Title

Immersive Reality Experiences (IRE) Technology for Reducing Social Isolation and Improving the Social Connectedness and Well-Being of Hospitalized Children and Young People: Open Trial

Authors

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Abstract

Background: Hospitalized children and young people can feel disconnected from their peers and families, which can in turn predispose them to psychological problems including anxiety and depression. Immersive Reality Experiences (IRE) technology, recently developed by the New Zealand Patience Project Charitable Trust may help to overcome these issues. IRE technology uses immersive 360-degree live-streaming and a virtual reality (VR) headset to enable hospitalized children and young people to connect through cameras located in either their school or home environment and via text messaging with a designated buddy.

Objectives: This trial was undertaken to 1) expand qualitative findings from a previous smaller 'proof of concept' trial to ascertain the views of hospitalized New Zealand children and young people, their caregivers and teachers regarding IRE technology and 2) quantitatively evaluate the effectiveness of IRE technology in reducing social isolation and improving social connectedness and wellbeing using validated outcome measures.

Methods: An open trial of IRE technology was conducted between December 2019 and December 2020 for which 19 New Zealand children and young people aged 13-18, who had been hospitalized at Starship Hospital—a specialist pediatric hospital in Auckland—for at least 2-weeks were recruited. All young people completed the Short Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS), an abbreviated version of the Social Connectedness Scale (SCS) and the Social Inclusion Scale (SIS) and at baseline. Ten participants used IRE technology as often as they wished over a 6-week period and completed post-intervention measures. Semi-structured interviews with a subset of the ten young people, four caregivers and six teachers were conducted immediately post-intervention.

Results: Participants reported improvements in social inclusion (mean change 3.9, SD 2.8, p 0.057), social connectedness (mean change 14.2, SD 10.0, p 0.002) and well-being (mean change 5.7, SD 4.0, p 0.001). Key themes from interviews with participants, caregivers and

teachers were the importance of support for using IRE technology, connecting vs connectedness, choice and connection, and the value of setting it up and getting it right. Recommendations for improving connectedness via IRE and related technology were also provided.

Conclusions: IRE technology can improve the social inclusion, social connectedness and well-being of hospitalized New Zealand children and young people. With some technological modifications and simplified implementation, IRE and related technology could become part of standard care and support hospitalized children and young people in New Zealand and elsewhere to sustain family and peer cohesion, experience fewer psychological problems and more easily return to normal life following completion of treatment.

Trial Registration

This study has been registered with the Australian New Zealand Clinical Trials Network Registry: ACTRN12619000252112p

Introduction

Between 10 and 12% of children and young people worldwide, and up to 22% of New Zealand Māori taitamariki (children and young people), experience long-term physical conditions (chronic illnesses) such as cancer, diabetes and cystic fibrosis [1]. Many spend weeks or months in hospital, disconnected from their wider families, peers and schools [2]. Social disruption and exclusion may be related to psychosocial problems including anxiety and depression, and be associated with reduced academic achievement [3,4,5]. Conversely, social inclusion during treatment may be associated with improved psychosocial functioning [6]. Psychosocial supports offered to hospitalized children and young people vary widely [7]. For example, many rural institutions or those in less developed countries offer minimal formal support whereas specialist pediatric centers in more developed countries have access to multiple resources (e.g., on-site consult liaison mental health teams, play specialists and volunteer organizations). Despite support available in more developed countries, resources are usually focused on supporting medical treatment, rather than improving social connection [8].

Over the past few decades, advances in technology have led to the development of a wide array of eHealth interventions including websites, self-help apps, health games and devices that provide immersive reality experiences (IRE) [9]. A number of these were developed for, or trialed with, children and young people with long-term physical conditions [10]. IRE technology engages users in an alternate real environment, virtual environment, or a combination of real and virtual environments [11]. IRE technology has been shown to reduce psychological stress and improve mental health in adults [12,13], children with disabilities [14] and the elderly [15]. In some cases, IRE technology has shown to enhance engagement in schoolwork and improve emotional wellbeing in children and young people with long-term

physical conditions [14,15,16,17]. However, factors affecting the use of IRE technology by this group, such as hardware issues, privacy concerns, and the impact of health status and hospitalization, are not well-described in the literature.

In 2018, the Patience Project, a New Zealand charitable organization headed by one of the members of our research group (BM) developed a virtual reality environment-based system of IRE technology to connect hospitalized children with peers at home and school. Two-way communication was possible through the young person using the IRE technology texting a designated buddy in their school environment to ask questions to the teacher on behalf of the absent young person or strike up a conversation with their peer. This was the first intervention of its kind in New Zealand. A formative assessment of the Patience Project was conducted with 15 participants in 2018 [18] aimed at developing an understanding of the perceived strengths and weaknesses of the project, to inform future directions. Five children receiving oncological treatment at Starship Hospital, a tertiary pediatric hospital in Auckland, New Zealand, along with their teachers and caregivers comprised the sample. Despite the small sample, the formative assessment elicited valuable information about young people who experience social disruption and the potential for immersive technology to facilitate and sustain connectedness to familiar environments and to peers. This exploratory investigation supported the viability of undertaking a more formal open trial described in this paper.

This trial was conceptualized by two authors (HT and CF) with the following aims:

1. To investigate the acceptability of IRE technology to hospitalized children, families, and school staff.
2. To examine the effectiveness of this technology in improving social connectedness, reducing social isolation, and improving the wellbeing of hospitalized children.

3. To provide information regarding the feasibility of a more definitive randomized controlled trial (RCT).

Methods

Recruitment and sample

A mixed method trial design was employed. We aimed to recruit a convenience sample of up to 40 children and young people admitted to Starship Hospital, a tertiary pediatric hospital in Auckland, New Zealand between December 2019 and December 2020. However, due to the COVID-19 pandemic and its potential risks to young people in our sample having already compromised immune systems, we were unable to recruit all 40 potential participants for six months between March and September 2020. Leading to a final recruitment of 19 young people to trail the IRE technology—10 of whom felt well enough to complete the intervention. In addition to study participants, we also aimed to recruit up to 10 caregivers and 10 school staff who supported the young person's participation in the classroom to participate in semi-structured interviews post intervention. Four of these young people and their respective caregivers together with seven teachers provided in-depth feedback. Fortunately, this number was sufficient for us to obtain rich qualitative data regarding the acceptability of IRE technology and some quantitative data regarding its effectiveness.

Participants were provided with information about the trial via their clinical teams. Participating teachers were actively recruited by a research assistant. All other participants learned about the project through waiting rooms conversations at the hospital with a doctor or nurse, or in one case a TV advertisement. The required inclusion criteria for young people to participate in this trial were: a) aged 13-18; b) with any medical condition; and c) admitted to Starship Hospital for more than a 2-week period or intermittently over a six-month

timeframe. Three exclusion criteria were set: a) Children under the 13 years of age or adults over 18 years of age; b) individuals with a physical or mental health issue that prevented exposure to IRE technology (e.g., severe seizures); and c) those not able to provide informed consent (or assent with caregiver consent). All participants received a $25 gift voucher for their participation.

A total of 19 young people were recruited via their usual clinicians at Starship Hospital and 10 of these used the intervention. Two of the nine young people who did not use IRE technology reportedly found it too difficult to use, one was too unwell for the duration of the trial and one left hospital sooner than expected and one did not provide a reason. The schools of four other young people declined to allow IRE technology to be used in their classrooms despite ethics committee approval of the project and personal explanation by a research assistant.

All 19 young people completed pre-intervention questionnaires at the time of recruitment and ten who completed the intervention filled out post-intervention questionnaires. Only four young people took part in semi-structured interviews and thus, their data was analyzed alongside that of caregivers and teachers. Characteristics of all young people recruited are further described in Table 1. To maximize confidentiality, no data was collected regarding the type of long-term physical condition(s) participants were experiencing.

Table 1: Characteristics of participants

	All participants	**Participants who completed the intervention**	**Participants who completed interviews**
Number	YP = 19 C = 4 T = 6	YP = 10 C = n/a T = n/a	YP = 4 C = 4 T = 6
Mean age (range)	YP = 14.3 (13-17) C = n/a T = n/a	YP = 14.2 (13-16) C = n/a T = n/a	YP = 14.5 (14-15) C = n/r T = n/r
Sex	YP = M = 9 (45%), F = 10 (55%) C = F = 4 (100%) T = M = 3(50%), F = 3 (50%)	YP = M = 5 (50%), F = 5 (50%) C = n/a T = n/a	YP = M = 1 (25%), F = 3 (75%) C = F = 4 (100%) T =M = 3 (50%), F = 3 (50%)
Ethnicity	YP = 5 NZ European; 5 NZ Maori; 5 Pacific Island; 3 Asian; 1 Other C = 3 NZ European, 1 Asian T = 6 NZ European	YP = 3 NZ European; 1 NZ Maori; 3 Pacific Island; 3 Asian C = n/a T = n/a	YP = 3 NZ European, 1 Asian C = 3 NZ European, 1 Asian T = 6 NZ European

**YP = young people, C = caregivers, T = teachers, n/a = not applicable n/r = not recorded*

Intervention

The IRE hardware used included an Oculus Go® all-in-one virtual reality headset and laptop, either of which could be used by hospitalized children to see and hear others, and an Insta 360 Pro® 360-degree revolving camera and screen that could be situated in homes or schools for the young person who was absent from that environment to virtually see and move around the environment. In addition, the intervention included a buddy system, whereby a designated individual could communicate with the hospitalized young person via text. The hospitalised young person would contact the teacher in advance of a scheduled lesson. Cameras were turned on by the teacher at the start of the class and left on until the young person no longer felt like participating. The equipment had no recording capability.

Data collection

Following the completion of consent procedures and paper-based outcome measures, for the quantitative portion of this study young people were given access to IRE technology for a 6-week period then repeated the outcome measures. We used the following outcome measures: The Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS); the Social Connectedness Scale (SCS); and the Social Inclusion Scale (SIS). The SWEMWBS is a short version of the 14-item Warwick-Edinburgh Mental Well-Being Scale (WEMWBS), which is comprised of positively worded items measuring different aspects of positive mental health [19, 20]. The SWEMWBS is a 7-item scale that asks participants to rate their experience of a range of thoughts and feelings (e.g., "I've been dealing with problems well") over the last two weeks on a 5-point Likert scale ranging from 1 ("none of the time") to 5 ("all of the time"). The score is calculated by summing individual ratings and transforming the total into a metric score using a transformation provided by the scale authors. Scores range from 7 to 35, with higher scores indicating greater positive mental well-being. The original scale has demonstrated good content validity and is correlated with other mental health and well-being measures [19]. The short version has demonstrated similar reliability and validity to the full version (α=.84) and is suitable to be used by adolescents [21, 22]. The SCS is a 20-item scale measuring the degree of interpersonal closeness that individuals feel between themselves and other people, both friends and society. Sample items include: ''I feel disconnected from the world around me'' and ''I don't feel related to anyone''. Items are rated from 0-6 and higher scores represent a stronger sense of belonging. The scale has been shown to have good internal and test-retest reliability [23, 24]. We used an abbreviated version of the scale, consisting of the first eight, positively framed, items, with a total score of 48. The SIS is a 22-item scale for measuring social inclusion that has been validated with young adults and contains three subscales for social isolation, relations, and acceptance [25]. We adapted some

of the language for use with our adolescent population but did not change any of the actual items.

Qualitative data were collected through separate semi-structured interviews, lasting between 30-45 minutes each were then undertaken by two members of the research team (CF, LC) with 16 participants including four young people (three female, one male), four caregivers (all mothers) and seven teachers (four female, one male) as well as the project custodian. The aim of the interviews were to understand views on the acceptability and usefulness of IRE technology. Interviewees reported that the number of engagements (i.e., times the young person connected to their classroom via IRE technology) varied between three to 12 sessions. The typical length of each engagement was between 30 to 60 minutes. Engagements were usually shorter when students were in hospital and receiving treatment on the day.

Data analysis

Quantitative data was analyzed by two authors (HT and HK) using Microsoft Excel® Version 16 and IBM SPSS Version 25 software. Quantitative analyses included basic descriptive statistics (e.g., changes in scores on validated scales and demographic characteristics of the sample) and changes in social connectedness, well-being and social inclusion were evaluated using the non-parametric Wilcoxon signed rank test. A p-value of <0.05 was taken to indicate statistical significance and 95% confidence intervals were used to establish the extent of any difference between pre and post measures. A sample size of N=40 was calculated a priori using Strata v15® software to enable detection of changes of +/- 0.5 SD in the primary measure of well-being (using the SWEMWBS) with 80% power. Interviews were audiotaped using a Phillips Voicetracer digital recorder. The recordings were transcribed and the transcripts de-identified by a registered transcriber who had signed a

confidentiality agreement with the University of Auckland. To analyze the data, individual transcripts were coded thematically using a six-step coding process in NVivo 12 software [26]. After transcript familiarization, separate codes were linked to one of three separate case grouping distinguished as either caregiver, teacher, or young people's reflections on the project. Under each of these groups, the codes were arranged into categories based on relationships established among them. Initial categories and subcategories were refined by two authors, only including codes in a category if two or more interviewees referred to the idea. Any differences were resolved by consensus. All authors were involved in drafting and reviewing the paper.

Ethical issues

The study received ethical approval from the New Zealand Health and Disability Ethics Committee in December 2018 (NZ HDEC reference: 18/NTB/241). Participants were approached via their clinical teams, rather than directly by the research team, to minimize coercion. Consent for participation was obtained directly for those over 16 years of age and via caregivers with participant assent for those under 16 years of age. Consent for participation in semi-structured interviews by young people, caregivers and teachers was separately obtained. School principals provided signed consent for their teachers and students to be involved in the trial. Participants were informed that they were free to depart from the trial at any stage. All data were de-identified prior to analysis and publication.

Results

Quantitative results

At baseline, participants reported moderate levels of well-being, social connectedness, and social inclusion. Following use of IRE technology, seven out of ten participants reported improved social inclusion, eight out of ten participants reported improved well-being and all participants reported improvement in social connectedness. Changes in social connectedness ($p < 0.05$) was statistically significant as described in Table 2.

Table 2: Changes in social isolation, social connectedness and well-being following use of IRE technology

	SWEMWBS		**SCS**		**SIS**	
	Pre	**Post**	**Pre**	**Post**	**Pre**	**Post**
N	10	10	10	10	10	10
Mean (SD)	22.4 (5.2)	28.1 (4.5)	27.6 (11.2)	41.8 (6.9)	42.1 (4.8)	46 (4.2)
Range	17-32	20-35	10-45	29-48	34-49	40-54
Mean difference (SD)		5.7 (4.0)		14.2 (10.0)		3.9 (2.8)
Wilcoxon Signed Rank Test						
Negative ranks		0[a]		0[a]		3[a]
Positive ranks		8[b]		10[b]		7[b]
Ties		2[c]		0[c]		0[c]
Total		10		10		10
P-value		0.12		0.005		0.074

N = mean, SCS = Social Connectedness Scale, SD = Standard Deviation, SIS = Social Inclusion Scale, SWEMWBS = Short Warwick Edinburgh Mental Wellbeing Scale

**a: post-IRE < pre-IRE, b: post-IRE > pre-IRE, c: post-IRE = pre-IRE*

Qualitative results

Four major themes were derived from the experiences of young people, caregivers and teachers involved in the trial:

1) support for IRE technology;
2) connecting vs connectedness;
3) choice and connection; and
4) setting it up and getting it right.

All participant quotes distinguished by the following:

- YP = Young person
- C = Caregiver
- T= Teacher

Support for IRE technology

Young people in this project echoed the sentiments of those who trialled the equipment assessment in 2018 in terms of their support for the technology [18]. Immersive feelings of 'being there' (*in the chosen environment*) and the project as 'cool' were still prevalent descriptors about the appeal of the technology by young people:

> It feels like you're kind of there, so I think that was really cool, when you think about it . . . I was fascinated about the idea, you know? On the headset . . . you could watch things . . . there were games and stuff. So, it was pretty cool doing that. (*YP 4*)

> I talked to my friends, and they said that it was pretty cool, and they would love to do it. (*YP 19*)

Caregivers also expressed the same enthusiasm for the technology:

> Funnily enough at parent interviews lots of parents have said, 'hey my daughter had come home' even though she wasn't in that particular Year 9 maths class, 'and talked about this camera. I think it's amazing that your school has taken this on board! (*T 18*)

Contributing to the appeal of the technology specifically was its ease of setup as noted by different teachers:

> It would take all of about a minute to get going and I didn't feel that was too time-consuming. (*T 24*)

> The camera is easy, it was all plugged in, you just had to press the button. (*T13*)

> The camera obviously was very unobtrusive, so it created no real difficulties for me in the classroom. It's just a very small device on a stand that we positioned in the middle of the class . . . it gave no real concerns about us getting around it. (*T 18*)

Barriers to support for the technology in schools were encountered initially in terms of the ethical concerns related to recording children. However, this was resolved swiftly once permissions were obtained and staff were briefed on how the technology would function:

> Other than the fact that the school had to sort permissions and stuff, but once they realized classes won't be recorded, there were no problems. (T 3)

Several teachers noted the capacity of the technology in the classroom to generate opportunities for improved understanding about fellow students who were home-bound or hospitalized. One teacher recalled discussion about inclusion and isolation had with her students:

> The biggest thing is that I saw it as a learning opportunity for the other students in the class. We had some really nice conversations about inclusion… When they see it there, they think, oh is that [*name of young person who is home or hospital-bound*]? And then my other students would notice the camera, particularly Year 12 or Year 10 and it's like, 'what's that?' I'd explain to them what it is, and they're like, 'What? So, she still has to do her homework?... Like oh that's ridiculous, you can't even escape it in hospital'. I'm like, no – I explained it's not for learning. They're like 'Oh Wow'. And then they realize the real reason ... That opens up conversations about isolation and how fortunate they are to be in school, healthy, with their friends, all that stuff. (T 6)

All caregivers and teachers acknowledged they would not hesitate to tell other families about the Patience Project because it helps young people retain a sense of familiarity with the learning environment and their peers. Young people echoed these sentiments as best exemplified by this participant:

> Everyone who's in hospital and going through the same thing, just to catch up with your friends and feel like you're kind of connected in the same way. It's just good . . .'cause you don't wanna miss out on being with your friends" (YP 4)

Connecting versus connectedness

While the IRE technology enabled young people to connect to their chosen environments, connecting did not always result in a sense of connectedness. Caregivers shared mixed perceptions (*see* Table 3) on whether or not the technology had significantly impacted the young person's connectedness to their peers or made/was making their ability to return school easier. Some caregivers concluded there was no significant impact in these areas and suggested there might even be an increase in stress due to a sense of obligation to participate. Others described the connections made to the classroom as beneficial to break up the monotony of hospital and recovery days. In a few instances, the same caregiver noted that the connectedness capacity felt a little superficial from their perception but also acknowledged the joy experienced through participating.

Table 3. Caregiver's mixed perceptions of participation benefits for the young person.

Participation as beneficial for connectedness	**Participation as non-significant for connectedness**
My opinion is that even if you're [*the YP*] just there in the lesson it's better than not being there, because you'll pick up something rather than nothing. (*C 20*)	You know they may have anxiety about, 'well I'm on this and I'm supposed to be doing this so many times a week. And it's not happening'. So yeah, I guess in some ways it

	could add to a bit of stress, feeling like they have to make sure they're on it. (C *2*)
I was in tears, tears of joy rather. Not sadness, joy. Thinking wow, there's something for kids who really do feel isolated. Because [she] was having a really tough time. And the first time when she connected I think I had the biggest smile on my face, seeing her smile. (C *5*)	I don't think that it built . . . any new friendships or anything like that. I don't think that the camera would have helped him feel like he can fit in again . . . I think it's superficial and I also think it's a huge novelty at the start. (C *29*)
I guess with the camera, the kids hadn't forgotten him. (C *29*)	I don't think it's really made a major significant difference to be honest. (C *2*)
I think there's been one child, one or two children who came and met her at hospital, which means that this connection does help. Because in the past we've really never had many people come and visit from school. (*C 5*)	She was excited the first time. The second time she was like 'Mum, it's boring. Cause English is boring'. She was only connecting because she had friends in that class. And the thing is, because the class is still going, you're not able to have a specific conversation with your friend, right? (*C 5*)

Caregivers predominantly held a *help more than hinder* attitude toward the technology. However, the acknowledgement that some aspects of the experience and the context within which it was engaged might be limiting, is an important reminder that technology might interrupt or reduce feelings of isolation but not always incite a sense of connection. Two young people also reiterated the fact that the novelty of participating wears off as exemplified by this quote:

> I kind of just got used to it. Turned it on, texted me just through text for a bit. And then when class started, they'd get back into it, they would be doing their work and I would be doing nothing much. (*YP 19*)

These connecting experiences were also influenced by a number of factors including whether or not the connection was stable, if the young person's buddy was reliable, the effectiveness of the interaction loop (i.e., between the young person, their buddy and the teacher) and if the young person was feeling unwell on the day they chose to connect. Despite these factors, and in light of the insights regarding participation as potentially non-significant for connectedness, future adaptions of the project should

consider actions to enhance the formation of strong connections as shared by this young person:

> It would've been nice to be able to shift classes and maybe even be able to participate a bit more or something like that. Maybe even be able to have like a virtual worksheet or something that I could do along with the class. Instead of sitting there watching them do the work. (*YP 28*)

The need for more interactive participation was stated by all of the young people.

While not producing a sense of connectedness in all instances, all participants in semi-structured interviews acknowledged that using the IRE technology was beneficial as means to maintain connection with the school environment best represented by this quote:

> I was able to connect with my teachers a bit more. And about who they are a bit and understand what their expectations or something are. They can get to know me and everything too. So, it was much more comforting than showing up to the first day of class and just being shocked because some teacher might yell at you for using the wrong kind of pencil or something like that. (*YP 28*)

Caregivers also saw gaining a familiarity with the school environment through the camera as facilitating the return to school:

> I think it would help her in the sense that she knows what's been going on. So, you know you'd hope that she'd be able to slot back in quite easily. (*C 2*)

Building on the idea of maintaining a connection, teachers noted the technology as a good way to ease back into school life after extended periods away through maintenance of connections with peers:

> The girls were very engaging with the camera, they would talk to her in the camera, I would call her name out on the role every day. We'd all wave to her . . . She couldn't talk back to the girls, but they would say, hey what are you doing? How's it going? We're doing this in class. Oh, we've got a mufti (casual attire) day today because of da, da, da. All that type of thing and then occasionally she'd message the buddy back on her computer and just say, hey, nice to see everyone, wish I was there, say hello to everyone for me. But

> instantly there was that connection going backwards and forwards, which was fantastic. (*T 18*)

Another teacher noted that education was a secondary benefit of using the technology:

> I think some of these kids are so sick, who cares if they're not doing the work . . . it's a connectedness, the feeling of belonging, able to see their peers through that lens, able to feel like they're part of that classroom again. It might just be a little, you know, half an hour of their day which they feel like a normal teenager. (*T 18*)

Caregivers shared similar sentiments about the purpose of the technology to be more about peer connection then education:

> It's not about learning English. It's more about connecting with your friends and being able to, as I said, go back and find it easier to go back. (*C 5*)

Choice and connection

For the young person, connecting and building connectedness was centred on choice (i.e., the who, what, when, where and how of their choices).

When and where to connect. Timing is crucial for young people wanting to and feeling physically able to connect. Young people predominantly made the choice to connect into the classroom where they could spend the most time (i.e., choosing English, because that class was also the young person's homeroom where they could have informal conversations). However, sometimes the choice of room or timing did not equate to a satisfying participation experience as noted by this young person:

> It was a very hit or miss sort of deal. Because, of course, if I had social studies in first period, I needed to make sure that I was up, like, by 9 o'clock, get on everything, do all that, especially considering when I first woke up, I would get, yeah, nausea, just a bit of sort of, like, not feeling great. And then you hop into virtual reality and you're surrounded by all this noise, and it's just sort of hard, yeah. (*YP 28*)

A caregiver reiterated this young person's sentiment in describing her daughters hit or miss experience:

> When you've got a sick child it's actually day by day. So the practicality of it—we'd wake up some days and she would be like yeah, I'm good to go . . .other days she'd wake up and go no, I'm not getting out of bed today…, it's one of those things. (*C 20*)

Having increased possibilities for when to connect may foster a sense of control or power over aspects of daily life that have been lost with the illness.

How and with whom to connect. Considering the social nature of the Patience Project, it is imperative to understand the different types of dynamics at play including the fact that there is a buddy system. In particular, it is important to consider how decisions about the buddy system are determined and perceptions of friendships are formed by other students. Some participants described very positive experiences with their buddy where others noted jealously arising amongst peers in the classroom who assumed they should be the designated buddy, with some disturbances arising in the friendships:

> At one stage, one was definitely on the outer. But I'm not sure. I wondered if it was because [the buddy] had been chosen as [the young person's] buddy. I even wondered if there was a little bit of jealousy there, I'll be honest . . . I did alert the dean to it just in case she could have a quiet word. (*T 21*)

Other disturbances to friendships were also expressed. One young person noted their disappointment after their chosen buddies stopped communicating frequently:

> My close friends . . . didn't come and I was just really upset about that. I didn't really wanna talk to all of them then, and I was just really upset because I would always put it in the group chat and be like, 'hey guys, you wanna come over?' . . . My friends that were really nice and wanted to come are on my headset thing. And none of my other friends really knew about it. But when I tried to tell them . . . it felt like their lives just kept going and they didn't really care about me. (*YP 4*)

This young person's experience is an important reminder to not underestimate the fact that when young people have choices with technology it may come with risks.

Why to connect. All caregivers and young people similarly stressed the need to view the project as non-compulsory as conveyed in this statement:

> I do recommend it to someone for socialisation. But I would probably stress to them, like, heavily stress to them it's not compulsory, it's not for education, it's for socialisation. (*YP 28*)

However, some caregivers and young people conveyed difficulty around engaging out of a sense of obligation because the opportunity versus genuine motivation on the day:

> This is purely from us and not from [*project custodian*] because I think she goes through so much trouble having it all set up and this camera couriering around the country, and the school setting it up and all of that. I think that you feel 'I really should [*connect*]'. Like all this trouble's happened for me. Not that there's any pressure at all put on from the *Patience Project* end. But I think that's just natural human nature, that if somebody's done something for you—you want to make the most of it. (*C 29*)

Setting it up and getting it right

When it comes to enhancing the experience of using the IRE technology to connect and build connectedness, participants asserted the need to get it fully right from the initial setup. Otherwise, it may become 'a bridge too far'. A young person's ability to engage was conveyed as hinging on three important factors:

1. *The technology must work well every time.* Participants in all groups recalled technical glitches in terms of noise, connection difficulties and inability to see the board or teacher effectively at some points.
2. *To maximise the use of technology, it needs to be easily movable.* This factor builds on findings previously mentioned and aims to put power back into hands of the young person—allowing them to facilitate choice over the environment for the camera.

Teachers communicated that increased mobility of the camera might enhance the educational capacity of the technology as well.

3. *The ease of use for all parties involved is imperative*. Participants indicated if they had to struggle with any part of the process of connecting, they'd give up and consider trying another time.

Participants across all groups suggested ideas concerning these three factors which they viewed as potentially enhancing the experience from the start, each fitting within one of the five categories:

1) Connecting participating teachers
2) Formation of bonds
3) Mock sessions pre-participation
4) Device mobility
5) Education about virtual connection

Connecting participating teachers. A channel to share specifics of the process and any inclusive activities to engage students on the other side of the camera.

Formation of bonds. Bonds with the teacher and a buddy were central to the project's success and moved it from the aforementioned 'a bridge too far'. From the young person's perspective, when a buddy was unreliable, their connecting experience was compromised. Young people reported mixed experiences in this regard:

> Because my buddy just really wasn't in touch at all. And then I couldn't find when my class. (*YP* 1)

Versus

> She turned it on and she turned it off. She was fun. She was a lot of fun in the class, so she could text me and I could text her. (*YP* 19)

Two caregivers suggested it might be best for the teacher to choose someone they perceive would be a reliable buddy as to not risk existing friendships and to create opportunities to build new connections. Caregivers indicated an individual such as the project custodian is imperative to young people's engagement and ensuring buddies and teachers fulfil their roles. Both caregivers and young people were appreciative of the participating teachers—specifically those who embrace a new way for young people to connect into the classroom. Participants deemed it essential to have a competent teacher who will make the most of the technology and use the experience to educate other students about illness and isolation. Gauging this enthusiasm early may be a good indication of the type of interaction loop that will arise between the young person, the buddy and their teacher.

Mock sessions pre-participation. Having an understanding of what the young person could see on the other side of the camera was described as an important consideration for teachers to understand the experience more holistically so that they can serve the students' learning and connecting needs more effectively (i.e., is board work clear? Is the camera close enough to see content?). The idea of participating in mock sessions were also proposed as a support to help the chosen buddy grasp the importance of the session.

Device mobility. It was unanimously suggested that if the device were easily mobile the number of engagements would be far greater and the student's experience would perhaps be increasingly meaningful.

Education about virtual connection. Participants referred to the need for education about the project and education about virtual inclusion initiatives. One teacher described their future tips for class education as being central to getting it right from the beginning:

> . . . the teacher needs to spend the time explaining the meaning behind it, why has it been designed, if you were in the students shoes do you think it would be helpful for you? Show the clip, Ben explaining his reasons for developing it . . . when the kids have full context they engage with it, they're completely on your side, they engage with the participant and then I think they get 100 times more out of it. Being totally honest and upfront with the class from the beginning I think gives you the best possible outcome. (*T 18*)

Two teachers described how in parent-teacher interviews caregivers said "*I think it's amazing that your school's taken this onboard"* after expressing their child had come home describing the technology and its purpose. Young people also highlighted the need for further training on how to use the technology:

> There was a bit of a problem with the VR set . . .because I didn't know how to make it 360, I couldn't find the setting. So it was just on a big screen. I was on my laptop. So, yeah. But it was fine other than that. (*YP 19*)

Both teachers and caregivers noted initial concerns about who else would see into the classroom, if the sessions were being recorded, and if the teacher was being judged by onlookers. The Patience Project was designed for the child's eyes only and after speaking with the project custodian, teachers and students in the classroom felt assured that privacy would be upheld.

Adding to a need for education, encouraging heads of schools to use the project as a tool to bridge unmet need was also described by a caregiver. Helping teachers and heads of school move beyond "*the too hard basket*" mentality when it comes to home and hospital-bound children was a significant concern of a few caregivers who struggled to find supports for their children upon initial diagnosis. Thus, the Patience Project helped with connection to educational and social environments, even if only for familiarity purposes— a need not previously met as described by one caregiver:

> About October she was feeling better and she goes ‘mum, can you get me some work?’ . . . I contacted her teacher and no one would get back to us. It was in the too hard basket for them. I asked, ‘Can these kids not Skype into their classrooms? We Skype all the time and you're telling me we can’t do this?’ (*C 2*)

Educating the staff (head teachers to classroom teachers) was also noted as a way to foster supportive environments for the IRE technology for schools:

> I spoke at a staff afterschool meeting, talked about it and showed how it worked… did some photos, did a little video clip of how it works in my general day to day class room and explained it to our staff of 120. And at the end they were . . . blown away! I guess, by the technology and the opportunity that students like [she] could get by having that camera in the class. (*T 18*)

These education sessions often turned into curiosity about the technology as another teacher noted:

> I obviously briefed all the teachers; told them about the camera in my class and the reason for it etcetera. They thought it was a worthwhile initiative and some came round to have a look at how it worked. (*T 3*)

Aside from one teacher who was respecting the privacy of the participant, all participants described sharing with staff and students as a positive experience and all stated they would happily be involved again.

Discussion

Our results provide valuable information regarding the acceptability of IRE technology and what might be required for its successful implementation. The technology appealed to many of our trial participants and there was acknowledgment of its potential to facilitate learning and ease the transition back to normal life, and particularly school following illness. Our findings also provide preliminary indication of its effectiveness at improving well-being and social connectedness, and to a lesser extent, improving social inclusion and disrupting social isolation, for young people with long-term physical conditions.

A handful of other devices and web-based, text, audio and video-based technologies have been trialed over the past couple of decades for connecting hospitalized children with schools and meeting their academic and social needs in international contexts outside New Zealand [27]. These include a communication app for young people with cystic fibrosis [28], an ambient technology-based orb in the classroom [29] and the Presence app [30]. To date, none have employed virtual/immersive reality. Most previously studied interventions demonstrated similar qualitative acceptability to IRE technology [14, 31]. Only one open trial of the two-way, web-based Bednet tool [32] has demonstrated improved social connectedness using a Likert scale and a non-randomized trial of a CareRabbit robot that helps children stay in touch with family and friends [33] has demonstrated non-significant differences in well-being between groups. So, ours is the first trial of a hospital to school communication system to demonstrate improvements in both social connectedness and well-being.

A number of participants in our trial experienced personal, health-related, technological challenges and school-related barriers to its use. Some simply did not find the technology engaging enough to continue using it. Others experienced challenges in getting the equipment to work. Duration and frequency of use were often related to users' state of health or treatment schedules, with greater use on days when they were feeling well or not attending medical appointments. Acceptance of cameras in classrooms, knowing how to use them and socializing classroom buddies and fellow students also proved difficult for some schools. These issues have all been experienced by the developers of similar interventions [27], and rather than being reasons for their disuse, are probably key barriers to target during implementation. They are also issues to consider during the design of a more definitive RCT.

Allowing greater time, sourcing participants from a larger catchment and engaging schools in advance of participant recruitment would all be useful.

Young people's sense of connectedness appeared to be dependent on everyone else's connection and ability to foster connectedness (e.g., the buddy connecting, friends continuing to engage with them through the device, family/whanau communicating with teachers when a child is unwell, and teachers communicating classroom activities and checking in via the device). For some, the social connectedness they experienced was superficial, but they still embraced the moments of interrupted isolation the technology offered. For others, it worked exceptionally well, indicating all the dependent factors functioned in cohesion. It was reassuring to know that most caregivers and teachers supported the use of IRE technology. Although some caregivers were focused on the educational benefits of connection between hospital and school, the majority could appreciate the value of social connectedness for their children's well-being. Teachers were also positive about the child's right to inclusivity and the formation of new, and maintenance of old, friendships between students in the classroom and hospitalized young people. This may be attributed to the fact they were witnessing (at least in part) what the young person was seeing on the other side of the camera in terms of peers in the classroom speaking to the camera, asking questions about the situation, and seeing the two-way communication loop (i.e., texting) between the buddy and young person occur. Effective education regarding the purpose of the trial and training in how to use IRE equipment were key parts of this process.

VR-based technology is not new. It has been shown to be useful for distraction, pain reduction and relaxation during the treatment of hospitalized children and young people and has improved in quality over the past decade [34, 35]. Illness or treatment-related nausea

reportedly detracted a subset from fully engaging with IRE technology. A future trial including VR and non-VR arms would help to clarify the additive value of VR headsets. Having a reliable 'buddy' at the other end of the connection was a more relevant issue for the majority of participants. Being able to connect in a flexible manner, including being able to choose between the use of VR and non-VR methods, also probably helped to foster a sense of control or power over aspects of daily life that have been lost with illness. The reliability of technology appeared to be especially important for participants, connection difficulties and inability to see the teacher or board and inability to move the camera sometimes proving 'a bridge too far'. Although the COVID-19 pandemic significantly affected recruitment, it may also have normalized children's access to educational environments through virtual media. Evident via the increasing openness of teachers to IRE technology toward the end of the trial, this phenomenon deserves greater investigation.

Strengths of the current trial include participation by young people with a range of long-term physical conditions, the collection of both quantitative and qualitative data with which to better understand the experience of individuals using IRE technology, and triangulation of participant views with those of their caregivers and teachers. Low recruitment due to COVID-19 related restrictions in access to hospitalized patients and consequent absence of any 17–18-year-old participants were the main trial limitations. So was the absence of any qualitative data from participants who did not use the intervention and those who were too unwell or elected not to be interviewed, which might have provided less favorable perspectives. Nonetheless, we were pleased to observe qualitative evidence of acceptability and improvement in all quantitative outcomes. Generalization of trial results to other settings cannot be assumed from our findings, nor can effectiveness and acceptability to individuals from different cultural backgrounds. A larger trial is needed to confirm our preliminary

quantitative results. It would also be useful to collect objective data regarding actual time spent using IRE technology. More in-depth analysis of hospital and school-related factors affecting engagement and set-up; the impact of COVID-19 on openness to virtual communication between hospitals and schools; the use of e-mentors, as suggested by Ellis et al. [36]; and the value of liaison workers in schools (e.g. health school staff, health school teachers) [37]; would be useful to undertaken in order to augment effective use of IRE. Considering feedback to date, IRE technology is being adapted and integrated into lower cost, multi-modal communication by the Patience Project Charitable Trust. This should improve its portability and applicability to a greater number of users.

Conclusions

This trial demonstrates that IRE technology has the potential to improve the well-being, social connectedness and social inclusion of hospitalized New Zealand children and young people. It also provides valuable information regarding the feasibility of a more definitive randomized controlled trial. With some technological modifications and simplified implementation, IRE and related communication technology could become part of standard care and support hospitalized children and young people in New Zealand and elsewhere to sustain family and peer cohesion, experience fewer psychological problems and more easily return to school and normal life following completion of treatment.

Acknowledgements

We sincerely thank the Starship Foundation for their sponsorship of this project (Grant A+8661) and all the young people, caregivers and teachers who provided us with their time and valuable feedback. We also thank Dr Alana Cavadino for her statistical advice, Stacey Yates for her efforts at maintaining recruitment during the initial phase of the pandemic and

Ben Martel for developing the IRE technology. The technology, methods and processes developed during this research are available upon request to any other party who wishes to extend or implement their own IRE engagement.

Conflicts of Interest

None of the investigators have any conflicts of interest to declare.

Abbreviations

IRE: Immersive Reality Experiences

VR: Virtual Reality

SWEMWBS: Short Warwick-Edinburgh Mental Well-being Scale

SCS: Social Connectedness Scale

SIS: Social Inclusion Scale

RCT: Randomized Controlled Trial

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