

Immersive Reality Experiences of Young People Living with an Illness: A Formative Assessment of *The Patience Project*

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Data have been presented in such a way as to protect individuals from identification.

The Patience Project

The *Patience Project* is aimed at promoting social connectedness for young people (aged 12-18 years) who experience a health condition that prevents them from participating in their usual social and/or educational environment. Young people living with an illness are considered amongst the most disadvantaged and isolated patients in the health care system internationally (Davis, Vetere, Ashkanasy, Dyson, Schofield, Thompson, Withers, & Thomas, 2008). The *Patience Project* aims to bridge the gap from exclusion to inclusion for young people, using head-mounted displays (HMD), often referred to as VR (Virtual Reality) Headsets, to live stream video images from a social or educational environment of the young person's choice. The project involves an immersive 360 live streaming experience, rather than computer-generated experience, where the young person can control the 360 field of vision in a real-world situation.

The potential of immersive technologies is still in the early stages of exploration and relevant scholarly literature is therefore limited. However, it has been suggested that it is increasingly important to investigate the potential of technology and its role in enhancing social connectedness for young people who live with illnesses such as cancer (Davis et al., 2008; Liu, Inkpen, & Pratt, 2015). A literature search was conducted for studies on the application of Immersive Reality (IR), Virtual Reality (VR) and '360 live streaming' in paediatric oncology and other child and youth health settings. Three databases were consulted, including Google Scholar, PsycINFO, and PubMed, to identify studies published between 2008 and 2018. No studies have been identified combining the search terms 'social connectedness' and 'virtual reality' or '360 live streaming'. The following keywords were utilised to identify related literature: 'virtual reality', 'immersive reality', '360 live streaming', 'cancer', 'illness', 'child/adolescent', 'young person', 'panoramic video', 'social exclusion', and 'inpatient'. An assessment of reference lists from reviews and meta-analyses was also performed to identify titles not captured in this search.

The search of the literature suggests that the *Patience Project* opens promising new opportunities of social connectedness for children and young people experiencing a socially-isolating health condition. A review of the literature resulted in five core findings:

- Virtual reality is a promising technology that offers unique opportunities to manage acute and procedural pain and to familiarise children with medical procedures by simulation

(Indovino, Barone, Gallo, Chirico, De Pietro & Giordano, 2018; Won, Bailey, Bailenson, Tataru, Yoon, & Golianu, 2017);

- The special qualities of virtual reality include: presence, immersion, and embodiment (Cummings & Bailenson, 2016; Slater & Wilbur, 1997; Won et al., 2017);
- Social and school connectedness is associated with the best outcomes for children and young people (Pate, Maras, Whitney, & Bradshaw, 2017);
- Immersive virtual environments (IVE) can provide benefits including a reduction in psychophysiological stress and enhanced mental health (Bowler, Buyung-Ali, Knight, & Pullin, 2010; Thompson Coon, Boddy, Stein, Wear, Barton & Depledge, 2011). This finding highlights a tentative link to the potential for reduced stress and enhanced mental health for *Patience Project* participants.
- Cybersickness symptoms are reported for some users during and after virtual reality experiences (Calogiuri, Litlekare, Fagerheim, Rydgren, Brambilla, & Thurston, 2017; LaViola, 2000).

Immersive virtual environments (IVE), and in particular IVE application to enhance social connectedness and inclusion amongst children and young people with a socially-isolating health condition, are seen as green-field research (research which lacks any constraints imposed by prior work). The literature highlights a number of benefits over and beyond the relief of physical pain. It raises the possibility that the *Patience Project* can enhance psychophysiological well-being, improve educational outcomes, and enhance social connectedness.

Objectives of the Formative Assessment

In partnership with the *Patience Project*, the Centre for Community Research and Evaluation (CCRE) at the University of Auckland conducted a formative assessment aimed at developing an understanding of the perceived strengths and weaknesses of the project, to inform future directions. The assessment incorporated the perspectives of various stakeholders to determine the perceived:

- effectiveness of the concept to aid inclusion;
- educational and social benefits and challenges of participating;
- limitations of the technology to enable inclusion.

Methodology

Formative assessments allow the facilitators of newly developed programmes to understand the strengths and weaknesses, and therefore the amendments and future actions required that will enhance the effectiveness of a project (Chappuis & Chappuis, 2008). The participants invited to take part in the formative assessment of the *Patience Project* included:

- young persons aged 12-18 years, who experienced exclusion from either their social or educational environments as a result of a health condition;
- parents or caregivers of the young persons;
- a nominated person (e.g. teacher, friend, etc.) who supported each young person through their engagement in the *Patience Project*.

Most participants were domiciled in the greater Auckland area and all received ongoing health services from Starship Children's Hospital. Potential participants with high medical needs at the time of interviewing were excluded from the formative assessment. A total of 15 participants eventually took part in this formative assessment. Ethical approval was obtained from the University of Auckland Human Participants Ethics Committee (UAHPEC) (ref number 021028).

Recruitment of participants was carried out by the *Patience Project* leader through existing partnerships with the Child Cancer Foundation, CanTeen and Starship Children's Hospital. Contact details for the young people and their caregivers were passed to the *Patience Project* leader by the adolescent nurse practitioner (Paediatric Oncology, Starship Children's Health), who facilitated the recruitment process. Upon indicating interest in testing the programme, young people and their families were then briefed by the *Patience Project* representative, who provided them with participant information sheets and consent forms. After agreeing to be part of the project, young people and their caregiver were interviewed separately before the young person was provided with a headset and Samsung mobile phone to enable them to participate. Training sessions were conducted with each young person to familiarise them with how to work the equipment.

Semi-structured interviews were used to elicit feedback about the experiences of the young people, their caregivers, and nominated support people in the environment in which they engaged with the technology. Interview guides using open-ended questions were developed in

Results

Analysis of participants' stories about their engagement with the immersive technology resulted in five overarching themes:

- 1) Appeal of the immersive reality experience;
- 2) Using the equipment;
- 3) Dual realities;
- 4) Social connectedness; and
- 5) Environments of hope.

Themes were organised to illustrate the process of participation in the *Patience Project*, from what initially sparked participants' interest in becoming involved and their experiences of using the equipment, to the feelings and reflections that emerged after engaging in the full experience, including recommendations to improve the *Patience Project* implementation in the future. All themes and sub-themes are illustrated in Figure 2.

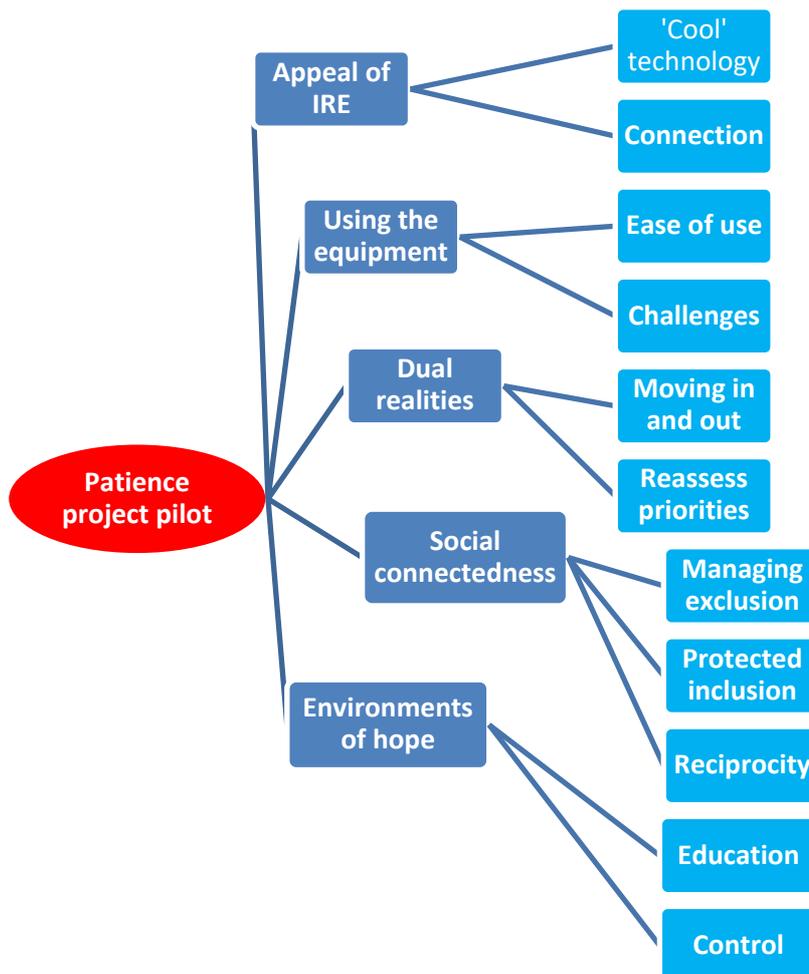


Figure 2. Thematic map of findings

1. Appeal of the immersive reality experience

‘Cool’ technology: The participants were unanimous in endorsing the appeal of the technology. The very nature of the technology and the ability it provides to connect to others were key drivers for young people involved in this project. The equipment included a 360-degree camera that was placed in the young person’s environment of choice and a VR Headset that they used to enter the environment from their location. This equipment and its functionality were identified by participants as being “cool.” This was repeated time and again:

I mean it was pretty cool that I could see the whole classroom just through a computer and it was a livestream. I thought that was pretty cool. *Niki*

Yeah, it’s pretty boring just being at home during the whole day as well. So it’ll be pretty cool to, yeah, interact with people when I’m at home. *Simon*

It was fabulous. I got the chance when Ben set it up to put the headset on and it was fabulous. Yeah and I mean being a science teacher, not too much takes my breath away. I see a lot of cool things, if you like. But it was very cool. *Mena’s Teacher*



Figure 3. 360-degree camera

It reminded Jack of technology he previously used in school that “was super cool”. Simon also considered the IR as a “cool” experience to be involved with: “... I just wanted to see what it was like.” Initially, access to the technology, the look of it and the fact that it was “cool” made the *Patience Project* an appealing proposition. These sentiments were echoed by a teacher who recalled the students in her class referring to the camera as “martian” and “alien” technology—adding an element of excitement to the classroom. Simon expressed his excitement about seeing his friends for the first time:

It was pretty exciting when they turned the camera on for the first time. And then I just saw everyone and just looking at the whole classroom and seeing all the, everyone study, everyone doing their work and everything and I was just like part of it as well, which was quite cool. *Simon*

Connection: The potential for interactivity with the young person was important for teachers, who described sadness about the absence of the young person in their class after diagnosis. Thus, the potential to reconnect was enticing:

... it didn't interfere. And the kids thought this is great (laughter). I said, "She can see you, but you can't see her." So, I said, "You have to wave and say hello." She quite enjoyed that I think really ... It was just business as usual ... cause it's not intrusive and you can just keep on doing what you're doing. And you can say, "Well Niki, if you turn to page forty-three now." She can do that ... she would have to text in of course with her questions. *Niki's Teacher*

Jack's teacher encouraged her class to talk to the camera to help Jack feel included:

... the kids were first a little bit shy I had a little laugh and said the students are finding it funny talking into the camera at times. And his mum had also said that he felt bad because he couldn't communicate back with us. I'd said to the kids how it's strange for Jack, 'cause he can't talk back at us. *Jack's Teacher*

Despite the difficulties with reciprocal communication the camera became the embodiment of the young person in the class:

I left it to the girls to do the communicating. So they welcomed her in and then I would say goodbye to the camera. And some of the girls would say goodbye. But I didn't monitor (it), like I got on with teaching. I just ignored it, if you like. I didn't make a big song and dance about it. *Mena's Teacher*

The camera also functioned to lift the spirits of the young people in the environment:

Well just that we would, as I say, we would talk to her and she would text back. And she would text back so the kids knew. I said, "Oh [student] says..." this that or the other thing. I think they quite enjoyed it. *Niki's Teacher*

Simon's mother described what she hoped would happen in the future:

He's definitely benefited just from his hour, an hour a day, but if he had, if it was in a classroom permanently and he had the ability to kind of come in and out of that classroom. If it was set up and switched on at nine o'clock in the morning and switched off at three o'clock in the afternoon. It was just a live stream happening. And for Simon or a kid to be able to come in and out of that classroom as and when they were able, would be an incredible feature to have. *Simon's Mother*

2. Using the equipment

Ease of use: The camera was placed in the centre of the classroom so that the young person could see the projection screen and look round and see their friends. They would have up to two hours a day using the equipment. Teachers and young people alike commented on the ease of use; how easy the technology was to adapt and assimilate into their specific environments and to enable connection:

When they asked me to be part of the project, I was more than happy, because I could see that my style of teaching would have been quite fitting with that. She [Mena] would've had the notes at home already and she would've been seeing what I put on the whiteboard. *Mena's Teacher*

Commenting on the integrative capacity of the IR technology in the teaching context, she stated:

It felt a bit weird the very first time you're saying hello to a camera, but the kids are so into this . . . where they don't have a physical audience in front of them, they're so used to it . . . the reality is it's very much their way of communication. *Mena's Teacher*

Josh's teacher also highlighted the user-friendliness of the technology, stating:

It's just part of the classroom now . . . It's portable... The only issue you'd have would be setting up the LAN access through the wires and stuff like that, but you'd just need a technician there to sort that out. *Josh's Teacher*

For students like Mena who are passionate about video gaming, incorporating the *Patience Project* technology into her routine was "really simple and easy." Describing his enjoyment using the technology, Simon said, "... it felt like you were playing. It felt like you were there at the moment." However, the static nature of the camera was raised as a potential challenge. Jack and Simon both mentioned the possibility of the camera being turned off by someone or someone sitting in front of the camera and blocking their view.

Jack wanted to be able to go from one classroom to the next, and again raised the option of artificial intelligence:

... a robot that walks and then that way you can go to all your other classes, ... to every single class.



Figure 4. Experiencing the VR headset

The robot was a particularly appealing idea because the personification of a machine might also encourage greater interaction from other young people in the classroom, or family members in another environment. It is possible to imagine a robot with a 360-degree camera, microphones and speakers, that could be controlled by the young person.

Challenges: The 360-degree camera effectively enabled the young people to enter the educational environment of their choice. As indicated above, the VR Headset was also very appealing to the young people. However, its use came with a few challenges. Three of the young people had problems using the headset, experiencing nausea and a dizzy sensation. Mena recounted her experience of motion sickness:

. . . The first time I did the goggles, everything . . . after like ten minutes I got really, really sick and so I just swapped to my laptop and did it through that.
Mena

Simon experienced a similar sensation:

I personally like the laptop better . . . ‘cause with the VR, with the virtual reality camera, like, I get quite dizzy. *Simon*

Simon and Mena both chose to use a laptop as a replacement for the headset. Other participants also enjoyed using the headset for gaming. Of those two, Niki used it to its full potential, while Jack used the headset with limited functionality. The headset provided an immersive experience, but the introduction of a laptop enabled the young people to enter the environment, see their friends, and have their hands free to make notes and text.

One of the recommendations for improving the experience in the *Patience Project* arose from the very fact that some young people felt more comfortable using the laptop instead of the VR headset. This reduced the likelihood of motion sickness, and also generated increased opportunities for educational participation:

Well with the VR I couldn't exactly write stuff down onto paper if I was using it to take down information . . . compared to like the laptop when it's like just sitting there and I look at my notes and like write notes down, while watching the class as well. *Simon*

Jack also identified that it would be difficult to undertake other tasks such as writing or drawing while using the headset.

3. Dual realities

'Moving in and out': All the participants shared their daily experience of dual realities - young people with formative social and educational experiences to be had, while also living with a serious medical condition. The opportunity to remain increasingly connected to their social and educational environments through IR was marked by a 'moving in and out' of the reality of being sick.

The young people and their family members or caregivers noted the unique capacity of the technology to help each young person escape the reality of being sick. Jack's mother shared her enthusiasm for this portal to enable Jack to escape reality, even if it was only temporary:

. . . he misses his brother and sister when they're not here. And just seeing familiar faces, I think . . . 'Cause when he's neutropenic, his immunity's low, so he's not allowed to go out anywhere at all. So, he's sort of wrapped in a bubble for that time . . . To just be able to see out into the world and get away from his reality . . . into another one. *Jack's Mother*

Jack also referenced this capacity for escape in his interview:

. . . There might be a teeny chance that you might forget that you're sick. . . In school you wouldn't know . . . it'll make you feel like you're not sick . . . school is a place of learning and then you might feel like you're not sick and going to school . . . *Jack*

Reassess priorities: The ‘moving in and out’ of two separate realities sparked Mena’s reassessment of priorities during an onerous stint with medication that decreased her ability to concentrate and process information during the project. As an academically motivated student, Mena was described by her mother as “putting too much pressure on herself.” Participating in the *Patience Project* was a powerful experience that enabled Mena to re-evaluate her academic goals more realistically, and thus lessen her anxiety about trying to keep up with her peers at school. This realisation assisted Mena and her mother to reach the same conclusion: “...the first priority is to fight this and to win and everything else comes second to that.” Despite this, Mena acknowledged that the *Patience Project* had both an educational and a social function, either of which would be valuable for children and young people experiencing similar health conditions to hers:

I thought like for other kids . . . even just having the opportunity, ‘cause obviously not everyone’s gonna have the same run as I have. So, if somebody, like if I was in a lot better health and I didn’t have the run I did and that kind of stuff, I would definitely use it more . . . It was really like satisfying, kind of, like just the fact that I’m not even at school yet, like I kind of am at school. *Mena*

The ability to return to their pre-diagnosis situation was an underlying motivation for young people to participate and deemed a benefit of IR. While young people imagined the possibilities the technology offered, after participating in the training sessions, they also acknowledged some difficulties that might arise, requiring a reassessment of what was possible:

It would be pretty hard, I guess, to get the information down, ‘cause you’d have like this big VR thing. You wouldn’t know what you’re writing or, kind of thing. So, I think it would be hard, in a way, to retain the information that you’d get from the teacher, if you’re (joining) in a school environment. *Simon*

Young people struggled to manage their dual realities, but it was clear that even if there was only a “*teeny chance*” that the young person may forget that they were sick for a brief moment, the project would be a success.

4. Social connectedness

Social connectedness was the one factor that most strongly influenced young people and their caregivers in choosing to become involved in the *Patience Project*. This is not surprising as young people living with an illness, and in particular, cancer, are “. . . recognised as amongst the most disadvantaged and isolated patients in the health care system . . . internationally”

(Davis et al., 2008, p. 1). In reflecting on the IR experience, the prospect of the technology to help overcome exclusion and gain a sense of inclusion was crucial to each young person, their caregivers and their nominated person.

Managing exclusion: Cancer treatment has a devastating impact on a young person, damaging their social connections and halting their educational and personal development (Lamb & Holley-Boen, 2016). The participants saw the potential for immersive reality to overcome some of the damaging impacts of cancer on a young person's social and educational life. When considering the opportunities that participating in the *Patience Project* might offer, Jack's mother commented:

Knowing that Jack would be far away from home for quite a while, it was important for me to allow him the chance to be where he felt safe and see people he might not see for a little bit. So that's, yeah that's why I jumped on board.
Jack's Mother

In the example above, Jack's mother begins to touch on the unique qualities of the IR experience of being located in one reality (such as a hospital ward) yet being immersed in another (such as a school classroom). While a hospital ward may not be perceived by the young person as a safe environment, the school classroom is familiar and may therefore be perceived as safe. Caregivers regarded participation in the project as a highly desirable means of avoiding the possibility of their child's becoming isolated as a result of their medical condition.

Simon expressed his frustration with exclusion as follows:

I can [see the benefits of IR] 'cause yeah people who are . . . like stuck in hospital and all that . . . they're not even allowed to go outside or anything . . . They can't really do much. They have to just . . . sit in the hospital and do nothing for ages and yeah being able to like, yeah be in like an environment where they can see what's happening outside of hospital, I think they would benefit from it . . . 'cause I hate, even if I'm in there for a couple of days I just hate it. I hate being stuck there . . . And everyone else . . . having fun and kind of, and I'm just stuck . . . in hospital and stuff. It's just annoying. *Simon*

In being sick, young people may become outsiders from every-day, significant events in their lives. The technology has the potential to enable them to be witnesses and even become active participants in their chosen environments once again.

However, being excluded from experiences was not consistently conveyed as negative. For example, while having to forfeit going to a party, Simon identified that there were some environments or events in which he would not like the camera to be placed:

It would have been cool to like see people having fun and all that kind of stuff, but I think it would also, it would be pretty annoying watching them all kind of having fun . . . while I'm just at home . . . And I can't, yeah, talk to them . . . Or drink with them and all that kind of stuff, having a lot of fun. *Simon*

Mena's mother also referenced the hardship experienced when young people living with an illness are confronted with images of their friends enjoying parties, being involved in school productions and having fun times together.

While describing her son as having similar struggles, Simon's mother nevertheless affirmed the value of technology for creating some kind of social normality:

. . . It's an incredible piece of equipment and an incredible project, because no one really knows what it's like for those kids. Even as parents we don't really know what it's like for those kids and how lonely they can feel, 'cause even listening to Simon talking to you this morning about his social media (use), it's like ohhh... "I don't go on my phone after treatment." And I'd never really considered why he didn't want to do that, which was really I just wanted time to think about what I'm going through. So, you don't fully, you never fully understand what it's like as one of those patients who have been diagnosed with something so life threatening. So, to have that social, to have that ability for some social normality is just priceless really. *Simon's Mother*

However, she also perceived the social media environment as a painful reminder of what Simon was unable to do:

. . . My perception is it can have that negative effect too, because you can see that life's kind of carried on for everybody else. And as much as I think Simon's had a really, really positive attitude towards this whole journey so far, it only takes a few of those postings to kind of bring your spirits down a little bit, because you're realising, "Oh man, I'm not able to go and do that with my friends. *Simon's Mother*

The re-engagement with the educational environment also confronted one student with the reality of her loss when she spent virtual time in class:

... when I first did it, I found it really difficult. I really enjoyed it and I loved the concept, but I felt really stressed 'cause I kind of came in towards when they

were starting an exam on it. And then I just kind of sat there the entire time and I was like I have no idea what's going on. *Mena*

This observation serves as a reminder that the lives of young people with a health condition are different from those of their peers, and access to social media may increase a sense of isolation as they see their friends continuing with their lives and having fun. Thus, there are times when the experience of 'being there' (through the IR technology) might evoke ambivalence for the young person or even intensify the sense of exclusion. The nature of their condition creates almost an inevitable circumstance in which they feel stuck in the world of illness and excluded from the normal activities significant to their lives, and they may not want to be reminded of that through immersive technologies.

Protected inclusion: Being included in their chosen environments elicited secondary benefits as well for the young people participating in the *Patience Project*. The 360-degree camera became a metaphorical shield for some of the young people, as light-heartedly described by Mena's teacher:

. . . She could have a conversation with her friends and they couldn't actually physically see her . . . she could literally be, bed hair. (laughter) No hair! But they're not judging, and she knows that they can't see her. So, they've got this shield. *Mena's Teacher*

The provision of this "shield" enabled the young person to remain in a safe environment—be it the hospital or home—while also participating in their chosen environment. This ability to be present, to see others, yet not be seen, was a key aspect that contributed to the positive experience for Jack:

It was really, really, cool! It was actually really cool! I liked how I could see all the people and I felt like I was, like a little night owl. *Jack*

Niki's father noted the capacity of the camera to shield his daughter from any vulnerabilities while also fostering a sense of confidence:

. . . She was out there, but still at home in that little safe environment. . . It just gave her the confidence—she could be out there but at home. And then slowly dip her toe in the pond, if you like. *Niki's Father*

Thus, as depicted by Simon, the camera afforded a graduated approach to a full physical re-entry into the environment if, and when, the young person felt ready.

Simon's mother expressed how valuable she considered the *Patience Project* for young people who were embarrassed by the disfiguring physical signs of their cancer treatment, but nevertheless wanted to engage. She saw her son experiencing the camera as a much-needed shield that supported his re-familiarisation with the chosen environment:

And you just can't help but not feel nice . . . you would wanna hide away. You do . . . You want to and you're not feeling well at all. But to be able to sit in a bed or sit at home and be part of that is just, honestly, it's priceless. It's just incredible— I just know how much it lifted Simon's spirits. He was buzzing when he first got onto it. And he still, he's really, he's very happy to re-engage in it all the time. So, if it was a common, permanent thing that was set up that they could (manage when they) come in and out of all the time, it would just be amazing. *Simon's Mother*

These accounts exemplify the strengths of the *Patience Project* in providing an invaluable means of affording inclusion for the young people in familiar environments of their choice, while also maintaining their personal sense of control and safety.

Reciprocity: Josh's teacher reported that she and her students were grateful for the camera keeping them connected to Josh:

The first couple days you're very like aware of the camera. But it just kind of, after a while it's just kind of like, Josh was in the classroom almost. The boys say goodbye to him as they leave and stuff like that and sometimes they'll walk up to the camera and say hello and stuff like that. So they kind of just acknowledge him as if they would if he was normally in the classroom. Yeah so it's, they're not fussed about it anymore. I felt really grateful in that we could have him included in the classroom. *Josh's Teacher*

This teacher's description of the way other young people in the environment interacted with the absent student provides evidence of the potential in the *Patience Project* for enabling reciprocal connecting. With regard to his peers, Josh's teacher elaborated:

. . . I think it has brought Josh more to the forefront of their minds, because he has been gone for quite a while and you know, when someone's not in your environment all the time, you stop thinking about them as much. *Josh's Teacher*

Mena's teacher also agreed that the technology helped maintain connectedness between students and the young person who was sick:

Well the girls really sort of appreciated it. I think, when she comes back they would be, sort of wouldn't have noted her absence as much. *Mena's Teacher*

In the case of Jack, young people in his chosen environment were worried at the possibility of losing their connection, a reflection of their caring for him:

Funny thing was though, when we came back at the start of this term, [interviewer] and I came and picked it up in the first weekend to take it down to his place. The kids came in on Monday. "Miss, where's the camera? Where's the camera?" They were really worried. *Jack's Teacher*

Josh's teacher indicated that participating in the *Patience Project* had also strengthened the relationship between Josh and his buddy in the environment:

So, he's really good [Josh's buddy] and he keeps me onto it and he's really good at keeping contact with Josh. So even though they're not necessarily really good friends it's been quite good for them . . . *Josh's Teacher*

Enabling connectedness between the young people with serious health conditions and their peers also created opportunities for opening up discussions that would generate understanding around illness, life and death:

I've turned off the camera and packed it up and then the kids have asked me more personal questions about Josh. Like, "Why isn't he at school?" And I'll just say, "Oh he's got cancer." And then they ask stuff like, "Is he gonna die?" *Josh's Teacher*

Thus, the benefits created by the use of this technology in the *Patience Project* extend not only to the young people experiencing illness, and their sense of connection with their teachers and peers, but also to the peers themselves.

5. Environments of hope

Education: Their experience of the *Patience Project* enabled the young people to envision hope for the future. Cancer results in loss of educational attainment, loss of social connection and lost hopes for the future. The value of the educational environment as a place of learning was very important for the young people, possibly more so than for their parents. The young

people were conscious of missing time at school and falling behind with their grades, as Mena explained when discussing why she wanted to be a part of the *Patience Project*:

I like learning and I care really deeply about my grades and everything, so it was kind of the fact that I had the chance to still learn. *Mena*

Jack also saw school as helping him achieve his dreams:

I would like to become a comic creator, because when I was little I was watching a show that my uncle had, and I got inspired to draw. He was actually the reason I started drawing... I've drawn so many comics that I wanted to actually start a comic, like a comic series. *Jack*

In essence, connecting to school was creating hope for a future and remediating some of the losses that had occurred as a result of their medical condition.

Control: The *Patience Project* encourages the young people to make their own choices around when and with which environment they want to engage. This allows an element of control and a semblance of agency, at a time when they have lost control over almost all other areas of their lives. Having choice was reinforced by Mena who stated:

... Even if you wanted to do it socially or educationally, it's really beneficial for both and like just having the opportunity. Like having the option to do it is like, it kind of brought comfort to me just like knowing that if I ever felt like I was up to it, I could do it and I could be there ... just having the option I thought was really good. ... even if you don't wanna do it ... I thought it would be really good, because the more options, the more like opportunities you have. *Mena*

In Jack's case, he acknowledged that just seeing the environment via the *Patience Project* could "truly cheer up someone". His mother confirmed that this had been the case for him in the times he decided to participate:

It was good to see him cheer up. Like laugh and giggle about being creepy and watching people. And then just like, "Oh there's so-and-so." ... it was really good ... I think he really enjoyed it and he loved seeing familiar faces and familiar surroundings. And it took him out of that room. (His decision to participate) took him out of the hospital room. *Jack's Mother*

For Mena, some of her experiences using the technology fostered a sense of accomplishment and purpose:

. . . If my friends, like one of my friends who was in there was like struggling or something and I got it, I knew I could help . . . like even though I wasn't there, I was through the thing. So, like in a way, I was able to help her. *Mena*

Not only being able to connect, but also experiencing self-worth from helping another individual in the chosen environment was confidence-building, demonstrating further the potential of the *Patience Project* to create a sense of possibility for the future

Recommendations

Key themes emerged in the analysis of the participants' recommendations for future implementation of immersive reality experiences for young people living with an illness. These include increased immersion, and suggestions related to the timing and place of the intervention.

Increased immersion: All the young people wanted to communicate with their friends and teacher in the environment and all participants suggested this aspect of the *Patience Project* could be enhanced. This also involved communication between people in the chosen environment and the young person. On the practical side, participants suggested that communication could be improved with mobile phone headsets for the teachers or by increasing the functionality of the 360-degree camera. Simon's teacher explained how she integrated Google Classroom with the experience:

I said to him, "And I put that on Google Classroom for you, Simon." So he could then go into it, but if I can just hear what he's saying, 'cause you don't have to have, really have a mic, you have to just have some, now I'm thinking FBI stuff, a little thing in your ear. *Simon's Teacher*

Mena solved the issue of communication by texting a buddy in the environment. Simon's mother also suggested:

Rather than sitting there reading the screen and processing it yourself. . . he might have the ability to be typing in some questions somewhere if he had something to ask. *Simon's Mother*

Simon followed up with how he imagined the problem of communication could be solved:

So get, put the headset on and have the phone and I'd just be at home and I'd just be like text, typing in and asking the question, asking questions and all that

kind of stuff. And then there'd be a camera in the class so they would all see it and everything. *Simon*

Mena's uncertainty about whether she was welcome and her concern about being intrusive indicate a need for teachers to create opportunities for more two-way communication:

Like I just didn't wanna get in the way of anyone, 'cause if I was there I kind of like can easily just wait until everyone's done and then ask [Teacher] to come help me later with something. I didn't nudge the person next to me and be like, "What's going on?" *Mena*

Thus, an invitation to participate was important to Mena. This was acknowledged by her teacher:

I guess that would have been good to know, because we could have put her at ease and said it's no distraction at all . . . but maybe Mena needed to understand that she was allowed to, like it wasn't a distraction. . . *Mena's Teacher*

In order to do this, it was identified that the chosen person in the environment should have a prior relationship with the young person:

Well I only ever had her physically in my room probably two or three lessons prior to her going away for her treatment. And again, because I hadn't taught her in previous years, perhaps she doesn't know me and know how I would have been more than happy [to communicate more]. Had we established a better physical relationship prior to using the virtual relationship, she might have felt differently. *Mena's Teacher*

All the participants were excited about other possibilities this technology could offer, including as a 'halfway house' for students experiencing mental health issues when returning to school, to view games of their sports teams, and to view school productions.

Timing and place of intervention: The parents and caregivers commented that the *Patience Project* should be implemented as early as possible after diagnosis to maintain connection with the school environment. It could be suspended during high-dose treatments and times of critical ill-health, and then reintroduced. Two of the young people and a teacher (in the context of secondary education) commented that the *Patience Project* should preferably begin at the beginning of a new school term or new course.

The early phases of treatment are marked by considerable support from the community, but this diminishes over time:

When a diagnosis first comes in you're absolutely surrounded by friends and family and love and care and support, and that's wonderful 'cause it's exactly when you need it 'cause your whole life has just stopped, and that's the outpouring. But then as time moves on everyone just, which is totally understandable, gets back into their norm and every now and again you get a friendly phone call. *Simon's Mother*

The *Patience Project* opens up an opportunity to sustain connections with the young person's peer group, and Simon's mother explained the importance of this:

That's not to say that they don't love and care for Simon, but they don't show that by their day-to-day interaction. And so I think ... for him to keep busy and be active and be engaging with people from all aspects (from the start) ultimately will have a better outcome. *Simon's Mother*

The school environment was the first place in which the participants thought about placing the 360-degree camera. Looking back, some of the young people came up with a range of alternative sites for future implementation, including home life, group situations or community activities. They might only be observers in some of these contexts, but they would still be sharing the experience. Niki indicated that in hindsight, her choice of environment (an out-of-school education programme) was not optimal because the students were involved only in online, individualised programmes. She had chosen this because a school classroom had seemed overwhelming. She recognised, though, that the project experience gave her the confidence to return to the real classroom as soon as she was able. Having realised that, Niki offered ideas about where the technology could work best:

But it would be good for people who can't go to school and they have the camera in their classroom. And they can work from the livestream and do work at home. So that's, it would be good to be at school, but not stuff where other people are doing online work. *Niki*

She suggested that in a familiar environment, like a school class, there was more likelihood that the young person would have a buddy to communicate with and to assist in their engagement.

Conclusion

Despite a small sample, this formative assessment of the *Patience Project* pilot has elicited valuable information about young people who experience social exclusion and the potential for immersive technology to facilitate and sustain connectedness to familiar environments and to peers. All participants enthusiastically embraced the use of the technology. The *Patience Project* was reportedly effective in reducing exclusion, increasing connectedness, countering isolation, and lifting the moods of the young people involved. Teachers, as the nominated persons, were equally supportive in their commitment to the use of this technology to reduce educational and social exclusion.

Overall the formative assessment of the *Patience Project* pilot has revealed that the technology was perceived by all the young people as “cool” and it facilitated a re-connection with the school environment. The equipment generally provided ease of use, and even became less difficult to use over time, to the point of serving as embodiment of the young person in the class. There were some challenges when using the headsets, including reports of nausea and a dizzy sensation. Some participants chose to use a laptop as a replacement for the headset.

Participants noted the unique capacity of the technology to help the young person escape the reality of being sick. The ability to return to their pre-diagnosis condition was an underlying motivation for young people to participate and deemed a benefit of the project. While young people imagined the possibilities the technology offered, they also acknowledged the need for an assessment of what was possible within the limitations of their health.

The prospect of using the technology to help overcome exclusion and gain a sense of inclusion was crucial to the young people, their caregivers and their nominated persons. The unique opportunity of being located in one reality (such as a hospital ward) while immersed in another (such as a school classroom) was reportedly very positive but came with the caution that there might be times when the experience of ‘being there’ (through the IR technology) may be challenging. The nature of their condition creates almost an inevitable paradox in which they feel stuck in the world of illness and excluded from the normal activities significant to their lives, yet they may not want to be reminded of that when using immersive technologies.

Being included in their chosen environments elicited secondary benefits, with the 360-degree camera becoming a ‘metaphorical shield’ which enabled the young person to remain in a safe

environment—be it the hospital or home—while also participating in their chosen environment. This ability to be present, to see others, yet not be seen, was regarded as very beneficial for some participants and provided a form of protective inclusion. Similarly, the ability of other young people to interact with the absent student and the facilitation of reciprocal connecting were regarded as particularly positive. Enabling connectedness between the young people with serious health conditions and their peers also created opportunities for opening up discussions that would generate greater understanding of illness, life and death.

Connecting to school contributed to creating hope for the future and to remediating some of the losses that occurred as a result of their medical condition. The *Patience Project* encourages each young person to make their own choices about when and with which environment they want to engage. This allows an element of control and a semblance of agency, despite their circumstances. Participating in *Patience Project* meant keeping up-to-date with their education and provided an outlet for positive envisioning of their futures.

The *Patience Project* offers multi-faceted learning that is potentially profound, not only for educational benefit, but also for personal development. On the whole, participants wanted more of this, to the point of exploring the effective use of artificial intelligence for this courageous population. They requested increased immersion, with more considered management of the timing of the intervention as well as the choice of environment.

Insights gained from the qualitative data gathered in this formative assessment will inform the next stage in the development of this project. When implemented with a greater number of participants, a robust evaluation of the outcomes of the *Patience Project* will need to incorporate both qualitative and quantitative measures.

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