bizarre, beautiful, uncanny moments that were just... I don't know just so ... unique. So much serendipity on the design process I have never seen so much I think, I don't know if it is because people are more vulnerable to ... to just what is happening there (…) sometimes design decisions [are done] so quickly, so are they arbitrary? (…) you know Anthony taking the coffee tap which we have been using to kind of play the game for like weeks now and (…) putting it in the pocket, oh we steal it and making a joke out of it (…) (Reflective diary, 10.07.19)

Yes it feels strange having finished everything (…) I managed to arrange the interviews here and there and Monday we still gonna, we are going to glue the box that is not glued, and so that is a bit more robust and can stay in the charity (Reflective diary, 17.07.19)

7.4.2.2 Ethical encounters

An ethical dimension is embedded in the whole of this thesis. This section in particular, which focussed on facilitating within mental health, stems precisely from a deep commitment to working with one another with utmost respect and care. Since an explicit analysis of the ethical dimension of this project is beyond the scope of this thesis, I have dedicated this subsection to what remained partly unresolved, to moments when I have become explicitly aware of the subject of ethics, which I have called ethical encounters.

This research project followed the ethical guidelines of Islington Mind and Psychosis Therapy Project and was approved by the Human Research Ethics Committee (HREC) at The Open University. Notwithstanding, ethical procedures and guidelines are considered insufficient in preparing researchers for the complexity of the field (Guillemin and Gillam 2004). Formal ethical procedures are but one aspect of research ethics, which come into play in everyday practices and relations (Guillemin and Gillam 2004).
Hence, in this section, I describe what I considered encounters with situations that were ethically meaningful in some way. Some of these brief passages do not arrive at any particular conclusion, yet open up interesting questions about situated ethics within co-design and mental health.

**Ethical encounter 1**

Uriel seemed to be engaging in the project informally, but when I talked about needing to formalize consent, he did not seem keen. I talked to the ethics committee about this, who suggested discussing it with supervisors.

Initially, I thought he could participate in the project without me gathering data, but this would prove to be challenging, since his contributions could be intertwined with the rest, and his influence would be inevitable.

We agreed I could talk about the sign-up procedure once again. I told him that he could participate in the project either way, but for me to be able to use any of his insights it was important that he understood what that meant and agreed. We went on to read through the information sheet and fill the consent form. I noticed that in the section ‘I have understood’ he had ticked ‘no’. When I asked him, if we could go over it again, he refused, simply stating that not he, nor anyone can ever be sure of understanding anything. This struck me, he was right. I found myself in a difficult situation with the ethical form, yet it was very clear that he wanted to be part of this project, he knew that I was doing research, and he was challenging the ethical procedures I had to comply with. Paradoxically, by ticking ‘no’, he demonstrated a deeper understanding of the complexities behind such form. I then had to make a judgement and considered his form valid.
**Ethical encounter 2**

Anthony seemed interested in the nationalities of people. When he learned I was Basque he was willing to discuss cultural heritage at length, and often knew more Basque mythology than myself.

After some time, he told me he had a card for me. I told him that I could not accept gifts due to ethical boundaries. He replied to me, that I could consider it data for the project. In the card, Anthony shared a dream that I was part of.

The contents of his unusual beliefs involved remotely impregnating women. As part of the confidentiality agreement, it was possible to share things clients say with other staff members, which enabled me to seek advice from the manager, who reassured me responding naturally would be appropriate. Anthony told me that he knew it to be a bit out there and that in reality, it is not likely to be the case, but for the infinitesimal possibility that the dream has any truth to it, he thought the right thing to do was to share it.

At the end of the project, Anthony sculpted a symbol from the Basque country. He knew I could not accept gifts, but reassured me this was for the project, yet it had special relevance for me. The sculpture is now stored in the university as an artefact related to the project, and difficult feelings arise as I am unsure about its destiny and future care, and I am aware that it is more meaningful to me than to the project as a whole.

Not receiving gifts was a policy I adopted from Islington Mind. In the Psychosis Therapy Project, this was each therapist’s responsibility.

**Ethical encounter 3**

In one of the interviews with a participant some distressing experiences were raised, to do with his unusual persecutory beliefs.
I tried my best to facilitate our conversation in a safe way that would avoid further distress for the participant, who seemed to have appreciated my listening.

However, at some point, he said maybe he should not be talking about this in a recording. I responded that we could delete the file, and he said that no, that he would leave that decision to me. This put me in a difficult position. I reiterated that we could get rid of the file, or otherwise suggested he choose what to delete and what to keep, but he insisted it was my decision.

The difficulty for me was having to decide. He made it very clear that he did not mind what I did with the file, keep it or not since he was only mentioning it for my safety – he believed that having his recording could harm me. As I do not share his beliefs, I ultimately did not see the need to delete the file, since doing so made me feel uncomfortable too, but it was surely an ethically challenging decision.

**Ethical encounter 4**

Nestor and I were drawing each other’s portraits without looking at the paper. It was an activity others did in the previous week. He said to me, this is crazy, you are crazy! And I laughed and said, no you are crazy! We could not stop laughing. Using terminology such as this which is often deemed inappropriate, is not uncommon, especially through humour and banter. It made me aware of the thin edge between what can help us connect and avoid patronizing behaviours, and can offend someone. There is no formula or set of rules that can help determine where this line lies, which is why it is ethically meaningful.

**Ethical encounter 5**

Uriel had agreed to be interviewed after the project. However, every time I would ask, or suggested for him to pick up a date, he would always say he was tired. The summer when the project ended, he had surgery, and he emailed his therapist and me saying we could visit him at his place. At the time, I thought perhaps it was not appropriate to visit him
there for an interview considering he was possibly recovering and that I was supposed to
do the interviews in the charity whenever possible.

When he recovered, I tried to schedule the interview a couple more times, but he always
said he was tired. At that point, I thought perhaps it was best to stop asking.

Uriel died a few months later, as I was notified by the manager. This was very hard to hear,
it was a great loss.

It had brought me back to question my decision of not going to interview him in his home,
and my inability to know for sure, what were his wishes. Doubts about whether I
honoured the participants or not, and whether it was the correct decision, came to mind
due to death’s finitude. Was being tired a way to communicate he was not interested in
the interview? or was he really just tired, and I lost the opportunity to honour his voice
because I did not go to visit him when he offered?

_Ethical encounter 6_

I was once working with Anthony on a journal paper on his experience of designing,
when I reflected on how he would feel about readers (e.g. psychiatrists) interpreting his
unusual beliefs as delusions.

I used hypothetical talk to make sure he knew the potential global reach of journal
publications, and ensure readers’ varying interpretations would not frustrate him. When
questioned about how he would feel about some readers making sense of his unusual
beliefs differently, he reported that for him it was still important to get the word out
there, because some other people with similar ideas may be locked in some psychiatric
hospital, and a psychiatrist seeing that someone with funny ideas of this kind can have a
relatively normal life outside could ultimately help them.
Ethical encounter 7

Anthony and Raymond chose to use their real names for the thesis, while other participants wanted to remain anonymous.

The issue of anonymity is ethically challenging, especially in research that is conducted not only about, but with, participants. Furthermore, in this case, participants co-designed great concepts and their contribution should be recognized.

More than once I brought the consent form back to some participants to make sure their wishes were respected, when I suspected their preferences around anonymity might have changed throughout the project. Uriel, for instance, had ticked that he did not want to be photographed or appear on video, yet when we recorded an activity he was willing to take part. By bringing back the consent form, I could make sure he was fine with that and adapt our agreement.

When I worked with Anthony on a journal paper proposal, I raised the issue of anonymity after he read the paper. When he refused to be co-author, I asked whether it had to do with being recognized or something else, as we could always use a pseudonym. He decided that he wanted to use his real name in the paper, but not as a co-author.

In discussing the issue of registering the board game with creative commons, I heard Niley encourage Anthony to use his names, to celebrate the achievement, having had chosen to remain anonymous herself at first. Recognizing she might have changed her mind, before the thesis, I contacted her and she decided to use her nickname.

On one hand, some of the issues discussed throughout the thesis are personal and sensitive, and participants must be protected from harm that their disclosure might cause. On the other, their contributions deserve recognition.

To navigate this complicated edge between protecting privacy versus honouring contributions, before writing up, I asked those I had contact with if they wanted to choose
their name. For the remaining, I chose names that were meaningful in some way. For instance, Amara did not know what name to choose but asked me if I could tell her once I know, because she may want to recognize what she had said in the interviews. I believed a name that resonates with her personally, is a decent enough compromise between the private yet unrecognized and acknowledged but exposed. Furthermore, she has since made an interesting question, whether having her real name attached to the board game design conditions her to also use her name in the thesis, and if so she would like to read it so she can make a decision.

**Ethical encounter 8**

When writing the thesis, I had moments when I had to consider what I was describing alongside participants’ ability to recognize themselves or others from the group.

With such small samples, although participants may not use their real names, it is likely they will be able to recognize each other from the contents of data fragments when they receive a copy of the thesis.

I considered it important to reflect on this to ensure participants wellbeing or ongoing relationships are not compromised.

In this project, all participants treated each other with respect and their accounts were predominantly positive, and I did not have to omit any data relevant to the research questions. However, I remained vigilant to any sensitive fragments and became aware that researchers could come across ethical dilemmas whilst weighing out the privacy of participants versus transparency concerning findings.

**Ethical encounter 9**

Unlike the project at the PTP, where sign up processes were happening whilst clients were getting to know me, the co-design for wellbeing kickstarted with one taster session which included the consent process.
The project was happening in the art room, and one of the regulars preferred to leave as he did not want to sign anything. I felt very uncomfortable with the fact that the location would be booked for the project, even if it was previously arranged, as it could have prevented him from attending.

Other people came around to the art room for short periods, for instance a lady who preferred to just observe without signing up. This brings attention to the tension between the accessibility of activities to everyone, versus the formal consent procedures that are needed prior to participation.

*Ethical encounter 10*

One of the participants had suggested that he would like part two of the design group. Although he was happy about the project, the fact that he wished for a continuation - which is something I could not offer or guarantee- made me reflect on what happens when time-limited projects conclude. Expectations from participants and the sustainability -or availability of other- projects is something to keep in mind.

### 7.5 Discussion

#### 7.5.1 Weaving and layered participation.

Weaving and layered participation are the fundamental concepts through which I imagined we could approach co-design in mental health. These are strategies that we can plan for, and the concepts intend to pave the territory for facilitators who want to craft and reflect ways of encouraging engagement that prioritize participants experiences and overall wellbeing.
In co-design, there are different ways in which participants may interact and work together (Zamenopoulos and Alexiou, 2018). The co-design for wellbeing project focussed on cooperation in which participants find synergies across their different interests but work independently on their respective goals. Still, other forms of co-design emerged and were encouraged when it was considered favourable for participant engagement (e.g. when participants preferred to adopt a supporting role). This research refers to such engagement as *layered* participation which aligns with the work of Kanstrup and Bertelsen (2018) who point to the designers’ obligation to legitimize a mixture of investments in participation, including peripheral and low participation.

Design opportunities are layered to encourage a variety of ways to engage. Furthermore, layered participation and the principles used in facilitating the co-design for wellbeing project may align with the process reported by Warwick et al. (2018) where co-designers of a perinatal mental health service who were experts by experience, primarily related an improved sense of wellbeing to using their own previous, often negative, mental health experiences, to create something positive for others.

On the other hand, in a way, design at PTP, was collaborative as we worked together toward a common goal. However, that goal was emergent and somehow serendipitous, where the final artefact perhaps reflects the process itself. I came to understand the board game we designed as a physical manifestation of how we related to one another. In a way, I realized only later that the game we created helped people discuss and connect in ways that we, as a group, also did. Did the emergent nature of the process enable a correspondence between process and outcome, or was it a coincidence? Perhaps the outcome simply reflects the interactions that took place. Perhaps the game somehow aims to replicate this process, our journey, in other groups of people, to help them connect at deeper levels. Does the game allow users to experience the reflective, philosophically stimulating side of experiencing psychosis?

Furthermore, interestingly, before the cultural probes were made, an activity was devised to communicate in general about our worlds and avoid creating cultural probes that were too prescriptive. However, there is some formal correspondence between this activity and
the game (Figure 42). Although the creation of the game can be tracked to participants’ cultural probes and responses to brainstorming, the emergent nature of the process may account for these correspondences. But this does raise the question of whether by creating this activity to make it less prescriptive, the way we interacted indeed prescribed the outcome too.

Sawyer and DeZutter (2009) suggest that failure to analyze collaborative processes is a significant lacuna in creativity research because a wide range of empirical studies has revealed that significant creations are almost always the result of complex collaborations. They use the term distributed creativity to refer to situations where collaborating groups of individuals collectively generate a shared creative product.

Indeed, in the context of theatre, Sawyer and DeZutter (2009) report that collaborative emergence is more likely to be found as a group becomes more aligned with the following four characteristics: (1) The activity has an unpredictable outcome, rather than a scripted, known endpoint; (2) There is moment-to-moment contingency: each person’s action depends on the one just before; (3) The interactional effect of any given action can be changed by the subsequent actions of other participants; and (4) The process is collaborative, with each participant contributing equally.

In conclusion, the role of the designer in this context might be to weave or layer within the distributed process which is co-design. As Anthony once articulated, I was the coordinating element. As a facilitator, one might not want to control such -ideally emergent- process, but in weaving and layering, one can integrate a wide variety of things into the process, encourage different ways to engage, and hence nurture mattering.

7.5.2 Nurture mattering

This concept contributes to our understanding of how facilitation may be intertwined with participants sense of mattering, raising awareness on how our various actions
throughout the process play a part. The concept of layered and weaved participation is partly in contrast with the well known Arnstein’s ladder of participation, in that it tries to question or transgress, hierarchical paradigms of power, and acknowledge mattering in its multiplicity of forms. This is not to say that hierarchies of power do not exist, indeed they are resistant within mental health (see sections 2.3 and 8.1.2 in this thesis), but that the framing of these inequalities carry within them the very seeds through which they re-emerge.

Arnstein (1969) envisioned different rungs labelled Manipulation and Therapy, Informing Consultation and placation, and partnership, delegated power and citizen control, out of which only the last three demonstrate citizen power or influence in decision making.

“The underlying issues are essentially the same – ‘nobodies’ in several arenas are trying to become ‘somebodies’ with enough power to make the target institutions responsive to their views, aspirations, and needs.” (Arnstein 1969, 216). I believe there is value in trying to question the notions of nobodies and somebodies altogether, challenging the assumption that such disempowered communities are those who lose from their non-participation. One may not want to participate in such a society anyway. An assumption of power as the ultimate goal for people is a symptom as much as a sign. Is it not impoverishing, psychologically, to seek or have no other but power and consumption?

As Tritter and McCallum (2006) remark, for Arnstein, the measure of participation is power to make decisions and seizing this control citizen engagement’s aim. As they remark, Arnstein’s model does not acknowledge the fact that some users may not wish to be involved. The authors, who review Arnstein’s ladder in the context of health participation, suggest that the key contribution ‘users’ make arises from their distinct personal experience and non-medical or technical frame of reference; it is asking questions that health professionals have not considered. One aim of user involvement may be to break down boundaries, share experience, and build understanding. This
suggests not a hierarchy of knowledge—but rather a complementarity between forms of knowing, set within a willingness to acknowledge differences.

Ramírez Galleguillos and Coşkun (2020) review 46 papers to distil how participatory design projects have been developed in practice with unprivileged or disadvantaged individuals. After categorizing the papers among three conceptualizations of participatory design, and describing six roles participants take in them, they found that most of the work in their corpus (n: 34) involves participants as informers, partakers or validators, roles which represent lower levels of influence when compared to the roles of design/research partners, that suggest a more shared perspective of responsibilities during the design process. I provided a variety of strategies that resonate with some of the ways other projects reviewed by Ramírez Galleguillos and Coşkun (2020) raise higher levels of involvement, such as making a cultural immersion to understand the group of participants before starting (Winschiers-Theophilus, Bidwell, and Blake 2012) including the participants as research partners by sharing the data collection with them (Xu and Maitland 2019) and (3) adapting the process to how the participants are doing, thinking, feeling (Kanstrup and Bertelsen 2016). They conclude there is no “participatory method” per se, but different ways of enabling people to get engaged in the development of projects that seek to improve their life.

I believe nurturing mattering is trying to step beyond the notion of seeing the people you are working with as unprivileged, without losing sight that there might be also suffering serious consequences for being in such a position. In this case, this was nurtured by my sincere appreciation of the unique and profoundly enlightening experiences that participants might have had. They had lived something I did not, they could understand something I could not. This approach does not mean I must forsake how I might be privileged, but it tries to transcend the hierarchy that such awareness already projects into our interactions. As hard and limiting as psychosis could be, as serious its consequences (e.g. disempowerment), nurturing mattering is a commitment to try to avoid abiding by those binaries or hierarchical frameworks -‘needed and needy’ or ‘powerful and powerless’- in our interactions. Rather than focusing on finding ways of enabling people
to engage in projects that seek to improve their lives - as Ramírez Galleguillos and Coşkun (2020) termed in summarizing Participatory designers role - I tried to wonder whose lives might need improving - or healing - to begin with.

Nurturing mattering is trying to move beyond the notion that some people matter more than others because of what they are or do. It considers every human being as mattering no matter what. From within this starting point, the possibilities of what could emerge are open.

### 7.5.3 Expressing emotions and attitudes

Flexibility, curiosity, humour, play are notions that are familiar to designers, and attitudes discussed in this chapter generally align with those promoted in the co-design and participatory design agenda. Perhaps what differed was that there was a lack of expectation, on my side, to design anything in particular. I did not introduce a brief to either of the groups. In this regard, the attitude aligns with what Sanders and Stappers (2012) described as societal-value cocreation.

In terms of my own attitude and emotions, I found special resonance with Akama and Light’s concept of readying ourselves for contingent Participatory Design and the need for attunement (Akama and Light 2018). I had found it important to share my personal, emotional landscape, precisely in response to their critique: that the close examination of personal commitments evades reporting due to a legacy that narrowly defines ‘generalizable’ knowledge (Akama and Light 2018). They argue readiness, on the micro-scale, helps us respond to small moments of intersubjective nuance and to feel a way through; and at a macro scale, to be dexterous and willing to work on turbulent, shifting sands. Furthermore, research on the impact of design research projects on the wellbeing of researchers is lacking (Escalante et al., 2017), and by emphasizing on my own journey I intend to encourage the beginning of such discussion.
Humour was one of the most commented sentiment by participants concerning the project. People dealing with mental health problems through history have often been ridiculed, and thus humour must be carefully navigated in this context. On one hand, neglecting the possibility of using humour in relation to experiences that are unusual, such as psychotic experiences, may result in losing healing opportunities, especially when someone might choose to come to terms and share these important moments humorously. Often, we fail to recognize that it is by the very act of laughing at oneself and with one another that very serious and often threatening experiences can be let out. On the other hand, there is a risk, and getting the balance right, especially in multi-cultural groups, requires experience.

As in individual therapy, humour within a group context may enable and facilitate the development of a sense of proportion and may help overcome exaggerated seriousness that often serves as a defence against ambiguity (Gelkopf 2011). The presentation of one's life in a humoristic manner may often help patients accept certain difficult situations in a more existential way, accepting life's absurdities and quandaries (Gelkopf 2011).

Ethics

Considering ethics a subject that is implicit throughout the project, I have focused on describing, plainly, ethical encounters which felt most meaningful and which raised important questions.

According to Steen (2012) the one branch of normative ethics that can offer a more useful lens through which to support practice in PD is ‘virtue ethics’, which according to Kelly (2018) allows for a creative exploration and personal growth and emphasis on learning to live better through reflecting on your own actions and learning from the virtuous behaviour of others.

The ethical encounters I shared represented moments of reflection and growth. Ethical encounters, in one way, align with Guillemin and Gillam (2004) definition of ‘ethically
important moments’, which are moments which do not necessarily involve ethical dilemmas, and often the right course of action might be clear, but are points when ‘where the approach taken or the decision made has important ethical ramifications’. In the ethical encounters, nevertheless, the right course of action was not always clear and remains still debatable. This is a strong reason to share them: as Kelly (2018) proposes, our research community has an important role to play by providing examples of ethical stories for practitioners to learn from.

Indeed, some ethical challenges described elsewhere by practitioners on other occasions resonate with my experiences in this project. Kelly (2018) identifies the kinds of ethical issues practitioners have to consider in participatory design (PD). For instance, in Kelly (2018) one participant described that, in the novel and emotionally complex contexts, greater attention had to be paid to clarifying the potential implication of participation as participants might not be able to imagine fully how it might impact them. In this project, I used hypothetical scenarios to deal with such a situation, for instance by talking to Anthony about how his unusual beliefs may be interpreted by psychiatry researchers that may read the journal article. Going over the possible consequences helps mitigate the chances of harm or frustration. Kelly also describes a participant’s regrets on ‘jumping straight into’ story-sharing about perinatal depression and feeling glad that councillors were coincidently present. In weaving and layered participation, talking about objects (not distressing experiences) first or sharing experiences anonymously are strategies used to mitigate risks associated with jumping straight in. I also think that having the appropriate (professional) support in place for situations where there is a risk of distress is important.

As discussed, in this study, I emphasize maximising the benefits of the experience of participation rather than focussing on the end product. Nevertheless, Amara and Nestor expressed their wishes for the board game to be developed by me, which led to some discussions on further funding, and us registering the idea with creative commons. However, this situation opens an important and urgent discussion on the further development of concepts that are created through co-design outside any pre-established and agreed agenda that determines their destiny from the start. Where the outcomes do
not belong to anyone, and participants may or may not want further involvement, what do we do? We are, simply, not ready for this, and there are no existing policies around copyright, benefits, employment etc.

Summarizing, the ethical principles implicit within this thesis resonate with the concerns described by previous practitioners in Kelly’s (2018) study, and with the principles she derives: free and informed participation, balancing participation with minimising the risk of harm, maximising the benefits of the experience and outcomes of participation and supporting fair and appropriate empowerment.

In addition, the ethical encounters I described, such as Uriel’s critical engagement with the consent form, hopefully, illuminate the more artful character of our commitments around what is good, what is bad and everything in between, encouraging the cultivation of what Dewey (in Dixon 2020) termed a ‘reflective’ morality, a form of negotiated, open-ended, imaginative inquiry undertaken in response to contextual concerns.
8 Discussion and conclusions

In this chapter, I summarize and reflect on the findings across the co-design for Wellbeing and design at PTP projects, in relation to an interdisciplinary body of literature. In particular, I put forward the notion of design as healing, or designerly healing, and examine it through three lenses, or levels of analysis: at systems, at social and at individual levels. I then follow on to discuss limitations, before offering some concluding remarks about the contribution of this thesis alongside future directions.

8.1 A designerly way of healing

‘I do think we should have design groups in a design group is just as (...) 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 is this the first is this the first?’ Amara

When I reflect on this thesis as a whole I think of a designerly way of healing, borrowing the term devised by Cross (2006) in discussing design knowledge.

As is common in nascent areas of inquiry and processes of exploration, this study has created more questions than answers. I nonetheless believe that the thesis demonstrated the potential of designing to support recovery and healing in a variety of ways.

Looking at the data in its totality and reflecting on participants as well as my own experience, I conclude that design healing has certain unique qualities that manifest at different levels of analysis. These insights are abstractions from the data in relation to existing literature and should be read with caution, as ideas which may help inform further research.
Before delving into the concept of designerly healing, it is important to consider what is there to heal to begin with. There are as many ways of understanding mental distress, as there are people who go through it. Each existing framework will describe the problem in ways that often correspond to the focus of recovery. Someone who believes that depression is a chemical imbalance, is more likely to resort to medication, than someone who believes in spirit possession, who might consult a shaman instead, for instance. Arguably, mental health issues are complex. Perhaps the pandemic we are living through has shown us that madness is often a healthy response to a mad situation. Therefore, I approach designerly healing holistically, as a comprehensive whole, which includes healing oneself, healing mental health problems, healing the environments within which these emerge and so on. Hence, I describe the concept by considering each of these levels, situating the concept of designerly healing within the complexity of mental health and distress, and contemplating ‘what is there to heal’ through various lenses simultaneously.

To provide a structure, I have separated this section into three levels of analysis or lenses. The systems-level considers and describes design healing as an emergent phenomenon. The social lens has to do with design healing at a societal level, looking at how does it manifests through - and affect - the collective. Finally, I will describe how design healing may occur from the point of view of one person, how it operates at the individual level.

Although I break the analysis in those three levels, I consider that these are not independent categories. These are parts of the same phenomenon. It is because design healing occurs across all these levels that it has the potential to support change at a systems and collective levels, while restoring a sense of agency for an individual or providing a sense of connection for another.
8.1.1 Designerly healing at the 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

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, leading to a growing recognition that mental disorders are dauntingly complex phenomena (Kendler 2012). According to Kendler (2012), for the three archetypal disorders examined - schizophrenia, major depression and alcohol dependence- the ‘difference-makers’ (aka causal risk factors) are distributed across the biological, psychological and social-cultural domains, and these levels are actively intertwined with each other in etiologic pathways. Kendler defends that the field needs to disentangle itself from the still-influential ghost of Descartes and adopt, in its stead, an empirically informed pluralism (Kendler 2012).

Yet, despite this growing acceptance of this systematic complexity, there has been little change in how psychopathology is studied, and most research remains stubbornly rooted in the monocausal 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. Specific approaches may still need to make use of particular frameworks - e.g. diagnose and medicate an illness or recognise and exorcise a ghost, for instance. Designerly healing does not depend on any assumptions of this kind. It does not need to make such judgements to operate. It exploits
the very complexity and uncertainty that would be problematic in other approaches to healing.

In this sense, designerly healing must not gravitate toward monocausal frameworks to situate its role within mental health or justify itself. The capacity to consider and hold on to, as a practice, to alternatives is part of its healing potential.

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. In this instance, the complexity works for, and not against, the possibilities for recovery.

Furthermore, Fried and Robinaugh (2020) argue that as mental disorders arise from complex systems, the ability to explain, predict, and intervene on mental disorders will hinge on the ability to make progress in understanding these systems. Designedly healing takes a slightly different approach. Despite acknowledging that the study of these complex systems is necessary, it does not assume that interventions necessarily hinge on explanation and prediction. This drive toward understanding and sense-making might become the intervention and treatment itself. Rather than studying these complex systems looking for answers in order to act -or treat-, it considers this within the process of acting, which becomes the treatment in itself. Fried and Robinaugh’s (2020) work provides clear guidance for psychiatric research, opportunities for collaboration, and a set of tools and concepts from which we can draw in efforts to understand mental health, helping us move toward our ultimate aim of improving the prevention and treatment of psychopathology, based on the opportunity that there is a rapidly evolving body of interdisciplinary research dedicated to investigating complex systems. Curiously, in the picture we have explored in this thesis, the very process of inquiry is intertwined with the notion of treatment. It does not need to simplify the complexity in order to build a framework from which to imagine and power through recovery and healing. It works with this complexity and thus healing becomes an emergent property.
Although it may be true that predictions may depend on the ability to understand these complex systems, interventions are possible through the understanding and not only after. Narratives and explanations within this complexity vary tremendously if you ask the doctor, the priest, the shaman, and perhaps two people with similar unusual experiences will have wildly different views. This is surely a tricky situation within the mental health community, because delusions, paranoia and many other experiences can be considered individual causal explanations, too, and they can be, truth be told, problematic and destructive. However, the complexity in itself is not problematic within a designerly healing paradigm as it might be in other approaches. By working through complexity and not against it, it gives leeway to the collectives and individuals who are part of these systems to navigate the complexity themselves.

The nature of designerly healing is that it can operate and thrive within complex systems, and functions from within the uncertain.

Complexity and unknown information do not limit the designer, nor does it compromise design as healing. Design problems are generally ill-defined or wicked (Buchanan 1992; Rittel and Webber 1973). Buchanan’s (1992) interpretation of wicked problems in design thinking helps illuminate how design as healing may manifest within the context of mental health. Rittel’s first published definition of wicked problems was presented by Churchman (1967) as ill-formulated social system problems where information is confusing, there are many clients and decision-makers with conflicting values and ramifications in the whole system are thoroughly confusing. Based on this, Buchanan (1992) points toward a fundamental issue that lies behind design practice: the relationship between determinacy and indeterminacy in design thinking. He argues that the designers’ task is to conceive and plan what does not yet exist, and this occurs in the context of the indeterminacy of wicked problems before the final result is known (Buchanan 1992). He argues that while the linear model of design thinking is based on determinate problems, within the wicked-problems approach there is a fundamental indeterminacy in all but the most trivial design problems. In ill-defined problems, one or more of the constituents is either unknown or incoherent, the initial state is usually vague, and the goal state either
unknown or ambiguous (Buchanan 1992), which certainly aligns with most design and mental health problems.

As Goldschmidt (1997) describes, design problems are ill-structured because one never has sufficient information in the initial state and because the properties of the goal state are never fully specifiable in advance, and therefore many different goal states are conceivable and acceptable, making solutions seldom predictable. This way of conceiving, considering, or framing different possibilities resonates with how some participants pointed towards being able to see through alternatives.

Furthermore, design problems ‘indeterminate’ and ‘wicked’, because design has no special subject matter of its own, apart from what a designer conceives it to be, it is universal in scope, where designers discover or invent (Buchanan 1992), or craft out, a particular subject.

This sharply contrasts with the disciplines of science, which are concerned with understanding the principles, laws, rules, or structures that are necessarily embodied in existing subject matters’ (Buchanan 1992, 16).

Design as healing aligns with the wicked problems approach, and in doing so transcends the determinism and monicausal frameworks which Fried and Robinaugh (2020) argued compromised the understanding of mental health problems for so long.

Goldschmidt (1997) is interested in the indeterministic nature of ill-structured problems and the cognitive processes that render them manageable. As she remarks, a predisposition to importing information into the problem space is particularly pronounced in design problem solving, but what makes this phenomenon especially fascinating is that 'imported' information obeys no rules whatsoever: it may come from any domain, be represented in any medium and penetrate any existing information structure at any point. In this project, this is reflected in the way participants brought their insights and stories to inform what we were doing. Designerly healing may integrate
insights from various domains or frameworks and operate at various levels to stimulate healing in a systemic and emergent fashion.

Furthermore, the design as a healing approach does not assume that there is an underlying determinism operating behind the emergence of mental health problems and that it is only our lack of knowledge that makes them unpredictable or unexplainable. It does not assume that with sufficient research it would be possible to unravel the mechanisms behind this complex phenomena and find the ultimate solutions. It includes the possibility of indeterminism, and within it, celebrates the benefits of diversity, the crafting of explanations based on personal experiences. After all, like Müller, Rumberg, and Wagner (2019) remarked, agents act within a physical environment: an environment that, for all we know, might be deterministic or indeterministic, raising questions concerning the compatibility of agency or freedom with determinism and indeterminism. This discussion is beyond the scope of this thesis, and the approach is not to adopt either assumption. It does not necessarily imply a reality that is indeterministic, but it includes this possibility, it does not depend on a deterministic framework.

If we frame a problem in deterministic ways, we begin from the need for certainty. When we frame something in indeterministic ways, we do not believe in the need for monocausal frameworks to explain the current situation and progress with healing. In fact, this cause and effect chain may be either so complex we cannot possibly articulate, or it may not exist.

Embracing this complexity in healing itself or in treatment may align with the notion of holism. Like designerly healing, holistic approaches to recovery are, in a way, building upon complexity too.

Arguably, if we consider mental health problems wicked or systemic, single interventions tackling one aspect or another may encounter strong resistance, often leading back to relapse. Designing as a holistic or systemic healing approach may operate at various levels simultaneously, and build upon various dimensions of experience.
This scenario, where mental health-related phenomena are highly complex, and the way design engages with complexity and indeterminacy, renders designerly healing an emergent phenomenon. Both the healing and the creation of the designs share this emergent quality.

From within this complex scenario that favours designerly healing as a holistic and emergent feature, collectives might have the freedom and power to define their journeys and change society.

8.1.2 Designerly healing at the social level

‘is 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

A systems perspective of mental health and healing brings with it the notion that designerly healing is about the simultaneous transformation of the different elements of that system. In a way, looking at healing from the social lens is acknowledging that people who are marginalized because of their mental health problems, whilst may be in need, may also have the key to heal what fuelled these issues in the first place. Within a systems perspective, the problem of psychopathology does not necessarily reside in the individual.

This understanding of mental health problems resonates with Neretti’s (2020) conception of eating disorders (ED) as an assemblage with a disordered agency, a network of individual, relational social and contextual elements in tension which allows ED’s agency to emerge as a coping mechanism to mediate the everyday life. Assemblage is a sort of anti-structural concept that permits us to speak of emergence, heterogeneity, the decentred and the ephemeral in nonetheless ordered social life (Marcus and Saka 2006). ‘In a book, as in all things, there are lines of articulation or segmentarity, strata and territories; but also lines of flight, movements of deterritorialization and destratification. Comparative rates of flow on these lines produce phenomena of relative slowness and
viscosity, or, on the contrary, of acceleration and rupture. All this, lines and measurable speeds, constitutes an assemblage.’ (Deleuze and Guattari 1980, 4)

Through Actor-Network Theory (ANT) (Latour 2005), Neretti (2020) describes a heterogeneous assemblage of actants, made of humans and non-humans (e.g., artefacts), no longer situating the eating disorder as enclosed in a subject, and focusses on designing new artefacts and adding them to the network to modulate the behaviour of the assemblage.

In this study, as Amara described in her interview, designing was about achieving something other than to better her mental health, changing her focus from improving her mind to something else, transcending the notion of problems being merely individual.

This opens possibilities to consider design healing as particularly empowering as it enables the transgression of concepts that confine mental health problems within the minds of those who manifest certain behaviours.

People with mental problems have historically suffered considerable disempowerment and stigma. One can argue that all healing is empowering, and the concept of recovery emerges with an agenda precisely to give power back to people who suffer from mental distress. However, in practice, this is far from the everyday of mental health services.

The concept of co-production originated in the USA during the 1970s and 1980s with the political economist Elinor Ostrom and the law academic and activist, Edgar Cahn (S. Carr 2016). Much of the policy and practice discussion on co-production has been generic to health and social care and led by academics and policymakers, rather than by those at the frontline, particularly service users themselves. However, mental health services and service user and survivor experiences have unique characteristics that potentially make mainstream mental health service transformation through co-production particularly challenging (S. Carr 2016). 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’. (S. Carr 2016)

As Carr (2016) summarize, 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) It is not surprising, hence, that participants do not always feel responsible for the design (Bowen et al. 2013), especially if projects are set up with a clear agenda and set of rules. In this PhD, the manners (rather than rules) of the game were formed collaboratively through interaction, before what to design was even a question.

Co-design in itself provides an opportunity to balance ‘the rules of the game’. Certain care should be taken for how the rules of engagements are set when co-designing, to increase the chances for genuine empowerment. In this project, manners were formed progressively, and participants crafted what was to be designed, or it emerged from interactions. In other projects, where a clear agenda is set by an institution, design as healing could remain sensitive to participants by at least facilitating rules of the game which are accessible to every stakeholder. This way, facilitators can open up the brief or agenda when necessary, such as in (Nakarada-Kordic et al. 2017), whom I believe expanded their initial brief and developed a resource much wider in scope, as they drawing out the unique experiences of the young participants with psychosis.

Navigating the openness of the design process, hence, could counteract regular complaints such as institutional agenda setting. This openness of the design process, and even the friction or rhythms between opening and closing the brief, may facilitate empowerment. Furthermore, when working within organizations and institutions, it is essential to be at least aware of the inequalities often embedded in how the project brief is presented and further developed, so designers and participants can make the most of the
project. Furthermore, the openness of the design process, and eliminating the expectation of the design outcome, could increase the possibilities for freely choosing the subject or matter of concern, whether it is or not about mental health or anything else (e.g. nature) and a genuine co-ownership over the outcome, when it does emerge.

Indeed, most activism around mental health survivor movements claim the right to have power over their own lives and care, but not much is discussed about power over matters 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 consistent with the values and aims of the mental health user and survivor movement, 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 (S. Carr 2016).

Often when clients of a mental health charity seek a service, they expect precisely that, a service. When they are involved in consultations or co-designing services, they are providing a service. In these two scenarios, there is a helping direction which is experienced, although in reality it is more complex – one feels purposeful in being part of a consultation and is contributing to the community and others when accessing a service or seeking help too. In design, this force is bidirectional. The healing is not only happening in both directions as an exchange where both must compromise to obtain something. But it is the very problem of one which heals the other. The mental health problem, as impregnated with insights on the wrongness of the world through direct experience, can heal the world, and this in turn, by being there to be identified and designed for, helps heal the mental health problem.

Engaging in purposeful activities together, thinking together, and generating concepts that may affect other users within and beyond mental health services are all part of design as healing at a social level.
This project demonstrates that co-design may present itself as a particularly empowering way of healing, as a form of practising power over other issues—beyond the individual. The way participants described their experiences suggest processes of empowerment took place as a result of the co-design project, manifested in different ways, and present some correspondence with the framework presented by Zamenopoulos et al. (2019), power over, to, with and within. They draw 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, may or not happen in relation to others, it is power to do something (Göhler 2009 as in Zamenopoulos et al. 2019). Gaventa and Cornwall (2008) distinguished 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 (Zamenopoulos et al. 2019). Of particular relevance to designerly healing at a social level is the notion of power over, especially because it seldom happens as part of other mental health initiatives.

In the context of mental health, ‘power over’ extends beyond the capacity to bring to the fore one’s own issues and practices to influence the design task, and includes the capacity, either actual or potential, to influence others beyond the design situation itself. The co-design situation presents mental health clients with a—relatively rare—opportunity to achieve something other than bettering their mind, as Amara would put it. There was a clear recognition of the valuable contribution that the group made to the world, with some participants thinking about how to market it, and others counting the number of people who had used the design outcome, the board game, and reflecting on how they were helped by it. Arguably some participants showed signs of being surprised by this achievement, which attests to the fact that mental health clients are often marginalized and prevented from being active contributors to society.

In line with Zamenopoulos et al.’s (2019) notion of co-design as power with, design as healing also builds the capacity to connect and act in concert with others to pursue a set of objectives. Some participants referred to having the chance to understand other’s thinking, feeling safe, thinking and playing with others. Some participants shared
psychotic experiences which they did not before, often through humour, for instance by bringing them to the fore during activities such as brainstorming.

As Zamenopoulos et al. (2019) identify as ‘power to’, the capacity to make sense of one’s matters of concern, frame design problems and develop design solutions was certainly developed in this instance. However, the notion of power to acquires a more profound significance when participants sense of agency is disturbed or diminished, something which is common in psychosis. Anthony, for instance, attested to becoming more driven and remarked that while collage should happen by gods direction, it was himself who designed. While in most populations co-design may enable an increase in power to, within mental health, this may mean the beginning of such process, by acquiring or developing the sense of agency necessary for it.

In a way, the witnessing of designerly healing at a social level within this project is distributed and beyond the scope of the current analysis. I can attest to it, to a certain extent, as I followed through how others engaged with the boardgame participants co-designed, and the purpose of stewardship that its use entails. The sense of empowerment, on the other hand, as it relates to designerly healing at the individual level (see 8.1.3), may or not live beyond the project. Nonetheless, participants that were interviewed 6 months later continued to frame their experiences along these lines, as is seen in the second or third interviews’ quotes. Whether a sense of empowerment continues, the memory of that power and the knowledge of that capacity seems to stay.

This project helped clients unlock and transform their knowledge and resources to carry out design tasks, which Zamenopoulos et al. (2019) associate with ‘power within’. Furthermore, within the mental health context, ‘power within’ acquires a further, healing dimension. Framing the process like therapeutic, acquiring mental health, becoming more confident or feeling better within oneself are examples of how participants described this process. The notions of ‘power within’ and ‘power with’ bring us to the next section, as they are inextricably part of designerly healing at an individual level too.
8.1.3 Designerly healing at the individual level

‘you know I have been well for years you know for a good while but I feel better in myself more ca you know sort of more you know like driven’ Anthony

8.1.3.1 Wellbeing effects and bettering

Before we delve into the qualities of designerly healing from an individual perspective, it is important to discuss the mixed methods study that specifically looked into the effects of the process on wellbeing. As there were only 5 individuals who filled the questionnaires, triangulation with interview data provided a means to generate some insight into how designing may affect wellbeing. Integrating data from the questionnaires and interviews, there is reason to suggest that designing might be healing at an individual level. Furthermore, some participants explicitly referred to the experience as therapeutic, or part of the process of feeling better. Amara in particular comments having achieved mental health, in reflecting on a comment she made to me during the project that she wanted to have my brain – meaning my mental health.

Even so, since it was a small group, and other things were happening in the lives of participants, including therapy, these findings should be interpreted with caution.

To my knowledge, this thesis presents the first study that focused on whether participating in co-design has an impact on the wellbeing of people that have mental health problems. Although positive feedback from participants about the design process is sometimes reported in co-design studies, this feedback is often gathered as part of a wider research agenda and the primary focus was not on exploring the effect of co-design in mental health (see 2.1 section of this thesis). From the questionnaires used, the WEMWBS demonstrated to be easier to understand by participants, and seems sensitive to individual-level analysis, although it was not designed for it. Because co-design groups within marginalized communities are rarely as large as quantitative study sample groups
(e.g. 60), this questionnaire may be worth considering for studying the effects of or evaluating co-design projects. However, it is also important to consider any risks of disengagement when using paperwork within mental health settings, perhaps working closely with staff to mitigate these. In the psychosis therapy project, my presence in the drop-in before formal procedures such as consent forms and questionnaires began might have helped.

Ryff’s questionnaires were lengthier and some sentences were confusing for participants in this study. Unfortunately, on this occasion, the Intolerance to uncertainty measurement was difficult to analyse because only one of the participants had data in the interviews with which this could be triangulated. Also, some participants struggled with the comprehension of the concept of uncertainty itself. However, uncertainty and how we tolerate it may be an interesting factor in designerly healing at an individual level for some participants, as we can see in the case of Anthony, who engaged most intensely with the project.

Summarizing, the wellbeing score of the four participants that engaged most consistently in the PTP project increased after the project, and their responses hold some correspondence with their accounts of the designing experience and its effects, revolving around notions of confidence, hope, connection with others, thinking and mood. The wellbeing scores of three of them decreased after six months from the completion of the project, although in their reflections six months later some refer back to the design project, for instance, Nealy concerning her new way of thinking.

These findings justify the need to make, as Warwick et al. (2018) put it, clearer the role of co-design in affecting wellbeing, and develop the dialogue around its impacts. This urgent need aligns with Vink et al. (2016) who 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 design process on wellbeing are also overlooked in co-design literature, which prevents important discussion about how to reduce and mitigate negative impacts’. (Vink et al. 2016, 396)
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, as they are a departure from standard ways of working. The multiple directional changes in the ‘fuzzy front-end’ could also feel alien to participant co-designers (Warwick et al. 2018). According to the authors, the uncertainty within these problems can impact stakeholders, who may be uncomfortable with ambiguity and open-endedness.

This PhD explored the process openly, precisely because this discomfort with ambiguity - among other qualities - may be part of the healing power of co-design, yet as Steen, Manschot, and De Koning (2011) suggest we need to consider “whether the intended benefits are indeed realized”, and the “risks of co-design.”

Concerning facilitation of co-design projects, which is explored in Chapter 7, ensuring and promoting wellbeing within the co-design process appears to be generally in line with Warwick et al.’s (2018) analysis on how to mitigate against factors that may negatively impact participants’ wellbeing, although there are also some differences. For instance, as the framing of the project was unique in that there was no expectation for a design outcome and the process was not constrained to service design, there was less need to gain participants’ trust that I would ‘deliver’, although Anthony clearly states that I seemed to be able to bring it together. Furthermore, it cannot be said that the wellbeing effects of participants from this PhD project were unplanned, as it happened with (Warwick et al. 2018), although they weren’t planned either. On one hand, the lack of a plan, or the lack of intendedness of healing oneself is part of the characteristics that makes designerly healing unique, as participants focus is not on their mental health. I did not frame the design project as a therapeutic pursue. Healing happens as a side effect of trying to improve something else. On the other, the project was informed by impacts on wellbeing as I observed them in past projects – hence I expected the design process to have a positive impact on wellbeing.
8.1.3.2 The phenomenology of healing and designing

Another important aspect explored by this research project is the phenomenology of what I have referred to as designerly healing. The first-hand experiences of designing reported by people who have psychosis provided a very rich and complex picture, expanding far beyond binary questions on whether or not wellbeing was improved, and providing insights into the nature of designing and the possibilities it opens for this particular group of people.

The notion of designing as achieving something other than bettering one’s mind is significant and it links to the social and systems levels of healing. Individuals within this historically disempowered community, especially people with severe mental health problems such as those associated with psychosis, have often experienced traumatic experiences that relate to a loss of control. In fact, one of the seven abuses of the concept of Recovery according to Slade et al. (2014), 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 in a recent study (Williams, Almeida, and Knyahnytska 2015). Hence designing, by opening opportunities to contribute to society, can help participants heal in this respect.

As there might be some correspondence between the contents of delusions and goals in life (Rhodes and Jakes 2000), the way purposeful activity interacted with personal purpose in the case of Anthony opens up the possibility that designing may help alleviate delusional ideation or mitigate possible risks such as those described by Isham et al. (2021) (e.g. social harm).

In a 15 month longitudinal study that collected data from 14-day centres Sutton, Bejerholm, and Eklund (2019) found that participants’ rating of empowerment was surprisingly stable before and after the period, questioning whether day centre occupations should necessarily lead to greater empowerment. In design, whether an idea goes through to development or not, just conceptualizing it necessitates thinking about a
user beyond oneself. The practice of designing in itself links with an implicit, embodied notion of servitude, making it ideal to promote healing that relates to this dimension, the sense that one counts, matters and contributes.

The notion of connecting, which is also inextricably linked to healing at a social level, was also heavily commented upon by participants. The Psychosis Therapy Project evidenced that in design, connections grow mostly through a shared purpose, but also because the process provides opportunities for connecting over things beyond usual worries. Again, connecting happens over something other than their mental health. Furthermore, not less important is the way unusual experiences are shared with other people, which Amara reported not having done before with other clients. Both Anthony and Amara seem to share concerns with this, while also appearing to appreciate this deeper connection. These unusual experiences were shared spontaneously in relation to design activities, often through humour, motivated by, whilst also informing, the design situation. This indeed demonstrated what Akama proposes, that ‘uncanny’ encounters of ‘perplexing alterity’ can become a generative methodology, but in this project, the uncanny came from experiences of psychosis rather than cultural diversity. In this case, sharing the uncanny is not only a generative methodology but may also have a healing dimension, encouraging a positive and expansive attitude toward different beliefs and the legitimacy and value of unusual experiences. Designerly healing is ontologically playful, but considers the individuals’ reality seriously in that it becomes part of the generative design process to inform what Anthony would call tangible stuff.

Making a parallel with Laing’s (1960) analysis of the therapist role, the facilitator of co-design must have the plasticity to transpose into another strange and alien view of the world, drawing from their psychotic possibilities without forgoing their sanity to understand participants’ existential positions and be able to design together. This resonates with Anthony’s reflection on the way he would like others to respond to his funny ideas, tilting toward it, but without giving up their position. The designing experience provided that possibility, because its tangible outcomes, could not be dismissed in the same way as his other works such as collage.
This celebratory attitude toward difference also contributes to design’s healing potential. Everyone is unique, hence everyone has different ideas, as well as assets they bring to the design process. In addition, meaning-making, although collectively negotiated, is reconcilable with individual narratives and the sense that each individual might make of the journey. The interviews evidenced that each individual seemed to give importance to one aspect or other of the experience of designing (connection for Amara, thinking for Nealy...etc), which provides a backdrop through which to build a wider variety of meanings and strengthen the other dimensions of experience too.

Another important aspect evident from the interviews was that of thinking, thinking more, and thinking differently. Nealy in particular remarked that she was still thinking in what we could consider designerly terms, months later, but also Liam from the design from wellbeing project suggested how the project had helped with thinking, and how that must be healthy. Furthermore, other participants also made references that point towards design as helping one think through different alternatives and open their mind.

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), the notion of stimulating thinking through designing should be given consideration.

Other important aspects of design as healing at an individual level have to do with the structures of 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 the enactment of designing.

As discussed in the design literature, 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 in that it calls for the context to define its goals, yet these goals are not given beforehand. In this sense, designing provides a backdrop for the re-emergence of agency in an embodied way. Hence, designing as healing may be in a unique position to restore healthy intentionality.

Agency is a fundamental pillar for the activity of designing. Let us imagine and speculate what happens when a person with experiences of psychosis is presented with a design brief. The person is confronted paradoxically with 1) having to pay attention to the constraints of what is ‘out there’ therefore being aware that their actions will have a potential impact in the external world and 2) the multiplicity of responses that the brief entails, which are endless. The person may make any decision but must also take into account the effects of their decisions and act accordingly. Being confronted with this situation, the person with psychosis needs to act upon external perception (i.e. brief) as well as personal narratives (as there are many ways to respond appropriately to the same brief). Anthony’s comparisons among different activities illuminate design as healing concerning agency. While a holly entity directs his collages, it is himself who designs. It appears that the complete freedom of artistic creativity enables Anthony to experience it as divinely inspired. The amount of direction provided by the designing situation, on the other hand, him feeling more driven, may benefit the actualization of his agency, as his therapist framed once.

The concept of embodiment also takes a central role in design research, often implicitly. As Peter et al. (2013) describe, there is a strong view in the literature that any practical activity, and perhaps especially designing, embodies different types of thinking and that these types of thinking can interact with one another in achieving a particular goal.

Amara referred to design as grounding, and Anthony talked about design being more rooted in reality because of function. Most strikingly, also, Raymond, from the design for wellbeing project, referred to design as to do with grounding, finding what grounds off things (and there is no indication that the different participants discussed this with one
The rootedness in the world because of function is interesting as it implies a relation, an interaction, a coordination of parts into a whole which often includes a thing (an artefact, a design), a user and a context. Design threads the person who uses something, with that thing and the reason for using it into a coherent event. For someone who has lost that coherent or collectively agreed connection with reality, engaging with generating function can be seen as restoring it, which can indeed have an embodying, grounding effect.

Watsuji’s (1996) example of intentionality as constitutively social is illuminating to understand Anthony’s claims of how function makes design rooted in reality. As Krueger (2020) summarizes, Watsuji tells us that, just in a simple experience of seeing a wall as a wall, “social consciousness has already intervened” (Watsuji’s 1996, 73). This is because walls have specific forms and functions—meanings—that both reflect their sociocultural context and distinguish them from other intentional objects such as desks, books, trees, and other people. In other words, we do not first perceive uninterpreted sensory units (colours, shapes, textures, etc.), and only then integrate and assign them meaning. Intentional objects like walls show up, experientially, as already saturated with meaning, as embedded in shared contexts that specify their salience and significance. The important point for Watsuji is that the form these tools take—the “how” by which they manifest as meaning-saturated intentional objects—is not the product of an individual consciousness but “rather exhibits a meaning common to all those who are concerned with this tool” (Krueger 2020). In this study’s case, the designing experience involves an engagement with not only seeing things impregnated with function and as embedded in shared contexts, but it involves the creation of it. For someone like Anthony, who may have an altered experience of intentionality, the act of designing may place a particular kind of demand that grounds him.

From a phenomenological perspective, Poulsen and Thøgersen (2011) argue that embodied engagement of the designers plays a fundamental role both in understanding the problem at hand and in opening up new ideas leading to a new design solution. According to their study, the verbal interaction constantly finds its meaning in reference
to a tacit level of embodiment, which remains unspoken. The verbal interaction is also integrated into the designer’s tacit use of items in the surroundings and design thinking relies on a more complex and multidimensional interaction, which is based on the pre-linguistic engaged perspective of the lived body.

As Loke and Robertson (2011) summarize, the thinking is not in words or propositions but visual, tactile and somatosensory forms. Now let us again imagine a person with psychosis who is presented with a design brief, and/or some tools to design, for instance, paper prototyping. Suppose the person experiences the body as separate from self or alien or even perceives their weight in an unusual manner. In responding to the brief, someone with psychosis is forced to use the body to react to the object of design through feedback (perception) and action. By following the design process, persons with psychosis may iteratively reconnect with their selves (mind and body) even if only in the specific context of designing.

Designerly healing, therefore, aligns in some way to activities that aim to help support embodiment, such as body awareness and movement techniques reviewed by Fuchs and Röhrich (2017), which may relate to it being grounding, but has also a key mental element, hence participants’ references to thinking. The unique characteristic of designing as healing is that these things happen in an integrated way as parts of the same process. Many other activities that aim to improve mental health place more weight on one or the other, or at least they use the body or the mind as a starting point (e.g. mindfulness meditation vs talking therapy). The designing experience is fundamentally embodied and embodying and does not assume a body versus mind separation.

8.2 Limitations of the study

This study has limitations. The sample was small, which was problematic for the quantitative analysis, and resulted in one set of data being excluded because it could not
be triangulated through mixed methods. Findings cannot be generalized. The small sample, on the other hand, made an Interpretative Phenomenological Analysis of interviews possible. The scale of the groups enabled a richness in my reflections, and an ability to observe the process intimately, which I would have not been able to do, on my own, with bigger groups.

Furthermore, I was the researcher as well as the facilitator of the workshops. Although this made a rich and complex analysis possible, my influence throughout the process cannot be underestimated. Whether that is an opportunity or a hindrance, within the paradigms I navigated throughout the projects, is an ample discussion, but it surely demands caution with the transferability of findings. I hope a critical and cautious stance would enable researchers and practitioners to engage with the more hypothetical and speculative outcomes of this research project (e.g. chapters 7 and 8) creatively and apply them into their work with prudence.

Its interdisciplinary nature was not without methodological challenges. Integrating the various analytical methods into a whole, and making sure each stage was coherent with the reasoning that corresponded to each method was not an easy task. As much a challenge as it was an opportunity, in a way it has been, as my supervisor put it once, an experiment in the wild.

### 8.3 Conclusions and future work.

Following nine years of experiences co-designing with people facing mental health problems and hearing their stories, this thesis is my open proposal to consider co-design as healing. It provides theoretical and methodological contributions in the area of co-design and mental health, alongside a set of pragmatic guidelines for co-design facilitation which could be readily used by researchers and practitioners working with different groups. By presenting an exploration of the designing experiences of people facing mental
health problems and what I learned regarding facilitation, I want to invite others to reflect on their existing projects, and encourage them to join the journey through and into the healing properties of what they do. Readers who are already in healing professions might find in these pages inspiration and insights that might inform their practice, or may consider using similar approaches with their clients, for instance. Future avenues for work in this regard can take infinite forms, and by speaking to different audiences, I have aimed to structure this thesis precisely in a way that prevents me from anticipating all the different directions future work could take. Here I conclude with final statements about key contributions alongside some ideas on how to advance research further.

The way the project wrestles with a variety of epistemologies and methods from different fields, and responds to these challenges, ultimately aiming toward their integration and threading all into an interdisciplinary whole, constitutes a methodological contribution. It presents the idea of an epistemological journey, considering how the very process of designing together -if accompanied by continuous philosophical reflection- may impact the paradigms with which you started the project. The journey concludes aligned with Akama’s (2018) proposal, welcoming the uncanny, in this occasion concerning the world of psychosis. Design research is methodologically fertile. Rather than ignoring the issue of philosophical foundations in name of plurality, or ‘choosing’ our research epistemology and ontologies as a mere duty, I make a call for further transparency throughout the process, to tap into the journey-like feature of research philosophies in co-design.

The thesis constitutes an in-depth analysis of participants experiences of co-design, which can inform a wide variety of existing practices that are currently ongoing, such as service design and co-design projects in the health sector, co-creation projects which have sometimes be critiqued for resulting in further alienation, or commercial design projects where collectives deemed vulnerable or unprivileged are involved in one way or other.

Chapter seven, as a reflection of my approach in relation to participants interviews, and a retrospective construction of a facilitating framework, is meant to function as an initial set of guidelines for this purpose. Weaving and layered participation, nurturing mattering
and facilitating attitudes, including ethical questions raised, will hopefully serve as general principles to other practitioners. These are novel concepts that evolved through a reflective process which included engaging with my own emotions, and articulating the more intuitive aspects of what we do which have been long overlooked. I hope this contribution serves to ignite an ongoing discussion of these largely neglected, more visceral aspects of our work, and that this set of guidelines expands as more facilitators begin reflecting on and sharing these subtle qualities of their practice.

Helping prevent design’s involvement in certain areas causing more harm than good is the most urgent. This is the somewhat ‘corrective’ contribution of this thesis. Future work could involve strengthening ways to evaluate or assess how participants experience projects, even when the main focus of the project might be outcome oriented (e.g. new service or product).

Sharing my emotional landscape and journey calls into considering how we could: (1) safeguard facilitators engagement - who may not be used to certain work- and support professional and personal growth. (2) imagine ways for researchers within mental health to communicate more openly and support one another, and learn from therapeutic communities who have already built their policies in this regard.

Furthermore, there is a proposal, to the world, of using designing activity for healing in itself - the contribution based on opportunity. It is an invitation for our design community to significantly extend their role once again. Rather than focusing on co-designing things that would be used for healing, it proposes the very act as healing. Overall, this proposal can be further investigated both with more in-depth qualitative studies using a range of methodologies or by organizing a larger study that uses quantitative measures to understand the impact on a larger scale. A controlled trial would be feasible in a hospital environment, for instance, where a group of people could be engaged in a design project and another could follow the treatment as usual. Chapter five and six provide different analysis, inductive and deductive, of how designing is experienced and how it affects wellbeing. Future avenues here are also based on
opportunity, and as such, wide in scope. I can imagine the formation of a new profession, with training programs that integrate design and mental health skills learning, or multidisciplinary teams where designers and counsellors work together to multiply the healing potential of what they do and empowering marginalized collectives to contribute to the community. Places such as the Psychosis Therapy Project or Islington Mind, where various services are in offer, provide great opportunities for such collaborations. Even following a similar schedule with other - or the same - people facing mental health problems will illuminate new aspects of design as healing, and result in different contributions and designs. One to one co-design projects with participants who may be struggling with problems that prevent them from joining groups or attending centres (e.g. isolation, severe depression or Covid related confinement) might also be conceived.

At a social level, the repercussions of such projects on empowerment, and how co-design could unleash the potential of people facing mental health problems to heal the social fabrics that contributed to their condition could be examined. The difficulty here is that even if the research community may be determined to follow this ideal, it is as much a political affair as anything else. In several years of experience, I have noticed that there is systemic resistance for the mental health community to be listened to, let alone empowered to address and inform the problems of our world in a more general sense.

In addition, as research through design, the project illuminates insights about mental health, highlighting dimensions of the experiences such as contributing, connecting, thinking and intentioning. Mental health practitioners belong to a wide variety of schools of thoughts. My hope is that this account provides a new perspective on psychosis through design. It provides a new lens through which to look at certain phenomena, for instance, intentionality, as affected by the experience of designing. Perhaps, as Anthony phrased it, it might help someone with similar ideas who is locked up. By furthering this research path, especially in combination with the insights from the phenomenology of psychopathology, new avenues for treatment and therapy may be informed.
Finally, at a systems level of analysis, the project advocates for accepting the complexity of mental health problems and tries to provide a way to move beyond a moncausal framework, not only in how we study but also in how we tackle them. As wicked problems, their reality is more complex than we could understand. The tools that we use to research, often fabricate the stories which sabotage part of the inherent complexity of what we are trying to understand. It is often our need for explaining and predicting that reduces these phenomena into linear, deterministic, narratives. Writing this thesis in a text format, when in my mind it was a web or a matrix, is an example of such paradoxes. Although in a way, I also failed, I have tried my best to honour such complexity, making transparency and honesty my ally. I hope to have been able to transmit a fraction of the world to which participants welcomed me, provide a lens to see the distributed nature of mental health problems and suggest co-design as capable of performing healing within this landscape. After all, through oppressive narratives of mental health and illness, certain individuals have historically been made to held and manifest, within themselves, problems that belong to the entirety of society. This project is a testament that in doing so, it is everyone who loses.


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Appendix 1: Design for wellbeing

project participants

These short introductions to participants are subjective and solely based on my memories and the reflective diary. Below I write about four participants. Although I briefly conversed with other people who signed up and encouraged them to join for certain things, we did not spend enough time together for me to be able to describe them.

_Damian_

Damian signed up for the group, possibly thanks to Bea, who reassured him during recruitment.

Damian struck me as a very honest person. He was kind and appreciative, he did not talk much, had an aura of innocence. He did give me the impression of being on strong medication, yet willing to engage with the group and the activities.

He seemed to have a good relationship with other clients, who showed a caring attitude towards him. Bea would sometimes explain things to him, guide him or talk on his behalf, using what she knew about him already to mediate.

Damian was smiley and cheerful all the time, even when he found the activities confusing, we would smile at each other and find another way. He never showed signs of frustration when ‘nothing came to mind’. Most times I would break the activity into smaller parts, or work with randomness to spark and guide imagination.

He worked on the subject of overcoming grief, which was probably what made him unwell.
My impression was that the project helped energize him.

**Bea**

Bea sometimes spoke in Spanish to me, as she knew I could. She quickly felt comfortable talking about her experiences with me. She signed up for the project and encouraged others to do so.

Her participation and engagement were somehow different, and that is a great example of how the studio environment could accommodate different ways to build trust and participate. She would usually be doing some art activity, such as weaving or colouring, when the workshop started. She would continue this activity as if officially, she was not in the workshop. However, she would always pay attention to the group, and while she continued her art activities, she would often add something to the discussion, join for specific activities, or engage by helping Damian.

**Liam**

Liam was very close to Damian, they were often seen together in the HUB. When together, it was often Liam who would ask me the questions, he was active and engaged. My impression was that he showed a little more resistance to do some of the activities, as if they felt silly, but he would always join. He would laugh a little about something he may have been asked to do, but do it regardless.

I remember him saying that the project seemed to have helped him with thinking somehow. Months later, when I visited the centre again to interview Raymond, he told me he had a girlfriend and that they were doing movie nights in the charity, and that he had a very fond memory of the project.
Raymond

Raymond had an amazing imagination. He sometimes spoke chaotically, and my understanding would fluctuate between the inability to follow his chain of thought, and being struck by a very deep insight that made sense to me in a profound way.

When I felt able to continue the threat by responding I would do so, and if it was not possible, or if we were far from our initial thoughts, I would often ask something which related to the activity at hand or tell him that I did not fully understand.

He was really skilled in mosaic and was often found doing that before the workshop began, trying to get something finished. My impression is that Raymond was a little frustrated when the project ended, he would have possibly loved to continue to create and develop his concepts, and he suggested a part two. I was always very honest about my limitations if I could not follow the complexity of his ideas.
Appendix 2: Design at PTP project

participants

As discussed, The Psychosis Therapy Project provides therapy for people who have experience with psychosis. Nine clients signed up to participate in the project, introduced here how I remember them, in the order in which they signed up.

Nealy

Nealy was very kind, I knew her a little from earlier work in the charity. Nealy looked joyful in the workshops, often smiling, she appeared shy but comfortable.

When asked to bring a meaningful object, Nealy brought a flower alongside a text which explained what flowers meant to her. I loved this response, it surprised me. How did that flower expand the meaning of design?

Discussing what we have designed before, Nealy talked about Jewellery that she used to sell, which I encouraged her to bring over. She brought a box, we had a look at the collection and a couple of participants asked whether they could buy one.

In one of the activities, Nealy said that she did not know how creative she could be because she once had a stroke.

Nealy and Amara knew each other from a psychiatric hospital, long time ago, I remember them telling me about this with a smile.

Nealy stopped having regular contact with the group from around the middle of the project. She said that she was too tired because she began fasting for Ramadan, and
reported having doctors appointments to attend to. Sometimes she could not join the
group because she would accompany another client shopping.

I remember when she came back to a session after a long time. She quickly caught up and
joined us playing and designing the board game.

Once I remember discussing the issue of spirituality with her in the drop-in area. She
mentioned how it was important to help people to be spiritual but not extremist. She
became spiritual when she got ill, as the experience was hard to understand.

Through the design project, Nealy changed her narrative on her ability to be creative,
reporting having learnt that she can think.

She expressed a sense of joy, smiling and laughing at jokes.

David

David was an artist. He was very articulate in discussing concepts and ideas. I remember
him chatting with Anthony around the objects he brought back. He was happy to be part
of the research project and do the questionnaires and interviews but warned me that he
was only in the charity once every two weeks. I reassured him that he could engage in
whichever way.

Most interactions with David happened informally in the drop-in area.

When prompted to bring an object of significance, he mentioned the pill organizer that he
inherited from his father, and asked if that would work, as he did often. He found it ironic
that he would inherit the pill organizer and use it for multivitamins. When discussing
objects, he also talked about his interest in walking sticks, in time making quite a great
collection, and an elephant horn, which he was gifted by a family friend and used as a toy
as a child.
I liked David’s laugh and his unique appreciation of absurdity and paradox. I remember him talking humorously about the idea of questionnaires. Humorously, he mentioned encountering a particularly bizarre question ‘was your mother a good mother?’.

One time, on my way to the charity, I was singing on the tube, and when I lifted my head, I saw him laughing as he caught me singing! he asked me are you going to the club? We both laughed.

Trying to weave his contributions into the project in his absence, I once asked him if I could print out the object photos and texts and add them to the group timeline of objects, to which he agreed.

David was not present at the exhibition opening but saw it afterwards. He suggested that one could do just an exhibition or publication just from the objects.

The notion of not wanting to overidentify with psychosis -which he shared in the interviews- may have prevented his engagement, yet he also believed the group could prevent participants overly identifying with their problems.

**Anthony**

Anthony was funny and skilled, a very positive person. I remember meeting him at the Christmas event, playing songs with his whistle.

He was the first person to engage with the project by bringing objects. He brought various milking stools and his collection of 2CVs. Those first conversations made other clients curious, and I got the sense that they were important for him. His therapist mentioned informally that it helped him actualize his agency. He also wrote several pages about the objects, where memories, imaginaries and reflections merged in a continuous stream.

Around this time, I remember seeing him exchange drawings or graphs with Uriel, with whom he began discussing spiritual matters. He would engage with others with ease.
For the cultural probes, he arranged all his religious objects and tools for the snaps and regretted not having the chance to get outside to take another picture he was planning to.

I have continued to work with Anthony on a conference paper and a journal paper. Toward the very end of writing this thesis, we worked over the phone to respond to the editor’s feedback. These phone conversations continued to inform insights, sometimes coinciding with what I was reflecting upon. For instance, when I was trying to articulate the way people connected, he mentioned that design would help them interact unselfconsciously.

One time Anthony made me a card in which he shared his dreams, involving me. I told him that I could not accept gifts, but he said I could use it as data, which I thought was cheeky, funny and smart. It related to his beliefs about his ‘green spark’ remote impregnations. It felt as if he knew me more than what I shared. Some perspective was given by my therapist, who, being a Jungian analyst, was accustomed to acknowledging how much we transmit beyond what we say.

I remember trusting him more than I trusted myself in doing certain things, like building models. I appreciated this feeling, made me feel that our team was more than the sum of us individuals.

**Nestor**

Nestor was a curious person. He would not hesitate to ask direct questions. He was assertive in arranging how much he was willing to participate.

When our interactions began, he would often ask why he was doing a certain activity, how it related to design or how it would benefit him. I would reply that I was not sure, that the research aimed precisely at finding out.
He told me about his university studies and shared his passion for chess. He talked quickly, and often will interrupt me to ask a question. I would usually reply and continue, slowly bringing the conversation back to the project, or relating my answers to the task.

A portable chessboard was his object of choice. He explained the game, and I inquired about the object. As time was finishing, he asked me to write the questions so he could think about them while away.

I began seeing Nestor every two weeks before the group. The second time, we met in the kitchen area, where passers-by could join. We were drawing each other’s portraits without looking into the paper when he - holding his laugh - said ‘this is crazy! You are crazy!’ to which I responded ‘no you are crazy!’ And we both broke in laughter.

Nestor’s participation gradually increased. He began coming every week, and staying a little longer each time, engaging with the cultural probes with enthusiasm, bringing photos, baklava (a Turkish dessert), books …

In relation to the game design, his questions were straight to the point. ‘If there is no winner what is the point?’ I would often reply with further questions. His scepticism was generative. He took the role of question builder, and every week he would increase the amount that was needed to sustain interest until we realized that people could create more. He insisted on including a lot of empty cards so the game would grow as you acquired knowledge.

Nestor was very satisfied with the outcome, although he could not play it in the exhibition due to auditory hallucinations. He would like to test it one day and would like me to market it, as he believes it would catch on.

Amara

Amara is a loving person. At the exhibition, she gave me a thank you card. She wrote that she once said she would like my brain, to which I replied, we are all different and
contribute in different ways, but that what she really meant was my mental health. She thanked me to have opened their hearts and minds. But it was her heart that was so open. I have felt that when I met her. When I asked to bring objects, Amara brought her extensive heart collection.

Even before she signed up for the project, she approached me with a drawing, a design of a logo, which we talked about.

Amara showed me affection and mentioned that I was able to bring out ideas in her, although I think it was the design process in itself, too.

Amara laughed and cried with grace and ease. Her emotional openness did not make me feel uncomfortable. Is as if she, with her ease to express herself, gave us, in turn, the comfort of that possibility, of being authentic.

She said she stopped believing in God for one year, which she found very boring. Her spirituality, to me, seemed to align with eastern philosophy. Her conversations with Jesus changed, who told her, not long ago, that he was fake, that he was in her head. She interpreted that she was him, and he was her. While praying, she began holding her hands around her heart rather than against one another, which changed back by the second interview.

Amara saw light in people. We shared unusual experiences through humour, questioning the boundaries that concepts of normality create. Amara wrote Anthony a card to thank him for bringing himself forward like that. They both did. Conversations arose about certain characters, such as the green witch who told Amara to write children’s stories.

Amara would love to see the game in the shops, although she was not convinced by the name - GAME could be any game.

She told me that her life would be different, that she had been told that the depression was going to be a feel from the past.
Baris

Baris did not speak English. I remember that Nealy, who speaks Turkish, helped translate for the sign-up process, making sure he understood.

He seemed shy but willing to engage, despite that Nealy would not always be around to translate for him.

I remember one day when Nealy was not around, and Anthony and Uriel began asking questions about the PhD research, leading to a discussion. I apologized to Baris because I guessed he could not follow such discussion, yet to my surprise, he appeared to enjoy being there.

More than once I saw him talk about a neighbour’s club which he wanted to be part of. He would explain the benefits of this to one of the volunteers, who agreed to help him search online.

In the first days, he explained he used to work doing CAD and working with machinery to do parts.

One time, Anthony came out of the therapy session and joined the group. He somehow knew that Baris had many dogs, and began planning the design of a lead to walk them all together. I remember them smiling and laughing.

Baris participated every week until he left to visit Germany for holiday, from where he did not return. He came back a few months later when the project had finished. The interview was going to be organized with a professional translator, but the manager thought his English was much improved, enough to engage in an interview. Unfortunately, while the arrangements were being discussed his dad passed away, and he returned to Germany.

I remember how Baris continuously expressed his appreciation through his body language. I felt we could communicate despite language limitations.
Ellaria

Unfortunately, I did not get the chance to get to know Ellaria well. She signed up for the project, but she did not attend the sessions. However, she and I had some informal conversations when we saw one another and I updated her about the project.

One of the things I invited her to participate in—since it did not involve joining the group—was the cultural probes. She seemed very pleased to do this. Around this time, she told me that the reason why she could not join the sessions was due to past traumatic experiences that had to do with her cultural and religious background, which could be indirectly triggered by the presence of others.

I remember she brought the disposable camera and asked me to take a picture of her since she had still some photos left. She appeared really pleased, and she brought many pictures of parks and nature.

She was very kind and appreciative. Unfortunately, I did not have a chance to interview her.

Jack

Jack’s therapist told me about him and said he had very interesting ideas about design he would love to share.

Unfortunately, he only participated briefly, around the time when participants were bringing objects. He brought to the group photos about iconic designs.

Although he was not there for long, he shared his stories about making toys when he was a child, and he remarked that designing was all about necessity.

He was outspoken. His ideas about design were very interesting and his stories about what he made as a child informed definitions around what design means. Jack did not continue coming to the workshops. Even before he joined the group he was not a regular in the
drop-in, so it was difficult to continue the conversations informally either. As he did not charge a lot, he was in high demand for his builder job, making it difficult to join. Man of all trades, he said once.

Although his feedback was positive, I wonder what would have made the project more appealing for Jack. Perhaps more opportunities for one-to-one work, or even online sessions, especially considering he had experience with designing and art, and he often entertained himself with personal projects, such as the machine he made to splatter paint dots around and make art.

**Uriel**

Uriel eradiated peace. He had a special presence and energy, and I often felt like hugging him. I learned Uriel had studied architecture a long time ago. He had white hair, he did not talk much. I remember him sharing with Anthony a drawing that looked like some form of eye, or seed, perhaps a vagina, as a participant pointed out. He would use the drawing to explain processes of birth and death, cycles of living and waste, and other kinds of phenomena. He used it to understand, structure and make notes of lectures. One time, discussing a brief he was interested in - for building a new hub, he drew something similar to that drawing, and begun explaining the small corners were rooms for individual therapy. When I asked whether that was the brief or the design response, he replied that briefs can also be geometrical, which had never occurred to me. Uriel was very intelligent.

During the consent form procedure, he ticked *no* in the section that refers to having read and understood the information sheet. According to him, nobody could ever be sure to have understood. He was philosophical like that, Uriel. He would get me thinking about things that I had taken for granted.

His facial expression upon seeing me changed following the first weeks. He once saw me wearing white and asked me if I was an angel. I replied I was not, that I was just doing my job. He smiled and said ‘that is exactly what an angel would say’.
He responded to the cultural probes by making things and sending me photographs via email for me to print. Despite the variety of themes emerging from the cultural probes, Uriel was able to suggest Stewardship as the overall purpose. He showed me the *sine qua non* of design, which, as he explained, meant ‘that without which is not’.

When we were thinking about whom to design for, Uriel talked about someone in a house in the UK and someone in a house in an African country and expressed some form of a connection to solve problems. He teared up when he described this and reminded me of a project I did a long time ago, which aimed to solve issues in this manner.

He readdressed the brief by stating that the question was how to make non-spiritual people wonder, rather than spiritual people. This insight possibly became the basis for what eventually emerged as a common design outcome – the board game. Concerning this, Uriel came to the workshop very excited once and told me he had the opportunity to play a game in the church about identifying yourself through numbers.

For the last few sessions, Uriel spent most of the time drawing figures that would be incorporated into the game. Anthony often shared that he once asked Uriel what he was doing, and he replied, ‘Erika will make some use of it’.

Unfortunately, Uriel could not attend the exhibition. I later saw him in the charity and showed him where we left the prototype for others to try. Although he initially agreed to be interviewed, he was often tired. During this time, his physical health got worse, and he moved to a care facility. When the game was accepted for a conference in Colombia, he said it was important to donate to compensate for the carbon footprint of such a trip, to which I agreed, especially since the game helped raise awareness around sustainability. It happened online due to Covid.

With profound sadness, I learned that Uriel passed away in hospital early in the summer of 2020.