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ORIGINAL ARTICLE

Co-designing a virtual world with young people to deliver social cognition therapy in early psychosis

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Aims: Co-design implies genuine partnership in the generation of knowledge between service users and researchers. Service user involvement in research has been encouraged in government policy, but it is rarely achieved, especially at trial initial stages. Co-designed with service users, we adapted existing manualised social cognition intervention for people with a first episode of psychosis to a virtual world environment.

Methods: We invited a group of young people who have used mental health services to co-design a virtual environment to deliver an accessible social cognition intervention to a hard to engage service user group. We used an iterative process with young service users and the design team that included developing initial ideas, creating a prototype and testing the virtual world.

Results: Twenty young service users of local mental healthcare services provided feedback on the design and delivery of the intervention. Reflecting the demographic of the sample, young people felt the virtual environment should be familiar, urban spaces, akin to therapy rooms or classrooms they have used in real-life situations rather than non-traditional therapy spaces that were initially proposed.

Conclusion: The co-design process led to the development of a specific design, approach and protocol to be tested in a proof-of-concept trial. Young service users were integral to an agile and iterative design. Technological innovations should be routinely co-designed and co-produced if they are to realise their potential to deliver acceptable and affordable mental health interventions.

KEYWORDS

co-design, first episode psychosis, psychosis, social cognition therapy, virtual worlds, young people

1 | INTRODUCTION

More than 59 studies in six countries have used experience-based co-design of healthcare interventions. However, the use of co-design of mental health services has not been as widely applied as for physical health services (Larkin, Boden, & Newton, 2015). Co-design implies a genuine partnership in the generation of knowledge between service users and researchers (Hickey et al., 2018). Service user involvement has been encouraged in Government policy for over 15 years (Department of Health and Social Care, 2005, 2006; European Group

on Ethics in Science and New Technologies, 2015) but is rarely achieved or well described, especially at the initial stages of trials (Briel et al., 2016; O'Cathain, Thomas, Drabble, Rudolph, & Hewison, 2013). One of the key challenges is how to support service users' participation in the research process in a truly meaningful way (Hill et al., 2018).

To address this challenge and in the context of youth mental health, Hagen et al. (2012) proposed a methodology guide for the implementation of participatory design of online promotion, intervention and treatment. Their work at the Australian-based Young and

Well Cooperative Research Centre detailed a framework that proceeds from phase to phase depending on the input from young people, other key stakeholders and the available evidence (Hagen et al., 2012, p. 8).

Online mental health interventions have the potential to reach people in a convenient, timely and cost-effective way (Barak & Grohol, 2011). Advances in technology mean there are new and potentially more engaging than traditional methods of delivering psychological interventions (Comer, 2015; Firth et al., 2015). For example, virtual worlds and online gaming have been used to delivered therapy for a variety of physical and mental health problems (Barak & Grohol, 2011; Mohr, Burns, Schueller, Clarke, & Klinkman, 2013). Virtual worlds refer to a computer-simulated environment that simulates physical presence in places in the real/imagined world. Studies have utilized a free online virtual reality platform Second Life (Linden Research Inc, 2018) to deliver treatment programmes for problems such as addiction, social skills training in schizophrenia, psychological distress, autism and rehabilitation from physical conditions such as diabetes and heart disease (Brewer et al., 2017; Ghanbarzadeh, Ghapanchi, Blumenstein, & Talaei-Khoei, 2014; Rosal et al., 2014; Siddiqi, Mama, & Lee, 2010).

An area of special interest for developing innovative ways of delivering psychological treatment is social recovery from psychotic disorders such as schizophrenia, which remains poor despite the use of antipsychotic medication (Penn, Sanna, & Roberts, 2008). Social cognition (the ability to process and use social information) is one factor that drives poor functional outcomes (Green et al., 2012). Newer psychological interventions that target specific cognitive deficits in psychosis appear to improve both social cognition skills and community functioning (Kurtz & Richardson, 2012). One such social cognitive therapy that appears particularly promising in an early psychosis population is social cognition and interaction training (SCIT; Roberts, Penn, & Combs, 2016). However, our experience in attempting to deliver psychological interventions such as SCIT, specifically group therapy, presents a challenge when attempting to engage hard-to-reach groups such as young males and those with negative symptoms of psychosis (Bartholomeusz et al., 2013). These groups often have greatest problems with social functioning, and finding ways to engage them in such therapies is essential for improving outcomes.

This article reports on the co-design process of a proof-of-concept trial to adapt a social cognition training intervention (the SCIT) to be delivered in a virtual world for people who have experienced a first episode of psychosis. We co-designed a virtual environment with clinicians, researchers, young service users and virtual reality designers with the aim of delivering a structured programme that service users could engage with and use in their own home.

2 | METHODS

The research team acquired a secure virtual world within Second Life (Linden Research Inc, 2018) that was “owned” and administrated by the research team only. This allowed a safe space where information shared between participants and therapist was private and confidential. In the following sections, we describe the process of co-designing

a virtual world created in Second Life to deliver an existing evidence-based face-to-face group-based social cognition intervention.

2.1 | Participants

Young people who had used mental health services and expressed interest on advising research in mental health were invited to be part of our design team. We asked known local contacts to pass on an invitation with details about the role as adviser to potential volunteers involved in Forward Thinking Birmingham (National Health Service, 2016; 28 June 2016), a city-wide mental health partnership for 0 to 25 years and local early intervention for psychosis (EIP) services. We published a call at the Warwick University/User Teaching and Research Action Partnership (UNTRAP; The University of Warwick, 2016; 9 June 2016). We submitted an application to present our project for consultation to the MQ Young People's Advisory group (MQ: Transforming Mental Health, 2016), a group of 16- to 25-year olds who are sponsored to advise research funded by the UK MQ Charity. Finally, we recruited a group of four university students to *beta test* the prototype version of the virtual environment before exposing early psychosis service users to the protocol.

2.2 | Materials

2.2.1 | SCIT intervention

The SCIT (Roberts et al., 2016) targets dysfunctional social cognitive processes. SCIT is a three stage, face-to-face group intervention specifically comprising: (i) emotion recognition training; (ii) recognizing attributional styles; and (iii) skills integration. Stages (i) and (ii) have a considerable training component that is delivered using slides, video vignettes and other teaching methods. Stage (iii) involves group work based on sharing real-life experiences and problem-solving. We intended to test the virtual environment using an abbreviated version of eight 45-minute weekly meetings covering the three stages of the SCIT intervention.

2.2.2 | Virtual worlds in Second Life

We planned to deliver the intervention through the free online virtual reality platform Second Life. Participants engage with the platform through an avatar that reflects a virtual representation of themselves. The avatar is able to interact with both created worlds and other avatars. This includes the ability to participate in education experiences through a variety of means (website, videos, presentations etc.) and interact in virtual groups through the avatar.

2.3 | Procedure

The co-design process involved five stages centred in key design questions (Table 1). We discussed each stage with young service users and used their suggestions to advance to the next stage. The stepped approach was based on the methodological guideline for the implementation of participatory design of online treatment for young people (Hagen et al., 2012).

We met five times with different groups of young people. Minutes were taken at each meeting (with the larger meetings being

TABLE 1 Stages of the co-design process of the virtual world and research questions

Stage	Research questions
1. Developing initial ideas	<ul style="list-style-type: none"> • What issues do young people see in designing a virtual world environment to deliver the social cognition and interaction training intervention? • How do these issues manifest in young people's participation on the intervention? • How do these topics need to be framed to be meaningful or relevant for young people?
2. Creating a prototype of the virtual world	<ul style="list-style-type: none"> • What does the environment need to do for young people to be motivated to use it? • Can they use it? How should young people use it?
3. Screening the prototype of the virtual world	<ul style="list-style-type: none"> • Is the prototype design successful from the perspective of young people? • Are there additional changes to make to the environment for young people to use it successfully?
4. Beta-testing of the virtual world	<ul style="list-style-type: none"> • Is the virtual world fit-for-purpose according to young people?
5. Piloting the intervention with target population	<ul style="list-style-type: none"> • Is the intervention successful from the perspective of young people? • Can they use the environment?

audio recorded). Participants in the focus group submitted written feedback. Quotes reported in this article were extracted from these written and recorded materials. We conducted an overall beta test (real world exposure) of the intervention. A pilot trial of the intervention is currently underway, and will be completed in autumn 2018.

3 | RESULTS

We received feedback on the design and delivery of the intervention from a total of 20 young people. They mainly resided in UK cities and were engaged on higher education or work placement schemes. Service user volunteers were actively involved in mental health advocacy and research. Details of each stage and changes made because of the consultation are presented below.

Stage 1—Developing initial ideas

The research team purchased “land” in Second Life to build the therapeutic environment, which by default is presented as a rocky island surrounded by water. The virtual platform provides vast possibilities for constructing virtual environments. We used the required specifications to deliver the SCIT intervention as reference for the initial design (Table 2).

We met the first two young service users from the local EIP services and presented these requirements as well as an overview of the SCIT intervention. They said the SCIT intervention was well structured with a feeling of progression that could be reflected in the environment design. Like in a videogame, people do not often stay in one place, they move around to achieve the next level. The service users suggested different rooms for sessions and activities; for example, a cinema when people needed to pay attention to watch a video. Tele-

TABLE 2 SCIT intervention requirements

Requirements
<ul style="list-style-type: none"> • Secure access for avatars to interact with each other in groups in confidence and without the risk of being overheard by others not involved in the intervention
<ul style="list-style-type: none"> • Ability to introduce three avatars during sessions with particular appearances and gestures that reproduce characters used in the SCIT intervention (ie, blaming Bill who blames others, my-fault Mary who blames herself and easy Eddie who is laid back)
<ul style="list-style-type: none"> • Two or three spaces to deliver the intervention, these would initially be: <ol style="list-style-type: none"> 1. a facial emotion recognition learning space (how to recognize emotional states) 2. a jumping to conclusion space (how we use evidence to make decisions) 3. an attributional style space (what is our natural tendency to explain situations and how might we adapt this)
<ul style="list-style-type: none"> • Spaces for avatars to come together and socialize amongst themselves and with therapists
<ul style="list-style-type: none"> • Spaces to conduct role plays (eg, job interview, classroom, café)
<ul style="list-style-type: none"> • Ability to deliver slide presentations and quizzes
<ul style="list-style-type: none"> • Ability to browse specific web resources
<ul style="list-style-type: none"> • Ability to show videos from the SCIT intervention and YouTube

Abbreviation: SCIT, social cognition and interaction training.

transportation (a default setting of Second Life to instantly transport an avatar to a location) could facilitate avatars' movements from one session to another.

The initial specifications and consultants' comments were communicated to the virtual world designers, who created a building in the centre of the Second Life Island surrounded by vegetation. The open plan interior had three sections equipped with different coloured furniture and screens to play videos and slide shows. There was an outdoor cinema overlooking the ocean and a beach. Figure 1 shows pictures of the initial design.

Virtual world designers could not include a “panic button” or characters that were pre-programmed to the environment due to technical constraints. A “chill out” room was designed. We decided to provide contact details for emergency services and local healthcare provider institutions at the start of the intervention.

Stage 2—Creating a prototype of the virtual world

Researchers met a focus group of 14 young people (from MQ) to seek their advice on how the intervention needed to be framed to be meaningful and relevant. Following a presentation and short video of the virtual environment, most young service users welcomed the idea of offering social cognition therapy at home for people recovering from psychosis as exemplified by this quote:

“I think there is possibility for this study as post-psychosis recovery, many spend long hours at home, unable to leave. Therapy from home is a great idea.” (P8)

Young service users said the virtual world needed to be more realistic, less game-like than in its current form. They suggested spaces should be functional and look familiar. Furthermore, focus group participants objected to the use of some of the possible and



FIGURE 1 Images of the initial design of the island

programmable features in Second Life, such as avatars portraying vampires and zombies, or the ability to fall and fly:

“Very concerned about how far from reality the virtual world is. A simple plain room looking like a group therapy room is as complex as you need with human-shaped avatars as a must and no ability to fly or jump off buildings.” (P1)

Service users warned about perceived barriers to the success of the study, focusing on accessibility to the technology. One focus group participant wondered about how the research team would address potential “limited accessibility due to requirement of computer and internet.” (P4). Finally, young service users suggested study participants would require comprehensive information about data security in relation to access to the environment and data storage.

“Be clear about security of data storage – who has access to the data, etc. this may be a particular issue for people with a history of paranoia/psychosis.” (P1)

Stage 3 – Screening the prototype of the virtual world

We met a different group of four young service users (two from Forward Thinking Birmingham and two from UNTRAP) for two separate co-design workshops. The aim of these workshops was to create an intervention that young people felt motivated to use. Service users made recommendations to the design and delivery of the intervention (Table 3).

Following the co-design workshops, we worked with the virtual world designers to modify the initial virtual world. More buildings were added to provide an urban environment and, three separate therapeutic spaces that resembled classrooms were created. We added more wildlife sounds and two beach sheds equipped with bean bags and log fires. Figure 2 shows pictures of the new environment.

Detailed information about data storage and security were added to the participant information sheet. The intervention protocol and manual were modified to include considerations for group rules and group rules posters based on the Second Life default features. A work phone and Ethernet cables for better internet connection were added to supplement equipment for study participants.

TABLE 3 Service users' recommendations after co-design workshops

Virtual world design

- Avoid open spaces and instead add walls to distinguish therapy rooms from relaxing spaces
- Include other buildings in the surrounding area to give an urban feeling to the island, the environment would look less empty and isolating
- Take inspiration from real young people centres which tend to be “cosy and comfortable” but not too extravagant
- Simple design to be less distracting
- Include wildlife (eg, birds) and calming sounds in the beach, inviting meditation and relaxation

Intervention delivery

- Provide participants with means to secure good internet connection during the therapy sessions (eg, Wi-Fi mobile connection)
- A work phone should be available for participants to contact therapists in case they lose connection during the intervention
- Access to a virtual library for participants to consult the content of the sessions and reinforce their learning
- Ask participants to commit to the group not to use characters that can be distressing to others (eg, zombie avatars) or engaged on disruptive behaviour (eg, entering therapy rooms when not in the group) at the consent stage.

Stage 4—Beta-testing of the virtual world

A beta test of the intervention was conducted with four young people over 2 days. These volunteers were similar in age to the target population but did not have a history of mental health problems. The decision to beta test with healthy volunteers was primarily a pragmatic one and seemed reasonable given that we were primarily interested at this point in gathering information about the technical usability of the environment to deliver specific aspects of the intervention. The main activities we wanted to test included slide presentations, video viewing, group games and role play with avatars controlled manually by therapists.

There were technical glitches during video viewing that were reported to the virtual reality (VR) designers. A teleport system to move people from one space to another worked well, and for most part, users were engaged with test activities. It emerged that success in delivering the intervention rested in providing adequate communication equipment (eg, headphones and microphone). Faults on the technology became quite disruptive of the group flow.

The beta test also highlighted the specific challenges of delivering therapy through a virtual environment. The lack of non-verbal clues in group interactions limited therapists' opportunities to shape group



Outside building



Therapy room

FIGURE 2 Images of the island after co-design

discussions. Therapists needed to deliver clear instructions and ask for constant verbal feedback from participants. It was also clear that the structured manual for delivering the therapy needed further adaptation to detail ways to use the environment to deliver the content. Further modifications to avoid technical faults and lack of communication were implemented before recruitment to the trial began.

Stage 5—Piloting the intervention with target population

A pilot trial of the intervention with 20 young people who are recovering from a first episode of psychosis started in February 2018. After each session, participants will be asked to rate the session from 1 (very poor) to 5 (excellent) using a simple online star rating system on aspects including: suitability and relevance of the content, quality of guidance received, engagement and safety of the intervention. We will also conduct qualitative interviews to gather young people's views about how they found the environment and how to improve the intervention.

4 | DISCUSSION

This article reported the co-design process of adapting a face-to-face group therapy protocol to a virtual world environment. Young people who experienced mental health issues, clinicians, researchers and virtual reality designers collaborated in building an environment that responded to the views and needs of young service users but still able to deliver the keys aspects of the intervention. The process of co-design led to the development of a specific approach and protocol to be tested in a proof-of-concept trial with people experiencing a first episode of psychosis.

Two features of this work limit the conclusions we can draw from this study. First, the results of our consultation depended on the views of a relatively small group of volunteer young service users. The final design reflected most service users' current living circumstances as urban dwellers attending higher education institutions (eg, college or university). It is possible that a different design and concept would have been obtained from other service users. Second, consultants varied at each step in the design process. This was contrary to a preference for continued membership and counsel from the same young people. Nevertheless, we were able to reach consensus and progress with a design that responded to issues raised by up to 20 young

service users from different groups, a higher number than most studies reporting this type of consultations.

Our findings suggested that interventions that can be delivered at home and focused on recovery after a mental health crisis, such a first episode of psychosis, were welcomed by the young service users we consulted, many of whom had personally experienced psychosis. This is consistent with previous survey studies that demonstrated that patients and their carers rated problems with community functioning as more of a priority in treatment and recovery than the psychotic symptoms themselves (Rosenheck et al., 2005). Service users supported novel methods of engagement of people who may be suffering in isolation and found virtual worlds to delivery therapy acceptable. This finding is consistent with previous studies that employed similar delivery methods (Brewer et al., 2017; Guillén, Baños, & Botella, 2018; Rosal et al., 2014).

One particularly interesting aspect of the co-design was finding that young people preferred designs that resembled familiar environments with an urban feeling, such as local therapeutic spaces (eg, hospitals or therapy rooms) or classrooms rather than stereotypical relaxing places that may have encouraged escapism. This was unexpected given the enormous potential of varied environments that can be created in a platform such as Second Life. This tendency may be explained by the overwhelming experiences that psychosis imposed on service users, and the need for feeling safe and grounded in reality after episodes in which perceptions are distorted. Participants in this study challenged researchers' understanding of what young people need during recovery. Our findings contribute to current efforts to develop environments that reflect the live experiences of young people. Better understanding should increase the acceptability and relevance of behavioural intervention technologies (Bucci et al., 2018; Reynolds et al., 2017).

Young people highlighted important issues in the design and were empowered to influence the development of the intervention. However, setting up these groups required considerable time and effort and came with caveats (eg, continuity). Our struggle reflects a lack of opportunities and support systems to facilitate collaboration between young people and researchers in developing research together, and this needs further attention in research environments. Meaningful input from user and carer consultants needs to be part of any study.

The co-design process permitted a feedback loop that continues to inform design and solve problems as they emerge in the pilot study. Using technology to deliver healthcare is an emerging field that brings

together a diverse group of experts from computer science, psychology, clinical sciences and design (Bate & Robert, 2006; Bucci et al., 2018). Common and established models to develop products in industry focused on end-of-user experience such as co-design and usability testing that can be borrowed to develop healthcare technology (Mohr et al., 2013). We hope future research continues to engage young people in developing new interventions that can take full advantage of technologies such as virtual worlds and virtual reality, which are increasingly becoming available to the mass market. Cheaper and more engaging interventions can potentially help address a multitude of unmet mental health needs of young people that traditional services are unable to fulfil.

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CONFLICT OF INTEREST

S.B. is a director of a not-for-profit company aimed at commercializing mental health apps. All other authors declare no competing interests.

Author contributions

A.T., S.B., M.B., I.V. and D.T. wrote the grant application for this feasibility and pilot trial. A.T., A.R., D.T. and F.E. were responsible for coordinating the design of the virtual world. A.T., A.R. and F.E. conducted the co-design workshops. A.R. and A.T. drafted the manuscript, all investigators have been involved in revising the report and all authors have seen and approved the final version.

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