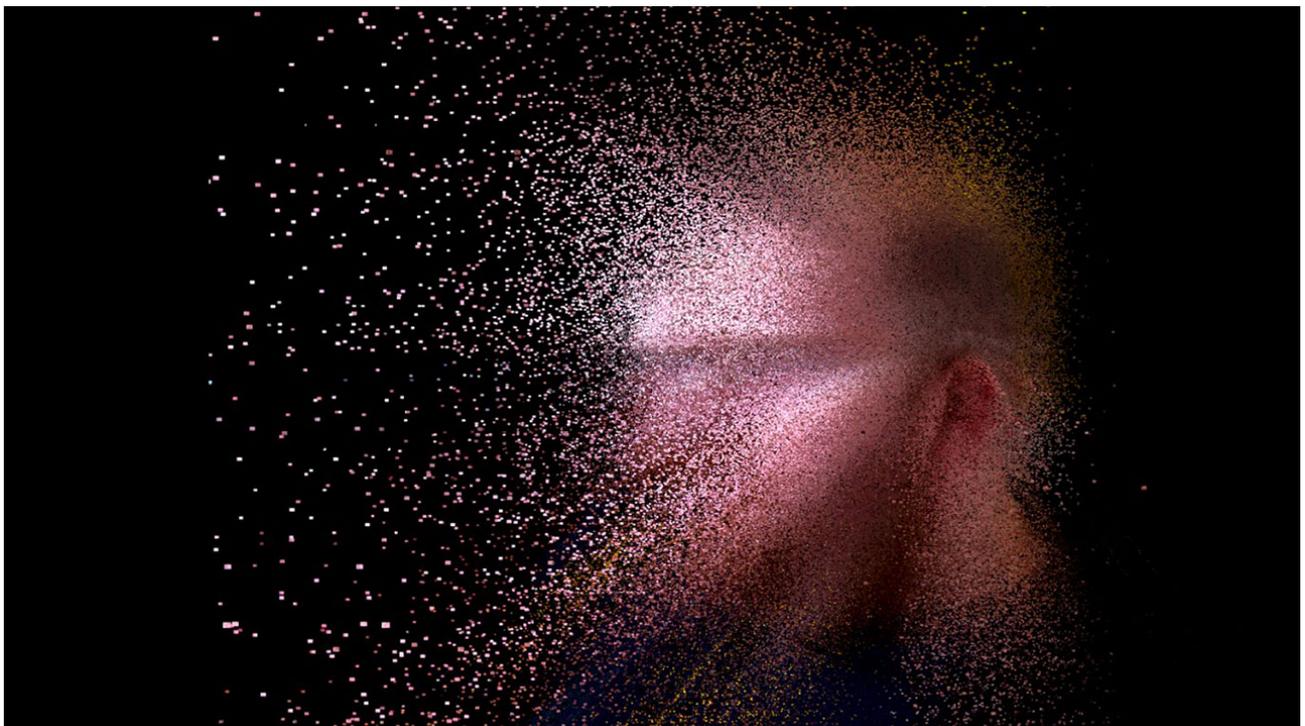


# DESIGNING INCLUSIVE REALITIES: A CASE FOR CO-CREATION IN VIRTUAL REALITY AS A CHALLENGE TO STIGMA ATTITUDES SURROUNDING PSYCHOSIS



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### TABLE OF CONTENTS

- ABSTRACT
- Project description & storyboard
  
- ALTERING PERSPECTIVES ON PSYCHOSIS
  - The dimensional diagnosis
  - Misconceptions that stick
  - Public interventions to challenge stigma
  
- ILLUSTRATING ALTERED STATES OF REALITY
  - Art Brut in psychiatry and the arts
  - Views on truth in "madness"
  - The role of storytelling
  
- VR IN MENTAL HEALTH WITH A VIEW TO CO-DESIGN
  - Therapeutic VR interventions
  - Involving co-design
  
- FINDINGS: CO-CREATING WORLDS IN VR, A SENSE-CHECK
  - Set-up
  - Experiencing Mania in VR
  - First co-creations in VR
  - Results
  - Responses from young medical students
  
- CONCLUSION

## ABSTRACT

This paper explores whether and how a creative intervention using co-design to create a VR world with multiple spaces may be useful for changing language and views around psychosis and schizophrenia. The exploration builds an academic backdrop to an artistic intervention planned by the creative company Anagram, that specialises in interactive storytelling and immersive experience design. The studio's theatrical virtual reality piece Goliath (in the making), has schizophrenia but more generally psychosis and so multiple realities at its core. To include people who experience hearing voices or unusual beliefs first-hand and to ultimately inform the recognition of the issue, Anagram ideated the Museum of Unusual Perception as a sister programme. Said virtual space is to be made up of rooms co-created with the people with lived experience. The paper looks at the theoretical background that surrounds said proposal.

Part one defines psychosis predominantly as a diagnosis and how it is changing from a categorical to a dimensional view. The chapter also looks at essential misconceptions that constitute stigma attitudes concerning psychosis and schizophrenia with a view to how these affect people suffering from the condition to establish the proposal's urgency. It also describes public campaigns and success factors in challenging stigma attitudes.

Part two moves one from the diagnostic and public perception of psychosis to the artistic perspective and the depiction of altered states of reality in different media and how these question society's sense of "real truth". This relativity of perception leads on to an emphasis on storytelling and first-person narratives.

Extending the thinking around storytelling and how objects, artefacts or art can help articulate a personal condition, section 3 stays within the creative world of media but forwards the discussion to look at immersive technology before focusing specifically at VR interventions in the mental health context. The selected examples have in common an emphasis on co-design approaches that involve users early on and help establish new knowledge in a peer-to-peer learning community. These methods also build bridges to disseminate information across multiple stakeholders, elements relevant and potentially instructive for Anagram's work.

The final part is the protocol of first sessions to test the chosen method of co-creation and VR technology and includes responses from participants. The concluding argument summarises the findings and speculates whether the chosen methods could indeed challenge stigma while pointing out future challenges of the work.

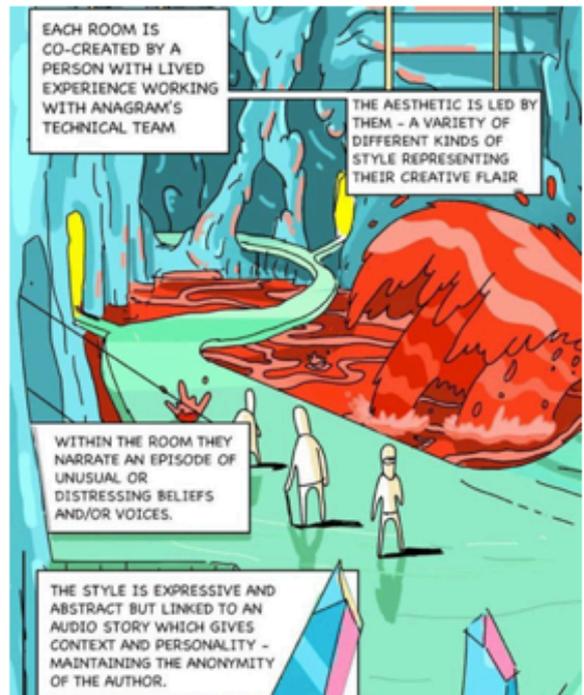
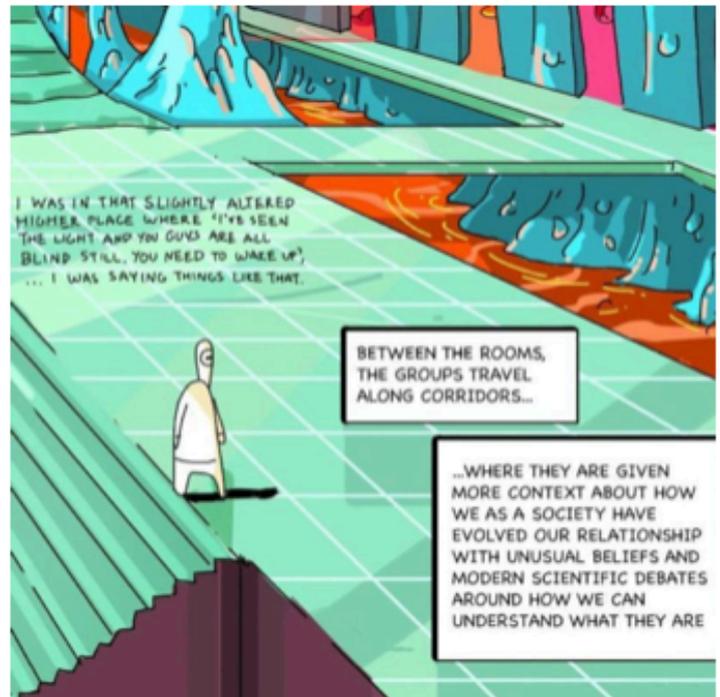
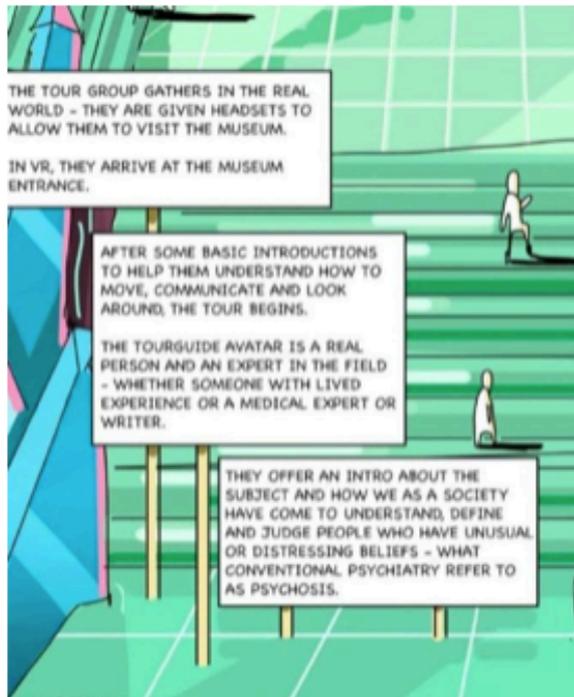
KEY WORDS: co-creation, co-design, community of practice, storytelling, virtual reality, immersive technology, mental health, psychosis, schizophrenia, hearing voices, museum of unusual perception, anagram

### PROJECT DESCRIPTION WITH STORYBOARD

The backdrop of this paper is a project proposal that awaits further funding. Researchers from the University College of London (UCL), the McPin Foundation and the author of this report together with third sector experts from the mental health charity Mind in Camden gathered under the lead of Anagram, a creative company specialising in interactive storytelling and immersive experience design. The award-winning studio is working, among other things, on a theatrical virtual reality piece called Goliath, that deals with schizophrenia. The story follows Daniel, a fictional character based on the real-life experience of a man that spent years detained in a psychiatric hospital and is now free and also a prolific online gamer.

Accompanying Goliath is its sister project The Museum of Unusual Perception. Co-created with people who have direct experience of hearing voices or extraordinary perception, also seen as symptoms related to psychosis, each individual story will be presented in an online virtual space, the multi-storey palace that makes up the Museum. The tour will meet virtually to explore the world and also hear about recent medical research into psychosis. The below storyboard helps to clarify the concept and user journey before this paper will explore the ideas that informed the proposal for the Museum of Unusual Perception and more so, the scientific base that makes the project an urgent one on the following pages.

Storyboard



## ALTERING PERSPECTIVES ON PSYCHOSIS

“The concept and language of schizophrenia have shifted dramatically. However, this is currently sitting in academia, and so there is a need to bring this into the public sphere and facilitate a shift in understanding specifically through young people and medical professionals including practising psychiatrists and students.”

(Hayes 2019)

Under the umbrella term of psychosis and schizophrenia, the medical profession includes altered perceptions of reality as auditory and visual hallucinations and the distortion of unusual belief systems. However, there is a reframing of the condition underway, that considers the diagnosis dimensional rather than categorical (with a set of seemingly fix symptoms, also outlined in the DSM-5<sup>1</sup>). This new views, alongside first-person accounts, form the basis for the Anagram project that is to bring these perspectives to the stakeholders (people with lived experience, their carers and medical practitioners) and broader audience. More specifically, in the proposal underlying this paper, Anagram applied for funding “to bring to the public and critical stakeholders the contemporary research on the subject of psychosis and schizophrenia - particularly the fact that term and one-dimensional diagnosis is fundamentally under question” (Anagram 2019).

The matter is urgent because, while academic research has shifted the interpretation, treatment, prevention and recovery of altered states of mind, the public and even practitioners’ perception of the condition has been slow to change. It is in this context that Anagram’s Museum of Unusual Perception aims to translate scientific findings and the breadth of the actual lived experience to other spheres<sup>2</sup>.

### The dimensional diagnosis

This new body of research the studio referred to has been outlined poignantly by the psychiatrists Guloksuz and Van Os in a text titled 'The slow death of the concept of schizophrenia and the painful birth of the psychosis spectrum' in 2018. The authors discuss that schizophrenia as a term has come to define everything psychotic one-dimensionally, thus hampering research and recovery-oriented practice (also compare Jablensky 2010 for a historical summary). So Van Os and others argue for the prospect of introducing the

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<sup>1</sup> "The DSM-5 classification of and criteria for primary psychotic disorders emphasize that these conditions occur along a spectrum, with schizoid (personality) disorder and schizophrenia defining its mild and severe ends, respectively." (Arciniegas 2015, p. 715)

<sup>2</sup> One funder seemed particularly suited and Anagram first ideated the Museum with the Wellcome Trust in mind, more specifically, the foundation’s Public Engagement Fund. The scheme aims to engage the public in state-of-the-art research through creative means.

concept of psychosis as a spectrum disorder (PSD), analogous to the recent changes in views on autism (ASD which now includes Asperger syndrome) and addiction in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) that also affect the public sphere<sup>3</sup>.

The idea to describe psychosis on a spectrum or dimensionally has advantages. Schizophrenia and more so psychotic conditions are challenging to classify categorically in their entirety as often symptoms such as depression or bipolar symptoms appear alongside auditory and visual hallucinations, for example, and are often episodic. So these mixed symptoms may be better described in a dimensional model.

Argues Jablensky in 2010:

“Dimensional models (as opposed to categorical) have the conceptual advantage of introducing explicitly quantitative variation and graded transition between forms of disorder, as well as between “normality” and pathology. This is important for classifying patients who fulfil the criteria for two or more categories of disorder simultaneously, or who straddle the boundary between two adjacent syndromes.” (ibid., p. 280)

Differently put, the categorical model assumes each personality disorder is a separate and distinct category, i.e. one is either psychotic or not, with little room for gradation and more so the differences in the lived experience and symptoms, that can overlap. So while (paranoid) schizophrenia in a dimensional model is at the end of the spectrum and must thus perhaps remain partially categorical, (also Jablensky 2010, p. 280) the dimensional view on psychosis may also include said experiences such as hearing voices, unusual belief systems and episodes of manic depression, now considered bipolar.

### Misconceptions that stick

While the terms of psychosis and more so schizophrenia open up an enigmatic field in diagnostics, the condition also transfixes the public's imagination but in a less nuanced way. The evoking of a “split mind”, the conception of someone turning into an otherwise hidden persona appears frightening.

However, the stigma also the more general psychotic conditions continue to carry (think: “psycho”) can have serious consequences. The stigmatisation leaves sufferers increasingly isolated, resulting in social anxiety, low self-esteem and, most critically, significantly decreased life expectancies.

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<sup>3</sup> The American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM), along with the International Classification of Diseases (ICD), is known as the “psychiatrist's bible”. It affects the “definitive” diagnosis of mental ill-health but also determines insurance benefits, affects the availability of special education and social services, and is used in court proceedings.

More so, most are misconceptions. People going through psychotic episodes, for example, can show harmful behaviour often towards themselves, not others, also by becoming catatonic or socially isolated. Besides, rather than exhibiting two distinct personalities, in the sense of a Jekyll and Hyde, the psychotic condition (Freud set it against the neurotic one) appears designated by the loss of a shared understanding of reality. It is a disintegration, sometimes of both the inner and the outer world.

The psychiatrist R.D. Laing put the process in an existentialist sense, as a sign of desperate attempts to protect an ego that had never been ontologically secure in the first place. Still, in Laing's view, the individual can retrieve or newly experience ontological security. This then embodied self is capable of engaging in what he calls person-to-person relations or the least uncover a fragment of self as "a rallying point around which integration could occur" (ibid. 1960. p. 203). So this suggests that it is not always a chronic condition and also curable in some cases. It can manifest chronically but also runs episodically and also depends on the help provided and at what point<sup>4</sup>.

This latter argument is particularly relevant in psychosis as stigmatisation often leads people to not seek help in the first place or too late. However, early interventions particularly for young people most at risk of psychosis, not only show a high success rate but also help to prevent repeated episodes that increase the likelihood of developing a chronic condition (Yang et al. 2013, Hagen et al. 2012).

### Public interventions to challenge stigma

The persistent stigma, especially of schizophrenia, has been established in many studies that look at ways to test the conditions for change. An example is the 2013 experiment, in which Yang and his team presented college students enrolled in an introductory psychology lesson with a vignette. Each student had a randomly assigned diagnosis, a "risk-label" that described the early symptoms of a condition that precede the characteristic manifestations of the acute illness. Schizophrenia elicited more negative stereotypes, and psychosis at risk elicited more social distance and less willingness to help compared to other diagnoses.

This pattern has been identified in similar studies as well. Angermeyer and Matschinger in 2003 compared the stigma attached to depression and schizophrenia. Again the latter elicited more fear in the respondents. Interestingly, however, the authors found indications that this perception of people being potentially dangerous increased when biological factors were assumed as the root cause. "By contrast, if psychosocial stress was

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<sup>4</sup> Laing also used psychoanalytic approaches to engage with the subjective delusions in the hope of uprooting the assumed causes from the unconscious. So instead of restraining and enforced treatment, Laing took the approach to let acute mental and emotional turmoil play out, thinking that it could have a positive value, i.e. for re-forming a self.

assumed as the cause, the reactions of the respondents were more favourable” (ibid. 2003, p. 533) so this means the information and explanation of the condition is essential as is the label.

To see whether a change in the public perception would hold, Wood et al. used data from the UK Office of National Statistics (ONS) and compared stigma attitudes from 1998, 2003 and 2008 to measure the effect of the changing mind campaign that ran from 1997 to 2003. The campaign aimed to develop a public and professional understanding of mental health problems. Overall stigma attitudes had decreased (from 1998 to 2008) but increased since 2003, leaving the authors to conclude, that public information campaigns that “promote a positive perception of psychiatric diagnoses should be continued on a long-term basis” (ibid. 2014, p. 606).

Moreover, there is another side to public stigma called self-stigma, where patients internalise (public) views of the condition (Corrigan & Watson 2002). Also, Evans-Lacko et al. have shown that there is indeed a trend for patients’ self-stigma to arise from the internalisation of surrounding stigmatising attitudes. In their study in 2012, they compared attitudes towards mental ill-health across 14 European countries.

The authors conclude:

“Targeting the general public through mass anti-stigma interventions may lead to a virtuous cycle by disrupting the negative feedback engendered by public stigma, thereby reducing self-stigma among people with mental health problems.” (ibid., p. 1741)

In other words, patients are prone to internalise the stigma attached to mental health problems by the general public, but educational campaigns that help both the public and patients to better understand a condition will likely have a positive effect. Indeed, recent years have seen a shift towards a better understanding in all involved following public information campaigns (also Koike, Yamaguchi et al. 2017, Luty et al. 2006, Piotrowski, Gondek et al. 2017).

There is also the diagnostic level and successful attempts have been made indeed, to challenge stigma in those with lived experience but also those trying to treat them by changing the way schizophrenia is diagnosed, starting with the name itself.

In 1993, a campaign led by people affected by or concerned with care for those diagnosed with schizophrenia in Japan resulted in renaming the “split-mind disease” in “Togo-shiccho-sho” in 2002 (統合失調症). The latter translates to “integration disorder” but carries a change in the diagnostic view as well, now stressing that symptoms are affected by a vulnerability to stress as opposed to biological factors, for example. The study conducted about 15 years later after the renaming, showed that the campaign had resulted in a significant increase and facilitation of diagnosis (up 50%) and hence access to diverse treatment (Koike, Yamaguchi et al.

2017). The authors consider reactions to the diagnosis to have run from “fatalistic pessimism to realistic optimism”, in both the doctors as well as patients and those around them. While results varied depending on the age of the participants, the bottom line after the name change is as follows:

Those who knew only the new term found it easier to imagine the illness (76% vs 24%), considered that the disease was less severe (23% vs 87%), felt that patients should disclose the diagnosis (93% vs 7%), and did not feel that the relationship with people with schizophrenia should be stopped (51% vs 37%). This means that especially young people growing up with a less stigmatised description of the condition are likely to be positively affected (compare Koike, Yamaguchi et al. 2017).

Also George and Klijn and the Dutch Anoksis project made a similar call for a name change<sup>5</sup>, although the first approach was “to provide open and honest self-portraits and information to the public about our condition as people with schizophrenia” (ibid. 2013, p. 1555).

Regardless of how clear these findings on labels, within the scope of Anagram's project, to propose a set name for a change would have been inappropriate if not impossible. There is not one single answer among researchers and other stakeholders as has been shown and more so, renaming alone is unlikely to change the public misconceptions and thus needs an educative and more so nuanced and personalised approach.

This ambiguity but also the findings on the effect of personalised campaigns added to the emphasis explored here concerning the importance of self-representation. How one views and articulates their condition is vital and the premise outlined here looks towards how co-design can be used as an approach to generate such articulations of self. This approach stands in opposition to accounts (or diagnosis) of psychotic illness generated in a top-down, or ‘outside’ manner. So with this intention in mind, Anagram’s final application document listed three primary outcomes that relate to the issues outlined above and put people with lived experience at the centre:

1. Engaging, empowering and representing those who experience distressing beliefs or hearing voices and their families to gain an in-depth understanding of the scientific research around the evolving diagnosis of psychosis to reduce the stigma, introducing new language which accurately reflects the experience.

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<sup>5</sup> The organisation proposes ‘Psychosis Susceptibility Syndrome’ (PSS) as new name. However, the text includes an interesting note from the chair of the appropriate DSM-workgroup, Will Carpenter, who in an email expresses his view that “it would be proper for the World Health Organisation (WHO) to use its convening authority to address this issue” (cited in George & Klijn 2013, p. 1556).

2. Bringing medical students, junior doctors, mental health professionals and trainees an in-depth understanding of first-hand experiences of distressing beliefs and unusual perceptions, what it means for patients, and how interactions with health practitioners affect them.
3. To engage people, including journalists, writers, opinion-makers and the general public, through accounts of first-hand experiences, to change opinions and the language that is used to describe the condition and lived experience.

## ILLUSTRATING ALTERED STATES OF REALITY

“There are parallels between generating and appreciating lasting stories and art, and generating and appreciating healing, therapeutic encounters.” (Francis 2016)

Moving on from medical descriptions and public perceptions of the condition, the following positions Anagram's proposal as a creative intervention within a tradition of artistic examples that describe, represent or transcend extraordinary perceptions in different forms of media, often using first-person narratives. Indeed, psychosis and schizophrenic episodes exhibit a historic connectedness to art.

### Art Brut in psychiatry and the arts

The debate on "the art of the mentally ill", arose in the 19th century with the new neurosciences, that later informed psychoanalytic theory. The medical circles have since discussed, whether "psychotic art" then also known as "art brut" or "outsider art", enabled the clinician to gain insights into the mind of those considered mentally ill.

Yet psychiatry is but one field Beveridge identifies in his historical summary in 2001 with artists and art critics on the other side, so that with more doctors taking note of the creative expressions of some of their patients, also questions on the aesthetics of the works arose, thus elevating them (potentially) to the realm of arts (also MacGregor 1981).

Over time, both the psychiatric and artistic perspective became intertwined. The Swiss psychiatrist Walter Morgenthaler, who first wrote about Adolf Wölfli, who has become the “most celebrated outsider artist” (Beveridge 2001, p. 596), must be included here as well as Hans Prinzhorn, a German psychiatrist. He stressed the point to consider the artist as individual rather than seeing the works through the lens of diagnosed madness.

### Views on truth in "madness"

The joint perspectives also relate to the notion of the "mad genius", that speculates whether patients have access to a higher state of perception, a view particularly appealing to artists and art critics. This "art of the insane" and the idea of heightened creativity in individuals with mental ill-health related symptoms became prominent through Jean Dubuffet, the French painter behind the concept of 'art brut'. He had discovered the works of Aloise, now a famous proponent of the field, who made all her drawings during her long internment for schizophrenia (Laird 2012). While Dubuffet claimed that her art had cured her, Aloise herself, considered the chance to create and to express herself artistically as beneficial in general. A critical element to her account that seems inline with other findings is then that art brut is not exclusive nor categorical to people of mental ill-health but instead is a trait of "individuals who have a mental – not visual – vision of the world" (Aloise cited in Laird 2012). This also expresses the artist's view on herself as predominantly creative, not "mad".

While this paper will not discuss in-depth whether mental ill-health fosters creativity per se and nor the aesthetics or healing value of the works, the idea of altered states of reality lending themselves to creative expression or artistic transcendence almost by nature informs this account as well.

Historically, this concept of making an otherwise hidden truth visible infuses the 19th and early 20th century. In particular romantic and later surrealist and expressionist circles hoped to find new perspectives and inspiration in the "madness" of others. Writes Paul Klee:

"In our own time worlds have opened up which not everybody can see into, although they too are part of nature. Perhaps it is really true that only children, madmen and savages see into them." (ibid. cited in Beveridge 2001, p. 599)

Again there is not only the artistic but also the psychiatric element to this view that essentially normalises madness by placing the above groups in the place of truth seers. Indeed, critical approaches to the psychiatric system around the 1960ies also made attempts to consider "the schizophrenic condition" as rooted in a refusal or inability to deal with a societally agreed "normality". In this societal view, taken by Arno Gruen for example, the pressure to conform to what the individual perceives as abnormal (as in opposed to one's inner drives or an individuals' existentialist autonomy) then leads to 'insanities' or breaking under said pressure. This approach not only reintroduces the idea that everybody is potentially psychotic and our sense of reality fragile, but it also introduces a view of psychosis as an increased sensitivity (or vulnerability) that may be considered a gift as well.

### The role of storytelling

Against this background, it is worth looking into literal storytelling. Numerous accounts of people diagnosed with schizophrenia reflect this practice with one of the earliest examples being Renée and the 'Autobiography of a schizophrenic girl'. She wrote it together with her analysts Marguerite Sechehaye in 1951, who lends the clinical commentary after treating Renée over many years.

The opposite of such a healing encounter and the slow reintegration of a self presents André Breton's biographical account 'Nadja'. In the book, the artist describes his relation with a young woman fighting to keep her sense of reality until she loses her-self under his observant eyes.

While his is an extreme case, still "it is far more common for people who suffer from mental illness to be written about—by caregivers, by researchers—than to offer their own accounts," according to Esmé Wang writing in the *New Yorker* and author of the recent autobiographical account 'Collected schizophrenias'. A notable exception is Nathan Filer, a mental-nurse and author, who often makes a point of not using diagnostic labelling in his writing. Filer is one of the potential tour guides through Anagram's Museum of Unusual Perception because of this reason. Ideally, he will provide a backdrop to the co-created worlds but without leaving those with the lived experience to whom these worlds belong with a feeling of "being talked about".

More so, the idea of enabling people with lived experience of hearing voices or unusual beliefs to tell their stories is an integral part of the project and substantial reason for the participatory approach. While co-design will appear in more detail later in the text, in the context of co-design, stories told by those participating in the design process, are essential.

Muller identifies different functions of stories in participatory work. First, they may "trigger conversation, analysis or feedback. Second, they may be told by users as part of their contribution to the knowledge required for understanding," here not so much a product but a condition, and for specifying needs or demands<sup>6</sup> (Muller. 2003, p. 25).

For the current proposal, stories as trigger for conversation as well as the users' contribution to the knowledge are essential and relate to ideas of personal representation and education as valid interventions likely to help decrease stigma as described in the previous parts.

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<sup>6</sup> The remaining two functions relay to designers in a commercial context.

## VR IN MENTAL HEALTH WITH A VIEW TO CO-DESIGN

Fast-forward to the 21st century when the mental health complex is increasingly employing digital and more so immersive technology, both from a therapeutic<sup>7</sup> and medical training perspective, but also to challenge attitudes towards mental ill-health.

Recent examples of the non-therapeutic and decidedly de-stigmatising type, include the video game 'Hellblade: Senua's Sacrifice' released by Ninja Theory in 2017 with an added VR version from 2018. The game's lead character, Senua, suffers from psychosis, expressed mostly through hearing voices and visual hallucinations, that play out on the screen and in the gamer's headphones. The visual and audio effects drag players into Senua's world that is as beautiful as it is disconcerting as perception proves volatile at any moment. More so, the game thus aims to increase the understanding of the condition through experiencing it (in simulation).

The psychologist Kelly Dunlap from iThrive Games, a foundation that works to benefit teens at the intersection of game development, education, and mental health, has heralded the game for taking a three-dimensional and thus de-stigmatising approach to mental health themes. Says Dunlap:

"Hellblade features character, narrative, and environmental representations of mental illness and delivers a thoughtful and emotionally engaging story that explores the complexities of mental illness without stereotype or sugarcoating." (ibid. 2018, p. 82)

More so, the game managed to do so because it was made in cooperation with mental health professionals and together with individuals who experience voice-hearing or other psychosis-related symptoms. The neuroscientist from the University of Cambridge, Professor Paul Fletcher, who helped to develop the game, makes a point of psychosis as a "continuum" rather than an "extreme phenomenon". He thus raises (almost surrealist) questions of what is normal about perception and ultimately wants to show how "all of us are prone to becoming separate from reality" (ibid. 2018).

The theatrical piece 'Manic VR' by Kalina Bertin is another example of a recent creative response to the condition, that seeks to show how it is to experience it. Her work focuses on mania as typically exhibited in bipolar-related symptoms. Anagram used the VR in the exploratory sessions, so it will appear in more detail later in this report.

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<sup>7</sup> Pioneering work in VR healthcare is being done by Virtual Bodyworks around Mel Slater in Barcelona and also by Stanford University in the Virtual Reality and Immersive Technology (VR-IT) Clinic and VR Lab.

### Therapeutic VR interventions

Creative responses aside, there have been interventions utilising immersive technology in a more decidedly therapeutic manner that also bank on change through engagement. In this context, VR technology is hailed as a chance for "immersion to achieve affective impact" (Leaver 2019, p. 2), a fact also pointed out by Hale and Stanney, among others:

"VR is distinguished from other computer technologies mainly by the high level of interaction and immersion it offers. Immersion is the sense of being physically there in the virtual environment." (ibid. 2014, p. 37)

Put differently, virtual reality can involve all the senses, although the sensationalised view that it is, therefore, an "empathy machine" has been contested if not overcome. This paper cannot discuss the debate exhaustively. However, a distinction to bear in mind is between sympathy and empathy, categorically understood as "being in someone else's shoes". For Ramirez in an article for Aeon magazine, thus "empathy is what we use when we engage in perspective-taking. Sympathy, meanwhile, involves the capacities that help us feel for another". This latter view also explains why VR has been shown the potential to change attitudes and can make social behaviour more likely<sup>8</sup>.

This more educational use, also in a mental ill-health context, has been well established. In 2018, Bozgeyikli et al. reviewed the use of virtual reality for people with autism spectrum disorder (ASD) and found evidence for VR being "useful in training and rehabilitation because the human brain excels at learning with visual, auditory and tactile senses simultaneously" (ibid. 2018, p. 134). More so, the authors pointed out the advantage of VR providing a seemingly real, yet safe environment, an effect that trauma therapy through exposure exploits.

Other researchers also explore the use of immersive technology with a more specific view to psychosis and the potential to challenge stigma. To summarise a study that looked at augmented reality applications for training medical students on psychotic symptoms, Da Silva says:

"Over the last few decades, the use of VR in psychotic disorders, such as schizophrenia, has been a promising candidate, for example, for a clearer understanding of symptoms, for training of instrumental and social skills, and for the treatment of the disease, as an adjuvant technique. With reference to the

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<sup>8</sup> The work of Fernanda Herrera at the Stanford VR lab offers nuanced accounts on conditions for behavioural and attitudinal changes through VR.

stigma, VR has been shown to be useful for diminishing negative stereotypes and as a supporting device to increase empathy and positive impressions towards schizophrenic people." (Silva et al. 2017)

Still, the authors point out that a careful approach is needed as not to increase certain attitudes, i.e. fear when the condition is framed as stark frightening for example or overstressing the severity of it<sup>9</sup>.

However, a creative approach may not so much angle for empathy or sympathy but for understanding the feeling, of, for example, not being able to trust one's senses or being misled (also Fletcher 2018, Rusch 2017).

### Involving co-design

While the previous examples underline the case for immersive technology lending itself almost naturally to show the vulnerability of perception, and to perhaps challenge stigma through immersion, further instructive for the case presented here was a study by Terp et al. in 2016 titled 'A room for design: Through participatory design young adults with schizophrenia become strong collaborators'. The researchers worked with adolescents diagnosed with schizophrenia and with the therapeutic aim to design an app that would help to detect an onset of another psychotic episode sooner. Terp made a strong case for applying principles from participatory approaches to involve patients in their therapy:

"Co-design means to develop technologies – with and not for users. It draws on a participatory mindset, where users are seen as active partners or co-creators. An advantage to this approach is that the co-designers will take pride in, and ownership of, the process leading to sustainable results." (ibid., p. 497)

More so, Terp and her colleagues in Denmark in their series of workshops used props such as mock-ups and storyboards to illustrate the vision but also cards with statements designed to understand needs alongside scientific findings. Another interesting element were the use of graphics in the communication and also what Terp calls a "room for design" - a "relaxed and undisturbed environment" for creation to unfold and to stimulate interaction (ibid. p. 499).

This communicative process can also be seen as a learning process which "consists in acts of cognition, not transferrals of information" (Freire 1993, p. 60). It sets researchers or facilitators and community in a dialogic relationship, ideal for exploring the context of the lived experience of psychosis without hierarchical modes of being told or diagnosed but having a say in ones' story.

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<sup>9</sup> Note also that both Laing and Bollas mention that practices such as comic strip drawing or essentially assigning characters as if in a novel may be the expression of psychotic belief systems rather than an integrated sense of reality.

Leading on from this dialogic view is the concept of "Communities of Practice", a term coined by Etienne Wenger. CoP has become an influential concept to describe peer-to-peer learning environments and education itself in various sectors. With regards to the field of (mental) health, Wenger considers Communities of Practice acting as bridges between stakeholders:

"In healthcare, communities of practice offer the potential of new learning partnerships that are not hostage to professional silos. The potential even extends to patients who are increasingly forming their own communities." (ibid. 2000, p. 7)

This is in line with the broader field of mental health development, where user-involvement still is uncommon but on the rise, primarily through the means of digital technology<sup>10</sup> (Ion et al. 2010 cited in Terp 2016, p. 497).

The idea of peer-to-peer and individual learning in the digital space presented here also informs the term of a generation of digital natives as given in a report for Nesta Futurelabs. Here Green, Facer et al. state the following numbers:

"It has been suggested that by the age of 21 the average person (of the new generation) will have spent 15,000 hours in formal education, 20,000 hours in front of the TV, and 50,000 hours in front of a computer screen." (ibid. 2005, p. 4)

What is more, these digital natives "are already using these resources to tailor their informal learning to their own interests, to access information of relevance to them, to communicate with people who can support their learning, and to share ideas and expertise within informal learning communities" (ibid. 2005, p. 4). So young people are forming CoPs already, in other words.

Green also follows Wenger further in the thought of bridging between stakeholders and establishes personalisation as a process of dialogue "between learners and advisors, between education institutions and communities, between different forms of knowledge" (ibid. 2005, p. 15).

However, there is another feature of co-design specifically with a view to workshops called the "third space or hybrid experience" that is useful in this context. Explain Muller and Druin in 2002:

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<sup>10</sup> Besides, co-design has proven useful for inclusive storytelling also with simpler digital technology enabling the involvement of multiple perspectives. Beeson comments on his community project in 2002: "Current hypermedia technology does appear to allow the construction and sharing of rich narratives or stories and even the maintenance of multiple perspectives within a narrative (...). The task is not to introduce a technical support system for existing community activity, but rather to see what kind of stories can be told by community members with the technology. Stories not previously told or considered may emerge, and new kinds of story might be tellable with this technology." (ibid., p. 647)

"A 'third space' is a fertile environment in which participants can combine diverse knowledges into new insights and plans for action. This can include articulating, clarifying, and informing the needs of themselves as individuals, and of the people they are connected to or responsible for." (ibid., p. 2)

The authors then add that "workshops usually introduce novel procedures that (...) take people outside of their familiar knowledges and activities and must be negotiated and collectively defined by the participants (ibid., p. 20). Workshops taking a participatory design approach are thus third spaces.

To summarise, co-design fosters user participation and communication in a dialogic process that encourages involvement and learning between peers but also spans bridges to other stakeholders. Co-design processes may also be supported by props and by spaces that stimulate innovation and help form community.

Joining the elements of co-design selected here with the benefits of immersive technology in the context of mental health, it appears that immersive technology has significant potential to illustrate psychotic experiences and evoke an unsettling feeling of not being sure of what is real.

In addition, forming a community of practice in participatory workshops sessions may engage all stakeholders beyond their comfort zones of "what one knows". It is with this in mind that the following section will look at first practical sessions Anagram held.

## FINDINGS: CO-CREATING WORLDS IN VR, A SENSE-CHECK

In preparation of the proposal, Anagram organised a first sense-check in London. These exploratory sessions (exploratory in their simplicity and informality) were framed as focus groups internally. These could also be called a "concept workshop" that builds on an initial idea and continues into further rounds of validation and clarification with additional sessions including prototyping and lastly the experience design (Umameh 2012). Note that for the project at hand, no additional sessions have been held but are the part that awaits funding.

However, even in this first round, the studio applied some of the elements outlined earlier. The sessions included qualitative interviews, practical explorations of virtual reality and prototyping, where individuals were asked to represent and narrate an experience visually in VR using a creative drawing tool.

### Set-up

Following an outreach via phone and email and with the help of the third sector partners, all participants were asked to come to the Immersive Lab at Digital Catapult in Euston. The session had been advertised as a workshop involving testing VR. The set-up at the modern studio space in a high rise in central London is in line with Terp et al. when creating a "room for design" where the use of imagination is encouraged (also Kanstrup & Bertelsen 2011) and also constitutes a third space in the sense of a new situation for all involved with partially open procedures in this case.

Overall, the two-hour session consisted of practical explorations in VR and in-depth interviews with each participant. The latter are confidential for now but inform the background of first-person narratives. Details of the session are provided in the following sections.

A total of six people from the greater London area took part and were first asked to introduce themselves to the group and to talk about their reasons for being there.

While all preferred the term "lived experience" once a participant had introduced it, all openly shared their medical or "official" diagnosis as well. These diagnoses ranged from bipolar to schizoid-affective disorder<sup>11</sup>. Although unintentionally all participants were female and mostly in the age bracket 25 - 35 plus two older participants aged between 50 - 65.

Also present were Anagram's creative technologist as facilitator, the studio's co-founder as lead and the author of this report as additional interviewer and observer.

### Experiencing Mania in VR

For a first proof-of-concept that VR is suited to illustrate the experience of mental ill-health issues, participants saw the piece as mentioned earlier on bipolar-related symptoms. The 'Manic VR' experience builds on recorded voice messages left by the director's twin siblings that both suffer from episodes of mania and depression, bipolar-related symptoms in other words. The teenagers tell their sister about their experiences in audio recordings that form the backdrop to the visuals the team developed.

After seeing Manic VR, each participant was questioned on their views about the experience. Overall, the answers, some highlighted below, were positive as well as varied. Participants agreed that virtual reality offers an exciting way to convey the experience but also stressed the importance of depicting the subjectivity of it.

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<sup>11</sup> While some participants were more self-conscious or aware of the stigma surrounding the medical terms, all also remembered having felt a sense of relief when they first heard a diagnosis as it allows them access to services paid for by the NHS for example.

"[My lived experience] is hard to describe in words so it would be nice to work with VR."

"I've done acting and poetry and writing, there's only so much you can do writing. This means you can create that world."

"This morning talking and creating has been the calmest that I have felt in a long time."

"No-one ever asks you what happens to you. What do the voices say or what do you see. When I speak to my doctor and say that I am hearing voices, he just ups my medication. It was really special to talk about it in details - I want to be listened to."

"[My lived experience] is completely denied at the moment, so no one sees that dark side. Especially professionals - no one sees. What if they did see that? They would understand, maybe have more empathy."

On the importance of making a multi-room VR to show the variety of voices and diversity of experience:

"I think VR would (help make people understand the experience better), but I think it would need to be strongly caveated with the idea as the experiences are very unique to everybody."

"I would much rather have somebody see three different versions of a manic episode to understand bipolar or other conditions than just having one example, that's quite important."

"The fact that it's an episode, getting that through to people that it's not to be experienced all the time - it's an experience that happens under intense stress and pressure. And using VR could do that because it kind of like facilitate different episodes."

Participants also confirmed that the virtual reality provided an environment that felt safe and leaves room to reflect on one's condition.

"This Manic VR to me is more of an exposure kind of therapy. So I'm going to learn to keep those emotions calm because it's not scaring me going through it. It's like when you hear a voice, and you expose it, rather than suppress it. So yes, this is what happens, but I'm not scared of the night or the depression or, you know, this battle, because I understand the experience is not really real. It doesn't feel scary. (...) It made me reflect; it's like a mirror. I could see it, so I am kind of stepping out, but I'm still in it, and I can still say: okay, this isn't me so I can work through it, see how it is."

"The (audio) commentary was positive, and not like scathing voices, and it is almost healing, to see: 'ah this is what is happening to me'."

### First co-creations in VR

In the second part of the session, each participant took part in a guided session using Tiltbrush, an existing tool for 3D drawings in VR that requires an HTC Vive Headset. The method was chosen to allow participants to have ownership over the tools so after a brief training session with the kit they were able to use the software in conjunction with the headset to freely create and animate their own worlds. This effect is typical for co-creative processes that facilitate the development from "tactical" approaches to "strategic ownership" of the technology that can be achieved with the "help of a few modest examples and at a pace governed by the users' learning" (Beeson 2002, p. 649 - 652). These are also known as cycles of expertise that are drawn by repeated practise (Umameh 2012, p.7).

In the next step, participants were asked to think of an experience to share and to begin illustrating it while telling the story behind it, for instance, their first episode of mania or hearing voices. Both the drawing process, as well as the told story, were recorded and where necessary or called for, the creation further facilitated<sup>12</sup>.

### Results

It was striking that all participants experienced both the existing Manic VR as a relief and a potentially healing and not traumatising experience. For the opportunity to create in VR, all participants were eager to not only represent the subjective lived experiences but also considered it a creative outlet. All participants felt it was beneficial and expressed a desire to continue to be involved and use the tool to create a piece that could be shared with others. During the interviews, they asked that the primary group that understand their condition was their family members and their doctors.

### Responses from aspiring medical practitioners

A second session as part of the sense-check included a group of medical students. They also watched the Manic VR experience and took part in a group discussion on views in their profession at the Mental Health Centre of Homerton Hospital in Hackney. The three participants were first questioned on their views and understanding of psychosis and any previous experience with virtual reality interventions.

- So do you believe VR would be valuable, in the sense of going to the other side of someone's experience?

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<sup>12</sup> These recordings of VR world-making are confidential as they were very early "prototypes" to see how participants take to the type of technology and the experience.

"I think it would be really useful for family members; there is often some sort of argument about not knowing what the patient is doing. For doctors, they have more of a handle on what is going on."

"What we need to do as psychiatrists is trying to understand someone else's perception of the world."

"Yes, but even hearing the description of someone with psychosis, I can still not picture it."

The students were sure to know enough but could see a benefit for others, carers in particular. However, after experiencing Manic VR, each student was asked to phrase his/her impressions again:

"It was interesting, quite disorientating. There was one particular moment that I quite liked when you are floating, that's where I can see, how people might be feeling in grandiosity, with objects popping up and come to your attention. And I like how suddenly you are just in a cell, to show how patients go through so many experiences."

"It was about not knowing what will happen. I don't like watching a horror film, but I don't like things like a ghost train, and when you are in it. It was so much more real than I expected it."

"It was a bit scary, and if you (as a doctor) hear people talking about hearing things, seeing something like this helps. And I think you can understand them a bit more and take them more serious in what they are experiencing. When people say they see things, I just don't know what to expect."

These replies point to a change of view and VR as a useful tool for medical students and practitioners as well. However, it is clear, that both sessions described here, can only be seen preliminary but deserving further exploration in the ultimately proposed series of longer workshops that are to result in the virtual Museum.

## CONCLUSION

This paper discussed medical, artistic and societal approaches that surround psychosis and schizophrenia, particularly issues regarding changes in stigmatising attitudes using creative means and immersive technology. A project by Anagram, the Museum of Unusual Perception in practice provided the starting point from where to venture into theoretical territory.

Findings on the diagnostic background presented in part one, established that the diagnosis or medical language as well as the use of the terms is controversial. It also affects the lived experience, which varies over individual symptoms that can overlap, so any project aiming to increase the understanding of the condition

requires an approach that leaves room for nuanced accounts and individual self-expression. Indeed, the multitude of rooms and personal accounts Anagram aims for with the Museum of Unusual Perception reflects and encourages this perspective.

Also, the clinical urgency of the case, i.e. the need to open up the diagnosis to include a broader view of the experience of altered states of perceptions, and the call to challenge stigma were established. The analysis also included examples of public campaigns to point out success factors such as dependency on the framing of the condition (information), timing, and labelling to bear in mind.

Especially the latter remains a problem and led campaigners to propose name changes. This also reflects early ideas at Anagram but to suggest a set name would have been inappropriate and beyond the means of a creative studio and this paper. At the same time, this ambiguity again supports the proposal's open approach and does not exclude the aim to change perceptions of the condition, of course. Undoubtedly, young people and peers will prove a relevant audience, to challenge misconceptions and to help this group at high risk of psychosis to discover signs early on and to seek varied treatment.

In part 2, the paper included an artistic view on psychosis, specifically the tradition of Art Brut, and discussed ideas of the fallibility of our perception of normality in the arts and psychiatry. It also positions Anagram's approach as a creative intervention. This then leaves room for nuanced accounts and creative responses which may evoke a sense of wonder and exploration of the Museum in a playful and artistic sense first. More so, the paper outlined the role of storytelling to show the difference between being talked about or telling one's own story. Owning a narrative is also the first indication for co-design, where storytelling is an essential part, particularly in communities.

Besides, recent years have seen attempts to use virtual reality and immersive technology to depict experiences of psychosis-related symptoms. The selected example described in part 3 served to go beyond the creative and into a therapeutic context and included the effectiveness of VR to recreate and play with multiple realities to challenge stigma attitudes.

Then involving co-design in this discussion, the select cases highlighted elements of participation within a mental health context. Particularly the peer-to-peer learning effects, also described in communities of practice, that helps to bridge gaps between knowledge-worlds of various stakeholders seem essential going forward.

The same holds for "third spaces" as Anagram wants to hold more in-depth workshop sessions with more participants. It seems safe to assume that effects of peer-to-peer relations and communities in safe spaces will

likely be highly positive and potentially change their perceptions (self-stigma) and these of other stakeholders by increasing and disseminating collective knowledges.

Lastly, the paper described the exploratory session Anagram held in London with an emphasis on the first-person accounts of the participants. They provide a distinct indication that further sessions and the chosen approach are beneficial and more so will lead to exciting results. Already two initial participants have agreed to stay connected to the project as peer-leaders.

Looking into the future of longer workshop sessions, the process alone may prove the most beneficial part when peers form a community of practice. Whether the sessions must involve a clinician, i.e. as observer or facilitator, remains to be seen. It could be helpful for explaining and discussing current scientific theories.

At the same time, much is in the process that can only be determined together with the actual users and potentially other stakeholders. For disseminating knowledge, not only tours with experts but also, live chats hosted by people with lived experience emerged early on in the ideation but have not yet been formulated towards realisation. Especially in this context but also throughout the workshop sessions, care is an issue.

Challenges will include discussions on how to convey the more scientific findings, if the educational seed upholds, but also to work with vulnerable groups. Engaging outreach will be essential, and new tools, i.e. for visual communications, may have to come more sharply into play.

A key factor will be the creation of not only a room for design but also a safe environment that, for example, allows participants to drop out at any time without explanation. Also risk of triggering requires further exploration in cooperation with clinical advisors.

However, as the project is decidedly not therapeutic, a sense of expression of the experience may prevail and a sharing of stories that may help others to recognise themselves as well or at least to talk more openly about their own experiences. Then any effect on stigma attitudes would need to be measured with survey tools and carefully monitored, but the indications are there.

Also, with a view to future shows, young people appear a prime target group when seen as digital natives and self-reliant learners that could visit the Museum in its legacy online. More so, young adolescents are at high risk of psychosis and would benefit from early intervention the most.

At the same time, the technology required to enter these planned Museum spaces, i.e. virtual reality chat rooms, continues to be at a price point out of reach of many adolescents. More so, those suffering from more severe mental ill-health already often have even less economic means and access to technology, also due to paranoid beliefs. So for the project to reach pre-dominantly affected audiences, live events and targeted

"screenings" will be vital and indeed, the Museum of Unusual Perceptions is to be a virtual exhibition space that may be entered both through live tours (in VR) and also online.

While this project is not therapeutic in a medical sense, it could borrow from other studies using participatory design and virtual reality both within a medical context as well as to better inform all stakeholders and the public as was outlined. The creative positioning, again, allows play that goes beyond empathy and sympathy but may inspire fascination, curiosity and deliberate attempts to uncover more information and perhaps questioning ones' all too sure sense of reality.

Conclusively, methods borrowing from co-design seem valid to enable the telling of a multitude of different stories with the added benefit of collective learning, while VR and its immersive nature appear a potent tool to convey the lived experiences. More so, the question of engaging participants as learners together with advisers in a co-design approach helps to navigate questions of control in the sense of a top-down lecturing approach, for example, and perhaps even diagnosis. Whether the Museum of Unusual Perception will help to decrease stigma or to what extent is a matter for different measures but it appears certain that Anagram's creative intervention will open up the debate on multiple perspectives and challenge many realities.

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