Exploring Children's and Caregiver's

Experiences of Receiving Remote

Psychological Therapy from Leeds Children's

Hospital

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1.0 Introduction

1.1 Physical Health Problems in Children and Young People (CYP)

Nearly a quarter of CYP aged 11-15 report having a long-term illness or disability (Brooks et al., 2015) which may require anything from a distinct period of treatment, to lifelong intervention. Data demonstrates that in any given year, over 10% of all children will be seen in a hospital outpatient department and 6-10 % will be admitted to hospital (Department of Health, 2003). Whilst the majority of CYP and their families cope well with adjusting and managing the illness, others might experience ongoing distress which may impact their schooling, family and social life (BPS, 2019c).

1.2 Paediatric Clinical Psychology

Paediatric clinical psychology is a growing area of psychological provision which aims to provide support to CYP with medical conditions, and the systems around them, both to improve psychological well-being and health outcomes (BPS, 2019b). The psychological impact of receiving treatment for a physical health problem can be great, particularly given that the majority of children who require hospital treatment are admitted as the result of an emergency, as opposed to a planned episode of care (Department of Health, 2003). This is reflected in literature, which shows that CYP living with physical health conditions are four times more likely to experience mental health problems such as low mood and anxiety (BPS, 2019a).

Clinical psychologists may become involved in the care of a CYP at different stages: at the point of diagnosis, during treatment, and after treatment (BPS, 2019a). The benefits of psychological interventions have been evidenced in research, for example Cognitive Behavioural Therapy (CBT) approaches have being shown to be effective in helping CYP to manage symptoms and continue to access treatment (Christie & Wilson, 2005). In addition to working with the individual, clinical psychologists collaborate with other professionals involved in the CYP's care, and work to improve understanding and evoke change at the wider levels of the system. This may be via providing teaching and consultation services, along with leading service audit and evaluation which can help to inform policy level changes (BPS, 2019b).

1.3 Service Context

The Leeds Teaching Hospitals NHS Trust (LTHT) is one of the largest NHS trusts within the U.K and is a regional centre for a number of specialist services (NHS, 2021). Within LTHT, Leeds Children's Hospital provides specialist care to CYP presenting with a range of health conditions, both locally across Yorkshire and Humber, as well as nationally.

There are a range of paediatric specialities that commission psychological input within LTHT¹. Typically, clinical psychologists, clinical psychologists in training, assistant psychologists and counsellors within LTHT are responsible for providing psychotherapy. In cases where the child is very young, or otherwise unable to engage in psychotherapy, this tends to be delivered indirectly, via the caregiver.

In order to ensure that CYP with heath conditions receive the best quality of care, both the NHS Long-Term Plan (NHS, 2019) and the British Psychological Society (BPS, 2019a) state that they must be supported to access high quality services, at convenient times, as close to home as possible. However, traditionally, families have been required to travel considerable distances for face-to-face appointments with professionals at Leeds Children's Hospitals.

In March 2020, the Covid-19 pandemic resulted in prolonged government-imposed restrictions on movement (The Crown Prosecution Service, 2021). In order to provide continued access to support, whilst minimising in-person interaction, physical and mental health services were promptly required to adapt to a new way of working (Mind, 2020). Psychology teams within Leeds Children's Hospital responded by transferring all face-to-face appointments to telephone or video appointments, to allow patients to be seen remotely.

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¹ The speciality departments include cardiology, cystic fibrosis, diabetes, oncology, neuropsychology, pain, PICU, renal and rheumatology. Plastics, orthopaedics and major trauma aligned to a difference clinical service unit but were also involved in this study due to the commissioners working into across these services.

1.4 Literature Review

When considering the impact of remote therapy on adults, the literature is comprehensive and indicates that remote interventions are generally effective and experienced positively by clients (Thomas et al, 2021). Literature exploring CYP's experiences of remote therapy is less prominent, which is likely a reflection of how uncommon this support was prior to the pandemic, particularly within NHS settings.

Despite this, research is emerging and a rapid review of one-to-one remote mental health interventions for young people (James, 2020) highlights advantages including: increased accessibility; young people feeling it is safer to talk, and an increased sense of control (Glasheen et al., 2016; Navarro et al., 2019; Street, 2013). Drawbacks of remote therapy for young people have also been highlighted, including poor signal disrupting the conversation, and the loss of body language as a source of information (James, 2020). Despite this, there appears to be a prevailing theme of young people wanting remote therapy as part of their treatment, but not as a replacement for being seen in-person (James, 2020; National Collaborating Centre for Mental Health, 2014).

With regards to effectiveness, systematic reviews exploring CBT as a remote therapy model found some evidence to support its role in reducing symptoms in CYP (Hollis et al., 2017; Sigurvinsdóttir et al., 2020). However, the research is often based on older adolescents with typically low level symptoms. The therapeutic relationship has also been considered, and James's (2020) review concluded that strong relationships could be formed, however this process might take longer than if in person.

Whilst it is helpful that these studies provide insight into the experiences and effectiveness of remote therapy for CYP, they often focus on remote methods which are less commonly used in the NHS, such as email and web-based chat (Mehta & Chalhoub, 2006; Rickwood & Rickwood, 2015), or combine a number of methods (James, 2020), making it difficult to determine the impact of video and telephone therapy. This is further complicated by a lack of universal terminology used to describe the different types of remote therapy (Smith et al., 2021).

Further to this there is a lack of research interested in the caregiver's experience of being involved in the child's therapy, remotely. Since interventions with CYP often take place via working with caregivers (BPS, 2020), particularly when the child is young, it is important that the caregiver experience is also captured. Finally, the existing research generally focuses on young people seen within mental health

settings, which may not be translatable to the paediatric service context, or more specifically, to CYP and caregivers seen for remote therapy within Leeds Children's Hospital.

1.5 Rationale for the Service Evaluation Project

This project was commissioned by clinical psychologists at Leeds Children's Hospital. Evaluative data is required to inform the future offering of video and telephone therapy within the service, by providing recommendations. The project is particularly relevant to the current context, with many services making decisions about whether to continue offering remote therapy following the Covid-19 pandemic.

1.6 Research Aims

The service evaluation project (SEP) aimed to use interviews to explore how CYP and caregivers, under the care of Leeds Children's Hospital, have experienced video and telephone psychotherapy. Within this, the project aimed to explore:

- General experiences e.g. How would you describe the quality of therapy that you received via telephone/video?
- Advantages and challenges to having therapy remotely e.g. what do you think is better/worse about remote therapy?
- Impact on the therapeutic relationship e.g. Do you think that having the sessions on the telephone/via video affected how understood you felt?
- Impact on therapy outcomes e.g. Did having therapy over the telephone/via video help you to reach your goals more quickly/slowly than expected?

N.B. The term 'remote' is used when referring to the video and telephone therapy delivered to participants.

2.0 Method

2.1 Design and Procedures

Semi-structured interviews were administered over the telephone to make participation as convenient as possible. If the CYP engaged in direct therapy, they were interviewed, however if therapy was provided indirectly, through the caregiver, or if the caregiver and the child attended sessions together, the caregiver was interviewed. The semi-structured interview design was considered most appropriate as it allows thoughts, feelings and beliefs about topics to be explored, whilst being guided by a set of topics or questions (DeJonckheere & Vaughn, 2019). It also allowed follow-up questions to be asked to explore interesting directions in conversation, and for the participant to be prompted to elaborate further to ensure the interview questions were answered fully.

Information about CYP and caregiver experiences could alternatively have been collected via a survey. Whilst this method may have proven more time-efficient, and possibly captured the experiences of a more wide-reaching group of participants, it would not have allowed for the exploration of interesting subjects that arose.

2.2 Participants and Recruitment

To inform psychologists of the recruitment criteria, the researcher attended a variety of paediatric speciality team meetings and emailed all known clinical, trainee and assistant psychologists working within paediatric services at Leeds Children's Hospital with a poster outlining recruitment steps (Appendix A). Further emails were sent following three alterations to the recruitment criteria, which permitted CYP and caregivers to take part if they had received a blend of face-to-face and remote therapy and also allowed the researcher to call potential participants to discuss participation.

Psychologists recruited CYP and caregivers to the researcher by emailing necessary personal information to a secure NHS email address created for the purpose of the study. To meet recruitment criteria, the therapy must have been delivered at least partially via video or telephone. The child must have been assessed to be Gillick competent, or if the caregiver was being interviewed, they must have been assessed as having the capacity to consent to taking part.

The sample size aimed for was between six and eight participants from each population, since this is considered sufficient for small scale projects (Braun & Clarke, 2013). CYP and caregivers were contacted by the researcher about taking part, either via a telephone call or email. A link to the participant information sheet (Appendices B and C) and consent form (Appendices D and E) in Qualtrics (2021), was then sent out. From the fifteen CYP and seven caregivers recruited to the study, six CYPs and five caregivers completed the consent form, and were interviewed.

Since the project is interested in the experience of remote therapy from the perspective of both child and caregiver, two slightly different interview schedules were required (Appendices F and G). The eleven interviews were completed between June and August 2019 and ranged from 16 to 37 minutes.

2.3 Data Analysis

To stay as close to the data as possible, the researcher transcribed all interviews verbatim, removing names to protect anonymity. Various qualitative approaches were considered, including rapid qualitative analysis which may have proven quicker and have allowed for more data to be collected (Vindrola-Padros & Johnson, 2020). However, Thematic Analysis (TA; Braun & Clarke, 2006), was deemed appropriate due to being relatively quick, along with its ability to summarise key features of a large dataset. A summary of the stages undertaken is presented in Table one.

Table 1

The process of TA (Braun & Clarke, 2006)

Stages	of TA	Description
1.	Transcription	All audio recordings were listened to by the researcher
		and transcribed verbatim.
2.	Familiarisation of	All transcripts were read through twice and initial
	the data	ideas about the data noted.
3.	Coding	All meaningful units of data within the transcripts
		were coded. All codes were then written onto sticky
		notes.
4.	Generating themes	Codes were clustered into meaningful groups. This
		process was repeated several times, until the researcher
		was satisfied that the overarching themes and
		subthemes were distinct and coherent.
		The themes were then checked against the codes and
		the original transcripts.
5.	Reviewed themes	Themes and subthemes were shared with the
		researcher's academic tutor, commissioner and a
		trainee, to check for face validity. Themes were
		adjusted accordingly and decisions made about how to
		present the similarities and differences between
		caregiver and children experiences.
		A thematic map was generated to visually display this.
6.	Producing the	Through the process of producing the report, themes
	report	were defined and explained, using supporting quotes.

2.4 Reflexivity

The researcher has experience of working with CYP and caregivers remotely and is currently delivering video therapy on a paediatric health psychology placement in a different NHS Trust. They therefore have assumptions and biases based on their personal experiences which will have inevitably influenced the interviews and data analysis. In attempt to minimise bias, credibility checks (see section 2.6) were carried

out. Verifying the themes with the participants would have helped to ensure that their experiences were accurately captured (Elliott et al., 1999), however this was not possible due to time constraints.

2.5 Credibility Checks

Elliott et al (1999) suggest that qualitative analysis should be subjected to credibility checks and recommend that an external individual acts as an 'auditor' to review the data. The initial themes and subthemes were shared with the researcher's academic tutor and a psychologist in clinical training, to gain an objective perspective and to assess the face validity.

2.6 Ethical Considerations

Ethical approval was provided by the University of Leeds Ethics Committee on the 4th March 2021 (DClinREC20-005) and subsequent amendments approved on the 24th May 2021 and the 7th July 2021 and 16th August 2021. The research governance manager within LTHT also reviewed the research protocol and confirmed that the project would be classed as service development (Appendix H).

3.0 Results

3.1 Demographics

Of the six CYP who took part, three were female and three male, and all were identified by their caregiver as being White British. Half had received a mix of face-to-face and remote therapy and three had only received it remotely. All remote therapy was delivered via Attend Anywhere. They CYP were recruited from a range of specialities: orthopaedics (2); plastics (1); chronic pain (1); craniofacial (1) and oncology (1). The CYP ranged in age from 10-16; the mean age was 13.

Of the five caregivers, three were female and two male. Three identified as being White British, one as British Pakistani and one as British South African. Three had received a mix of face-to-face and remote therapy and two received it only remotely. As with the CYP, remote therapy was via Attend Anywhere, and two caregivers also received some telephone appointments. The children they cared for were seen under orthopaedics (3), plastics (1) and major trauma (1) and the mean age of the children they cared for was 9. The caregivers interviewed ranged in age from 30-46; the mean age was 40.

All participants had received therapy via video, except two caregivers who received a mix of telephone and video appointments.

3.2 Descriptive Findings

All participants, except for one caregiver who had recently moved house, reported having the practical equipment (i.e., laptop, WiFi) necessary for the remote sessions to work. Since all participants received video therapy remotely, with just two caregivers experiencing a blend of telephone and video therapy, the majority of participant responses are based on experiences of video therapy.

Two CYP and one caregiver felt they would have felt more listened to face-to-face however the remaining participants stated no difference between how listened to they felt remotely, and how they would feel face-to-face.

All CYP and caregivers expressed positive feelings towards their therapist. When asked how they thought their therapist may think of them, all responded that they

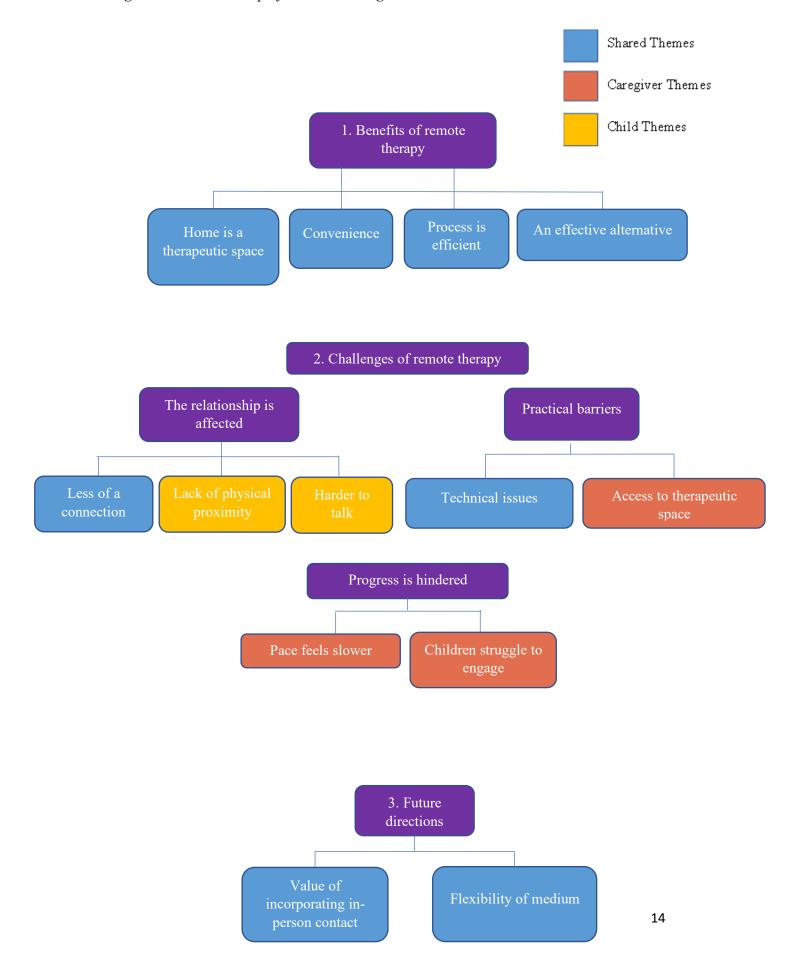
imagined their therapist thought positively of them, except from one caregiver who reflected that the therapist may feel worried that they were not connecting well with the child.

Finally, the majority of participants said that having the sessions remotely did not impact the amount of say they had in the sessions; one child and two caregivers said this had been slightly impacted online.

Thematic Findings

The child and caregiver interview transcripts were analysed separately. Although the main themes generated did not differ between the two groups, there was variation between the subthemes, outlined in a thematic map (Figure 1).

Figure 1: Thematic map of CYP and caregiver interviews.



3.3 Theme One: Benefits of Remote Therapy

In every interview, CYP and caregivers spoke of positive experiences associated with having therapy remotely. This theme consisted of four subthemes, which were present for both CYP and caregivers; supporting quotes from each group are presented in table 2.

Home is a Therapeutic Space

Three of the CYP spoke of how being in a familiar environment was helpful for therapy. Reasons for this included that it was more relaxing, so they could remember what they wanted to say and focus on what was important, as well as easily show their therapist resources relevant to the session. There was also the sense that some CYP felt safer at home and so were more willing to discuss their experiences. Feedback from two caregivers supported these findings; they commented on how the child was more receptive to therapy at home and could be themselves since they were more comfortable. One caregiver commented that the home environment was more therapeutic to her child with autism spectrum disorder, who encountered fewer barriers to treatment when at home.

Convenience

Five CYP spoke of how having their sessions remotely was more convenient for them, in terms of missing less school as well as generally saving time and reducing travel. If school was impacted, it tended to mean only missing a lesson, rather than the whole day. All caregivers except one echoed this, particularly focussing on the reduction in travel which was helpful in juggling family life and reducing stress. They also reflected that it meant one less trip to the hospital, when the child was already attending frequently for medical appointments.

Process is Efficient

Three CYP and two caregivers reflected on how efficient and easy setting up and joining the video calls was, commenting that it was a clear process that encouraged

efficient time management from the therapists. Caregivers commented that the efficiency of the process eliminated the delays typically encountered when attending a face-to-face session, such as the therapist running late from overrunning in a previous session. Caregivers experienced the remote sessions as being well organised and on time compared to sessions face-to-face.

An Effective Alternative

All CYP interviewed felt that the sessions had helped or were helping them to get to the place that they wanted to be. Some reflected that therapy progressed as it would have done if they were seen in person. Although two caregivers seemed less sure of how effective the sessions had been, this was more related to the child's physical health journey or the child being too young to engage online. The remaining caregivers felt the goals of therapy had been more or less met and commented on symptom reduction.

 Table 2

 Subthemes and supporting quotes for Theme 1: Benefits of Remote Therapy

Subtheme	Supporting Quotes
Home is a	Quotes from children:
Therapeutic	"Going in, sometimes I'm a bit nervous I might forget things. But at home, I
Space	remember everything" (Child 1, line 163)
	"I'm in a more comfortable environment that I'm familiar with" (Child 5,
	line 65)
	"erm knowing that my dad would be around (was better than face to face
	therapy). I don't think like in person he would be able to come back unless
told." (Child 2, lines 73-74) Quote from caregivers:	
	at home" (Caregiver 3, lines 105-106)

"I think he actually saw (the patient) how he is at home [...] whereas when he goes out there's a lot of pretending and covering up and being different" (Caregiver 1, line 115)

"I actually think he (the patient) remembered more, because we were at home" (Caregiver 1, line 106)

"probably worse actually, to go in to someone else's office, at least she was in her bedroom [...] which was a safe space essentially" (Caregiver 3, lines 62-64)

Convenience

Quotes from Children:

"It saved me from going to hospital because I'm so far from hospital, that's quite a long drive" (Child 1, lines 23-24)

"...otherwise I would have to be off for an entire school day, but instead I had them quite early in the morning and it meant I only missed like one lesson" (Child 3, lines 76-68)

"If I'm at school... or before school or after school, it's easier for me to get home and log on and stuff rather than having to drive all the way to the hosp... to the clinic" (Child 4, lines 59-60)

Quotes from caregivers:

"It's much less hassle than having to wait at a bus stop and... with (the child) whatever the weather, and get in and wait and... I don't know what it is about waiting in the hospitals... it really grates on his nerves" (Caregiver 1, lines 65-67)

"Not having to travel to get, sort of, the best doctor for the job if you like" (Caregiver 3, line 108)

"(in relation to face to face appointments) you have to go all the way to the other end of Leeds which is the worst bit of Leeds to get to [...] (Caregiver 4, line 158)

	"Actually it helps a lot with having work and childrenother children, and um other commitments" (Caregiver 3, line 300)
Process is	Quotes from children:
Efficient	"It was efficient you know, just (the therapist) would email a code for
	the room and we would just put it in and it was easy- it wasn't difficult"
	(Child 1, lines 70-71)
	"I just had to click on the link and fill in all my information it was really
	easy to do." (Child 4, line 78)
	Quotes from caregivers:
	"There was no sort of delay in waiting for an appointment or anything
	beforehand, you know sometimes you can arrive and someone else has
	overrun" (Caregiver 3, lines 192-194)
	"I think perhaps that's one of the benefits of it because you've got a
	set time to be there whereas sometimes you go to other places and you're sat
	there for half an hour before you even get in andyou know what I mean
	it's she's very 'on it' and I think the technology makes you be more 'on
	it" (Caregiver 4, lines 328-331)
An Effective	Quotes from children:
Alternative	(about reaching therapy goals remotely vs in person) "um not made any
	different to whether I was in clinic or not" (Child 4, line 171)
	"Got where I wanted to be quicker I guess [] I guess it's justhmm
	easier to get through things than when you're in person" (Child 5, lines 132-
	135)
	"I was scared of [] and he made that go away" (Child 6, line 27)
	Quotes from caregivers:
	"She even said to me the other day 'oh mummy I don't wake up crying in the
	night anymore' and I've been saying 'yeah that's why we've been seeing

(the therapist) [...] so she's quite positive about it now" (Caregiver 3, lines 221-223)

"it is hard work, it is stressful, but I think, I think in the end we did get things roughly as we wanted" (Caregiver 4, lines 455-458).

"For me, I feel like we've come on leaps and bounds" (Caregiver 3, line 269-270)

3.4 Theme Two: Challenges of Remote Therapy

CYP and caregivers also spoke of challenging experiences associated with receiving therapy remotely. Under the superordinate theme of 'challenges', three themes were generated: 'the relationship is affected'; 'practical barriers' and 'progress is hindered' (see figure one). Subthemes that were shared, as well as those unique to CYP and caregivers will be presented.

The Relationship is Affected

Less of a Connection

A shared subtheme highlighted how participants felt less connected to their therapist, or presumed they may feel less connected, had they not met them face-to-face previously. Four CYP mentioned this, including not being able to tell what their therapist was thinking, feeling that they didn't know as much about them, and alluded to their being less rapport. Three caregivers also referenced the CYP, or themselves, knowing their therapists less and tended to speak more about the missing, or misinterpretation of body language impacting on the connection. Both caregivers and CYP referred to the 'feeling' you get when in a room with someone, and how this was missing from the online environment.

Lack of Physical Proximity

All of the CYP except one made reference in some way to not being physically with their therapist, yet this was not identified from the caregiver interviews. There was a sense from the CYP that if they were physically with them, they might be interacting with them more, for example showing them items relevant to therapy as well as being assured that the therapist was listening to them.

Harder to Talk

All of the CYP except one made reference to finding it harder to talk to their therapist online. Some CYP described how it would feel easier to speak and ask questions if they were face-to-face and some referenced increased confidence and it feeling more personal, as reasons why talking might be easier in person. Lack of privacy at the child's end was described as a factor impacting how able they felt to talk, as well as not knowing who may be present in the therapist's room.

 Table 3

 Subthemes and supporting quotes for the Theme 'The Relationship is Affected'

Subtheme	Supporting Quotes:
Less of a Connection	Quotes from children:
	(about seeing therapist face to face) "um you can like learn
	more about him" (Child 6, lines 174-175)
	"I still felt listened to but I it feels more personal when
	you're in clinic and in the room" (Child 4, lines 93-94)
	(about seeing therapist face to face) "it's just you're
	actually talking to the person and it just makes it feel like
	you can talk to them better" (Child 3, lines 140-141)
	Quotes from caregivers:
	"when we started it he (the child) didn't know her (the

therapist) so maybe that's the reason (that it didn't work), cos he didn't want to talk to her" (Caregiver 2, line 154)

"I think the downside for me, from somebody who is a person that looks and observes, I'm that kind of learner [...] I think I missed out on some of the body language from her because I could only see her head [...] maybe misinterpreting some of it. (Caregiver 4, lines 59-69)

"I can't really tell what she's thinking" (Caregiver 4, line 172)

"You know that feeling you get from seeing someone face to face, the facial expressions..." (Caregiver 3, lines 134-135)

Lack of Physical Proximity

Quotes from children:

"well face to face is well more interaction and you're talking to somebody more but on video it's more like... digital" (Child 4, 39-40)

"you're actually talking face to face with someone instead of over the computer... so you're actually having a proper conversation with a real person instead of just talking with a... just talking through a video screen." (Child 5, 50-52)

(about face to face therapy) "they might like see... like, how big the tablets are... cos that's what I was scared of-how big it was" (Child 6, 146-147)

Harder to Talk	Quotes from children:
	"you never know like who is like in the (therapist's) room"
	(Child 4, line 117)
	"it would be easier for me face to face to like I'll be
	like able to speak more confidently." (Child 2, line 86-87)
	"it's nothing against anyone in my house. It's just I
	don't want I don't want to feel heard." (Child 1, line 111-
	112)

Practical Barriers

A further challenge described by CYP and caregivers was around practical barriers. Both groups referred to issues with technology, yet only caregivers considered the importance of a therapeutic space and how this was harder to access at home.

Technical Issues

Four CYP and two caregivers considered problems with technology to be a barrier to therapy working online. Poor signal resulting in an unreliable connection was described and CYP also commented on equipment failing, such as not being able to hear the therapist or their microphone not working. One caregiver described having an old computer which was very slow to connect to appointments.

Access to Therapeutic Space

Three caregivers highlighted how the home environment was, at times, not conducive to therapy. Reasons cited included having a noisy home, feeling that home was chaotic, as well as disruptions from family members. One caregiver also reflected that having a separate space for therapy, which is provided in-person, helps to settle into the session and prevents 'normal' life intruding on the therapy.

 Table 4

 Subthemes and supporting the Theme: 'Practical Barriers'

Subtheme	Supporting Quotes
Technical	Quotes from children:
Issues	"Um the connection isn't always that reliable" (Child 1, line 65)
	"sometimes it like it cracked, and then you can't hear him
	properly" (Child 6, line 23)
	Quotes from caregivers:
	"we've got a very old computer and sometimes it's on a really
	go slow" (Caregiver 3, line 51)
	"Cos it's a bit grainy and sometimes the sounds cuts out"
	(Caregiver 1, line 128)
Access to	Quotes from caregivers:
Therapeutic	"we had a bit of bother [] because (the therapist's) office, it's
Space	next to the ambulance station, so he had a bit of noise, and we
space	had a bit of noise didn't we?
	[] and there's things like when the light comes through the
	windows each side it bleeds the picture" (Caregiver 1, lines 80-85)
	"at home you're not necessarily in that zone, you're still thinking
	about what's for dinner and what's going on whereas if you're
	in a centre you're you know what you're there for" (Caregiver
	4, lines 273-275)
	"our son did walk in a couple of times and, you
	know, it's her business not his, do you know what I mean?"
	(Caregiver 4, lines 184-185)

"we moved to my in laws house and we living there and just kind of like [...] everything was upside down to be honest with you, at times" (Caregiver 2, line 139-140

Progress is Hindered

The final theme within the challenges of remote therapy, highlights how some caregivers felt that progress was hindered. This did not seem to be reflected in the child interviews, with CYP tending to comment that they thought therapy was going at a similar pace, or quicker, than how it might be face-to-face.

Pace feels slower

Three caregivers felt that therapy might have progressed more quickly in person, in terms of the young person feeling better and change occurring. With barriers such as delays to starting remote therapy or accessing resources, they seemed to communicate that therapy was slower online.

Children struggle to engage online

Three caregivers, all with the youngest children of those interviewed, commented on their children struggling to engage online. Reasons for this included that the child was too shy to talk, they were more distractible, and that they didn't know how to behave online. These caregivers all commented that their children also struggled to engage with and enjoy other online activities such as school lessons or hobbies. One caregiver ended up requesting face-to-face sessions for their child, due to attempts to engage the child via video and telephone proving ineffective.

 Table 5

 Subthemes and supporting quotes for the Theme: 'Progress is Hindered'

Subtheme	Supporting Quotes
Pace Feels	Quotes from caregivers
Slower	(when discussing if their child would have got better more quickly if
	seen face to face) "yeah more quickly yeah definitely" (Caregiver 2,
	line 202)
	"we may have we might have gone into a bit more detail (face to
	face) a bit quicker if you know what I mean" (Caregiver 5, line 217)
	"I just think the initial bit was tricky. Because we're in this thing where
	he couldn't contact us, it was all anonymous, you couldn't ring it back
	when it didn't work and and and he'd think 'oh they're not wanting to
	do it', or you don't know what's going on do you?" (Caregiver 5, lines
	111-116)
Children	Quotes from caregivers:
Struggle to	"when she's at home she finds it difficult [] and she would runs
Engage Online	off, just (doesn't) get involved in it somehow [] it's obviously down
	to the person and where they are developmentally and things like that"
	(Caregiver 5, lines 118-122)
	"he just like wasn't like talking to her, it just was like a waste of time to
	be honest with you" (Caregiver 2, lines 90-91)
	"maybe cos partly she does not know how to behave in front of her
	computer compared to a physical person" (Caregiver 5, lines 235-236)
	"but it soon became evident that she wasn't going to do them without
	me sitting next to her [] all of them have been with me sitting next to
	her" (Caregiver 3, lines 37-38)

3.5 Theme Three: Future Directions

CYP and caregivers commented on their preferences in relation to therapy medium. Both groups commented on the value of face-to-face contact, and suggestions were made around flexibility of session medium in the future.

Value of incorporating in-person contact

Four CYP and three caregivers highlighted the value of the child seeing the therapist in person. CYP said they would prefer to have met them face-to-face as they might not feel they know them otherwise. In cases where CYP had met the therapist face-to-face previously, they commented that they felt less nervous and shy than if they never met them before. Caregivers felt similarly and commented that meeting the therapist in person before starting sessions would help engagement and build rapport. However, one caregiver felt the opposite of this was helpful for her child; that to be able to get to know the therapist on video prior to meeting them in person was helpful.

A flexible future

When asked to think about their preference for the future, four CYP raised the idea of accessing a mixture of face-to-face and remote therapy. Reasons behind this included allowing them to make the most of being in hospital for appointments, by seeing their therapist too, but not wanting to go for each therapy appointment. Being able to have remote sessions when away or busy, or when struggling with their mental health were also discussed. Four caregivers also referenced flexibility going forwards, with the option to chose blended sessions with at least some face-to-face contact.

 Table 6

 Subthemes and supporting quotes for the Theme: Future Directions

Subtheme	Supporting Quotes
Value of	Quotes from children:
incorporating in-	"I think I'd be like, worried and anxious that I don't know
person contact	who they are if I'd not met them" (Child 4, lines 140-141)
	"If I like just did zoom therapy then like one day went in I
	would find that quite nervous like meeting her you
	know (Child 1, lines 60-61)
	Quotes from caregivers:
	"I think had she not had that initially um face to face meeting
	with (the therapist) I think it would have been a lot more
	different because she I was able to remind her of that nice
	lady we met in Leeds." (Caregiver 3, lines 122-123)
	"I think if you've already built that rapport, you just keep it
	going don't you" (Caregiver 4, lines 518-519)
	"It only came out from his mouth when he spoke to her face to
	face" (Caregiver 2, line 69)

A flexible future

Quotes from children:

"well if I was in hospital, just for an appointment anyway I'd rather do it face to face. But if I just went into hospital for that appointment I probably wouldn't now." (Child 1, lines 190-191)

"I'd prefer going in the clinic but if it just...like a check-in or we're really busy, it'd be good... if you're if, like, away on holiday and you needed like a session, but you couldn't get to clinic" (Child 4, lines 200-201)

"um a bit of both cos sometimes I'm scared of going into the hospital" (Child 6, line 180)

Quotes from caregivers:

"I've kind of been thinking it might be handy to kind of mix up the sessions? [...] just sort of have a monthly meet up or... and then some zoom sessions... or, I dunno maybe a one or twice a month meet up and then zoom sessions" (Caregiver 5, lines 345-347)

"personally I would like the odd session in the centre cos I just think you get a different relationship [...] but I don't necessarily want the inconvenience of it every single week" (Caregiver 4, line 510-514)

"maybe one session (face to face) if possible, with who you're going to meet" (Caregiver 3, line 290)

4.0 Discussion

The interviews were successful in addressing the aims of the study and provided information regarding participant's general experiences, both positive and negative in nature, as well as the impact on the therapeutic relationship and outcomes. Whilst some subthemes mirrored the questions asked, the researcher did not pre-judge the participant's responses and provided space to reflect.

4.1 Benefits of Remote Therapy

The positives of video therapy identified in this study are largely congruent with the literature on remote therapies, particularly that having psychotherapy remotely is considered more convenient for patients (Drum & Littleton, 2014), and young people describe feeling safer and better able to discuss their problems online than when face-to-face (Navarro et al., 2019). Interestingly, some of the positives of video therapy commonly described in the literature were not replicated in the interviews, such as CYP feeling a greater sense of power or control over their sessions compared to when in-person (James, 2020). With only two caregivers experiencing occasional telephone therapy, the project did not generate meaningful findings about the medium of telephone

Although a robust evidence base looking into the effectiveness of remote therapy for children is lacking (Hollis et al., 2017), studies have shown promising outcomes (Bischoff et al., 2014; Gloff et al., 2015; Slone et al., 2012), consistent with participant responses in the current study.

4.2 Challenges of Remote Therapy

The experience of technical issues as well as difficulty accessing a private, therapeutic space were some of the practical challenges described by participants which are consistent with existing research (James, 2020). However, whilst CYP did highlight challenges in accessing a private space at home, they did not raise concerns around the security of their information online which has been mentioned as a concern in other research studies (Ring, 2014). However, this may be a reflection of the

interview questions, which did not explicitly explore feelings of safety and security with remote therapy.

The negative impact on the therapeutic relationship was frequently described as a consequence of having therapy remotely. This was often directly referred to, with participants expressing a disconnect between themself and their therapist, or more indirectly, with the relationship being alluded to; an example of the latter being how it might feel 'more personal' if they were in the room with the therapist. Interestingly, therapists also appear wary of the impact on the relationship, with concerns that technology-based communication may impede the ability to develop rapport and a connection with the young person (Orlowski et al., 2016). Had this been a larger scale project, interviewing clinicians would have facilitated validation of the data through triangulation, and offered an important perspective.

In cases where children struggled to engage with remote therapy, age seemed to be a crucial factor. When children perceive an activity to be 'work' rather than 'play', their ability to pay attention may be impacted (Moyer & Gilmer, 1954); speaking to somebody on a computer screen may be experienced as 'work' and may explain the difficulty young children face in paying attention online for prolonged periods of time. Engaging online also requires learning a new way of behaving, which may be harder for younger children (Bologna, 2020).

4.3 Future Directions

Despite the challenges described, participants typically did want remote therapy to feature in their care in some capacity, which is in line with previous research (James, 2020; National Collaborating Centre for Mental Health, 2014). Whilst some wanted to continue having sessions entirely remotely, others wanted the option of remote sessions as a 'back-up' if they were unable to attend the clinic in person. Most often, CYP and caregivers spoke of wanting a blend of online and face-to-face sessions.

Offering remote therapy certainly speaks to the NHS long-term plan (NHS, 2019), which stipulates that children's health services should be person-centred, closer to home, and consider the use of technology. As remote therapy continues to be offered, the breadth and quality of the research base is likely to grow, allowing for better informed remote interventions.

4.4 Strengths and Limitations

Application of the findings should be considered in the context of the study's strengths and limitations. Whilst the project would have benefitted from recruiting a more ethnically diverse sample and considering the perspectives of families from different income groups, efforts were made to sample CYP and caregivers from a diverse range of paediatric specialities. Furthermore, interviewing caregivers alongside CYP offered valuable insight into the experience of the family, particularly when the therapy was delivered via the caregiver.

Due to difficulties in recruitment requiring multiple changes to the recruitment strategy and inclusion criteria, the variation in participant's prior experiences was broader than initially anticipated. Participants differed in their previous therapy experiences; for example, some had received a portion of face-to-face therapy in the past, whereas others had not, and some had met their therapist face-to-face whereas others had not. This variability influenced participant's responses, since some naturally drew upon previous experiences as a reference for comparison. Further to this, variability was present in the caregiver's experiences; those interviewed had different levels of involvement in the therapy, from being present with the child in a supportive capacity, to the work being delivered entirely through the caregiver and the therapist never meeting the CYP. For the purposes of this project the caregivers were considered one group, and so differences in their experiences, depending on how they were used in the therapy, may have been concealed.

Finally, interviews with CYP relied on the researcher taking a lead in the conversation due to children providing briefer responses and requiring more frequent prompts. This may have increased the power difference, preventing the CYP from voicing their true opinions (Einarsdóttir, 2007). Conducting the interviews via video or face-to-face may have helped to mitigate against this.

4.5 Recommendations

The interviews have provided valuable insight into how CYP and caregivers of Leeds Children's Hospital experience remote therapy, predominantly via video. The suggestions outlined in Table 7 hope to inform both how the service, and individual therapist's, approach remote therapy.

Table 7

Service Recommendations

- To consider offering a choice of therapy medium where possible, with the option for the CYP and/or caregivers to choose a blend of face-to-face and remote therapy if preferred.
- To consider offering an initial in-person session to allow the child and/or caregiver to meet them face-to-face and to assist in development of the therapeutic relationship. This may be best facilitated through arranging to meet them at the time of a medical appointment.
- If seeing the child and/or caregiver remotely, to consider an initial telephone call to assess whether they can access a private space and have the appropriate technical equipment, WiFi etc.
- To ensure the child and/or caregiver is made aware of the location of the therapist e.g., alone in clinic room, cannot be overheard by other professionals.
- To consider the child's developmental stage, and previous experiences with engaging in online sessions (e.g., for school, hobbies), when deciding which therapy medium may be most effective.
- Where body language is used to convey meaning e.g., that the therapist is actively listening or communicating empathy, consider accompanying this with a verbal explanation to account for difficulties interpreting body language online, or deliberately exaggerate non-verbal behaviours.
- To encourage the child and/or caregiver to provide ongoing feedback on the impact of having therapy remotely, to allow the therapist to change to faceto-face if required.
- To consider the value of commissioning a Service Evaluation Project interested in the therapists' experience of delivering psychotherapy remotely.

4.6 Dissemination

Given that best clinical practise should always be shared (NHS, 2019), the findings will be disseminated in the following ways:

- Presentation at the University of Leeds Clinical Psychology SEP conference in October 2021.
- Presentation at Leeds Children's Hospital departmental meeting.
- Full report shared with the paediatric psychology services.
- Summary of findings emailed to participants who wished to be informed of the results.
- Dr Richard Hobbs (SEP commissioner) to present the findings at an NHS England improvement workshop.
- Presentation at a relevant UK poster conference.

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6.0 Appendices

Appendix A: Recruitment Poster

Service Evaluation Project: 'Children's and Caregiver's Experiences of Receiving
Remote Psychological Therapy within
Leeds Children's Hospital'



Study Overview:

The aim of this service evaluation project is to interview approximately 6 children and 6 caregivers about their experiences of engaging in remote psychological therapy either through video consultations or over the telephone. We want to interview children/caregivers where the child has received remote therapy from a Clinical Psychologist, Trainee Clinical Psychologist or Assistant Psychologist.

The reason for interviewing caregivers alongside children is that many children will have been too young to engage in direct psychological therapy, so psychological therapy will have been provided indirectly, through the caregiver. Interviews will take place over the phone, will be approx. 30 minutes long, and will be recorded and later transcribed (anonymously). We hope to understand what the children and caregivers found helpful or unhelpful about receiving a therapeutic intervention in this way, how it may have impacted their perceptions of the therapeutic relationship, and whether engaging in psychological therapy remotely had achieved the outcomes they had hoped for.

Who to recruit?

- Any child aged 8+ who has engaged in remote (either telephone or video)
 psychological therapy. This can include children and young people who are still
 engaging in this episode of psychological therapy.
- Where the child is younger than 8 and the therapy was delivered via the caregiver, the caregiver should be recruited instead.
- Children/caregivers can be recruited if they were seen face to face and then switched to telephone/video, or if they were seen purely virtually (no face to face).
- Please consider all of those who have engaged in remote psychological therapy (i.e., not just the cases that have gone well!) so that we can access the range of experiences.
- All children must be assessed by the Psychologist involved in their care as being Gillick competent. All caregivers must be assessed by the Psychologist as having the capacity to consent to the study.

- The Psychologist should discuss the possibility of taking part in the study with the child/caregiver, emphasising that this is entirely voluntary and will not impact their treatment in any way. The Psychologist should check that is it ok that I first give them a call to check whether they are interested in taking part. They can also reassure the child/caregiver that the information given during the interview about their experiences will not be shared with the Psychologist they are working with and they will remain anonymous.
- Please email <u>leedsth-tr.virtualtherapypsychologyproject@nhs.net</u> with the name of the person being interviewed, state whether they are the child or caregiver, provide their email address, telephone number and the health speciality they receive care from within the Leeds Children's Hospital e.g. liver, rheumatology, chronic pain, oncology etc.
 - Please send this email from your secure NHS.net email account and do not provide any further information about the participant to ensure that only necessary personal information is shared.
- The Psychologist can let the participant know that the next stage in the process would be for them to have these details passed on to the researcher (Jasmine Maydom- Trainee Clinical Psychologist) and that they will be sent out a link via email, containing information about the study and asking them to provide consent if they choose to take part. Following completion of this, the researcher will call the participant to arrange a suitable time for the interview.

Thank you for your help with recruitment!

Appendix B: Child Participant Information Sheet (Presented in Qualtrics)



<u>Children's and Caregiver's Experiences of Receiving Remote Psychological Therapy at Leeds</u> Children's Hospital.

About the project

Due to the COVID-19 pandemic, Leeds Children's Hospital had to stop seeing children face-to-face for therapy, and all appointments changed to being over the telephone or by video.

We want to find out what it was like to have therapy on the telephone or by video, and this is why you have been chosen to take part. The reason that this is important to us is because with your feedback we will be able to learn from your experiences in order to help you, and other young people, get the best help and support.

What would happen if I take part of the project?

You would be telephoned by the researcher for a discussion about what your experience of having therapy at home was like. You would be asked questions about what it was like, what was good and what was not so good, as well as any ideas you have about how to make it better.

We think that this will take about 30 minutes, and you can have this call at home, or any quiet space that works best for you. If it makes you more comfortable, you are welcome to have someone you trust (like your parent/caregiver) in the room with you. The interview will be recorded by the researcher who calls you up, so that they can listen back to it.

Who is running the project and who will interview me?

This research is being organised by two Clinical Psychologists who work at Leeds Children's Hopsital, called Dr Catherine Reid and Dr Richard Hobbs. They are working with a researcher called Jasmine Maydom who is training to become a Clinical Psychologist at the University of Leeds. She will interview you if you decide to take part. She will also be interviewing other young people like you, and adults, and is interested in hearing about your experience.

Do I have to say yes to being part of this project?

No, it is totally up to you. There is no pressure to take part and you can change your mind at any point beforehand, or even during the interview, and don't need to tell the interviewer why you don't want to take part. Also, you don't need to answer any questions you don't want to.

If you say yes to taking part and have the interview, but then decide afterwards that you don't want the things you said to be analysed for the project, you can ask for your recording to be deleted for up to 7 days afterwards. You would just need to ask your parent/caregiver to email leedsth-tr.virtualtherapypsychologyproject@nhs.net. You would not need to explain why.

If you say no, it won't affect your normal appointments at Leeds Children's Hospital, and no one will be upset.

Will anyone know what I say in the interview?

The researcher who calls you up will record the interview and will listen to it back to make notes about what you said. The recording, and the typed interview notes will be stored in a safe, secure place where no one can access them without permission. Other information collected about you, such as your name, will also be stored safely. The University of Leeds will delete all of the data, including the recordings, 3 years after the project ends.

A report will be written up after everyone has been interviewed, and we will include quotes from what you and other people shared, but we won't use any names.

The only time that what you say might be shared with other people is if you say something that makes us worried that you, or someone else, might be in danger of harm. If this happens, we will have to tell someone who can help.

What happens with the things I say, after the interview?

After everyone has been interviewed, the findings will be written up into a report which will be handed in to the University of Leeds. The main findings will also be presented to a group of trainee psychologists at the University of Leeds.

To help people to understand how to make things better, we will pass on the findings to people working at Leeds Children's Hospital, like psychologists, as well as people who might be about to start having therapy on the phone or by video to let them know what it might be like.

There is also a possibility that the findings will be published so that they can be read by more people across the country, such as those working at other hospitals, or the results might be presented at talks.

What are the pros/cons to me taking part?

Although you will never be asked to tell the interviewer any of the things you spoke about in therapy with your psychological therapist, there is a small chance that the interview could make you upset if it reminds you of anything difficult that you talked about in therapy.

You are free to stop at any time should if you feel upset.

You may worry about making any negative things about your experience. However, any negatives about what therapy was like for you are actually really helpful in letting us know how we might be able to improve things in the future.

The findings from the project will help Leeds Children's Hospital to understand what remote therapy is like for you and other young people. We hope that the interview will help you to feel that your experiences are important and valued.

Will I receive anything for taking part?

Unfortunately, we can't offer you anything for taking part but we hope that you have a good experience of the interview, and enjoy speaking to someone about what therapy is/has been like for you.

What if I have more questions?

If you have any other questions you can contact the researcher, Jasmine Maydom, on the following contact details:

Researcher: Jasmine Maydom – <u>leedsth-tr.virtualtherapypsychologyproject@nhs.net</u>

If you have any questions or concerns regarding ethical procedures related to this study, please contact the Chair of the Psychology Ethics Committee, by post at School of Psychology, University of Leeds, Leeds, LS2 9JT, by telephone on+44 (0) 113 343 7247.

Ethical approval has been sought from the School of Medicine Research Ethics Committee (SoMREC project number.....)

Concluding Remarks

Thank you for taking the time to read this information. If you have any more questions or worries about taking part, please do get in touch.

Appendix C: Caregiver Participant Information Sheet (Presented in Qualtrics)



<u>Children's and Caregiver's Experiences of Receiving Remote Psychological Therapy within</u> Leeds Children's Hospital.

We would like to invite you to take part in a service evaluation looking at caregivers and children's experiences of receiving psychological therapy remotely. Before you decide whether to participate it is important for you to understand why the project is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please email the researcher if there is anything that is not clear, or if you require more information. Take time to decide whether or not you wish to take part.

Part 1 tells you the purpose of the study and gives a summary of what will happen if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Part 1

What is the purpose of this project?

Due to the COVID-19 pandemic, Leeds Children's Hospital responded by suspending routine face-to-face outpatient activity and transferring all routine outpatient appointments to telephone calls or video consultations via Attend Anywhere. The current study aims to explore how caregivers and children under the care of Leeds Children's Hospital have experienced remote psychological therapy.

The study is using telephone interviews to ask both children and caregivers about their experiences of remote psychological therapy provided by psychological therapists. Questions will be asked in relation to your experiences, including the challenges and advantages of remote psychological therapy, the therapeutic relationship, and how useful it has been.

Study summary

The researcher will be a Trainee Clinical Psychologist and will conduct the interview in a quiet, confidential environment. You have the option of choosing where you would like to be for the interview i.e., at home, or somewhere more convenient such as work, so long as this is in a private space.

Why have I been chosen?

Approximately 6 children and 6 caregivers will be interviewed as part of this project. You are reading this information sheet because you were approached by a psychological therapist in

the Paediatric Psychology service at Leeds Children's Hospitals and asked if you were interested in taking part.

Do I have to take part?

Participation is completely voluntary, and it is entirely your decision whether you wish to take part. If you decide to participate you can still withdraw from the study for up to 7 days after the interview has taken place, by informing the researcher that you do not want your data to be used in the study (contact: leedsth-tr.virtualtherapypsychologyproject@nhs.net). No questions will be asked about your decision.

What are the possible disadvantages of taking part?

There is a small risk that discussing your experience of remote therapy could be distressing. Although at no point will you be asked to touch on the reason for the therapy, or content of the sessions, discussing your experience may naturally result in reflection on the reason for therapy which may be distressing. You are free to stop at any time should you feel upset or distressed and do not have to answer any questions you do not wish too. If you do feel any distress or negative emotions after the study we would recommend getting in contact with the psychological therapist involved in your care.

You may worry about making any negative comments about the service you, and the child you care for, received/are receiving, however any negative themes regarding how remote therapy is being delivered in the service will hopefully increase understanding and will likely be incorporated into improving the delivery of remote psychological therapy across the service. Your responses will also be anonymised.

It may also be inconvenient for you to give up your time to have the interview. You should think carefully about how you will feel about taking part and if you will be able to commit to arranging a time for the interview with the researcher. However, it is important to remember that if you agree to take part you can withdraw at any point without having to explain your reasons.

What are the benefits of taking part?

Whilst there are no immediate benefits, the findings from the project will help Leeds Children's Hospital to better understand how remote psychological therapy is being experienced by those in which it serves. It is hoped that the interviews will help you to feel that your experiences are important, and your voice is valued.

All interviews will be recorded. All interview recordings and personal information will be handled sensitively and the study will strictly adhere to ethical practice. Detailed information is given in part 2.

Will I receive anything for taking part?

Unfortunately, we are not able to offer any form of compensation for taking part, but we hope that you have a positive experience of the interview, and benefit from the space to have your experiences heard.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will I have to do if I take part?

Engage in a telephone interview for 30 minutes. It is up to you where you would like to be for the telephone interview, however we recommend you remain in your home environment, or if that is not possible, somewhere quiet and private.

What happens to the data collected and is it confidential?

Personal information collected, such as your email address, telephone number and the demographic information provided on the consent form, will be stored in the researcher's personal university storage area permitted for highly confidential data by the university's data protection policy, separate to the transcript of your interview. Only the researcher will have access to your interview recording and when transcribing, will listen to the recording through headphones. All interview transcripts will be anonymised (e.g., you will be assigned a number such as Participant 1) and the demographic information you provide will not be linked to this transcript. Transcripts will also be held in the researcher's personal university storage area. Your data will be deleted after 3 years, in line with information governance requirements.

Although most of the interview will remain confidential, direct quotes will be included in the write-up of the evaluation. Since you are being interviewed because you are in a unique situation (i.e., a child or the caregiver of a child under the care of Leeds Children's Hospital, who have experienced remote therapy) that only a few can comment on, deductive disclosure may be possible. This means that, although unlikely, there is a possibility of people who know you being able to identify who you are based on quotes included in the write-up.

Confidentiality may be broken if you disclose information which suggests that you pose a risk to yourself or others. If this situation arises then this will be discussed with you and may need to be discussed with the commissioners and the psychological therapist. If the psychological therapist is not a qualified Clinical Psychologist (i.e. they are an Assistant Psychologist or Clinical Psychologist in Training) this will need to be raised with the qualified Clinical Psychologist clinically responsible for the care of the child.

Findings from the project will be written up into a report which will be submitted to the University of Leeds and presented to staff and trainees associated with the Clinical Psychology Doctoral training course. Findings will also be disseminated within Leeds Children's Hospital, for example, as a patient leaflet containing quotes, and presented as a summary in a department meeting. There is also the possibility that findings may be published in an academic journal or presented at relevant local or national conferences nationwide.

What will happen if I don't want to continue?

If at any point during the study you no longer wish to continue, you are free to withdraw without having to give an explanation for your reasons. If the interview has not yet taken place, please let the researcher know via emailing the address located below. If you decide not to continue during the course of the interview, please let the researcher know and they will stop the interview immediately. If you decide that you do not wish your interview responses to be analysed as part of the service evaluation, please email the researcher on the address provided below within 7 days of being interviewed and your data will be deleted.

Who is organising, funding and reviewing the study?

This research is commissioned by Leeds Teaching Hospitals Trust (LTHT) and is supervised by Dr Catherine Reid, who works in the Cleft Lip and Palate service and Dr Richard Hobbs, who works in Major Trauma and Orthopaedics. They are working alongside a researcher, Jasmine Maydom, who is training to become a Clinical Psychologist at the University of Leeds. She will interview you if you decide to take part. All research is assessed and approved by the School of Medicine Research Ethics Committee at the University of Leeds, to protect your interests and wellbeing. There are no funding bodies included in this research.

Who can I contact for further information?

If you have any remaining questions regarding your participation, you can contact the researcher, Jasmine Maydom, on the following contact details:

Researcher: Jasmine Maydom – <u>leedsth-tr.virtualtherapypsychologyproject@nhs.net</u>

If you have any questions or concerns regarding ethical procedures related to this study, please contact the Chair of the Psychology Ethics Committee, by post at School of Psychology, University of Leeds, Leeds, LS2 9JT, by telephone on+44 (0) 113 343 7247.

Ethical approval has been sought from the School of Medicine Research Ethics Committee (SoMREC project number.....)

Concluding Remarks

Thank you for taking the time to read this information sheet. If you have any additional questions or if something is unclear or does not make sense, please do not hesitate to ask.

If you would like to receive a summary of the results of the project, please be sure to let the researcher know either at the end of the interview or by emailing leedsth-tr.virtualtherapypsychologyproject@nhs.net

Appendix D: Child Consent Form (Presented in Qualtrics)

Please ensure that your parent/caregiver reads through the following questions with you, and that they provide a typed signature at the end

I agree that (please tick):	
I have read and understood the information sheet and have been able to ask any questions I have.	
I know that I do not have to be interviewed if I don't want to be, and I can stop the interview at any time. I know that even if I finish the interview but do not want my answers to be used in the research, I can ask for the recording of my interview to be deleted up to 7 days afterwards.	
I understand that if I tell my interviewer anything about me or someone else that worries them, they will have to tell my therapist. If my therapist is not a qualified Clinical Psychologist, they will have to speak to the Clinical Psychologist responsible for my care. (An example is if they thought you were being hurt at home)	
I understand that once the interview has finished, the research that is carried out will include quotes from me and other people who were interviewed but won't mention any names.	
The interview will be recorded, and this recording will be stored for 3 years.	
It is ok for the information I give in the interview to be used to help improve services at Leeds Children's Hospital, to be written up in a report that might be read by people around the country, and to be presented at talks.	
I agree to take part in this study.	
Child's Name:	
Caregiver's Signature:	
Date:	

Appendix E: Caregiver Consent Form (Presented in Qualtrics)

Statement of agreement	Please place a check in the box to confirm agreement
I confirm that I have read and understood the participant information and have had the opportunity to ask questions.	
I understand that my participation is voluntary and that I am free to withdraw at any time prior to or during the interview without giving a reason. If I choose to withdraw, I understand that I can ask for my data to be withdrawn for up to 7 days after the interview, at which point transcription will have begun and it will no longer be possible to remove my data.	
I understand that should I make any disclosures during the interview that the interviewer is concerned about, they will have a duty of care to inform the psychological therapist involved in my care. Where the therapist is an Assistant Psychologist or A Psychologist in Clinical Training, the qualified Clinical Psychologist clinically overseeing their work will be informed. An example would be if the child is at risk of harm.	
I understand that once the interview has finished, all data will be anonymised, but that direct quotes will be used in the dissemination of the findings and there is a small chance that people who know me may be able to identify me from these.	
I agree to the interview being audio recorded and am aware that this recording will be stored securely for 3 years.	
I give permission for the anonymised data collected from the interview to be used for audit and service evaluation purposes.	
I give my permission for the anonymised data to be submitted for publication and presented at conferences.	
I agree to take part in this study.	
Name:	
Typed Signature:	
Date:	

Appendix F: Child Interview Questions

Introductions/establish rapport and review consent to take part. Remind participant that they can stop at any time during the interview.

Establish what type of support was offered: Attend anywhere (video)/Telephone/Both

Any comments on this:

- 1. Experience of online/remote options
 - a) What was it like having therapy online/over the phone?
 - b) How good was the therapy you had on the phone/via video? Follow up questions: Why is that? What has helped/not helped with that?
 - c) What do you think would be/had been the main difference between having therapy in this way, compared to having it face-to-face?
- 2. Challenges and advantages of online/remote therapy.
 - a) What has worked well? Do you think there was anything better about you having therapy at home, than if/when you had had it face-to-face?
 - b) What has been more difficult? Do you think there was anything worse about you having therapy at home, than if/when you'd had it face-to-face?
 - c) How easy was it to have the appointments at home? Did you have everything that you needed to make it work?
 - d) Is there anything about you having therapy on the phone/video that could be improved?

3. Therapeutic relationship

- a) Do you feel that having the sessions on the phone/via video affected how listened to you felt by the Clinical Psychologist?
- b) Do you think that having the sessions on the phone/via video affected how understood you felt by the Clinical Psychologist?
- c) Do you think that having therapy on the phone/via video affected how much you got to have a say in what you did in the sessions? Did it affect how able you felt to talk about how you were feeling? Did it affect your ability to ask questions?
- d) As a results of having therapy on the phone/via video, have you developed good or bad feelings about the psychologist? Can you describe how you feel about them and why you might feel that way? Do you think you'd feel the same if you met with them face-to-face?
- e) From having therapy on the phone/via video, what thoughts or feelings do you think the psychologist has about you?

4. Outcomes

- a) Would you say that having therapy over the phone/via video has gone quicker than expected, slower than expected, or something else?
 What do you think it was about the phone/video therapy that made it quicker/slower/something else?
- b) Do you feel like you focussed on things that were important to you over the phone/video? If yes, what has helped with that? If not, why not?
- 5. Do you have anything else you would like to tell me about? Any advice for what you think could make having therapy on the phone or video better? Or something which has made it good for you?

If you could go back to f2f, would you?

Any advice for anyone?

Appendix G: Caregiver Interview Questions

Introductions/establish rapport and review consent to take part. Remind participant that they can stop at any time during the interview.

Establish support offered: Attend anywhere (video)/Telephone/Both

Any comments on this:

- 1. Experience of online/remote options
 - d) How would you describe your experience of (child's name) having phone/video therapy?
 - e) How would you describe the quality of therapy that (child's name) received via phone/video? Why is that? What has helped/not helped with that?
 - f) What do you think would be/or has been the main difference compared to if/when (child's name) had experienced therapy face-to-face?
- 2. Challenges and advantages of online/remote therapy:
 - e) Do you think there is anything better about accessing psychological therapy online, compared to if/when (child's name) had it face-to-face?
 - f) Do you think there is anything worse about accessing psychological therapy online, compared to if/when (child's name) had it face-to-face?
 - g) How have you managed the appointments at home? Did you have all the equipment/safe space or any other practical demands?
 - h) Is there any part about your experience of (child's name) receiving online/remote therapy that could be improved?

3. Therapeutic relationship

- f) In what ways do you feel that video affected how listened to you and (child's name) felt by the Clinical Psychologist?
- g) Do you think that having therapy remotely affected how understood have you and (child's name) felt by the Clinical Psychologist?
- h) Do you think that having therapy remotely affected how much input you and (child's name) had in the sessions? Did it affect your ability to express your thoughts, feelings and experiences? Did it affect your ability to ask questions?
- i) As a result of having therapy on the phone/via video, do you think (child's name) developed positive or negative feelings about the psychologist? Why do you think they felt that way? Do you think (child's name) would feel the same if they met with them face-to-face?
 - How about you, as a result of remote therapy, what feelings have you developed towards the psychologist?
- j) Through (child's name) having therapy remotely, what thoughts or feelings do you think the psychologist has about (child's name) and about you?

4. Outcomes

- a) How has the therapy progressed over the phone/video? As expected, delayed, quicker? If so, what has helped with this or made it more difficult?
- b) Do you feel that things that were important to (child's name) and you were focussed on over the phone/video? If yes, what has helped with that. If not, why not?

5. Do you have anything else you think it would be helpful to share? Any advice for what you think could have made having therapy remotely better for (child's name)? Or something which has been good about it? If they had a choice of whether to have f2f or remote which do you think they would prefer? Which would you prefer?

Would you like me to email you a summary of the findings once the project has been written up?

Appendix H: LTHT Research & Development Approval Email

From: GOWING, Anne (LEEDS TEACHING HOSPITALS NHS TRUST) < anne.gowing@nhs.net >

Sent: 08 January 2021 11:32

To: Jasmine Maydom [bs12j2m] < bs12j2m@leeds.ac.uk >; RESEARCHOFFICE, Ltht (LEEDS

TEACHING HOSPITALS NHS TRUST) < ltht.researchoffice@nhs.net>

 $\textbf{Cc:} \ \, \text{ATKINSON, Kate (LEEDS TEACHING HOSPITALS NHS TRUST)} < \underline{\text{kate.atkinson6@nhs.net}} > ; \\ \text{HOBBS, Richard (LEEDS TEACHING HOSPITALS NHS TRUST)} < \underline{\text{richard.hobbs1@nhs.net}} > ; \\ \text{REID,} \\$

Catherine (LEEDS TEACHING HOSPITALS NHS TRUST) < catherine.reid@nhs.net>

Subject: RE: Service Evaluation Project

Dear Jasmine,

Thanks for the email and the protocol. That was really helpful to see. Unfortunately I was on leave over Christmas and New year hence not able to reply until now.

You project would certainly be classed as service development/quality improvement and not require Health Research Authority (HRA) or NHS Research Ethics Committee (REC) approval. You should gain ethical approval from the University however.

I hope this is helpful. Kind regards, Anne

Anne Gowing

Research Governance Manager Leeds Teaching Hospitals NHS Trust

E: anne.gowing@nhs.net

R&I Office email: ltht.researchoffice@nhs.net

I am currently working from home.



