**“I’m just kind of talking to my screen and it responds back”: A thematic analysis exploring the experiences of adults with an intellectual disability who received a virtual cognitive behavioural therapy-based intervention during the COVID-19 pandemic**

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**Thesis Portfolio: Candidate Declaration**

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| **Title of degree programme** | **Professional Doctorate in Clinical Psychology** |
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| **Declaration and signature of candidate** |
| I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work.  I confirm that the decision to submit this thesis is my own.  I confirm that except where explicitly stated, the work has not been submitted for another academic award.  I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis.    Signed: Date: 27.04.2023 |

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# Thesis Abstract

People with intellectual disabilities (PWID) were disproportionately impacted by the rapid switch to virtual delivery of mental health support necessitated by the COVID-19 pandemic from March 2020, yet their needs are frequently overlooked in this research area. This thesis aims to understand the experiences of PWID and the professionals that supported PWID during the pandemic in order to inform policy and training as we navigate the post-pandemic world.

Paper one is a literature review which explores what is known about the experiences of psychological professionals (PPs) who provided psychological support to PWID during the COVID-19 pandemic. Eleven papers were identified, critically appraised and thematically synthesised. Four themes were synthesised from research data: *Impact at service level, The emotional impact on PPs, The limitations of virtual support,* and *Unexpected gains.* PPs shared the impact of remote working on their psychological well-being, with contributing factors of increased pressure, feeling abandoned by management and difficulties managing work-life balance. Increased flexibility and the benefits of virtual psychological support for autistic people were also raised. Future research exploring the experiences of PWID receiving virtual therapy is recommended.

Paper two is an empirical research paper which explores the experiences of adults with an intellectual disability who received a virtual CBT-based intervention during the COVID-19 pandemic. Eight participants completed a semi-structured interview which was analysed thematically (Braun & Clarke, 2022). Four overarching themes were identified: *Power, Therapy process, Therapeutic relationship,* and *Safety in the virtual environment.* This empirical study highlights the importance of psychological safety for PWID when receiving virtual support as a lack of psychological safety impacted the quality of therapeutic relationship and engagement in intervention. The unique challenges faced by PWID, such as reliance on non-verbal communication and confidentiality in residential environments, must be considered. Future research exploring the development of therapeutic alliance when working virtually is recommended.

The final paper in this thesis is an executive summary which provides an overview of the completed empirical paper. There is a Brief and Extended version of the executive summary included. Both have been written with PWID in mind and have been reviewed by service users.

# Paper One: Literature Review

**“We don’t have the answers”: What do we know about the experiences of Psychological Professionals providing virtual psychological support to people with intellectual disabilities during the COVID-19 pandemic?**

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Supervised by Dr Kim Gordon

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*This literature review has been written in accordance with author guidelines for The Journal of Applied Research in Intellectual Disabilities (Appendix A)*

# Abstract

**Background**

Government restrictions enforced globally in response to COVID-19 necessitated changes to the delivery of mental health services, with many psychology professionals (PPs) forced to transfer their face-to-face practice to virtual means (telephone/video call) overnight. This review explores what is known about the experiences of PPs providing psychological support to people with intellectual disabilities (PWID) during the pandemic.

**Method**

Literature was systematically searched and eleven papers were identified, critically appraised and thematically synthesised.

**Results**

Four themes were synthesised from data: *Impact at service level, The emotional impact on PPs, The limitations of virtual support,* and *Unexpected gains.*

**Conclusions**

This review highlights the challenges and positives in experiences of PPs, whilst acknowledging the inequalities experienced by PWID. It is hoped that the findings can be used to aid education and training, and inform future practice and policy. Future research exploring the experiences of PWID receiving virtual therapy is recommended.

**Keywords**

Intellectual disability, COVID-19 pandemic, virtual, psychological support, experiences, psychology professional

# Introduction

On 11th March 2020, the World Health Organisation (2020) declared a pandemic due to the rapid transmission of a respiratory disease called COVID-19 (Morgül et al., 2020). The pandemic necessitated sudden and radical changes to many aspects of daily life, and restrictive measures were introduced globally (Feijt et al., 2020). For example, the United Kingdom (UK) Government introduced police enforced lockdowns which mandated people leaving their home infrequently and working from home where possible (Davies et al., 2021).

Between 1 to 3% of the global population are people with an intellectual disability (PWID; Maulik et al., 2011; Salvador-Carulla et al., 2018), categorised by an IQ of less than 70 and significant limitations in adaptive skills present before the age of 18 (Totsika et al., 2022). PWID are equally as likely as the general population to experience anxiety or depression, however more likely to receive a diagnosis of a psychiatric condition (Foundation for People with Learning Disabilities, 2022). This may be due to greater exposure to social and physiological determinants of health such as poverty, reduced health literacy and low levels of exercise (Emerson & Baines, 2011). The pandemic has exacerbated health inequalities for PWID as they are at greater risk of contracting COVID-19 (Courtenay & Perera, 2020) and experienced associated mortality at 4.1 times higher than the general population as health needs are often overlooked or misattributed to their ID (Public Health England, 2020). With the disproportionate impact of COVID-19 on PWID, access to mental health support is essential (Gregson et al., 2022).

Psychology Professionals (PPs) play a central role within specialist teams which support the psychological well-being of PWID, typically providing individual or systemic support within a face-to-face capacity pre-pandemic. Many psychological interventions are adapted for delivery to PWID (Beail, 2017), including consideration of the client’s level of understanding, ability, and needs and strengths; some interventions may require changes to delivery to accommodate physical, cognitive, sensory and communication impairments (National Institute for Health and Care Excellence, 2016).

The pandemic generated fear and panic globally (Brooks et al., 2020; Pillay & Barnes, 2020), with reports in the UK of reduced psychological well-being, increased anxiety and increased loneliness in the general population (Office for National Statistics, 2020). Within healthcare settings, declines were reported in the mental health of clients (Troyer et al., 2020) and healthcare professionals who experienced increased anxiety, stress, and sleep disturbances (Jalili et al., 2021; De Kock et al., 2021; Pappa et al., 2020). The reasons for reductions in healthcare professionals’ well-being are reported as poor access to safety equipment, risk and fear of COVID-19 transmission, juggling family and care commitments, and uncertainties around the pandemic (Shanafelt et al., 2020). Whilst the evidence provides an overview of healthcare professionals’ experiences, there is limited evidence focusing on specific professions.

In light of the pandemic, significant pressures were placed on healthcare providers to adapt service set up to accommodate new ways of working (Pillay & Barnes, 2020). Changes to the delivery of psychological support were necessitated, with many PPs forced to work from home and transfer their face-to-face practice to virtual means (telephone/video call) overnight (Feijt et al., 2020). Some mental health services were suspended unless they provided essential care, such as inpatient psychiatric intensive-care units (Hughes & Anderson, 2020). Some psychological and behavioural interventions were also suspended as they were unable to be adapted to virtual format (Courtenay & Perera, 2020). Common barriers to online support for PWID are highlighted as lack of physical presence, loss of virtual cues and limited access to technology (Kalvin et al., 2021).

Little to no guidance was available regarding how to provide psychological support virtually at the time of the first lockdown as restrictions rapidly changed (Gregson et al., 2020). In May 2020, the British Psychological Society (BPS) released guidance which outlined the need for PPs to continue working, how to implement reasonable adjustments and the limits of working psychologically during the pandemic. However, this document did not advise how those unable to access computers or telephones should be supported (Lake et al., 2021). It remains unclear how this guidance was received by PPs and how they experienced the pandemic whilst supporting PWID.

## Rationale

It is important to systemically capture the experiences of PWID who received psychological support during the pandemic, including the views of services and systems (Courtenay & Perera, 2020). Whilst existing research captures the experiences of healthcare professionals, there is less focus on the experience of PPs who supported PWID. As the post-pandemic world is navigated, it is essential to explore and compile these experiences to further educate and inform future practice and policy. This literature review asks the question: “What is known from existing literature about the experiences of PPs providing virtual psychological support to PWID during the COVID-19 pandemic”?

# Method

## Search Strategy and Terms

Following a scoping review of the literature, search terms were derived that were felt to capture those most commonly used in the literature base. Search terms were refined using the Participant, Concept and Context framework (Peters, 2016) given the reviews focus on understanding experiences. The following terms were used: Any field contains “Psychologist” OR “Psychological Therapist” AND “Experiences of Delivering Online Support” OR “Experiences of Delivering Virtual Support” AND “Learning Disabilities” OR “Intellectual Disabilities” AND “COVID-19” OR “Coronavirus-19”. An NHS librarian was consulted regarding search terms.

The search terms were utilised on the following databases on 2nd May 2022: EBSCO, Scopus, Directory of Open Access Journals, APA PsycArticles, and the BPS Bulletin of the Faculty of People with Intellectual Disabilities. Titles and abstracts were screened and, if deemed appropriate, the full text was retrieved and subjected to the inclusion and exclusion criteria. The reference lists of the included studies were also screened for relevant papers. To identify all relevant literature, the search was restricted to January 2020 onwards; the first cluster of COVID-19 cases was reported in Wuhan, China on 31st December 2019 (WHO, 2020). The search was not limited by geographical location.

Unpublished literature was searched via Open Grey and Ethos to limit the possibility of publication bias, described as the increased likelihood of publishing findings based on the direction and strength of study findings (DeVito & Goldacre, 2019). No additional studies were identified for inclusion in this way.

## Inclusion Criteria

* Includes the PPs experience of providing psychological support to PWID or autism spectrum disorder (child or adult) through a virtual methodology (e.g. online, video). ID and autistic individuals are commonly supported within the same services due to comorbidities (Srivastava & Schwartz, 2014), therefore both experiences were captured in this review.
* Both qualitative and quantitative studies were included as limited literature was available
* Full text available in English Language

## Paper Selection and Data Extraction

The search produced 593 results before 191 duplicates were removed, a further 365 were removed by screening the titles based on the inclusion criteria, and 37 were assessed for eligibility. Of these, 26 were excluded for reasons stated in the PRISMA flow chart (Figure 1), such as focusing on PPs experiences of supporting neurotypical clients (n=14).

## Figure 1

*PRISMA Flow Chart of Study Inclusion Process (Page et al., 2020)*

**Identification of studies via databases and registers**

Records removed *before screening*:

Duplicate records removed (n = 191)

Records identified from:

EBSCO (n=190), Pubmed (n=98)

Scopus (n=158), Directory of Open Access Journals (n=116), APA PsycArticles (n=29),

BPS Bulletin of the Faculty of People with Intellectual Disabilities (n=2)

**Identification**

Records screened

(n = 402)

Records excluded\*\*

(n =365)

Reports sought for retrieval

(n =37)

Reports not retrieved

(n = 0)

**Screening**

Reports excluded:

Neurotypical Participant Group (n=14)

Outside of COVID-19 Timeframe (n=3)

Review Paper (n=3)

Focus on Client Experience (n=3)

Unable to isolate psychologist response (n=3)

Reports assessed for eligibility

(n =37)

Studies included in review

(n=11)

**Included**

# Results

Eleven studies met the inclusion criteria for review (Table 1).

## Table 1

*Data Extraction Table*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Author and Country | Sample | Client Group | Method | Analysis and Main Findings |
| Embregts et al. (2021)  Netherlands | N=5 psychologists working across three residential services | N=2 providing support to adults with mild to moderate LD  N=3 working across all levels of adult LD | 22 audio messages were sent to the researcher with a mean duration of 4.5 minutes per week, and a total of 2-5 audio messages per participant | Thematic Analysis  Main themes:   * Working from home * Adapting to the new reality * Advising and coaching support staff |
| Kalvin et al. (2021)  USA | Authored by 8 PPs | Supporting autistic children aged 8-14 | Commentary of the transition to remote delivery | Main themes:   * Children were more comfortable in home environment * Difficulties adjusting to remote delivery * Boundaries lost during sessions |
| Oudshoorn et al. (2021)  Netherlands | N=5 psychologists, n=1 art psychotherapist, n=1 psychomotor therapist | Supporting adults and children with mild LD, mental health difficulties and/or challenging behaviour  Community and inpatient facilities | Audio recording (mean 12.8 minutes, SD= 5.3) per person | Thematic Analysis  Main themes:   * An immediate transition to virtual working * Developing virtual ways to support clients both in coping with COVID-19 related stresses and continuing therapy * Lacking the appropriate equipment * Limitations in virtually attuning to PWID * Unforeseen opportunities for distance-based psychological assessments and therapy |
| Chemerynska et al. (2022)  UK | N=11 HCPC registered psychologists (ranging from psychologist to consultant) | NHS adult Community Learning Disability Team (CLDT) | Virtual semi-structured interviews averaging 52 minutes (range= 43 to 62 minutes) | Interpretive Phenomenological Analysis (IPA)  Main themes:   * Survive or thrive * Left to their own devices |
| Langdon et al. (2021)  UK | N=97 HCPC registered psychologists living in the UK | Supporting adults or children with all levels in a variety of services in the NHS | Online cross-sectional survey  Free text comments | Thematic Analysis  Main themes:   * Being human * Being an employee   Quantitative findings:   * Occupational stress, learning new roles, demands at home, and changes due to COVID-19 were associated with poorer mental well-being. * Role uncertainty, a shortage of PPE, and poorer well-being were associated with occupational stress. |
| Gregson et al. (2022) | N=12 HCPC registered psychologists | Supporting adults or children with all levels in a variety of services in the NHS and private sector | Virtual semi-structured interview | Thematic Analysis  Main themes:   * Delivering psychological services * Well-being of PWID * Learning and future practice |
| Datlen and Pandolfi (2020)  UK | N=3 Art psychotherapists | Supporting n=5 adults with LD in private practice | Commentary of transitioning a group intervention to Whatsapp | * Challenges with communication needs * Challenging boundaries * Living with uncertainty |
| Theodore et al. (2020)  UK | N=95 PPs (81% qualified, 17% assistant psychologist, 2% art therapist/PBS specialist) | Supporting adults or children with all levels in a variety of services in the NHS and private sector | Online questionnaire  Free text comments | * Technological barriers to providing support * Increased flexibility   Quantitative Findings:   * Mixed experiences implementing virtual support * Difficulties getting set up to deliver virtual support |
| Hardcastle et al. (2021)  UK | N=1 Clinical psychologist, N=1 trainee Clinical psychologist, N=1 Assistant psychologist | NHS Adult CLDT | Commentary of delivering a CBT-based group programme | * Difficulties collecting post-intervention scores * COVID-19 related anxieties changing the focus of psychological intervention |
| Power et al. (2021)  UK | N=105 Art Psychotherapists and Trainee Art Psychotherapists with BAAT membership that had attended a BAAT peer support group | Supporting adults or children with all levels of LD in a variety of services in the NHS and private sector | Virtual focus groups | Reflexive Thematic Analysis  Main themes:   * The pandemic as a leveller * The joy and jeopardy of working online * Art after the eclipse * The function of the professional support group * Insight and understanding to meet client diversity |
| Windsor (2021)  UK | Assistant Psychologist | NHS Adult CLDT | Reflections of working in a CLDT | * Experiencing worry and panic * Challenges in adapting to virtual methods * Supporting staff well-being |

## Quality Assessment

Summaries of quality assessment for each study can be seen in Appendix B, C and D. A scoring system was applied to the appraisal tools which allowed studies to be quantitatively compared for the ease of the reader. All studies were rated of high quality. Due to the relative novelty of this field, an overview of quality assessment for the studies within this review is included below.

Mixed method papers were appraised using the Mixed Method Appraisal Tool (Hong et al., 2018) which comprises of 5 items. The Critical Appraisal Skills Programme Qualitative (2018) is a 10-item appraisal tool and was used for qualitative studies. Commentaries were appraised using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet et al., 2004).

### Sampling

Sampling strategy across studies varied, namely convenience sampling (Embregts et al., 2021; Oudshoorn et al., 2021) and purposive sampling through social media advertisement (Gregson et al., 2022; Langdon et al., 2021) and professional networks (Chemerynska et al., 2022; Theodore et al., 2020; Power et al., 2021) were used. Given the context of providing virtual support, recruitment via social media may bias findings as social media users may be more used to using technology and hold prejudice when discussing their experiences (Gregson et al., 2022).

Sample sizes ranged from 1 (Windsor, 2021) to 105 (Power et al., 2021). All papers except Theodore et al. (2020) and Power et al. (2021) provide demographic information (gender, age) for their participants which increases internal validity. Of the commentaries, Windsor (2021) and Datlen and Pandolfi (2020) provide details of authors, however Hardcastle et al. (2021) and Kalvin et al. (2021) would benefit from additional information regarding author demographic and role to increase credibility. Similarly, Langdon et al. (2021) does not provide detail on the context of psychological work (e.g. inpatient, community, children or adult), therefore these findings are hard to generalise. All studies have more female than male participants, and minority groups are underrepresented within this literature review, with only Chemerynska et al. (2022) and Gregson et al. (2022) reporting inclusion of one participant from a racialised background.

Data saturation is reached when no new insights are generated from qualitative data and data collection is stopped (Fusch & Ness, 2015). Gregson et al. (2022) were the only study to report reaching data saturation, therefore it is unknown whether sample sizes in other papers were sufficient to reach saturation; failure to reach data saturation can reduce study validity (Kerr et al., 2010).

### Methods and Data Collection

Four commentaries (Kalvin et al., 2021, Datlen & Pandolfi, 2020, Hardcasle et al., 2021, Windsor, 2021), five qualitative papers (Embregts et al., 2021, Oudshoorn et al., 2021, Chemerynska et al., 2022, Gregson et al., 2022, Power et al., 2021), and two mixed methods papers (Langdon et al., 2021, Theodore et al., 2020) were included in this review.

Audio Recording. Embregts et al. (2021) and Oudshoorn et al. (2021) asked participants to collect self-recorded audio on a smartphone at a time that was convenient for them and suggested topics for participants to reflect on. The use of audio recordings may have biased findings as participants selected what to send the researcher, which reduces internal validity and could lead to demand characteristics whereby participants may have been more likely to reflect on a day worth reflecting on (e.g. busier day). Recordings were translated from Dutch to English for transcription which may have incurred missing data and low internal validity (Birbili, 2000).

Online Interviews.Gregson et al. (2022) and Chemerynska et al. (2022) completed virtual semi-structured interviews and provided adequate detail of their data collection procedure. Gregson et al. (2022) were the only study to offer financial reward for participation which can introduce cognitive bias to findings (Gignac, 2018).

Focus Group. Power et al. (2021) completed six online focus groups and incorporated time for reflective discussion. Handwritten notes were taken in real time which limited the internal validity of findings due to inevitable loss of data.

Commentaries. Kalvin et al. (2021), Datlen and Pandolfi (2020), Hardcastle et al. (2021) and Windsor (2021) provided commentaries on the adaptation of a singular psychological intervention. All provided adequate theory-practice links and described what influenced their approach. Information was generally lacking regarding how contributions from authors were collated in a systematic way in all except Windsor (2021).

Mixed Methods.Langdon et al. (2021) and Theodore et al. (2020) developed questionnaires for their research, however only Langdon et al. (2021) provided detail on how questions were collaboratively developed based upon clinical and research experience. Langdon et al. (2021) also used validated measures which increased internal validity.

### Ethical Issues

Consideration of ethical issues fluctuated through papers, from limited reference to ethics in some to full ethical disclosure in others.

### Data Analysis

Triangulation is a process of verification in qualitative research which reduces internal validity (Flick, 2004). Embregts et al. (2021), Oudshoorn et al. (2021), Chemerynska et al. (2022) and Langdon et al. (2021) triangulated qualitative findings with authors, however Gregson et al. (2022) completed triangulation with an external researcher which reduced confirmatory bias. Power et al. (2021) provided a clear, detailed account of data analysis and was the only paper that triangulated findings with participant which increased internal validity. Langdon et al. (2021) triangulated qualitative and quantitative data which found support for the majority of their findings; mixed methodology provided richer exploration of experiences by providing a holistic summary and increasing rigour. However, no detail of methodological analysis or triangulation is provided by Theodore et al. (2020) which minimised study rigour.

Only two studies (Chemerynska et al., 2022; Gregson et al., 2022) outlined reflexivity and consideration of their relationship with participants which increased rigour.

## Thematic Synthesis

A thematic synthesis was completed on qualitative data (Thomas & Harden, 2008). The results sections and text relating to the author’s experience in commentaries were extracted from all included papers and coded line-by-line by HB. Initial free codes were developed inductively before clustering into similar areas to develop descriptive themes which were interpreted beyond the content of their original study to generate analytic themes (Thomas & Harden, 2008). Coding quality and validation through consensus was established between HB and KG (Braun & Clarke, 2022; Levitt et al., 2018).

Four themes and 14 subthemes were identified across the 11 papers: *Impact at Service level, The emotional impact on PPs, The limitations of virtual support,* and *Unexpected gains.*

### Theme 1: Impact at service level

This theme describes the impact on services that PPs report impacting their experience, and includes subthemes *Left to try and make sense of it all, Changes to the role,* and *Team dynamics.*

1.1. Left to try and make sense of it all.PPs were frustrated over unclear guidance around how services should deliver virtual support to PWID (Chemerynska et al., 2022; Datlen & Pandolfi, 2020; Gregson et al., 2022; Langdon et al., 2021; Power et al., 2021; Theodore et al., 2020). On occasions, service managers lacked empathy towards their teams, which resulted in PPs feeling uncontained and unsupported (Chemerynska et al., 2022). The quality of guidance was mixed across NHS Trusts and between services (Power et al., 2021) which contributed to frustrations; PPs working with PWID felt that they faced greater challenges than those working in general mental health services (Chemerynska et al., 2022; Langdon et al., 2021). Furthermore, PPs felt that PWID were “overlooked in [the] pandemic” (Chemerynska et al., 2022, p. 591) by government and society, which left PPs unsure where to turn when seeking professional guidance (Gregson et al., 2020). Interestingly, the papers included within this subtheme were conducted within the UK, which may indicate that PPs outside of the UK felt more supported due to differences in responses to the pandemic.

1.2. Changes to the role. Services experienced an increase in referrals and waitlist demands (Chemerynska et al., 2022; Langdon et al., 2021; Oudshoorn et al., 2021) during the pandemic, which led to the role of some PPs focusing on service adaptations (Windsor, 2021) and overcoming difficulties with understaffing (Langdon et al., 2021). PPs described threats of redeployment (Embregts et al., 2021; Chemerynska et al., 2021; Power et al., 2021) and a need to be “Covid-useful” (Gregson, et al., 2022, p. 179) which contributed to feelings of uncertainty.

PPs became the “container for a lot of [their] colleagues distress and loss and sadness” (Gregson et al., 2022, p. 180). They offered psychological support to staff within their teams and more widely across employing NHS Trusts (Langdon et al., 2021; Windsor, 2021), which emphasises the transferable skills of PPs such as empathy and containment. This support included facilitating virtual debriefs and reflection spaces (Langdon et al., 2021; Windsor, 2021), virtual coffee breaks (Gregson et al., 2022), and manning staff support lines (Gregson et al., 2022).

Many PPs were required to pause therapeutic work where this could not be adapted to virtual means, and instead undertook basic well-being checks and risk-related triage calls for PWID (Embregts et al., 2021; Hardcastle et al., 2021; Windsor, 2021; Power et al., 2021), and their carers (Windsor, 2021). This left some PPs feeling deskilled (Gregson et al., 2020).

1.3. Team dynamics. There were reduced opportunities for informal conversations between professionals when working remotely which contributed to increased social isolation and disconnect from colleagues amongst PPs (Chemerynska et al., 2022; Datlen & Pandolfi, 2020; Gregson et al., 2022; Langdon et al., 2021). With great importance placed on team cohesion and support from colleagues (Gregson et al., 2022) when supporting PWID, some PPs struggled to adjust to the isolation of remote working.

Increased clinical supervision was sought in some cases which helped PPs to both manage case complexities and feel more supported by their team thus able to persevere with the challenges of remote team working (Datlen & Pandolfi, 2020; Gregson et al., 2022; Langdon et al., 2021). Some PPs attended peer support groups which improved their psychological well-being and increased social connectedness (Power et al., 2021). Initiatives such as virtual coffee breaks were introduced and successfully increased team connectivity in early phases of the pandemic (Embregts et al., 2021), although PPs participating in later research reported they had “fatigued” (Gregson et al., 2022, p. 181), of virtual coffee breaks perhaps as initial camaraderie and the novelty of remote working had reduced.

### Theme 2: The emotional impact on psychology professionals

This theme describes the emotional impact working through the pandemic had on PPs, and includes subthemes *Well-being, “We don’t have the answers”,* and *Juggling work and life.*

2.1. Well-being. The changes necessitated by the pandemic were reported to negatively impact the emotional well-being of PPs across all papers except Kalvin et al. (2021), likely due to this study focusing on commentary of CBT adaptations within the pandemic context. Some PPs experienced burnout and emotional exhaustion (Chemerynska et al., 2022; Gregson et al., 2022; Power et al., 2021), with increased demands testing their flexibility (Oudshoorn et al., 2021) and prolonged screen time contributing to increased tiredness (Langdon et al., 2021; Power et al., 2021; Theodore et al., 2020). Quantitative findings provide further support for this subtheme, as higher levels of occupational stress and changes due to COVID-19 were associated with poorer mental well-being (*p*=.01; Langdon et al., 2021).

Individual differences amongst PPs experiences were noted, as previous experience in providing virtual psychological support was highlighted as advantageous in reducing the consequences of the “traumatic change” (Power et al., 2021, p. 6) from face-to-face to virtual delivery of support. For some PPs, the negative impact of the pandemic well-being limited the long-term sustainability of remote working post-pandemic (Chemerynska et al., 2022), whilst others reported that the pandemic offered an opportunity to adopt a slower pace of life, reflect, and “remember what’s important” (Power et al., 2021, p. 6).

2.2. “We don’t have the answers”.Higher than normal pressure and demands were experienced by PPs during the pandemic which increased levels of frustration and experiences of struggle (Gregson et al., 2022; Oudshoorn et al., 2021). Pressure stemmed from management level in some cases which contributed to PPs feeling as though they were not valued by their service (Chemerynska et al., 2022; Langdon et al., 2021), which further impacted well-being. A sense that PPs were looked at to problem solve without acknowledgement that they may too be struggling added to frustrations across papers: “We don’t have the answers and we also feel very uncertain [..] we are also adjusting and adapting to new normality” (Gregson et al., 2022, p. 180). These increased pressures were called out by PPs who emphasised that they did not have a “magic wand [and] can’t take COVID away” (Chemerynska et al., 2022, p. 592).

Experiences of guilt were shared where PPs felt unable to provide enough support to clients in the face of higher than normal pressure (Langdon et al., 2021) and felt helpless to support clients who did not have access to technology (Gregson et al., 2022). PPs shared feeling helpless and powerless (Gregson, 2022) as they were unable to provide the “service [they wanted] to provide to people” (Chemerynska et al., 2022, p. 589) due to COVID-19 restrictions. This led some PPs to overcompensate as the quality of face-to-face communication could not be replicated (Datlen & Pandolfi, 2020). Moral injury, whereby individuals were unable to work inline with their values, was reported (Chemerynska et al., 2022), and coupled with a reduction in confidence supporting PWID (Chemerynska et al., 2022; Gregson et al., 2022; Langdon et al., 2021; Power et al., 2021) and reduced job satisfaction (Power et al., 2021).

Guilt was also expressed by PPs based on being able to “work from home without the risk of infection” (Embregts et al., 2021, p. 296) unlike frontline colleagues and clients, which perhaps contributed to PPs feeling detached from multidisciplinary team (MDT) members and excluded from camaraderie.

2.3. Juggling work and life. Some PPs struggled to maintain a work-life balance when working remotely (Chemerynska et al., 2022; Datlen & Pandolfi, 2020; Embregts et al., 2021; Langdon et al., 2021; Power et al., 2021). Working from home encroached on privacy and blurred professional boundaries as clients were able to see more of their PPs life than before, such as home environment (Datlen & Pandolfi, 2020; Langdon et al., 2021), which left PPs feeling vulnerable (Chemerynska et al., 2022). Many PPs who worked from home were reminded of challenging client conversations and emotive content when looking around their house which further challenged work-life balance and was emotionally challenging to navigate (Chemerynska et al., 2021; Embregts et al., 2021; Gregson et al., 2022; Power et al., 2021): “you see your laptop sitting there and you think, oh god yeah, I’ve just had that awful conversation, and [..] it just brings it all back” (Gregson et al., 2022, p. 179).

Childcare commitments necessitated by COVID-19 restrictions left some PPs home-schooling and caring for their children whilst working which challenged boundaries and confidentiality for the client and PP, for example if PPs children entered the room during appointments (Embregts et al., 2021; Langdon et al., 2021). Concentration was also reduced due to sudden transitions between being a parent and being a PP which unavoidably impacted on professionalism (Chemerynska et al., 2022; Langdon et al., 2021) and increased frustrations. Indeed, occupational stress (inclusive of juggling demands at home) was associated with poorer mental-well-being (*p*=.02; Langdon et al., 2021), which emphasised the sacrifices made by both PPs and other professionals.

### Theme 3: The limitations of virtual psychological support

This theme explores the limitations of virtual psychological support raised by PPs, and includes subthemes *Changes to the course of support, Losses to therapy, Power dynamics, Technological barriers*, and *Remote risk management*.

3.1. Changes to the course of support.All papers acknowledged that PPs faced changes to their ways of working which encompassed greater challenges; PPs were concerned that virtual support felt more distanced and diluted (Datlen & Pandolfi, 2020; Kalvin et al., 2021; Langdon et al., 2021; Oudshoorn et al., 2021; Power et al., 2021). The focus of support altered to accommodate factors which related to COVID-19, such as health-related anxiety, in some cases (Datlen & Pandolfi, 2020; Hardcastle et al., 2021; Kalvin et al., 2021; Langdon et al., 2021; Oudshoorn et al., 2021). For example, “the clinician and family shifted the treatment plan to focus on the child’s separation anxiety, which was becoming increasingly prominent and ties to COVID-19 related concerns (Kalvin et al., 2021, p. 4242). This elongated the time clients spent within services as time was taken away from their primary intervention.

PPs were unable to obtain routine outcome measures from participants where measures did not translate to virtual means (Hardcastle et al., 2021) and response rates to feedback requests were poor (Datlen & Pandolfi et al., 2020), which was problematic for service development.

3.2. Losses to therapy.Therapeutic relationships and rapport were more challenging to develop virtually (Chemerynska et al., 2022; Embregts et al., 2021; Gregson et al., 2022; Kalvin et al., 2021; Oudshoorn et al., 2021; Power et al., 2021; Theodore et al., 2021). Specifically in child therapy, PPs struggled to build rapport as activities “such as drawing or working on a puzzle” (Kalvin et al., 2021, p. 4245) did not translate to virtual means.

Concern for the therapeutic relationship was highlighted in the absence of sensory aspects of the relationship, with face-to-face containing remaining preferable for rapport development (Power et al., 2021). PPs found it easier to foster an emotional contact with clients when using videoconferencing opposed to telephone as they were able to visualise the client which felt more personal than voice alone (Theodore et al., 2020). It was easier to continue psychological support when an existing rapport had been established face-to-face (Power et al., 2021), which strengthened the importance placed on in-person connectivity.

The implications of absent non-verbal communication, such as body language, were highlighted across papers. A reliance on verbal communication led to misunderstandings and confusion for both the client and PPs (Gregson et al., 2021), particularly as PWID may rely on non-verbal cues when communicating (Oudshoorn et al., 2021).

The lack of live contact prevents me from noticing non-verbal signs. Due to the use of videoconferencing and phone calls, I miss these signals. Under normal circumstances, with live contact, I can easily spot those signals, but now they’re hard to pick up on. (Embregts et al., 2021, p. 296)

As non-verbal communication was missing from assessments, PPs felt that formulations were incomplete (Chemerynska et al., 2022; Gregson et al., 2022), which potentially impacted on their ability to plan effective psychological interventions.

3.3. Power dynamics.Clients exerted more power when receiving virtual support than observed when face-to-face (Datlen & Pandolfi et al., 2021; Gregson et al., 2022; Hardcastle et al., 2021; Oudshoorn et al., 2021; Power et al., 2021; Theodore et al., 2021), for example PPs were spoken over or ignored during appointments, and struggled to re-direct and re-focus conversations (Kalvin et al., 2021). An overall reduction in engagement and motivation was also observed as some clients had poorer concentration and generally took support less seriously, and consumed food or were doing their shopping during an appointment (Power et al., 2021). These changes to dynamics may have occurred due to a lack of physical boundary, distractions within the home environment, or anxiety around virtual methods of accessing support (Kalvin et al., 2021; Theodore et al., 2021).

An increase in last minute cancellations (Oudshoorn et al., 2021, Hardcastle et al., 2021) and inappropriate contact with facilitators outside of sessions (Datlen & Pandolfi, 2020) created feelings of frustration. All included papers discussed the importance of establishing clear boundaries and expectations when first meeting to maintain safety for both the PP and client; boundary agreements should be communicated in different formats to ensure communicative inclusivity (Datlen & Pandolfi, 2020; Gregson et al., 2022).

3.4. Technological barriers.All papers highlighted that both PPs and clients experienced difficulties with technology, such as time delays with set up (Theodore et al., 2020) and poor internet connection (Oudshoorn et al., 2021). Individual differences in the ease of transition to virtual support amongst PPs and clients emerged (Theodore et al., 2020), as those with higher computer literacy levels found this easier (Power et al., 2021).

Some clients were unable to access or continue with psychological support without means to access virtual support (Gregson et al., 2022; Hardcastel et al., 2021; Power et al., 2021), which was morally complex for PPs. In some instances, PPs contacted social care for additional funding and advocated for client rights to access technology (Chemerynska et al., 2022). Additionally, clients often required support from family or support workers to access virtual appointments (Theodore et al., 2020, Langdon et al., 2021, Power et al., 2021) which posed a threat to risk-management and concern over power.

It has potential to be quite disempowering, sometimes they’re asking someone to set the call up for them or they’re using, say their carers laptop or the staff members laptops, and I think that comes with all sorts of issues [..] I suppose about power and confidentiality. (Gregson et al., 2022, p. 175)

PPs empathised with the difficulties experienced by PWID when navigating new virtual platforms (Chemerynska et al., 2022), with preference expressed for familiar platforms such as Zoom (Theodore et al., 2020). However, some PPs shared that holding initial preparation sessions prior to the commencement of interventions with clients allowed barriers with technology and unfamiliar platforms to be overcome (Gregson et al., 2022; Theodore et al., 2021; Kalvin et al., 2021).

3.5. Remote management of risk.All papers acknowledged challenges with the remote management of risk and establishing therapeutic safety; PPs needed to be more vigilant and pay greater attention when remotely managing risk. PPs highlighted difficulties when managing confidentiality during appointments as they were unable to establish who was in the room with the client and for what duration (Theodore et al., 2020; Oudshoorn et al., 2021), especially when clients did not want their video camera on (Power et al., 2021), lived in supported accommodation (Hardcastle et al., 2021), or where children were supported by parents during child-only segments of support (Kalvin et al., 2021).

[I] have to explain and clarify things more and question what is actually happening to someone else [..] a man [client] began to cry very loudly and actually disappeared out of sight [moved away from the screen]. Urgh, that felt unpleasant because [I] couldn’t do anything at that moment, I didn’t know where the [client] was and [I was] really at a distance. (Oudshoorn et al., 2021, p. 6)

Increased anxiety was experienced by PPs when managing risk remotely, alongside a sense of pressure and unknowing how to manage and recognise a risky environment virtually (Oudshoorn et al., 2021). Furthermore, PPs shared concern that parents supporting PWID to access virtual support can reduce the client’s sense of agency and independence (Datlen & Pandolfi, 2020), and that they felt unsure how to respond to confidentiality when parents remained present for the duration of the appointment.

### Theme 4: Unexpected gains

This theme focuses on the unexpected gains that PPs experienced when delivering virtual support, and includes subthemes *“Opportunities to experiment in everyday practice”, Flexibility and efficiency*, and *Benefits to the client*.

4.1. “Opportunities to experiment in everyday practice”.Virtual working provided opportunities for PPs to be creative and engage meaningfully with clients in new ways (Chemerynska et al., 2022; Embregts et al., 2022; Gregson et al., 2022; Power et al., 2021; Theodore et al., 2021; Kalvin et al., 2021; Oudshoorn et al., 2021). This experience afforded an unforeseen opportunity to learn and develop professionally, as increased confidence in working remotely and satisfaction with positive outcomes (Oudshoorn et al., 2021) were highlighted.

It’s just expanded our repertoire really in a way that we can engage with people differently [..] It’s forced us to step out of our comfort zones and get used to this technology and see who it may work for. (Chemerynska et al., 2022, p. 590)

All papers shared effective ways of working virtually, which included using the chat function (Theodore et al., 2021), whiteboard space (Power et al., 2021), screen sharing (Gregson et al., 2022; Theodore et al., 2021) and websites or videos (Gregson et al., 2022; Kalvin et al., 2021). Furthermore, Datlen and Pandolfi (2020) found the use of emoji’s on Whatsapp by PPs and clients beneficial when communicating their emotions. The versatility of virtual support was highlighted as PPs successfully used Makaton (a language programme), British Sign Language, and Intensive Interaction (Power et al., 2021; Theodore et al., 2021) virtually.

4.2. Flexibility and efficiency. PPs reported greater flexibility with their time and approach that they had not experienced when working face-to-face (Chemerynska et al., 2022, Oudshoorn et al., 2021, Gregson et al., 2022, Langdon et al., 2021). As PPs were not required to commute to work or meetings (Theodore et al., 2020), they were able to offer more appointments and reported that the efficiency of online MDT meetings increased (Gregson et al., 2022). Furthermore, systemic working was made easier (Oudshoorn et al., 2021, Power et al., 2021, Theodore et al., 2021) as MDTs and agencies could be brought together virtually at short notice for consultation, contributing to better outcomes for PWID. It was also easier for PPs to gain insight into the client’s home environment, meet with carers or relatives, and implement exercises such as exposure within the targeted context (Oudshoorn et al., 2021, Kalvin et al., 2021). Indeed, some PPs expressed that the benefits of remote working meant they did not want to return to exclusively providing face-to-face support (Oudshoorn et al., 2021).

4.3. Benefits to the client. Some clients were observed as more comfortable and relaxed during virtual support (Kalvin et al., 2021; Oudshoorn et al., 2021) as this felt less intense than face-to-face contact (Gregson et al., 2022; Theodore et al., 2021), which was beneficial to the therapeutic process. PPs also observed that clients who had accessed virtual support independently appeared confident and empowered (Chemerynska et al., 2022, Theodore et al., 2021, Datlen & Pandolfi, 2020), as PPs appeared to have underestimated the ability of PWID in accessing virtual support. In some cases, cancellations were minimised by the removal of travel barriers (Gregson et al., 2022; Hardcastle et al., 2021; Kalvin et al., 2021; Oudshoorn et al., 2021) which increased the ease of parent/carer attendance (Theodore et al., 2021).

Virtual support particularly benefitted autistic people (Chemerynska et al., 2022; Gregson et al., 2022; Power et al., 2021; Theodore et al., 2021), as they appeared more able to engage with support content without the intensity of face-to-face communication. However, autistic children appeared to become preoccupied by seeing themselves on the screen which posed a barrier to engagement (Kalvin et al., 2021), and further emphasised the need for method of delivery to be assessed on an individual basis.

# Discussion

The rapid switch to virtual delivery of psychological support to PWID was necessitated by the COVID-19 pandemic, however little is known about how PPs experienced this switch to inform research and clinical practice. As COVID-19 restrictions ease and mental health services adopt a hybrid model of face-to-face and virtual support (Wappula, 2022), this literature review identified and summarised the experiences of PPs; four themes and 14 subthemes were identified from the 11 papers included in this review.

The negative psychological impact of providing remote support to PWID was highlighted, which emphasised that the pandemic has impacted the psychological well-being of clients and PPs alike (De Kock et al., 2021). This decline in psychological well-being (e.g. Langdon et al., 2021) appears concordant with that observed amongst other staff groups such as healthcare professionals (HCPs; Tiete et al., 2021) and nurses (Stelnicki et al., 2020), and the general population (ONS, 2020) during the pandemic. These findings also mirrored that of HCPs during previous infectious disease outbreaks such as SARS (Brooks et al., 2018). Many reasons for poorer psychological well-being among PPs were highlighted in this review, including changes to their role (Embregts et al., 2021, Hardcastle et al., 2021, Windsor, 2021, Power et al., 2021), burnout (Power et al., 2021, Chemerynska et al., 2022, Gregson et al., 2022), and adjustment to virtual working. Thus, it is important to consider what support is available for PPs own psychological well-being.

PPs experienced moral injury, which is defined as psychological distress which results from one’s actions or inability to act, which violates their ethics or morals, and is commonly miss-labelled as burnout (Ford, 2019; Mantri et al., 2020; Murray et al., 2018). Primary factors of moral injury, such as increased workloads (Chemerynska et al., 2022; Langdon et al., 2021; Oudshoorn et al., 2021) and stress (e.g. Gregson et al., 2022), working under high pressure (Chemerynska et al., 2022, Langdon et al., 2021, Oudshoorn et al., 2021, Gregson et al., 2022) and feeling unable to provide adequate care (Langdon et al., 2021, Gregson et al., 2022, Chemerynska et al., 2022, Power et al., 2021) are amongst predictors of moral injury, with exposure to morally injurious events precipitating feelings of distress amongst PPs. As these experiences mirror those of HCPs before the pandemic (Sibeoni et al., 2019; Sorenson et al., 2016), the pandemic may have exacerbated and highlighted existing difficulties within already-struggling healthcare systems (Litam & Balkin, 2021). Furthermore, PPs felt unsupported and abandoned by leadership and overlooked within policies which resulted in feelings of uncertainty, and is recognised as a precipitating factor of moral injury in literature (French et al., 2022; Mantri et al., 2020). Organisational distrust and fractured relationships with leadership may continue unless moral repair is completed (French et al., 2022), therefore it is important for leaders to engage in moral-repair to improve the job satisfaction and psychological wellness of PPs (Shale, 2020). This review provides important contributions from PPs to the growing evidence base of moral injury during the pandemic which will inform how HCPs are supported moving forward (Litam & Balkin, 2021).

The highlighted difficulty of maintaining boundaries between home and work (Langdon et al., 2021, Chemerynska et al., 2022, Embregts et al., 2021, Datlen & Pandolfi, 2020, Power et al., 2021) provide support for boundary theory (Hunter et al., 2019). Boundary violations, such as children disrupting home working, were associated with poorer mental well-being and job satisfaction (Langdon et al., 2021), and are also observed in literature (Hunter et al., 2019). Boundary violations can lead to high levels of work-family conflict (Barriga Medina et al., 2021) which did not emerge in this review. However, moral injury can harbour increased guilt and impact the families of HCPs (Figley, 1997), therefore it is suggested that future research systemically explores the experiences of PPs.

A notable finding of this review is that PPs experienced difficulties with obtaining outcome measures, which is problematic as the evaluation of outcomes is essential for developing effective interventions, delivering person-centred support, and minimising bias (Hatfield & Ogles, 2004). There is limited guidance on how to adapt outcome measures for online delivery, therefore it is important to consider how measures can be adapted in future research and to explore the experiences of PWID receiving virtual support to ensure these views are captured in the absence of measures.

Losses to therapy, such as non-verbal communication and clear boundaries, are echoed as barriers to engagement and therapeutic alliance with non-LD communities during the pandemic (Heyworth et al., 2020; Zoumpouli, 2020). PPs shared difficulties with recognising client emotions in the absence of non-verbal cues (Embregts et al., 2021) and communicating concepts (Power et al., 2021), which may have interfered with the therapeutic process. PWID also hold preference for clear communication, physical presence and facial expressions (Mencap, 2022) and display a reliance on non-verbal communication (Hinzen et al., 2020), therefore it is important to PPs to overcome these challenges to enable affective support to continue.

Rapport should be established with clients before engaging in interventions such as CBT (Beck, 2011) to increase therapeutic alliance (Ekbeg et al., 2013), even when delivered virtually. However, PPs experienced difficulty with establishing rapport in the absence of face-to-face contact and usual rapport building activities (Kalvin et al., 2021). PPs shared that facilitating preparatory sessions prior to the commencement of intervention allowed clients to increase confidence with technology and work through practical issues (Gregson et al., 2022; Theodore et al., 2021; Kalvin et al., 2021); although no impact on therapeutic alliance is highlighted, it is hypothesised that this opportunity allowed clients to become familiar with the PP thus increasing rapport and strengthening therapeutic alliance, which may in turn increase efficacy of interventions (Berry & Danquah, 2020).

All papers reported that PPs found the transition to remote working distressing, however PPs with previous experience of virtual support felt more competent using computers and faced less barriers when transitioning (Power et al., 2021). Therefore, training in the use of online platforms and how to adapt virtual support for PWID may increase PP confidence (Békés et al., 2021) and minimise negative prejudice towards virtual support. Indeed, PPs own negative beliefs about virtual therapy can become a barrier to use (Simpson et al., 2021), therefore reducing prejudice may minimise this barrier and increase job satisfaction. However, consideration is given to the timing of data collection, as research completed later in the pandemic may include PPs who have greater confidence due to duration of virtual working.

## Limitations

This review focused on an understudied area, therefore available papers were not focused to a single country due to scarcity of research which is a noted strength. However countries differed in their response to COVID-19 due to the pandemic occurring in waves at different time points in each country (Borek et al., 2022; Toshkov et al., 2022) therefore it is challenging to establish the context in which the included papers were completed, which reduced internal validity. Although paper quality was comparable, there was notably less information available for analysis within the four reflective pieces which may bias results. Furthermore, PPs differed by occupation, setting (inpatient/community), cohort (adult/child) and employer (private/NHS), which may confound results; as new research is published, reviews should focus on homogeneous groups of specific PPs to increase internal validity of findings. Although a systematic approach was adopted which allowed for transparency and replication, rigour is compromised as this review was completed by one researcher which introduces bias (Johnson et al., 2020).

## Conclusion

This review aimed to inform future practice and policy by exploring what was known from existing literature about the experiences of PPs who provided psychological support to PWID during the COVID-19 pandemic. A thematic synthesis was completed to analyse findings from 11 papers. These results highlighted the challenges and positives in the experiences of PPs, whilst acknowledging the inequalities faced by PWID and the impact this has on their support system, inclusive of PPs. Evidence of moral injury is presented, alongside the negative impact of the pandemic on PP well-being and job satisfaction. This current review also makes recommendations for training needs. In a post-pandemic world, the decision to deliver virtual psychological support to PWID must be assessed on an individual basis and take the training and experience of the PP into consideration.

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# Appendices

## Appendix A

*JARID Author Guidance*

https://onlinelibrary.wiley.com/page/journal/14683148/homepage/forauthors.html

## Appendix B

*Mixed Method Appraisal Tool (Hong et al., 2018)*

|  |
| --- |
| **Screening Questions (for all papers)**  S1. Are there clear research questions?  S2. Do the collected data allow to address the research questions?  **5. Mixed methods**  5.1. Is there an adequate rationale for using a mixed methods design to address the research question?  5.2. Are the different components of the study effectively integrated to answer the research question?  5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?  5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?  5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?  Responses: Yes (Y = 2), Can’t Tell (P = 1), No (N = 0)  Quality Rating: 0-33% = low quality, 34%-66% = medium quality, 67%-100% = high quality |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Author** | **S1** | **S2** | **5.1** | **5.2** | **5.3** | **5.4** | **5.5** | **Score** |
| Theodore et al. (2020) | Y | Y | Y | Y | P | Y | P | 86% |
| Langdon et al. (2021) | Y | Y | Y | Y | Y | Y | Y | 100% |

## Appendix C

*Critical Appraisal Skills Programme Qualitative (2018)*

|  |
| --- |
| 1. Was there a clear statement of the aims of the research?  2. Is a qualitative methodology appropriate?  3. Was the research design appropriate to address the aims of the research?  4. Was the recruitment strategy appropriate to the aims of the research?  5. Was the data collected in a way that addressed the research issue?  6. Has the relationship between researcher and participants been adequately considered?  7. Have ethical issues been taken into consideration?  8. Was the data analysis sufficiently rigorous?  9. Is there a clear statement of findings?  10. How valuable is the research  Responses: Yes (Y), Can’t Tell (P), No (N)  Quality Rating: 0-33% = low quality, 34%-66% = medium quality, 67%-100% = high quality |

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| **Author** | **Q1** | **Q2** | **Q3** | **Q4** | **Q5** | **Q6** | **Q7** | **Q8** | **Q9** | **Q10** | **Score** |
| Embregts et al. (2021) | Y | Y | Y | Y | P | P | Y | Y | Y | Y | 90% |
| Oudshoorn et al. (2021) | Y | Y | Y | Y | P | P | Y | Y | Y | Y | 90% |
| Chemerynska et al. (2022) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 100% |
| Gregson et al. (2022) | Y | Y | Y | Y | Y | P | Y | Y | Y | Y | 95% |
| Power et al. (2021) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 100% |

## Appendix D

*Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Field (Kmet et al., 2004)*

|  |
| --- |
| 1. Question/objective sufficiently described?  2. Study design evident and appropriate?  3. Context for the study clear?  4. Connection to a theoretical framework/wider body of knowledge?  5. Sampling strategy described, relevant and justified?  6. Data collection methods clearly described and systematic?  7. Data analysis clearly described and systematic?  8. Use of verification procedures(s) to establish credibility?  9. Conclusions supported by the results?  10. Reflexivity of the account?  Responses: Yes (Y = 2), Partial (P = 1), No (N = 0)  Quality Rating: 0-33% = low quality, 34%-66% = medium quality, 67%-100% = high quality |

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| **Author** | **Q1** | **Q2** | **Q3** | **Q4** | **Q5** | **Q6** | **Q7** | **Q8** | **Q9** | **Q10** | **Score** |
| Kalvin et al. (2021) | Y | Y | Y | Y | P | P | Y | Y | Y | P | 85% |
| Hardcastle et al. (2021) | P | Y | Y | P | P | P | Y | Y | Y | P | 75% |
| Windsor (2021) | Y | Y | Y | Y | P | Y | P | P | Y | Y | 85% |
| Datlen and Pandolfi (2020) | Y | Y | Y | Y | P | P | Y | Y | Y | P | 85% |

# Paper Two: Empirical Paper

**“I’m just kind of talking to my screen and it responds back”: A thematic analysis exploring the experiences of adults with an intellectual disability who received a virtual cognitive behavioural therapy-based intervention during the COVID-19 pandemic**

Student ID: 20024990

Supervised by Dr Kim Gordon

Word Count: 7,998

(Excluding Title Page, References and Appendices)

*This empirical paper has been written in accordance with author guidelines for The Journal of Applied Research in Intellectual Disabilities. The author guidelines are in Appendix A.*

# Abstract

**Background**

People with intellectual disabilities (PWID) were disproportionately impacted by the rapid switch to virtual delivery of mental health support necessitated by the COVID-19 pandemic from March 2020, yet their needs are frequently overlooked in research in this area. Cognitive behavioural therapy (CBT) based interventions are the recommended treatment for depression and anxiety in PWID (NICE, 2016), therefore greater understanding PWID’s experience of virtual therapy is vital for service development post-pandemic.

**Method**

Eight participants were recruited from one mental health Trust. Semi-structured interviews were completed over telephone, Microsoft Teams or face-to-face and were analysed thematically (Braun & Clarke, 2022).

**Results**

Four overarching themes and twelve subthemes were identified: *Power, Therapy process, Therapeutic relationship,* and *Safety in the virtual environment.*

**Conclusion**

This paper highlights the importance of psychological safety for PWID when receiving virtual support, with lack of safety impacting the quality of therapeutic relationship and engagement in intervention. The unique challenges faced by PWID, such as reliance on non-verbal communication and confidentiality in residential environments, must be addressed when navigating virtual approaches post-pandemic. Future research exploring the development of therapeutic alliance when working virtually is recommended.

**Keywords**

Intellectual disability, COVID-19 pandemic, virtual, psychological support, CBT-based therapy, experiences

# Introduction

The COVID-19 pandemic saw the sudden introduction of global restrictions and regulations, which included working from home where possible in the UK (Davies et al., 2021); COVID-19 restrictions radically impacted many aspects of daily life and led to increased use of video technology (Morgül et al., 2020; Rahimi et al., 2020). Rapid changes were made to the delivery of psychological support due to COVID-19 restrictions (Feijt, 2020), such as psychological professionals (PPs) transferring their practice to virtual delivery (telephone/video call; Hughes & Anderson, 2020; Selick et al., 2021). This included delivering virtual psychological support to people with intellectual disabilities (PWID). Cognitive behavioural therapy (CBT) is the National Institute for Health and Care Excellence [NICE] (2016) recommended psychological intervention for depression and anxiety in PWID thus commonly used by services supporting PWID, and will therefore be the focus of this paper. Although COVID-19 restrictions have now eased in the UK, economic benefits and increased accessibility to services have led to some services combining an approach of delivering face-to-face and virtual psychological support post-pandemic for PWID (Zangani et al., 2022). However, limited research to date has explored the experiences of PWID who accessed virtual support during the pandemic, thus little is known about how virtually delivered CBT-based talking therapies were received and whether this is a helpful method of delivery moving forwards.

PWID were disproportionately impacted by the pandemic (Totsika et al., 2022). Specifically, PWID were at greater risk of contracting COVID-19, and experienced higher mortality and case fatality in comparison to the general population as health needs were frequently overlooked or misattributed to ID (Courtenay & Cooper, 2021; Courtney & Perera, 2020; NICE, 2016). Furthermore, PWID experienced increased anxiety, depression and loneliness, alongside reduced access to social support during the pandemic (Navas et al., 2021), therefore ongoing access to mental health support was essential for PWID and their carers (Gregson et al., 2022; Theodore et al., 2020). Given the vulnerability of PWID to COVID-19, virtual delivery was pertinent to ensure their safety (Blocksidge et al., 2022). However, a digital divide exists between the general population and PWID (Theodore et al., 2020) due to limited access to the internet or internet-enabled devices, and the finances, support and skills available to use technology (Chadwick et al., 2013; Kalvin et al., 2021), which further disadvantaged PWID accessing virtual support. Employed carers or family members typically support PWID to access the internet, however this relies on them having adequate knowledge and time which many do not and raises confidentiality concerns (Chadwick et al., 2013). Research to date has largely focused on the therapeutic experience of the general population during the pandemic, therefore it is imperative to capture the experiences of PWID given the prevalence of vulnerabilities and COVID-19 related inequalities (Feijt et al., 2020).

CBT is an evidence-based, structured talking therapy which focuses on links between thoughts, emotions, and behaviour to manage mental health difficulties (Beck, 1964; Fenn & Byrne, 2013). CBT-based interventions are efficacious when delivered to PWID face-to-face or virtually (Cooney et al., 2017), however research has suggested that PWID have recovery rates of over 10% less than neurotypical clients (Dagnan et al., 2013). CBT-based interventions should be adapted for delivery for PWID (Beail, 2017) after consideration of the client’s level of understanding, ability, needs and strengths; adaptations should take into consideration the client’s cognitive, physical, sensory and communicatory impairments (NICE, 2016). For example, PWID may receive shorter CBT-based sessions and greater creative interactivity to increase engagement (Vereenooghe et al., 2017; Whitehouse et al., 2006).

Research prior to the pandemic has focused on experiences of computerised CBT-based interventions, opposed to virtually delivered CBT-based talking therapies. For example, MacHale et al.’s (2013) literature review highlighted psychological benefits of computerised CBT-based programmes, including improved quality of life and self-confidence (Cooney et al., 2017; Vereenooghe et al., 2021). However, MacHale et al. (2023) also outlined increased risks to confidentiality in virtual support and an expressed preference for face-to-face support (Vereenooghe et al., 2017). More generally, virtual environments can be challenging for PWID due to reliance on physical presence, visual cues and adapted communication aids such as easy read documentation (Mateescu, 2020) which can be challenging to use virtually (Selick et al., 2021). Although CBT is a core psychological intervention for PWID, little remains known about the experiences of PWID who received virtual CBT-based interventions.

Recent research has explored the experiences of PPs whom supported PWID virtually during the pandemic (Burton & Gordon, 2023), and provide some insight into the experiences of PWID. PPs highlighted that virtual environments were difficult to manage due to challenges with technology and confidentiality, such as carers walking in and out during appointments (Gregson et al., 2022; Oudshoorn et a., 2021). Furthermore, some PPs felt that their clients appeared more relaxed and engaged in virtual appointments (Blocksidge et al., 2022). The pandemic was many PP’s first experience of working virtually (Selick et al., 2021) and they felt unsupported by professional guidance (Chemerynska et al., 2022), thus it is important to understand the experiences of PWID who received virtual CBT-based intervention to inform future guidance and policy (British Psychological Society, 2020; van Kessel et al., 2022).

Whilst it is positive that psychological support was able to continue during the pandemic for PWID in some contexts, there is stark uncertainty around how this was experienced by PWID due to lack of research. This research aims to address this gap in knowledge by capturing the strengths and limitations of this delivery method from the perspective of PWID, and is the first study to focus on PWID’s experiences of virtually delivered CBT-based interventions during the pandemic.

## Research Question

What are the experiences of adults with an intellectual disability who received a virtual CBT-based intervention during the COVID-19 pandemic?

# Method

## Design

As there is limited research relating to this topic area, a qualitative design with purposive sampling and semi-structured interviews was used to capture and understand rich accounts of experiences (Campbell et al., 2020). Data were analysed using Reflexive Thematic Analysis (RTA; Braun & Clarke, 2022) as it complemented the aims of this research as an initial exploration of individual’s experiences (Braun & Clarke, 2012). The researcher chose RTA over other qualitative methodologies as it allowed the researcher to acknowledge and embrace their own reflexive influence on the interpretation of subjective accounts (Byrne, 2022). RTA allowed the researcher to make sense of a large amount of data and articulate these in a constructive, readable, and meaningful way (Braun & Clarke, 2012).

Experts by experience employed by the Local NHS Trust were involved throughout the research process. They provided consultation regarding the project idea, development of the interview schedule and easy read documentation to ensure relevance and suitability of materials for PWID (Tapsell et al., 2020).

## Recruitment

The study was advertised from August 2022 – February 2023. Participants were identified using the inclusion/exclusion criteria (Table 1) by healthcare professionals within their existing care team at one mental health Community Learning Disabilities Team (CLDT) or Improving Access to Psychological Therapies (IAPT) team by direct identification or referral from caseload. Identified participants were given a study invitation (Appendix B) which included the participant information sheet (PIS; Appendix C, easy-read version Appendix D). Those that contacted the researcher were given the opportunity to discuss the research and ask any questions. The researcher then read through the consent form (Appendix E, easy-read version Appendix F) with the participant and obtained verbal informed consent. A suitable time and method (face-to-face, online or via telephone), and accessibility arrangements, such as wheelchair access for face-to-face interviews, were also arranged.

## Eligibility Criteria

The inclusion/exclusion criteria were developed with a Clinical Psychologist and CBT Therapist in the CLDT and IAPT services involved to ensure homogeneity within the sample. Eight sessions of CBT-based intervention was identified as the average number of completed sessions and therefore the minimum duration of support required for inclusion. All participants had a confirmed diagnosis of ID and reside on the ID register, verified by their healthcare professional.

## Table 1

*Inclusion and Exclusion Criteria*

|  |  |
| --- | --- |
| Inclusion Criteria | Exclusion Criteria |
| Over 18 years old  English speaking  Has completed eight 1:1 sessions of CBT-based intervention for a mental health difficulty with IAPT or the CLDT through a virtual platform (e.g. telephone or video communication software)  Formal diagnosis of ID  Capacity to consent | Under 18 years old  Non-English speaking  Has completed less than eight 1:1 sessions of CBT-based intervention for a mental health difficulty with IAPT or CLDT through a  virtual platform (e.g. telephone or video communication software)  Does not have a formal diagnosis of ID  Does not have capacity to consent |

## Participants

There were eleven expressions of interest. Two were ineligible (non-CBT-based intervention) and one did not reply, which resulted in eight participants for the study (Table 2). Within RTA, a sample size of 8-10 is suggested as sufficient for a project of this scope to reach data saturation (Braun & Clarke, 2012).

## Table 2

*Participant Socio-demographic and Support Details*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Name | Age | Gender | Ethnicity | Delivery Method | Service |
| David | 27 | Male | White British | Telephone call | CLDT |
| Helena | 25 | Female | White British | Video call | CLDT |
| Aishling | 46 | Female | White British | Video call | CLDT |
| Steven | 30 | Male | White British | Telephone call | CLDT |
| Jacob | 25 | Male | White British | Video call  and telephone call | IAPT |
| Aimee | 26 | Female | White British | Video call | CLDT |
| Edward | 20 | Male | White British | Video call  and telephone call | CLDT |
| Bobby | 22 | Male | White British | Video Call | IAPT |

Participants were aged 20-46 (m=27.63) years, resided in the UK and were White British. Participants had varied experiences of virtual support through telephone (n=4) and video (n=6), and had received support from IAPT (n=2) or the CLDT (n=6). There were n=3 females and n=5 males in this research. The participants had received virtual CBT-based intervention for varied difficulties which included social anxiety, low mood, and voice-hearing. All participants had a diagnosis of ID and four had an additional diagnosis of Autism Spectrum Conditions. Additional information on severity of ID was not available from the service at the time of data collection, therefore was not included.

## Procedure

One-to-one semi-structured interviews were conducted and followed the interview schedule (Appendix G). Adaptations to the qualitative research process for PWID were considered, which included development of an easy read interview schedule (Appendix H) for participants to follow during interviews (Nind, 2008) and a break halfway through each interview. It is common for PWID to bring a ‘supporter’ to therapy sessions for motivation and support (Dagnan et al., 2023), therefore this was also offered to participants.

Two participants completed their interview over Microsoft Teams (MS Teams), three were completed face-to-face and three via telephone call. Interviews were conducted between November 2022 and February 2023 and lasted an average of 47 minutes (range: 24 to 88 minutes). One interview was completed over two sessions, with all others completed in one. One participant opted to have a ‘supporter’ present during their interview and was provided with a ‘supporter’ PIS (Appendix I) prior to interview. Participants received a debrief sheet (Appendix J, easy-read version Appendix K) and the opportunity to ask additional questions at the end of their interview.

Interviews were audio-recorded using MS Teams and transcribed verbatim by the researcher. Pseudonyms were allocated to participants and any identifying information (e.g. places, clinician names) was removed to uphold confidentiality and privacy. Analysis was completed by the researcher using a password protected laptop within a work-from-home (private) or NHS setting.

## Ethical Considerations

Ethical approval was obtained from Coventry and Warwickshire NHS Research Ethics Committee (Appendix L), NHS Health Research Authority (Appendix M) and peer-reviewed by Staffordshire University Ethics Committee (Appendix N). The local NHS Trust for the research site provided capacity and capability approval (Appendix O).

The consent form was communicated to participants in verbal and easy-read format, with opportunity to ask questions, to ensure informed consent was obtained. Participants provided verbal consent for participation, including consent for the use of direct quotations within this paper. Participants were encouraged to schedule their interview at a time and location where privacy could be ensured to facilitate open discussions of their experiences. No psychological or physical harm was anticipated to incur as a result of participation, however all participants were signposted to sources of local support on the PIS. If signs of distress were noted during the interview, consent was gained to inform their support team as appropriate. Any disclosures or safeguarding concerns were to be communicated to the relevant support team, however no issues arose in this regard. Further detail on risk management is provided in the risk assessment (Appendix P).

## Analysis

RTA allowed the researcher to acknowledge their reflexive influence whilst respecting the subjectivity of the participants’ experience (Byrne, 2022). An inductive approach was followed whereby theme identification was driven by content and occurred at a semantic level (Byrne, 2022; Clarke et al., 2015). Braun and Clarke’s (2012, 2013, 2014, 2020) six-step RTA framework was followed (Appendix Q) throughout analysis. RTA is a recursive process which involved listening to each interview recording prior to transcription, re-reading each transcript twice to facilitate familiarisation with the data whilst making note of initial ideas (Braun & Clarke, 2014). A reflective journal was maintained to note reflections and key ideas. Initial codes (Appendix R) were noted in transcript margins based on information from the data which was relevant to the research aim. Coding was systemically completed using semantic and latent coding. Initial codes were then collated using a word document and reviewed, before overlapping codes were developed to produce broader codes and patterns were identified. These were then collapsed to generate subthemes and themes which offered aggregated meaning. These were subjected to review by the lead researcher, refined, defined, and considered in relation to each other and the data set which continued during the report write-up (Braun & Clarke, 2021). Data extracts which best represented participant contributions towards each theme were identified.

## Rigour

The six-phase analysis in RTA was followed and increases the study’s rigour by following a consistent procedure (Braun & Clarke, 2006). Themes were discussed, shared and reflected upon with the research supervisor (KG) and peers during workshops which provided credibility checks (Connelly, 2016). Furthermore, the use of direct quotation provides interpretive rigour by increasing validity and credibility (Fereday & Cochrane, 2006; Patton, 2002). Samples of the data analysis are provided (Appendix S).

## Epistemological Position and Reflexivity

The researcher adopted an essentialist, realist epistemological standpoint whereby a simple relationship was assumed between meaning, experience, and language (Braun & Clarke, 2006). The researcher acknowledged that PWID provided their version of their experiences and this was accepted as reality, which allowed for participants’ experiences and meanings to be considered in a straightforward way (Braun & Clarke, 2019).

This research was derived from the researchers’ clinical experience with PWID. The researcher is passionate about giving voice to this underrepresented group, and aimed to capture their unheard voices experiences of virtual support with the intent to be mindful and respectful. The researcher’s prior knowledge and experience was complementary to helping make sense of participant’s experiences. The researcher upheld reflexivity through supervision and maintained a reflective diary throughout analysis which supported transparency and credibility (Braun & Clarke, 2022).

# Results

The RTA identified four overarching themes: *Power, Therapy process, Therapeutic relationship,* and *Safety in the virtual environment.* Twelve subthemes were also identified. Although findings are presented within these themes, it should be noted receiving therapeutic support during the COVID-19 pandemic was a complex experience which has multiple and varied contributing factors.

## Table 3

*Themes and Subthemes*

|  |  |
| --- | --- |
| Theme | Subtheme |
| 1. Power | 1.1. Feeling disempowered |
| 1.2. Relying on others |
| 1.3. Autonomy |
| 2. Therapy process | 2.1. Novel experiences |
| 2.2. Adaptations |
| 2.3. “Just hearing a friendly voice” |
| 2.4. Stifling the therapeutic process |
| 3. Therapeutic relationship | 3.1. Building a connection |
| 3.2. Therapist factors |
| 4. Safety in the virtual environment | 4.1. Risk management |
| 4.2. Environmental factors |
| 4.3. Confidentiality |

## Theme 1: Power

This theme captures the role of power and the influence this had on experiences of virtual support. The theme comprises of three subthemes: *Feeling disempowered, Relying on other people,* and *Autonomy.*

### 1.1. Feeling disempowered

Four participants felt out of control or frustrated by the lack of control they had over the decision to receive virtual support due to pandemic related restrictions. After being on waitlists to receive therapy, participants felt powerless to challenge or delay their therapy despite having a preference for face-to-face support due to uncertainties with the pandemic, power imbalances and wanting to receive support as soon as possible: “You can’t see the person like, that you want to see in person, but you can’t because you have to use the computer” (Helena, p.13).

Four participants reflected that they had to put themselves in situations where they felt uncomfortable, such as using webcam, to receive support which left them feeling trapped and “stuck” (Edward, p.11). During later stages of the pandemic when face-to-face support was permitted, one participant shared that they were still unable to have their preference of delivery method due to their therapist’s preference, demonstrating feelings around power, disempowerment, and control.

### 1.2. Relying on other people

Six participants experienced difficulties accessing virtual therapy which included not having access to their own laptop, or needing support from caregivers to access the platform. Two participants felt disempowered as they relied on their residential service’s computer being available to access virtual appointments. Furthermore, one participant described how their therapist would contact the communal phone or email to arrange appointments with support workers on their behalf which caused frustration and disempowerment as the participant felt capable of arranging their own appointment.

And the problem is everybody knows your business when you’re virtual because the staff will say like ‘Yeah [Helena’s] got an appointment at three o clock’ because [staff] answer the phone [..] And then sometimes you have residents that answer the blooming phone all of the time too. (Helena, p.8)

For some participants, relying on caregivers or parents to support with access was disempowering and presented a fear of judgement. Even during appointments, support workers were present to monitor technology use, which they would not do face-to-face, which left participants feeling “a bit awkward” (Steven, p.11) and unable to use their therapy space as intended.

### 1.3. Autonomy

All participants described the flexibility of virtual therapy and the associated autonomy this afforded. For Bobby, the flexibility of virtual therapy meant that he could begin his therapy from outside of the country and ascertain when would be a “good time to do it” (p.1). Meanwhile, Aishling was able to continue receiving support whilst she was in hospital by accessing her sessions using her mobile phone.

Completing virtual therapy from the participant’s home environment eliminated travel time, travel-related costs to the participant, and reduced pressure on time-keeping skills: “You haven’t got to have good time-keeping skills because you know you’re already at home and you can just do it from home” (Helena, p.5). For Jacob and Edward, the flexibility of accessing therapy from home allowed them to attend therapy when they were not feeling well enough to leave the house and remain autonomous in this decision. Also, two participants explained that virtual support removed anxiety typically accrued on commutes to face-to-face appointments, which increased accessibility and meant they could enter their therapy in a relaxed state and equipped to make best use of their time.

Furthermore, two participants felt confident using technology and found the experience of virtual support empowering as a result. Their familiarity with virtual platforms allowed independence and an opportunity to exert control in a way they were unable to face-to-face, such as disconnecting from the internet or texting during sessions.

I think the only way I avoid being on virtual is if, obviously, if I felt more shit whilst doing it I’d just move my cursor and cut the internet off, like ‘nope’ [..] And there’s nothing they can do about it. (Edward, p.13)

## Theme 2: Therapy process

All participants shared insight into the virtual therapy process and how it was received in the context of the COVID-19 pandemic. The theme, *Therapy process* comprises of four subthemes: *Novel experiences, Adaptations, “Just hearing a friendly voice”,* and *Stifling the therapeutic process.*

### 2.1. Novel experiences

All but one participant received an email from their therapist or administrator with instructions which outlined how to access virtual therapy and found this straight forward to follow. Virtual therapy was a new experience for all participants, which Aimee, Helena and Aishling described as weird and unfamiliar, and felt shocked by the capabilities of technology. There was a mutuality around virtual support for some participants, whereby it was an unfamiliar experience but therapy was useful. Participants recounted a period of adjustment and getting used to meeting their therapist virtually: “It was a bit difficult at first but then after a bit you get used to it” (Aimee, p.25).

Many participants had not used webcams before. For Aishling and Jacob, the novelty of seeing themselves on camera distracted their attention away from therapy content, whilst Steven and Bobby felt having their camera on held them accountable for participating. Use of camera again felt “weird” (Aimee, p.3) as the therapist was able to see the client’s bedroom in the background, which felt like an invasion of privacy.

Whilst the experience was novel to all, some participants felt disheartened and disappointed with the virtual therapy process. Helen felt that virtual therapy was “awful, I’d never wish that upon anybody. It’s not really a good experience because you don’t get the full experience of it” (p.13).

### 2.2. Adaptations

All participants were sent visual, accessible material to support therapy session content prior to or following appointments via the post or email, and found this helpful to consolidate learning. For David, receiving easy read documentation through the post prior to telephone appointments was crucial to him understanding and benefitting from therapy: “With me going off the pictures and things like that obviously I understood what it was” (p.7). However, Jacob received documents via email and struggled to read these on his smartphone during therapy appointments which he felt limited his engagement and understanding at times. Six participants found it harder to understand therapy skills and process information virtually, which caused feelings of overwhelm and being disadvantaged.

It was a little bit harder to process [..] you just feel like they’re firing loads of questions at you [..] like baffling your head, and I know he’s a therapist but Jesus, could you like fire them questions a little bit slower please, because it’s hard to process all questions in one go. (Steven, p.8)

Bobby felt that it was harder to go through resources collaboratively during virtual therapy compared to face-to-face. For example, worksheets which Bobby felt needed explaining to him in more detail were overseen by the therapist. Some therapist’s sent participant’s links to supplementary resources to aid the learning of skills, such as leaflets and YouTube videos, which Bobby found useful:

And it’s easier, I suppose, to sort of like, if you’re trying to share like resources or like links to things [..] And then my therapist is saying like ‘oh well, you know you should look at this or this or this, or there’s this leaflet etcetera’ like you’ve been able to do it all virtually instead of having to print everything out, which means you might lose it. (Bobby, p.4)

Helena, Aimee and Aishling found YouTube videos helpful when trying to understand concepts which related to their CBT-based intervention, such as “challenging the voices” (Helena, p.15), and felt that the use of visual material was more helpful than somebody talking in the absence of face-to-face support. However, the limits of technology are highlighted as Aishling struggled to see the shared resources when joining virtual video appointments on her mobile phone: “It would be small, I’d be like, ‘I can’t see that!” (p.15).

Therapists attempted to adapt CBT-based tasks for virtual use, for example Aimee’s therapist shared her formulation with her and her support team through screen sharing. All participants were set homebased tasks to complete between sessions, such as CBT-based exposure tasks for anxiety, which Bobby’s therapist supported him to engage in by maintaining a shared document of activities on the computer.

### 2.3. “Just hearing a friendly voice”

At the beginning of the pandemic, some participant’s interventions were paused whilst others changed in nature to well-being checks whilst therapists navigated new ways of working.

Although challenges were encountered by participants when adjusting to virtual delivery, six participants highlighted that therapy was useful and shared positives of their experience. For Steven, “just hearing a friendly voice” (p.4) from his therapist via telephone during the pandemic was positively impactful on his well-being. Three participants felt anxious and lonely during the pandemic as day services had been cancelled, and identified therapy as a protective factor. Therapy provided a space for them to “release some of the things that [they] were thinking about” (David, p.8) which otherwise were not shared.

### 2.4. Stifling the therapeutic process

All participants experienced disruption to their experience due to technical difficulties, which included device batteries running out of power, distorted audio and difficulties with internet connectivity. Particularly for participants living in residential environments where “too many people using the internet [caused] it to crash or slow down” (Helena, p.14) and resulted in regular drops in connection. Helena felt that this made it harder for her to process information as segments of dialogue were regularly missed out, which caused frustration.

Bobby, Aishling, Edward and Jacob recalled feeling anxious when their connection was lost during a therapy appointment, and felt helpless when their flow of conversation was interrupted by unexpected disconnection, best exemplified by Bobby’s account:

Like you know it’s if your connection isn’t very good, or like [therapist’s] computer wasn’t working well like it would be hard to have a conversation ‘cause you couldn’t hear what they’re saying or it was like, you know, things like that can be quite frustrating, and so you don’t necessarily get a lot out of it. (Bobby, p.6)

Losing “the thread of conversation [..] if you are sharing something deeply personal and something gets cut off“ (Jacob, p.9) contributed to feeling like elements of therapy sessions were lost and participants were unable to get as much out of these sessions. Some participants found it hard to navigate re-joining virtual appointments and picking up conversation where it was left once the flow had been disrupted: “you can’t just take a five minute break and then just immediately throw us back into a conversation at the same depth you were before, like, you were interrupted” (Bobby, p.7). Encountering technical difficulties resulted in participants withholding information they would have shared if they were not interrupted. Empathy was shown by participants that these difficulties cannot be avoided, but nonetheless caused inconvenience and frustration.

## Theme 3: Therapeutic relationship

All participants spoke about the therapeutic relationship they held with their therapist and the impact this had on their virtual therapy journey. This theme has two subthemes: *Building a connection* and *Therapist factors.*

### 3.1. Building a connection

All participants identified that it was harder to foster a connection and build a successful relationship with their therapist over virtual therapy compared to face-to-face, and found this tricky to navigate. Indeed, Aishling, Steven and Aimee had met with their therapist face-to-face before lockdown and had a pre-existing rapport which they felt made the switch to virtual therapy easier: “It’s like the same, when you are on the computer but talking to him and also face-to-face, they’re both the same” (Aishling, p.10).

Four participants felt grateful that they were able to see their therapist through video even though they were not in the same room as they were able to see the therapist was a “real person [..] not kind of like a disembodied voice” (Bobby, p.9). Participants found it harder to establish therapeutic relationships over the phone as the absence of visual cues made this feel less tangible. Edward detailed how he felt uncomfortable when therapy was over the telephone and made a conscious choice to exert control and end the contact:

[Webcams are] a god send. Even though it felt like I was talking to the machine, I could still see them, whereas on the mobile it was like ‘What do I do? I can’t see you so I’m not opening up to you, bye bye. (Edward, p.21)

Virtual therapeutic relationships were described as distant and artificial with references made to them being mechanical in nature with little emotional investment: “I’m just kind of talking to my screen and it responds back” (Bobby, p.9). Most participants felt anxious and unsafe due to increased uncertainty and discomfort with virtual methods which negatively impacted the connection they felt with their therapist. Edward needed “a secure base, a bit of security [..] making sure that I feel safe” (p.9) to get the most out of therapy but felt this was lacking. In Bobby’s experience, lack of connection with his therapist led him to feel disconnected and perceive therapy as inconsequential: “You know the therapy was something that I did for that hour, and then afterwards I was kinda just living my life” (p.10). By contrast, Steven had met his therapist in person before having virtual support, and felt safer and less anxious meeting his therapist in person which enabled him to “open up a little bit more” (p.3). However, autistic participants felt safer in the virtual environment, with less “nerves” (David, p.9) and “dread” (Jacob, p.3) than when attending face-to-face appointments.

### 3.2. Therapist factors

Four participants felt that therapists were harder to gauge virtually and that they were unable to get a sense of the therapist’s individual characteristics which made it more challenging to establish rapport: “you don’t know their personality until you see them, do you?” (Steven, p.2). Aimee also highlighted that feeling unsure of the therapist’s personality felt challenging to her when trying to talk about her feelings. The importance of mutual respect and the therapist appearing confident was also identified by Edward as difficult to ascertain through virtual means, and felt that mutual respect required efforts from both participant and therapist to develop as “it doesn’t just happen” (p.7). Some participants shared challenges of being unable to perceive non-verbal communication, such as body language, through virtual methods. The loss of non-verbal communication created barriers to understanding both the therapist and therapy content: “it’s easier if you are seeing them face-to-face as you can see their body language” (Helena, p.10).

Two participants explained the importance of trust in the therapeutic relationship and the difficulties establishing this virtually. Particularly within the context of COVID-19 and therapists working from home, participants felt that how the therapist navigated personal and professional boundaries was subsequently impactful on their trust of the therapist and overall experience of support.

[therapist’s] home was blurred out but you could see [them], but you can hear [their] kids coming in and out of the house and bedroom, asking for their [parent] so it was a bit odd [..] and the [pets] or [their partner], whoever coming in. (Aimee, p.22)

Uncertainty over the therapist’s environment posed a barrier to trust and impacted how comfortable Edward felt disclosing information during therapy. Edward also felt unsure of how engaged his therapist was in their appointment when receiving telephone support as “they could just have [him] on speaker and be pissing about or something, you don’t know what they are doing” (p.17) which was a further barrier to building connections in the therapeutic relationship.

## Theme 4: Safety in the virtual environment

All participants described experiences of safety in the virtual therapy environment as integral to their overall experience. This theme comprises of three subthemes: *Risk management, Environmental factors* and *Confidentiality.*

### 4.1. Risk management

Participants felt that measures had been taken to keep them safe and manage risk whilst receiving virtual support. This included support from family or from support workers who were available within the home after or during appointments to provide emotional or physical support. Some participants engaged themselves in tasks straight after therapy to regulate their emotions as they were agitated by the virtual therapy session which included playing “console or just watch TV, listen to music” (Steven, p.7), “talking to my friends” (Bobby, p.10) and “breathing a sigh of relief and allow yourself to kind of calm down a bit” (Jacob, p.17).

Aimee recalled that particular topics in therapy “used to wind [her] up and then [she’d] tend to have behaviours afterwards” (p.7) which resulted in support workers intervening to manage risk which included verbal de-escalation and giving her a “calming tablet” (p.9). Aimee felt that her support workers were worried when she had virtual therapy at home as they “didn’t have a clue” (p.21) how the session would go and “wouldn’t know what to do in the situation” (p.7) regarding risk. Her therapist later modified online support accordingly and “suddenly kept cutting the meetings shorter and shorter” (p.11) when triggering topics were bought up to manage risk. Aishling’s therapist completed a follow-up well-being check the day after difficult appointments to ascertain risk.

### 4.2. Environmental factors

Some participants felt more comfortable in their home environment as opposed to the clinic, and were therefore able to get more out of their therapy experience. Home comforts included their own bedroom and grounding objects, such as a teddy bear: “I got a little upset and I remember it was helpful because I was in my room and like I had my little like teddy, right? [..] I can have this and that’s quite comforting” (Bobby, p.2)

However, distractions around the house, such as mobile phones or computer games, meant that Edward and Steven struggled to concentrate at times. Helena found the residential environment challenging to complete virtual therapy in, however lockdown restrictions meant this was unavoidable:

Loud noises in the background, music playing, banging, kicking, screaming, and all of this kind of stuff. It was too loud of an environment, it was. Even though I was in my bedroom I could still hear what’s going on downstairs [..] And it’s really hard to concentrate on one thing if there’s loads of noise going on, and that’s one thing I hated about the experience. (Helena, p.13)

### 4.3. Confidentiality

All participants raised confidentiality as a threat to psychological safety which negatively impacted their experience of virtual therapy. Some participants who usually attended face-to-face appointments alone received one-to-one observations within their residential environment which meant they were unable to complete virtual therapy without a support worker present. For Steven, the presence of support workers felt threatening to confidentiality and limited his engagement in therapy as it was “hard to tell people things when you’ve got your carers here [..] because he’s like [a] trained therapist and they aren’t. It’s a bit hard” (p.11). Confidentiality was similarly challenging to manage within the home environment:

It limits what you can talk about really because obviously, say you wanted to talk to your therapist about something to do with how you interact with family, you may not potentially share something that, you’ll never share something that might embarrass you if your family’s nearby. (Jacob, p.10)

Additionally, participants living in residential environments were concerned that other residents were listening to their therapy sessions: “I was worried in case everyone was listening in the house” (Helena, p.11). Bobby, Helena and Aimee felt preoccupied and distracted by their concerns that people were listening to their sessions, which limited their engagement in virtual support. Participants took steps to ensure confidentiality where possible, which included scheduling appointments for when no-one else was around and completing therapy sessions at the library in a private-room when lockdown restrictions permitted: “[the library] was brilliant, it was. At least I get peace and quiet without somebody else being there” (Aishling, p.7).

Furthermore, Edward and Aimee expressed concern over confidentiality within the therapist’s home environment as both heard ambient voices in the therapist’s background during appointments. Certainties which are tangible in person, such as being alone with the therapist in the room, felt unattainable virtually which reduced engagement: “On the laptop because even though you can see this part [of the room], you don’t know who’s on that part [..]” (Edward, p.17).

# Discussion

The COVID-19 pandemic necessitated face-to-face psychological support for PWID to abruptly switch to virtual methods of delivery. As many services in the UK are now adopting a hybrid-model of working in a post-pandemic world, this research aimed to understand the experiences of PWID that received virtual support to inform future practice and policy (British Psychological Society, 2020). An RTA of eight semi-structured interviews was conducted which resulted in four themes*: Power, Therapy Process, Therapeutic Relationship,* and *Safety in the virtual environment.* These themes highlight the diverse needs and experience of PWID who received CBT-based virtual psychological support during the pandemic.

Some participants felt powerless in decision-making around their care due to COVID-19 restrictions, and felt obliged to place themselves in uncomfortable scenarios such as going on webcam, completing therapy within their family home or relying on support workers in order to receive support, all presenting obstacles to satisfactory care. The concept of powerlessness is not new for PWID who are reported as vulnerable and at risk of exploitation due to perceived lack of ability (Marsland et al., 2015). PWID commonly experience power imbalances within their wider system (Collins et al., 2022), particularly within the health and social care context where needs are sometimes overlooked (NICE, 2016). A position of power is typically adopted by the therapist during CBT-based interventions, where the therapist holds evidence-based knowledge and uses this to guide the participant (Proctor, 2008). Although lack of choice caused by pandemic restrictions were unavoidable, power imbalances can contribute to psychological distress and hinder therapeutic progress (Proctor, 2008). Therefore, it is important for PPs to consider how virtual support is offered and set up with a collaborative focus, including pre-emptive risk management plans, as to not accentuate imbalance and minimise disruption.

The provision of virtual support afforded increased flexibility and autonomy for PWID by offering practical solutions to overcome commonly experienced barriers to accessing mental health services (Alborz et al., 2005; Dalen & Pandolfi, 2020). Participants reported benefits of virtual therapy similar to those reported in the literature (MacHale et al., 2013), such as reduced pressure on time-keeping skills, greater flexibility and no cost of travel to clinics. Some participants also described feeling more comfortable in virtual environments as it alleviated anxiety associated with face-to-face appointments, such as eye contact and travel to appointments, particularly for people with autism (Kalvin et al., 2021) and social anxiety disorder (Warnock-Parkes et al., 2020). Additionally, some participants felt more comfortable in their home environment when talking about sensitive topics, which allowed for more engagement with the virtual process, and these experiences are also highlighted in the literature from neurotypical populations (Kocsis & Yellowlees, 2018).

The level and quality of therapeutic relationship and connection between therapist and client is impacted by psychological safety (Geller & Porges, 2014). This research highlights lack of physical presence in virtual therapy as a barrier to psychological safety which prevented engagement in therapy, also highlighted by Vereenooghe et al. (2017) and in neurotypical populations (van Kessel et al., 2022). Furthermore, participants described virtual therapy as distant and impersonal, which is also highlighted by PPs (Blocksidge et al., (2022). Indeed, poor therapeutic alliance is likely to negatively impact on overall therapeutic outcomes (Blocksidge et al., 2022) therefore it is important to consider how this can be overcome when working virtually. PWID often rely on non-verbal communication during interactions (Martin et al., 2010), therefore many participants found therapeutic relationships easier to establish face-to-face; those that had met their therapist previously face-to-face reported an easier transition to virtual support (Fernández-Álvarez & Fernández-Álvarez, 2021).

Therapist factors, including confidence, personality and respect, were contingent in developing rapport and building connections for PWID, however were challenging to perceive virtually (Blocksidge et al., 2022). Interestingly, Burton and Gordon (2022)’s literature review reported that PPs felt less confident when working virtually during the pandemic, attributed to unfamiliarity with virtual platforms and lack of guidance. Therefore, future training in providing virtual CBT-based therapy is imperative to develop PPs knowledge and confidence in order to increase the psychological safety and containment of clients, and potentially improve therapeutic outcomes (Hinde & Mason, 2020).

The importance of environmental safety when engaging in virtual therapy was prevalent across participants’ accounts. Participant’s family and caregivers were relied on to manage risk remotely, which can perpetuate disconnect and friction between the participant and caregiver (Rawlings et al., 2021). Within the subtheme of *Risk management*, a perceived lack of confidence in support workers ability to manage risk behaviours during or following virtual therapy sessions is highlighted. As behaviours that challenge in PWID are commonly expressions of communication in response to perceived threat, it is important that behaviour is responded to appropriately to reduce risk (Collins et al., 2022). This finding highlights a need for earlier risk assessment and systemic communication between services and caregivers when managing risk remotely to prevent client distress (Millar & Greenhill, 2022). Good practice, such as well-being checks following difficult sessions, led to participants feeling supported in some cases.

Confidentiality appeared tricky to navigate and limiting in various ways. Boundaries appeared blurred in some participant accounts, which often preoccupied participants during appointments. Confidentiality remains of central importance to the therapeutic process across populations (Roback & Shelton, 1995), however this current research highlights unique challenges for PWID that live in residential environments and/or had a caregiver present for virtual appointments as they felt unable to share information with their therapist. As detailed in the subtheme *Confidentiality*, participants were also concerned over confidentiality within the therapist’s work from home environment. It is noted that PPs supporting PWID also recognised and struggled to navigate this within the pandemic context (Langdon et al., 2021), however it is important that the client’s need for confidentiality is prioritised to ensure their engagement in psychological support.

The digital divide(Chadwick et al., 2013) posed barriers to PWID accessing virtual psychological support. Participants with access to their own computer and subsequent familiarity with this technology were afforded greater independence and felt empowered during virtual support, whilst those accessing interventions via telephone or video call on their mobile phone felt they had received an incomplete service. Research suggests that social care funding and training for PWID may help overcome technological barriers which interfere with the delivery of virtual therapy (Chemerynska et al., 2022). Whilst the scope of funding is unknown, it is important to consider how digital barriers are overcome for PWID as offers of virtual support continue in the UK.

Adaptations that had been made to therapy were highlighted by participants and stressed the potential versatility and application of virtual methods in CBT-based support. Although Dowling et al. (2022) expressed concerns over virtually supported exposure for anxiety treatment, participants in this study recounted positive experiences of completing exposure exercises during virtual therapy, which highlights individual differences in levels of required support. Screen sharing was also important when discussing therapy concepts and documentation to aid understanding (Blocksidge et al., 2022). Whilst adaptations can be made to CBT-based support for virtual delivery for PWID (van Kessel et al., 2022; Vereenooghe, 2021; Warnock-Parkes et al., 2020), training remains an imperative part of this being successful as differences in outcomes for PWID who received CBT-based support during the pandemic with IAPT are attributed to fluctuations in therapist’s skill level (Rodhouse et al., 2022). Pre-pandemic, IAPT therapists reported feeling powerless to adapt their practice for PWID as training was not prioritised by their senior leadership team (Chinn & Abraham, 2016), further emphasising ongoing struggles with upskilling in therapeutic adaptations for PWID.

Participants highlighted contact with their therapist as a valued and enjoyable activity regardless of delivery method (telephone/video call) and session content (therapeutic/well-being check) during the pandemic in the absence of regular activities, such as volunteer roles and day-centre visits. This finding supports existing literature whereby virtual connectivity during the pandemic was central to overcoming loneliness and social isolation for PWID (Lawford et al., 2022; Navas et al., 2021).

## Clinical Implications

Many individual factors relating to the experience of PWID are highlighted in this study; thus it is pertinent for services to take into consideration the needs, preferences, access to technology and digital skills of clients when exploring ways of working virtually post-pandemic (Zangani et al., 2022). Clinicians must maintain collaborative practices whilst making decisions regarding method of delivery to avoid highlighting power imbalances.

Services should consider how they can accommodate those wishing to participate in virtual therapy to uphold privacy and autonomy, particularly within the context of residential services and when caregivers are present for appointments. The creation of psychological safety within the virtual environment and its impact on therapeutic relationship quality and PWID’s engagement in virtual support must be considered by services (Geller & Porges, 2014). Where CBT-based interventions are NICE (2016) recommended for PWID, training is recommended for PPs working virtually and should include adaptations of the model, confidentiality, remote risk management and psychological safety; improving training for PPs in a post-pandemic world could increase both positive therapeutic outcomes for PWID (Rodhouse et al., 2022), and PP confidence and job satisfaction (Burton & Gordon, 2023).

**Future Research**

As restrictions no longer prevent face-to-face interaction, it would be relevant for future research to focus on how a blended approach of face-to-face and virtual therapy can be improved for PWID. Furthermore, future research could explore the therapeutic alliance in more detail to ascertain how this is best navigated virtually to increase positive experiences of virtual therapy for PWID.

## Strengths and Limitations

This sample was recruited from two services within the same NHS Trust which may introduce sampling bias due to differences in referral processes and the exclusion of participants who had no involvement from these services (Tuffrey-Wijne et al., 2014). Whilst existing research has samples of PWID with more female than male participants (see MacHale et al., 2023), this research had more male (n=5) than female (n=3) and therefore may capture underrepresented views. As all participants were White British, it is recommended future research seeks a representative sample with greater diversity (Allmark, 2004).

Data collection was not commenced until almost 3 years after the first UK lockdown was imposed in 2020 due to delays with recruitment and NHS approval, which inevitably impacted participant’s recall of experience and may have led to missing information.

The researcher held a dual role of both researcher and trainee clinical psychologist; dual-roles are mutually beneficial (Hay-Smith et al., 2016) and produce high quality research projects due to the researcher inadvertently drawing on clinical skills during interview to produce richer participant accounts (Fleet, 2016).

## Conclusion

The rapid switch to virtual therapy mandated by the COVID-19 pandemic had both positive and negative effects on the experience of virtual CBT-based therapy in PWID. In most cases, CBT-based support was successfully adapted to virtual means, however the method of delivery (telephone/video call) impacted participant experiences. The importance of psychological safety for PWID receiving virtual support is highlighted, with lack of safety impacting quality of therapeutic relationship and engagement in interventions. The unique challenges faced by PWID, such as reliance on non-verbal communication and confidentiality in residential environments and/or when caregivers are present, must be addressed when navigating the delivery of virtual or blended therapeutic approaches post-pandemic.

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Zangani, C., Ostinelli, E. G., Smith, K. A., Hong, J. S., Macdonald, O., Reen, G., ... & Cipriani, A. (2022). Impact of the COVID-19 pandemic on the global delivery of mental health services and telemental health: systematic review. *JMIR mental health*, *9*(8), 38600. https://doi.org/10.2196/38600.

# Appendices

## Appendix A

*JARID Author Guidance*

https://onlinelibrary.wiley.com/page/journal/14683148/homepage/forauthors.html

## Appendix B

*****Study Invitation*

**Version 1.0 11.11.2021**

**IRAS ID - 312471**

Dear Invitee,

We are contacting you as you are on the North Staffordshire Combined Healthcare NHS Trust ‘Contact for Research’ register.

We are kindly asking for your participation in a doctoral research study called: Exploring Experiences of Virtual Cognitive Behavioural Therapy (CBT) in Adults with a Learning Disability during the Coronavirus-19 Pandemic. This research is being completed by a trainee Clinical Psychologist at Staffordshire University and North Staffordshire Combined Healthcare NHS Trust.

We are conducting interviews lasting approximately 1 hour as part of this research study. We hope that this research will increase our understanding of how adults with a learning disability have experienced virtual (via Microsoft Teams or telephone) CBT. We are particularly interested in the experience of individuals who received virtual CBT during the coronavirus-19 (COVID-19) pandemic due to the quick transition to delivering therapy virtually.

Your participation will be a valuable in strengthening the NHS’s understanding of how virtual therapy can be used across the NHS services and adapted successfully to meet the needs of adult clients with a learning disability.

**There is a Participant Information Sheet attached which contains more information about this research study.**

If you are interested in participating in this research or have any questions, please email the researcher. Details provided below.

Thank you,

Holly Burton  
Trainee Clinical Psychologist  
b024990k@student.staffs.ac.uk

## Appendix C

*****Participant Information Sheet (General)*

**Version 3.0 01.06.2022**

**IRAS ID - 312471**

**Invitation**

We would like to invite you to participate in this research project which forms part of a Doctorate of Clinical Psychology thesis. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Please ask the researcher if there is anything that is not clear or you would like extra information.

**What is the purpose of this research?**

We are interested in how adults with learning disability have experienced virtual (e.g. via telephone or online video communication software) cognitive behavioural therapy (CBT) for a mental health difficulty. We are particularly interested in the experience of individuals who received virtual CBT during the coronavirus-19 (COVID-19) pandemic due to the quick transition to delivering therapy virtually. We are hoping to gain an understanding of what CBT was like for you and your perspective. We hope that this research can strengthen the NHS’s understanding of how this can be effectively used across NHS services and adapted successfully to meet the needs of adult clients with a learning disability.

**Why have you been invited to take part?**

You have been invited to take part in the research because you meet the criteria outlined below:

- You are over 18 years old

- You have completed at least 8 1:1 sessions of CBT for a mental health difficulty (e.g. anxiety, depression, psychosis) with the Community Learning Disability Team (CLDT) or Improving Access to Psychological Therapies (IAPT) through a virtual platform (e.g. telephone or online video communication software).

- You have been recognised by the CLDT or IAPT in North Staffordshire Combined Healthcare NHS Trust as having a diagnosis of a learning disability.

**What will happen if you take part?**

If you consent to taking part in this research, you will be contacted by the researcher to arrange an interview. You will meet with the researcher on a virtual platform (e.g. Microsoft Teams) or face-to-face to complete an interview which will last around 1 hour. If you decide to take part in this research, you will have a discussion with the researcher prior to your interview to make any adjustments and overcome any hurdles with technology. Your interview will be audio recorded. The researcher will have their camera on during the interview and you will be encouraged to have your camera on too, however you do not have to if you do not want to.

During the interview, you will be asked questions about your experiences of virtual CBT. The questions will focus on how you experienced CBT delivered in a virtual way, things that you enjoyed and things that you did not enjoy. You will also be asked questions about things you would like to happen differently if you had this experience again. We understand that this may be a sensitive topic. You are able to have a parent or carer present during your interview if you wish, as long as they do not answer the questions on your behalf. We can take a break halfway through the interview if you wish.

Following the completion of all of the interviews with participants in this research, you will be given the optional opportunity to review and comment on the emergent themes. The researcher will contact you via email to discuss this opportunity.

**What are the possible risks of taking part?**

Every effort will be made to make the interview an enjoyable experience. However, we acknowledge that talking about experiences of therapy may be difficult and upsetting. We have included some useful links at the bottom of the information sheet if you feel you need support after the interview.

**What are the possible benefits of taking part?**

It is hoped that this research can drive the implementation of educational IAPT webinars for practitioners and contribute to service guidelines for adapting CBT for online delivery to improve the experiences of adults with learning disabilities who receive virtual CBT. Participating in research can be a rewarding activity, and benefits can include feeling heard by the interviewer and having the chance to reflect on your experiences.

**Will taking part in this research be kept confidential?**

The information that you give will be confidential. The interviewer will not talk to anyone else about your information, unless they are worried about your safety. If the researcher becomes aware of any risk of harm to self or others or criminal activity, they are obliged to report this to the relevant authorities. The recordings from the interview will be stored on a password protected computer. The researcher will not use any information with your name or address, and you will be assigned a pseudonym. Your data will be processed in compliance with the UK General Data Protection Regulations (UK GDPR), tailored by the Data Protection Act 2018. Personal data will be stored for 6-12 months following the study completion. The study data will be stored electronically via Staffordshire University’s secure server for 10 years following study closure in adherence with Staffordshire University policy.

The data controller for this project will be Staffordshire University. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under the data protection law is a ‘task in the public interest’. You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you.

**How will we use information about you?**

We will need to use information from your medical records for this research project. This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

**What are your choices about how your information is used?**

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that you already have. We need to manage your records in specific ways for he research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information at [www.hra.nhs.uk/information-about-patients](http://www.hra.nhs.uk/information-about-patients), by sending an email to [b024990k@student.staffs.ac.uk](mailto:b024990k@student.staffs.ac.uk) or calling the research team on 07814830760.

**What if you change my mind about taking part?**

You are free to withdraw at any point of the study up to a certain point, without having to give a reason. Withdrawing from the study will not affect you or your care in any way. You are able to withdraw your data from the study up to four weeks after the interview date, after which withdrawal will not be possible as any identifying information will have been removed and will have already been processed for analysis.

**What will happen to the results of this study?**

The results will be used within the researcher’s Clinical Psychology Doctoral thesis and will be shared with the CLDT and IAPT. We hope to publish the results in a peer review journal and present at relevant conferences or events in the future.

**Who is organising the research?**

This project is being undertaken, by the main researcher, as a part of a professional doctorate in Clinical Psychology, sponsored by Staffordshire University.

**Who has reviewed the research?**

All research in the NHS is reviewed by an independent group of people, called a Research Ethics Committee, which is there to protect your rights, safety, well-being, and dignity. This project has been reviewed and approved by the Research Ethics Committee. This project has also been subject to peer review, to the scientific merit of the research, and approval has been granted by the Faculty of Health Research Ethics Committee at Staffordshire University.

**Who should you contact for further information?**

If you have any questions or want more information about this study, please contact the researcher using the following contact details.



Holly Burton  
Trainee Clinical Psychologist  
[b024990k@student.staffs.ac.uk](mailto:b024990k@student.staffs.ac.uk)

07814830760

**What if you have further questions, or if something goes wrong?**

If this study has harmed you in any way or if you wish to make a complaint about the conduct of this study you can contact the study supervisor (kim.gordon@staffs.ac.uk) or the Chair of the Staffordshire University Ethics Committee for further advice and information at [ethics@staffs.ac.uk](mailto:ethics@staffs.ac.uk) or 01785 353662.

**Thank you for reading this information sheet and for considering taking part in this research**

**USEFUL LINKS**

|  |  |
| --- | --- |
|  | [**www.easyhealth.org.uk**](http://www.easyhealth.org.uk/)  Easyhealth was made so that people know where to find accessible health information. Accessible information is information that uses easy words with pictures. |
|  | **Foundation for People with Learning Disabilities**  [**www.learningdisabilities.org.uk**](http://www.learningdisabilities.org.uk/)  Raising awareness of learning disabilities and information on website. |
|  | **Learning Disability Helpline**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 0808 808 1111** [**www.mencap.org.uk**](http://www.mencap.org.uk/)  Advice and information on all aspects of learning disability, issues covered include benefits for people with a learning disability and their carers, housing options and independent living, education, employment options and the support available for people in work or trying to find work, community care (including direct payments). |
| https://www.mind.org.uk/media/7845/portraits_unsplash-4.jpg | **Respond**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 020 7383 0700**  [**www.respond.org.uk**](http://www.respond.org.uk/)  Works with children and adults with learning disabilities who have experienced abuse or trauma, as well as those who have abused others, through psychotherapy, advocacy, campaigning and other support. |
| [Image result for samaritans](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwi0kv3txo_bAhVKtBQKHdefBhQQjRx6BAgBEAU&url=https%3A%2F%2Fwww.wolvesunion.org%2Fents%2Fevent%2F5519%2F&psig=AOvVaw3Z_6_fSYAJlhl2jTljUtDw&ust=1526742934347148) | **Samaritans**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 116 123**  We know a lot about what can help you through tough times. We can help you explore your options, understand your problems better, or just be there to listen. |

## Appendix D

*****Participant Information Sheet (Easy-Read)*

**Version 3.0 01.06.2022**

**IRAS ID - 312471**

|  |  |
| --- | --- |
| C:\Users\burtho\Downloads\PastedGraphic-4.png | My name is Holly Burton |
|  | My role is a researcher |
|  | We are writing to ask if you want to take part in a research study |
|  | To help you understand this sheet you can |
|  | * Ask someone to read it for you |
|  | * Talk to your parent or carer about it |
|  | * Ask the researcher questions |
|  | |
| **What is this research about?** | |
|  | We want to find out more about the experiences of adults with a learning disability who have engaged in virtual cognitive behavioural therapy (CBT) |
| Virtual means you may have had CBT with a therapist on your phone or on your computer |
|  | |
| **We want to find out about** | |
|  | * What went well with your virtual therapy |
|  | * What could have gone better with your virtual therapy |
|  | * We are looking for 8 to 10 people to take part |
|  | |
| **Why do we want you to participate?** | |
|  | We want to see you because   * You are over 18 years old * You have a learning disability * You have completed at least 8 sessions of 1:1 CBT for a mental health difficulty |
|  |
|  | |
| **What will happen if you take part?** | |
|  | You do not have to take part if you do not want to |
|  | If you say YES to taking part, you will take part in an interview |
|  | We will call you before the interview to make any adjustments and make sure you are comfortable |
|  | We will meet on a virtual platform, such as Microsoft Teams |
| C:\Users\burtho\Downloads\PastedGraphic-4.png | The researcher will keep their camera on. You do not have to keep yours on if you do not want to. |
|  | The interview may take up to an hour |
|  | You can have a parent or carer with you during your interview if you want to, as long as they do not answer the questions for you |
|  | We can have a break half way through the interview if you would like to |
|  | Your voice will be recorded during the interview |
|  | Once all interviews have been completed, you will be given the optional opportunity to review and comment on themes from the research  The researcher will contact you via email to discuss this opportunity |
|  | |
| **The researcher will ask questions about** | |
|  | * What is your experience of CBT delivered in a virtual way? |
|  | * What did you enjoy? |
|  | * What did you not enjoy? |
|  | * Is there anything that you would change about your experience? |
|  | |
| **What are the risks of taking part?** | |
|  | There are no serious risks of taking part in this research |
| Sometimes talking about experiences of therapy may be difficult and upsetting |
| There are a list of useful links at the end of this document if you feel upset after the interview |
|  | |
| **What are the possible benefits to taking part?** | |
|  | We hope this research can be used in teaching for therapists and psychologists |
|  | We hope we can improve the experience of adults with a learning disability who have virtual CBT |
|  | |
| **What happens with your information?** | |
|  | We will need to use information from your medical records for this research project  This will include your name and contact details  People will use this information to do the research or to check your records to make sure that the research is being done properly |
|  | The information that you give will be confidential (private)  We will keep all information about you safe and secure. |
|  | The researcher will not talk to anyone else about your information |
| The researcher will only talk to someone else about you if they are worried about your safety |
|  | The recordings from the interview will be stored on a password protected computer |
|  | People who do not know who you are will not be able to see your name or contact details. Your data will have a code number instead  You will be given a fake name (pseudonym) when this research is written and we will write our report in a way that no-one can work out that you took part in the study  The researcher will not use any information with your name or address |
|  | |
| **What happens if you change your mind about taking part?** | |
|  | You can stop taking part at any time |
|  | You do not have to give a reason for withdrawing from the study and this will not change the care that you get |
|  | |
| **What will happen to the result of this study?** | |
|  | The results will be used in a Clinical Psychology Doctoral thesis and will be shared with the Community Learning Disability Team and the Improving Access to Psychological Therapies Team. |
| The researcher hopes to publish the results in a peer review journal or present at a conference in the future |
|  | |
| **Who can you contact?** | |
|  | Holly Burton Trainee Clinical Psychologist b024990k@student.staffs.ac.uk |
|  | You can contact the researcher if you have any questions about the study |
|  | You can contact the researcher if you are **not happy** with the study or if anything happens in the study that you feel uncomfortable about |
|  | If you want to make a complaint, you can contact Staffordshire University at ethics@staffs.ac.uk or 01785 353662.  Or the study supervisor, Dr Kim Gordon, at [kim.gordon@staffs.ac.uk](mailto:kim.gordon@staffs.ac.uk). |
| C:\Users\burtho\Downloads\PastedGraphic-4.png | If you have any questions you can contact the researcher on [b024990k@student.staffs.ac.uk](mailto:b024990k@student.staffs.ac.uk) or 07814830760. |
| **Thank you for looking at this information** | |

**USEFUL LINKS**

|  |  |
| --- | --- |
|  | [**www.easyhealth.org.uk**](http://www.easyhealth.org.uk/)  Easyhealth was made so that people know where to find accessible health information. Accessible information is information that uses easy words with pictures. |
|  | **Foundation for People with Learning Disabilities**  [**www.learningdisabilities.org.uk**](http://www.learningdisabilities.org.uk/)  Raising awareness of learning disabilities and information on website. |
|  | **Learning Disability Helpline**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 0808 808 1111** [**www.mencap.org.uk**](http://www.mencap.org.uk/)  Advice and information on all aspects of learning disability, issues covered include benefits for people with a learning disability and their carers, housing options and independent living, education, employment options and the support available for people in work or trying to find work, community care (including direct payments). |
| https://www.mind.org.uk/media/7845/portraits_unsplash-4.jpg | **Respond**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 020 7383 0700**  [**www.respond.org.uk**](http://www.respond.org.uk/)  Works with children and adults with learning disabilities who have experienced abuse or trauma, as well as those who have abused others, through psychotherapy, advocacy, campaigning and other support. |
| [Image result for samaritans](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwi0kv3txo_bAhVKtBQKHdefBhQQjRx6BAgBEAU&url=https%3A%2F%2Fwww.wolvesunion.org%2Fents%2Fevent%2F5519%2F&psig=AOvVaw3Z_6_fSYAJlhl2jTljUtDw&ust=1526742934347148) | **Samaritans**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 116 123**  We know a lot about what can help you through tough times. We can help you explore your options, understand your problems better, or just be there to listen. |

## Appendix E

*****Verbal Informed Consent (General)*

**Version 3.0 01.06.2022**

**IRAS ID - 312471**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. Can you confirm that you have read and understood the information sheet. | Yes |  | No |  |
| 1. Can you confirm that you have been given the opportunity to ask questions, and have had any questions answered satisfactorily. | Yes |  | No |  |
| 1. Can you confirm that you understand that your participation in this study is entirely voluntary and that you can withdraw at any time without having to give an explanation. Withdrawing from this research will not affect your current or future treatment in any way. | Yes |  | No |  |
| 1. Can you confirm that you understand that the interview will be audio-recorded. | Yes |  | No |  |
| 1. Can you confirm that you understand we will need to use information from your medical records for this research project, such as your name and contact details. | Yes |  | No |  |
| 1. All research may be audited to ensure it is carried out to the best standards. Do you understand this means that sections of your medical notes, and data collected during the study, may be looked at by individuals from Staffordshire University, or from regulatory authorities, and from the NHS Trust where it is relevant to your taking part in this research. Do you give permission for these individuals to have access to your records related to this study? | Yes |  | No |  |
| 1. We would like to use anonymised quotes from your interview in the write-up, report, publications, and presentations about this study. Do you give consent for your quotes to be used in this way? | Yes |  | No |  |
| 1. Although all information collected will remain confidential, the only exception would be if you disclosed any information that would put you or someone else at risk of harm. Do you agree with this? | Yes |  | No |  |
| 1. Do you understand that you can withdraw your data from the project up to four weeks after your interview without having to give an explanation? | Yes |  | No |  |
| 1. Knowing the above information, do you hereby give consent to take part in this study? | Yes |  | No |  |
| 1. Would you like to receive an executive summary of this research once it has been written up? | Yes |  | No |  |
| 1. After the completion of all the interviews with participants in this research you will be given the opportunity to review and comment on emergent themes. Do you consent for the researcher to contact you about this opportunity? | Yes |  | No |  |

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name of Participant Date of Consent

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name of Researcher Signature of Researcher

## Appendix F

*Verbal Informed Consent (Easy-Read)*

**Version 3.0, 01.06.2022**

**IRAS ID - 312471**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | This is a form to give your consent to taking part in our research. | | | |
|  | We are looking at experiences of virtual (e.g. video call) cognitive behavioural therapy in adults with a learning disability during the Coronavirus-19 pandemic. | | | |
| Choose V3 | For each point, the researcher will ask you to say whether you agree with them.  You can give your consent by saying ‘yes’ or ‘no’ | | **✓**  Yes | **X** No |
|  |  | |  |  |
|  | Can you confirm that you have read the information sheet that you were given | | **✓** | **X** |
|  | Can you confirm that you understand the information that was given to you on the information sheet | | **✓** | **X** |
| Anything else V3 | Can you confirm that you have asked any questions that you may have | | **✓** | **X** |
|  | You can stop the interview at any time without having to give an explanation  Withdrawing from this research will not affect your current or future treatment in any way.  Can you confirm that you understand this? | | **✓** | **X** |
|  | Can you confirm that you are happy for to have your voice recorded | | **✓** | **X** |
|  | We will need to use information from your medical records for this research project, such as your name and contact details.  Can you confirm that this is ok? | | **✓** | **X** |
|  | Sometimes, Staffordshire University and the NHS Trust may check the researcher’s interviews. This means that they may read your interview.  Can you confirm that this is ok? | | **✓** | **X** |
|  | All of your quotes will be anonymised. This means that they will not be linked to your name.  We would like to use anonymised quotes from your interview in the report. Can you confirm that this is ok? | | **✓** | **X** |
|  | Your information will be kept confidential (private), unless you say anything that puts you or someone else in harm. Do you agree with this? | | **✓** | **X** |
|  | You can withdraw your data from the research for up to four weeks after the interview without having to give a reason. Do you agree with this? | | **✓** | **X** |
|  | Knowing all of this information, do you **agree** to take part in this study? | | **✓** | **X** |
| book / cartoon vector and illustration, black and white, hand drawn, sketch  style, isolated on white background. Stock Vector | Adobe Stock | Would you like to receive a summary of this research once it has been completed? | | **✓** | **X** |
|  | After the completion of all the interviews the participants in this research will be given the opportunity to review and comment on themes from the data.  Do you consent for the researcher to contact you about this opportunity? | | **✓** | **X** |
|  |  | |  |  |
| Name of participant |  | | | |
| Date of consent |  | | | |
| Name of researcher  C:\Users\burtho\Downloads\PastedGraphic-4.png | | Signature of researcher | | |

## Appendix G

*****Draft Interview Schedule*

**Version 3.0 08.06.2022**

**IRAS ID - 312471**

**Establishing Rapport, Reading Information Sheet and Gaining Consent**

My name is Holly and I am a trainee Clinical Psychologist studying at Staffordshire University.

 Do you give consent for me to audio record this interview?

*Begin audio recording on Microsoft Teams.*

Can you please confirm that you have received the consent and information form through email? They were attached to the same email that you have had the link for today from.

 Have you had a chance to read through them?

 Would it be ok if we read though them now together?

 Would you like me to share the easy read copy on this screen whilst we read through?

*Proceed to read through information and consent form. Gain verbal consent from participants. Confirm that participant knows where to find useful links if they need this after the interview.*

There was also an easy read copy of the questions for today attached to the email I sent you. You are welcome to have these open on your screen or I can share them on this screen if that is helpful? I can also write the question in the chat box if that is helpful.

*Share screen with easy read questions, if needed.*

I have planned a break around half way through, but you can take a break or end the interview at any time.

**Introduction**

I am interested in experiences of virtual cognitive behavioural therapy in adults that have a learning disability, like yourself, since April 2020 during the COVID-19 pandemic. I would like to ask you some questions about your experiences.

I hope to use this information to feed back to services and improve these services.

 To start with, can I ask some general questions about yourself?

 What is your age?

 What is your gender?

 What is your ethnicity?

 Thank you.

 (TRANSITION: Let me begin by finding out more about the beginning of your virtual therapy journey.)

**Online Modality**

 When did you start your virtual CBT?

*PROMPT: Clarify we are interested in virtual therapy experiences from April 2020 onwards.*

*REMINDER: If you received face-to-face therapy before virtual, for this interview I am only interested in your experience of virtual therapy.*

 When you started with virtual cognitive behavioural therapy, what method did you use?

*PROMPT: Over the telephone? On the laptop? Over MS Teams? Whatsapp? One Consultation? Other?*

 What support or guidance did you receive from staff to use the software?

*PROMPT: If they have had no support - How could you have been more supported to access the online software?*

 How did you feel about the length of these sessions?  
*PROMPT: Did they feel long? Did they feel short? Did you have a break?*

**We are about half way through the interview now. Shall we take a comfort break so that we can get a drink? 5 minutes or 10 minutes?**

(TRANSITION: I’m going to ask you a little bit more about your experiences of virtual therapy now)

**Experience**

What was it like for you doing virtual therapy?

*PROMPT: Describing their experience then prompt/explore for more detail -*

What do you think was good about being virtual for your therapy?  
*PROMPT: What went well with being virtual? What did you enjoy about being virtual?*

 What do you think was bad about being virtual for your therapy?

*PROMPT: What did not go well with being virtual? What did you not enjoy about being virtual? What could have been done better?*

If you could change anything about your virtual therapy, what would it be?

IF THEY HAVE RECEIVED PREVIOUS FACE-TO-FACE THERAPY: Can you describe the differences between being face-to-face and virtual for your cognitive behavioural therapy?

*PROMPT: Is there anything you preferred more about being virtual than face-to-face? Is there anything you disliked more about being virtual than face-to-face?*

**Further questions**

How did you find being at home for your virtual therapy sessions?  
*PROMPT: What about any times that there were other people in your home when you had an appointment?*

 Can you describe what it was like seeing your therapist through a camera?

*PROMT: What was it like not seeing your therapist in person?*

 How did you find having your camera on?

 Did your therapist use any visual aids during your sessions? *PROMPT: What types of visual aids did they use? How did you find this? Was this useful? Is this something you would have liked?*

Were you set any tasks to do in between sessions?  
*PROMPT: How did your therapist do this? Describe your experience of this.*

Is there anything else that you would like to share?

 Is there anything else that you want to add about your experiences of virtual CBT?

**Closing Statement**

Thank you for participating, is it ok for us to end the interview here?

 How are you feeling?

*If the participant is not feeling ‘okay’ and they require additional support, the researcher will obtain consent from the participant and pass on their details/inform their support team accordingly.*

If you do not wish for me to pass your details on and require any additional support, please refer to the sources of support listed on the participant information sheet.

You can withdraw your data for up to four weeks following the interview.

 It is hoped that the results will assist the service to improve their delivery of virtual CBT to adults with a learning disability.

 I will now stop the recording.

*Stop recording on Microsoft Teams.*

## Appendix H

*Easy-Read Interview Schedule*

**Version 2.0, 08.04.2022**

**IRAS ID - 312471**

|  |  |
| --- | --- |
|  | **ABOUT YOU** |
|  | How old are you? |
| Support Women&#39;s and Gender Studies at Your Institution - Gale Blog: Library  &amp; Educator News | K12, Academic &amp; Public | What is your gender? |
| 20,211,826 Ethnicity Stock Photos, Pictures &amp; Royalty-Free Images - iStock | What is your ethnicity? |
|  | |
|  | **VIRTUAL THERAPY** |
| When you started having therapy, was this: | |
| Face-to-Face Counseling and Telehealth | Face to face or |
|  | Virtual |
|  | I am interested in your experience of virtual therapy from April 2020 |
| What is WhatsApp?  Microsoft&#39;s Jeff Teper: Teams &#39;will be even bigger than Windows&#39; |  VentureBeat | What method of virtual therapy did you use? |
|  | What support did you get from staff to access virtual therapy? |
|  | How could you have been more supported to access virtual therapy? |
| Length-of-time-help-will-be-needed2 - ShelterBox Australia | How did you feel about the length of these sessions? |
|  | |
|  | What was it like doing virtual therapy? |
|  | What was good about being virtual for your therapy? |
|  | What do you think was bad about being virtual for your therapy? |
|  | What would you change about your virtual therapy? |
| Face-to-Face Counseling and Telehealth | If you had face to face therapy before |
|  | Can you describe the differences between being face to face and virtual for your therapy? |
|  | |
|  | |
|  | How did you find being at home for virtual therapy sessions? |
|  | How did you find having your camera on? |
|  | Did your therapist use any visual aids in your session?  How was that? |
| Coronavirus: People with learning disabilities have six times higher death  rate from COVID-19 | Were you set any tasks to do in between sessions?  How was that? |
|  | |
|  | Is there anything else that you would like to share about your experience of virtual therapy? |
|  | |
|  | Thank you for your taking part |

## Appendix I

*****‘Supporter’ Participant Information Sheet*

**Version 1.0 01.06.2022**

**IRAS ID - 312471**

**Invitation**

Thank you for providing your time to support someone participating in this research project which forms part of a Doctorate of Clinical Psychology thesis. Please take your time to read the following information carefully. Please ask the researcher if there is anything that is not clear or you would like extra information.

**What is the aim of this study?**

We are interested in how adults with learning disability have experienced virtual (e.g. via telephone or online video communication software) cognitive behavioural therapy (CBT) for a mental health difficulty. We are particularly interested in the experience of individuals who received virtual CBT during the coronavirus-19 (COVID-19) pandemic due to the quick transition to delivering therapy virtually. We are hoping to gain an understanding of what CBT was like for these participants and understand their perspective. We hope that this research can strengthen the NHS’s understanding of how this can be effectively used across NHS services and adapted successfully to meet the needs of adult clients with a learning disability.

**What is the purpose of having a ‘supporter’ present during interviews?**

The researcher has considered that service users may feel more comfortable with a ‘supporter’ (e.g. parent, carer, guardian) present, therefore participants have been given this option. People with learning disabilities often have ‘supporters’ present during their psychological support. The role of the ‘supporter’ is to provide support to the participant with accessing the interview (virtually or face-to-face) and to provide comfort in the instance of distress experienced.

**What will happen to the information provided by the ‘supporter’?**

Although we recognise that ‘supporters’ may have opinions on this topic, this research is interested in the experiences of the individual and not the ‘supporter’. Therefore, responses to interview questions from the ‘supporter’ are discouraged. Any ‘supporter’ responses will be clearly identified by the researcher and removed during the transcription stage. Participant data which comprises more of ‘supporter’ responses than the participant will be removed from the research.

**What are the possible risks of taking part?**

Every effort will be made to make the interview an enjoyable experience. However, we acknowledge that hearing a participant share their experiences of therapy may be difficult and upsetting. We also acknowledge that sharing experiences of therapy may be distressing for the participants that you are supporting. We have included some useful links at the bottom of the information sheet if you feel that you or the participant that you are supporting may need support after the interview.

**Who should you contact for further information?**

If you have any questions or want more information about this study, please contact the researcher using the following contact details.



Holly Burton  
Trainee Clinical Psychologist  
[b024990k@student.staffs.ac.uk](mailto:b024990k@student.staffs.ac.uk)

07814830760

**What if you have further questions, or if something goes wrong?**  
If this study has harmed you in any way or if you wish to make a complaint about the conduct of this study you can contact the study supervisor (kim.gordon@staffs.ac.uk) or the Chair of the Staffordshire University Ethics Committee for further advice and information at [ethics@staffs.ac.uk](mailto:ethics@staffs.ac.uk) or 01785 353662.

**Thank you for reading this information sheet**

**USEFUL LINKS**

|  |  |
| --- | --- |
|  | [**www.easyhealth.org.uk**](http://www.easyhealth.org.uk/)  Easyhealth was made so that people know where to find accessible health information. Accessible information is information that uses easy words with pictures. |
|  | **Foundation for People with Learning Disabilities**  [**www.learningdisabilities.org.uk**](http://www.learningdisabilities.org.uk/)  Raising awareness of learning disabilities and information on website. |
|  | **Learning Disability Helpline**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 0808 808 1111** [**www.mencap.org.uk**](http://www.mencap.org.uk/)  Advice and information on all aspects of learning disability, issues covered include benefits for people with a learning disability and their carers, housing options and independent living, education, employment options and the support available for people in work or trying to find work, community care (including direct payments). |
| https://www.mind.org.uk/media/7845/portraits_unsplash-4.jpg | **Respond**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 020 7383 0700**  [**www.respond.org.uk**](http://www.respond.org.uk/)  Works with children and adults with learning disabilities who have experienced abuse or trauma, as well as those who have abused others, through psychotherapy, advocacy, campaigning and other support. |
| [Image result for samaritans](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwi0kv3txo_bAhVKtBQKHdefBhQQjRx6BAgBEAU&url=https%3A%2F%2Fwww.wolvesunion.org%2Fents%2Fevent%2F5519%2F&psig=AOvVaw3Z_6_fSYAJlhl2jTljUtDw&ust=1526742934347148) | **Samaritans**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 116 123**  We know a lot about what can help you through tough times. We can help you explore your options, understand your problems better, or just be there to listen. |

## Appendix J

*Debrief (General)*

**Version 1.0, 11.11.2021**

**IRAS ID - 312471**

**Thank you for your participation in this research.**

The aim of this research is to explore the experiences of adults with a learning disability that have experienced virtual Cognitive Behavioural Therapy during the Coronavirus-19 pandemic.

There is limited research that already exists in this area. It is hoped that this research will help aid our understanding of how adults with a learning disability experienced virtual Cognitive Behavioural Therapy during the Coronavirus-19 pandemic, and can improve experiences of virtual Cognitive Behavioural Therapy in the future.

If you wish to remove your interview data from this research, you are able to do so up to 4 weeks after the date of your interview. You do not have to give a reason for removing your data and it will not impact any treatment you receive in the future. It will not be possible to withdraw your data after this point as any identifying information will have been removed and your data will have been processed for analysis. You can remove your data by emailing the researcher on [b024990k@student.staffs.ac.uk](mailto:b024990k@student.staffs.ac.uk).

If you have any questions about this research, please contact Holly Burton (b024990k@student.staffs.ac.uk) or the research supervisor, Dr Kim Gordon ([kim.gordon@staffs.ac.uk](mailto:kim.gordon@staffs.ac.uk)).

If you wish to make a complaint about this research, you can contact Staffordshire University at [ethics@staffs.ac.uk](mailto:ethics@staffs.ac.uk).

We understand that talking about your experiences of virtual Cognitive Behavioural Therapy can be emotional. If you feel upset after the interview and need support, we have included a list of ‘useful links’ on the back of this form.

**USEFUL LINKS**

|  |  |
| --- | --- |
|  | [www.easyhealth.org.uk](http://www.easyhealth.org.uk/)  Easyhealth was made so that people know where to find accessible health information. Accessible information is information that uses easy words with pictures. |
|  | **Foundation for People with Learning Disabilities**  [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk/)  Raising awareness of learning disabilities and information on website. |
|  | **Learning Disability Helpline**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 0808 808 1111** [www.mencap.org.uk](http://www.mencap.org.uk/)  Advice and information on all aspects of learning disability, issues covered include benefits for people with a learning disability and their carers, housing options and independent living, education, employment options and the support available for people in work or trying to find work, community care (including direct payments). |
| https://www.mind.org.uk/media/7845/portraits_unsplash-4.jpg | **Respond**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 020 7383 0700**  [www.respond.org.uk](http://www.respond.org.uk/)  Works with children and adults with learning disabilities who have experienced abuse or trauma, as well as those who have abused others, through psychotherapy, advocacy, campaigning and other support. |
| [Image result for samaritans](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwi0kv3txo_bAhVKtBQKHdefBhQQjRx6BAgBEAU&url=https%3A%2F%2Fwww.wolvesunion.org%2Fents%2Fevent%2F5519%2F&psig=AOvVaw3Z_6_fSYAJlhl2jTljUtDw&ust=1526742934347148) | **Samaritans**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 116 123**  We know a lot about what can help you through tough times. We can help you explore your options, understand your problems better, or just be there to listen. |

## Appendix K

*****Debrief (Easy-Read)*

**Version 1.0, 11.11.2021**

**IRAS ID - 312471**

|  |  |
| --- | --- |
|  | Thank you for your taking part in this research |
|  | The aim of this research is to find out more about adult’s with learning disabilities experiences of virtual Cognitive Behavioural Therapy (CBT) |
|  | There is not a lot of research that already exists in this area |
|  | We hope that this research will improve our understanding of how adults with a learning disability experienced virtual Cognitive Behavioural Therapy during the Coronavirus-19 pandemic  We hope this research can be used in teaching for therapists. |
|  | We hope that findings from this research will improve experiences of virtual Cognitive Behavioural Therapy in the future |
|  |  |
|  | You can withdraw your data from the research for up to four weeks after the interview without giving a reason |
|  | You can remove your data by emailing the researcher on [b024990k@student.staffs.ac.uk](mailto:b024990k@student.staffs.ac.uk). |
|  | |
|  | If you have any questions about the research, you can contact the researcher (Holly Burton) at b024990k@student.staffs.ac.uk  Or the study supervisor, Dr Kim Gordon, at kim.gordon@staffs.ac.uk |
|  | If you want to make a complaint, you can contact Staffordshire University at [ethics@staffs.ac.uk](mailto:ethics@staffs.ac.uk) |
|  | |
|  | Sometimes talking about experiences of therapy may be difficult and upsetting |
| There are a list of useful links at the end of this document if you feel upset after the interview |

**USEFUL LINKS**

|  |  |
| --- | --- |
|  | [www.easyhealth.org.uk](http://www.easyhealth.org.uk/)  Easyhealth was made so that people know where to find accessible health information. Accessible information is information that uses easy words with pictures. |
|  | **Foundation for People with Learning Disabilities**  [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk/)  Raising awareness of learning disabilities and information on website. |
|  | **Learning Disability Helpline**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 0808 808 1111** [www.mencap.org.uk](http://www.mencap.org.uk/)  Advice and information on all aspects of learning disability, issues covered include benefits for people with a learning disability and their carers, housing options and independent living, education, employment options and the support available for people in work or trying to find work, community care (including direct payments). |
| https://www.mind.org.uk/media/7845/portraits_unsplash-4.jpg | **Respond**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 020 7383 0700**  [www.respond.org.uk](http://www.respond.org.uk/)  Works with children and adults with learning disabilities who have experienced abuse or trauma, as well as those who have abused others, through psychotherapy, advocacy, campaigning and other support. |
| [Image result for samaritans](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwi0kv3txo_bAhVKtBQKHdefBhQQjRx6BAgBEAU&url=https%3A%2F%2Fwww.wolvesunion.org%2Fents%2Fevent%2F5519%2F&psig=AOvVaw3Z_6_fSYAJlhl2jTljUtDw&ust=1526742934347148) | **Samaritans**  **[Image result for telephone clipart](https://www.google.com/url?sa=i&source=images&cd=&cad=rja&uact=8&ved=2ahUKEwiSqfz6tY_bAhUDrRQKHWRmCnEQjRx6BAgBEAU&url=http%3A%2F%2Fwww.clker.com%2Fclipart-black-telephone-icon.html&psig=AOvVaw1-miUGpd3qeP0upTSjCBNN&ust=1526738405832220) 116 123**  We know a lot about what can help you through tough times. We can help you explore your options, understand your problems better, or just be there to listen. |

## Appendix L

*Coventry and Warwickshire NHS Research Ethics Committee Ethical Approval*



**West Midlands - Coventry & Warwickshire Research Ethics Committee**

The Old Chapel

Royal Standard Place

Nottingham

NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval.

14 June 2022

Miss Holly Burton   
Trainee Clinical Psychologist   
Midlands Partnership Foundation Trust   
St George's   
Corporation Street   
Stafford   
ST16 3SR

Dear Miss Burton

Study title: Exploring Experiences of Virtual Cognitive Behavioural Therapy in Adults with a Learning Disability during the Coronavirus-19 Pandemic REC reference: 22/WM/0103 IRAS project ID: 312471

Thank you for your response which was received on 08 June 2022, responding to the Research Ethics Committee’s (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and a named member of the Committee.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The [UK Policy Framework for Health and Social Care Research](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/) sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of [research transparency:](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/research-transparency/)

[registering research studies](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/research-transparency/registering-research-studies/)

[reporting results](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/research-transparency/making-results-public/)

[informing participants](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/research-transparency/informing-participants/)

[sharing study data and tissue](https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/research-transparency/making-data-and-tissue-accessible/)

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that all clinical trials are registered on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, ‘clinical trials’ are defined as:

clinical trial of an investigational medicinal product

clinical investigation or other study of a medical device

combined trial of an investigational medicinal product and an investigational medical device

other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: [Research registration and research project identifiers)](https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: [https://www.hra.nhs.uk/planning-and-improving-research/applicationsummaries/research-summaries/](https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/)

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven’t already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at:

<https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/>

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

Notifying substantial amendments

Adding new sites and investigators

Notification of serious breaches of the protocol

Progress and safety reports

Notifying the end of the study, including early termination of the study

Final report

Reporting results

The latest guidance on these topics can be found at [https://www.hra.nhs.uk/approvalsamendments/managing-your-approval/.](https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/)

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

|  |  |  |
| --- | --- | --- |
| *Document* | *Version* | *Date* |
| Copies of materials calling attention of potential participants to the research [CORE Leaflet] | 1 | 19 May 2021 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indemnity Insurance] | 1 | 08 March 2022 |
| Initial Assessment for REC |  |  |
| Interview schedules or topic guides for participants [Interview Schedule - Easy Read] | 2 | 08 April 2022 |
| Interview schedules or topic guides for participants [Interview Schedule - General] | 1 | 08 April 2022 |
| IRAS Application Form [IRAS\_Form\_13042022] |  | 13 April 2022 |
| Letter from sponsor [IPR - Approved] | 1 | 08 December 2021 |
| Letters of invitation to participant [Sample Invitation Letter/Email] | 1 | 11 November 2021 |
| Other [GCP Certificate] | 1 | 21 October 2021 |
| Other [Debrief - Easy Read] | 1 | 11 November 2021 |
| Other [Debrief - General] | 1 | 11 November 2021 |
| Other [Risk Assessment] | 1 | 11 November 2021 |
| Other [IRAS Responses ] | Received on  08 June  2022 | 08 June 2022 |
| Participant consent form [Consent - General] | 3 | 01 June 2022 |
| Participant consent form [Consent - Easy Read] | 3 | 01 June 2022 |
| Participant information sheet (PIS) [PIS - Easy Read] | 3 | 01 June 2022 |
| Participant information sheet (PIS) [PIS - Supporter] | 1 | 01 June 2022 |
| Participant information sheet (PIS) [PIS - General] | 3 | 01 June 2022 |
| Research protocol or project proposal [Project Proposal] | 3 |  |
| Research protocol or project proposal [Project Proposal] | 4 | 01 June 2022 |
| Summary CV for Chief Investigator (CI) [CI CV] | 1 | 30 March 2022 |
| Summary CV for student [HB CV] | 1 | 30 March 2022 |
| Summary CV for supervisor (student research) [Dr Kim Gordon - CV] | 1 | 30 March 2022 |
| Summary of any applicable exclusions to sponsor insurance (nonNHS sponsors only) [Employers' and Public Liability Insurance] | 1 | 08 March 2022 |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: [http://www.hra.nhs.uk/about-the-hra/governance/qualityassurance/](http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/)

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: [https://www.hra.nhs.uk/planning-and-improvingresearch/learning/](https://www.hra.nhs.uk/planning-and-improving-research/learning/)

IRAS project ID: 312471 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely

PP.

Anfal El-Awaisi

Dr Helen Brittain Chair

Email: coventryandwarwick.rec@hra.nhs.uk

## Appendix M

*NHS Health Research Authority*

Miss Holly Burton

Trainee Clinical Psychologist Email: approvals@hra.nhs.uk

HCRW.approvals@wales.nhs.uk Midlands Partnership Foundation Trust

St George's

Corporation Street

Stafford

ST16 3SRN/A

15 June 2022

Dear Miss Burton

|  |  |
| --- | --- |
| **Study title:** | **Exploring Experiences of Virtual Cognitive Behavioural**  **Therapy in Adults with a Learning Disability during the Coronavirus-19 Pandemic** |
| **IRAS project ID:** | **312471** |
| **REC reference:** | **22/WM/0103** |
| **Sponsor** | **Staffordshire University** |

I am pleased to confirm that [**HRA and Health and Care Research Wales (HCRW) Approval**](https://www.myresearchproject.org.uk/help/hlphraapproval.aspx) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the “Information to support study set up” section towards the end of this letter.

**How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation.

The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](https://www.myresearchproject.org.uk/help/hlpnhshscr.aspx) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

**How should I work with participating non-NHS organisations?**

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](https://www.myresearchproject.org.uk/help/hlpsitespecific.aspx#non-NHS-SSI) in accordance with their procedures.

**What are my notification responsibilities during the study?**

The standard conditions document “[*After Ethical Review – guidance for sponsors and investigators*”](https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/research-ethics-committee-review/applying-research-ethics-committee/), issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

Registration of research

Notifying amendments

Notifying the end of the study

The [HRA website](https://www.hra.nhs.uk/) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

**Who should I contact for further information?**

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **312471**.Please quote this on all correspondence.

Yours sincerely,

Amber Slack

Approvals Specialist

Email: approvals@hra.nhs.uk

## Appendix N

*Staffordshire University Ethics Committee*

**INDEPENDENT PEER REVIEW APPROVAL FEEDBACK**

Researcher Name Holly Burton

**Title of Study** Exploring Experiences of Virtual Cognitive Behavioural Therapy in Adults with a Learning Disability during the Coronavirus-19 Pandemic

**Award Pathway** Doctorate of Clinical Psychology

Status of approval: Approved

Thank you for forwarding the amendments requested by the Independent Peer Review Panel (IPR)

**Action now needed:**

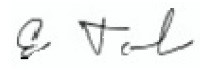
You must now apply through the Integrated Research Applications System (IRAS) for approval to conduct your study. You must not commence the study without this second approval. Please note that for the purposes of the IRAS form, the university sponsor is Dr Tim Horne, tim.horne@staffs.ac.uk

Please forward a copy of the letter you receive from the IRAS process to ethics@staffs.ac.uk as soon as possible after you have received approval.

Once you have received approval you can commence your study. You should be sure to do so in consultation with your supervisor.

You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

When your study is complete, please send the IPR coordinator (Dr Edward Tolhurst) an end of study report. A template can be found on the ethics BlackBoard site.



S**igned**: Dr Edward Tolhurst University IPR coordinator

**Date**: 8th December 2021

## Appendix O

*Local NHS Trust Capacity and Capability Approval*

Holly Burton (RRE) MPFT

|  |  |
| --- | --- |
| From: | LouiseC Alston (RLY) NSCHT |
| Sent: | 02 September 2022 14:20 |
| To: | Holly Burton (RRE) MPFT |
| Cc: | GORDON Kim; Ruth Richards (RLY) NSCHT; Zoe Booth (RLY) NSCHT; Shaun Crank  (RLY) NSCHT; Kerri Mason (RLY) NSCHT; Research & Development |
| Subject: | IRAS 312471 Student Research - Trust Authorisation of Research - North  Staffordshire Combined Healthcare NHS Trust |
| Attachments: | OID HBSR 01.09.2022 Executed.pdf |

Dear Holly

Trust Authorisation of Research at North Staffordshire Combined Healthcare NHS Trust

|  |  |
| --- | --- |
| Short Title: | Experiences of virtual CBT in adults with learning disabilities |
| IRAS ID.: | 312471 |
| R&D ID.: | CHC0234/RS |
| Principal Investigator: | Holly Burton |

This email confirms that North Staffordshire Combined Healthcare NHS Trust has granted Trust Authorisation, and can deliver the above referenced study. Please find attached our agreed Organisation Information Document as confirmation. We agree for you to start this study from the date of this email communication as advised.

Please take time to read the conditions of Trust Authorisation below. You will need this email as proof of Trust Authorisation.

Trust Authorisation has been granted on the basis described in the HRA approval application. The documents received and to be used at site are:

|  |  |  |
| --- | --- | --- |
| Document | Version | Date |
| Proposal | 5.0 | 12/08/2022 |
| Participant Information Sheet – General | 3.0 | 01/06/2022 |
| Participant Information Sheet – Easy Read | 3.0 | 01/06/2022 |
| Participant Information Sheet – Supporter | 1.0 | 01/06/2022 |
| Participant Consent Form – General | 3.0 | 01/06/2022 |
| Participant Consent Form – Easy Read | 3.0 | 01/06/2022 |
| Participant Invitation Letter / Email | 1.0 | 11/11/2021 |
| Interview Schedule – General | 1.0 | 08/04/2022 |
| Interview Schedule – Easy Read | 2.0 | 08/04/2022 |
| Debrief – General | 1.0 | 11/11/2021 |
| Debrief – Easy Read | 1.0 | 11/11/2021 |
| Organisation Information Document | 1.0 | 23/03/2022 |
| Schedule of Events | 1.0 | 23/03/2022 |

Trust Authorisation is granted on the understanding that the study is conducted in accordance with the UK Policy Framework for Health and Social Care Research, ICH GCP (where applicable), and NHS Trust policies and procedures. Trust Authorisation is only granted for the research activities which have received approval from all applicable regulatory bodies.

1

We wish you every success with your research.

Please contact the R&D Office should you require any further information.

CONDITIONS OF TRUST AUTHORISATION

Please read the following conditions in order for your Trust Authorisation to conduct research to be valid:

Please submit the following to the Trust’s R&D Office:

All amendments submitted to the HRA (please refer to the HRA guidance on amendments)

Recruitment figures on a monthly basis (at end of study for non-portfolio research)

New researcher details (prior to them commencing on the research study) (please refer to the HRA guidance on HR arrangements for researchers)

Changes to the status of the research study

A copy of reported urgent safety measures (USM), adverse events (AE) and serious adverse events (SAE) (please refer to the HRA guidance on safety reporting)

A final report (or summary report) (please refer to the HRA guidance and publication and dissemination of findings)

A copy of all progress reports as submitted to the regulatory body(ies) (please refer to the HRA guidance on progress reports)

A copy of the end of study declaration as submitted to the regulatory body(ies) (please refer to the HRA guidance on ending your study)

Details of any study publication(s)

Please ensure to acknowledge the Trust in final reports, presentations or publications

Please note that the Trust shares research findings internally (please contact the R&D Office for further information)

Please ensure to complete and return in a timely manner any monitoring or audit forms sent by the R&D Office (research is subject to monitoring by the R&D Office)

Kind regards,

Louise Alston

Research Governance Facilitator

North Staffordshire Combined Healthcare NHS Trust

Please note that I am currently working from home

Email: louise.alston@combined.nhs.uk

PID: louise.alston@nhs.net

R&D Generic Inbox: research@combined.nhs.uk

Follow us on Twitter

Visit our Website

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## Appendix P

*Risk Assessment*

**Version 1.0, 11.11.2021**

**RESEARCH ETHICS RISK ASSESSMENT AND MANAGEMENT**

This form should be used to support the assessment of risks associated with your research project and their mitigation.

|  |  |  |  |
| --- | --- | --- | --- |
| **Identified Risks**  Identify the risks/hazard present | **Likelihood**  High/Medium/Low | **Potential Impact/Outcome**  Who might be harmed and how? | **Risk Management/Mitigating Factors**  Evaluate the risks and identify precautions (e.g. health and safety) |
| Physical risk associated with the use of Microsoft Teams for interviews | Low | Researcher and Participant:   * Eye strain * Computer/screen fatigue * Muscle-skeletal pain * Repetitive Strain Injury | Researcher:   * Follow workplace health and safety practices to mitigate risks including laptop riser, computer char, appropriate lighting, breaks between interviews and other tasks.   Participant:   * Encourage the above when arranging interviews online * Offer a break during the online interview process to reduce consistent screen time. |
| Risk associated with use of computer for transcribing data | Low | Researcher:   * Eye strain * Computer/screen fatigue * Muscle-skeletal pain * Repetitive Strain Injury * Emotional distress transcribing experiences of therapy | Researcher:   * Follow workplace health and safety practices to mitigate risks including laptop riser, computer char, appropriate lighting, breaks between interviews and other tasks. * Support from supervisor * Maintain a reflective diary throughout process * Self-care practices e.g. effective time management around interview timetabling and allowing a break in-between interviews |
| Online security / data breach | Low | Researcher and Participant:   * In the case of data security breach within online software, the interview recording may be shared with third party sources breaching confidentiality. | Researcher and Participant:   * Secure and reputable online software, Microsoft Teams, will be used to reduce risk of data breach. * Once the recording has been downloaded by the researcher, this will be transferred from Microsoft Teams to a password protected file and anonymised. |
| Discussion of a sensitive topic in an interview which has potential to cause distress related to   * Reflection on experiences of cognitive behavioural therapy for a mental health difficulty * What didn’t go well during this experience | Medium | Researcher:   * Possibility of distress due to triggering recounts mirrored in researcher’s own well-being * Distress associated with seeing a participant potentially distressed during interview   Participant:   * Possibility of experiencing distress due to reflection on aspects virtual cognitive behavioural therapy that may have not gone well * Possibility of experiencing distress due discussion of therapy bringing reason for therapy, previous or enduring mental health difficulties and possible previous trauma to focus | Researcher:   * Participant information sheet and interview process to minimise excessive personal disclosure * Support from supervisor * Maintain a reflective diary throughout process * Self-care practices e.g. effective time management around interview timetabling and allowing a break in-between interviews   Participant:   * If distress is experienced, participants can use the ‘useful links’ section on information sheet where containing avenues where they can receive mental health support and contact online/telephone support services if required * Debrief sheet will be shared after interview and contains ‘useful links’ section * Inform participants of limits of confidentiality at the commencement of the interview * Break offered during interview * Encourage participants to engage in self-care activities following the interview * Participants are allowed to have their carer/parent present during the interview and will be encouraged to discuss topics covered with them. Participants who do not have their carer/parent present will also be encouraged to discuss the interview with them or a friend. * Interview can be ceased at any point as made clear in the consent and information sheet; this will be reminded to the participant if they become distressed. |
| Whistle-blowing (i.e. researcher made aware of unsafe practices within CLDT or IAPT when virtual therapy was received) | Low | Researcher:   * Emotional distress from hearing reports of unsafe practices * Emotional distress and possible discomfort of reporting negligent practice carried out by clinician’s within supervisor’s clinical team   Participant:   * Emotional distress from disclosing event * Emotional distress from participating in any necessitated reporting, such as paperwork. | Researcher:   * Participant information sheet and interview process to minimise excessive personal disclosure * Familiarisation with NHS whistle-blowing policies and knowledge of identified person to pass on details of reported events * Support from supervisor * Maintain a reflective diary throughout process * Self-care practices e.g. effective time management around interview timetabling and allowing a break in-between interviews   Participant:   * Participants made aware of limits of confidentiality before commencement of interview to minimise distress if researcher raises a whistle-blowing case. * At the time of significant disclosure, the interview will be ceased and more information about the incident will be gathered appropriately. * If distress is experienced, participants can use the ‘useful links’ section on information sheet where containing avenues where they can receive mental health support and contact online/telephone support services if required * Debrief sheet will be shared after interview and contains ‘useful links’ section * Inform participants of limits of confidentiality at the commencement of the interview * Break offered during interview * Encourage participants to engage in self-care activities following the interview * Participants are allowed to have their carer/parent present during the interview and will be encouraged to discuss topics covered with them. Participants who do not have their carer/parent present will also be encouraged to discuss the interview with them or a friend. |
| Safeguarding (i.e. if the participant discloses information warranting concern around abuse or neglect) | Low | Researcher:   * Emotional distress from hearing reports of abuse or neglect   Participant:   * Emotional distress from describing events of abuse or neglect | Researcher:   * Participant information sheet and interview process to minimise excessive personal disclosure * Familiarisation with NHS safeguarding policies and knowledge of identified person to pass on details of reported events * Support from supervisor * Maintain a reflective diary throughout process * Self-care practices e.g. effective time management around interview timetabling and allowing a break in-between interviews   Participant:   * Participants made aware of limits of confidentiality before commencement of interview to minimise distress if researcher has a safeguarding concern. * At the time of significant disclosure, the interview will be ceased and more information about the incident will be gathered appropriately. * If distress is experienced, participants can use the ‘useful links’ section on information sheet where containing avenues where they can receive mental health support and contact online/telephone support services if required * Debrief sheet will be shared after interview and contains ‘useful links’ section * Debrief sheet to be given to participants with useful contacts * Inform participants of limits of confidentiality at the commencement of the interview * Break offered during interview * Encourage participants to engage in self-care activities following the interview * Participants are allowed to have their carer/parent present during the interview and will be encouraged to discuss topics covered with them. Participants who do not have their carer/parent present will also be encouraged to discuss the interview with them or a friend. |
| Breaches in privacy and confidentiality due to video call interview with both participant and researcher being in their home environment during the interview | Low | Researcher   * Concern around possibly hearing other people in the household who are not on camera but may be able to hear what is being said * Possible emotional distress from seeing unkempt home environment from the participant   Participant   * If unfamiliar with Microsoft Teams, possibility of embarrassment adjusting camera and sharing home environment, breaching privacy boundaries * Upset at potential breaches of confidentiality * Bias in answers given | Researcher and Participant   * Telephone call held before the interview to overcome any technical difficulties, such as positioning of camera’s and explaining how to do things such as blurring background or turning off camera. Participant will be encouraged to find a quiet space where they will be alone (or with carer/parent if specified) * Encouraging participant to keep their camera on so that the researcher can see if anyone enters the room during the interview * Interview will be paused if anyone enters the room, and participant will be reminded of boundaries and confidentiality. * Any potential safeguarding or whistleblowing concerns will be actioned (as in above points) * Reassurance and verbal support given in the instance of distress. |

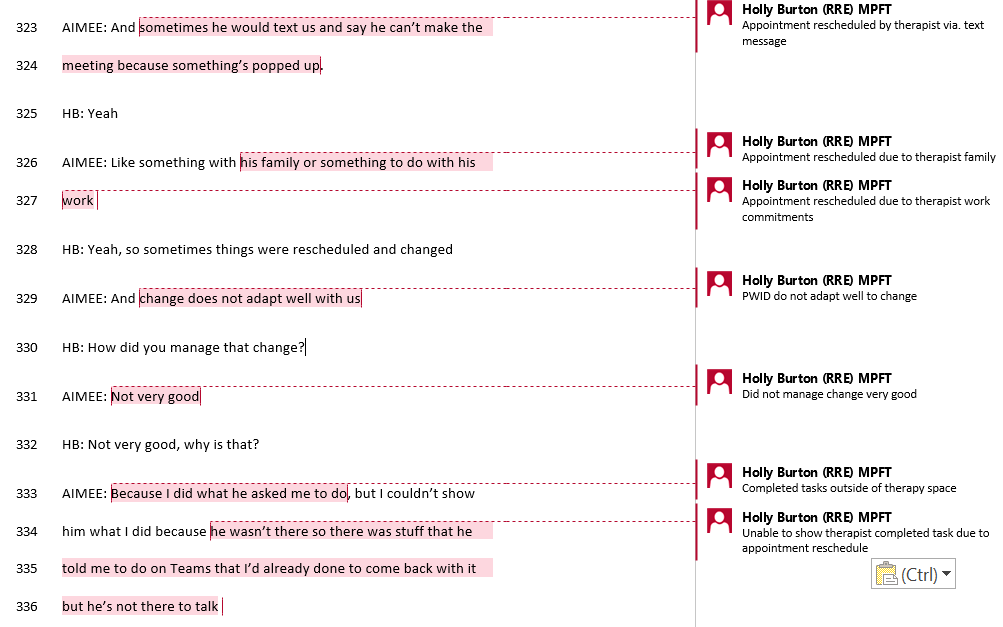
## Appendix Q

*Braun and Clarke’s (2012) Six-Step Reflexive Thematic Analysis Framework*

|  |  |
| --- | --- |
| Phase | Examples of procedure for each step |
| 1. Familiarising oneself with the data | Transcribing data, reading and re-reading, noting down initial codes. Notes of reflexivity added to record the researcher’s initial reaction to the data. |
| 2. Generating initial codes | Coding interesting features of the data in a systematic fashion across the data-set, collating data relevant to each code. |
| 3. Searching for the themes | Collating codes into potential themes, gathering all data relevant to each potential theme. |
| 4. Involved reviewing the themes | Checking that the themes work in relation to the coded extracts and the entire data-set, generate a thematic ‘map’. Quality check to be completed on themes by researcher and academic supervisor. |
| 5. Defining and naming themes | Ongoing analysis to refine the specifics of each theme and subthemes within these, generation of clear names for each theme. |
| 6. Producing the report | Final opportunity for analysis selecting appropriate extracts, discussion of the analysis and relating back to the research question or literature. Produce report. |

## Appendix R

*Initial Coding of Transcript*



## Appendix S

*Thematic Analysis Sample*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Theme** | **Subtheme** | **Supported by** | **Example quotes** | **Participant** |
| 1. Power | 1.1. Feeling disempowered | Steven, Helena, Aimee, Jacob, Edward, Bobby, | “Yeah. And I'd say you shouldn't like talk to professionals on the phone but you have to sometimes don’t you” (p.15) | Steven |
| “It was online because of COVID. I don’t really think it was my choice because it was because of COVID” (p.7) | Helena |
| “Yeah, you can just block everything out. You can choose what you do, well you can choose what you do in any situation, but I think if you had to go on video I’d be like ‘ugh I’m stuck’” (p.11) | Edward |
| 1.2. Relying on others | David, Helena, Aishling, Aimee, Steven, Edward | “Yeah, when I was out and about I used, I’d either go to the library to use theirs or sometimes because I have got one anyway, erm, I used the computer to do it or I’d use the phone, he used to ring me up and I’d think “who’s this” and he’d say “[therapist name], and I’d be like ah” (p.1) | Aishling |
| “Basically because I live with whoever’s on shift 24/7 they’d get and notice a pattern when certain topics were bought up so they just keep coming up and up and up and” (p.10) | Aimee |
| “It’s hard to tell people things when you’ve got your carers here sometimes. It depends what the question is. [..] Because he's like, trained therapist and they aren’t. It’s a bit hard” (p.11) | Steven |
| “And the problem is everybody knows your business when you’re virtual because the staff will say like ‘Yeah [Helena’s] got an appointment at three o clock’ because [staff] answer the phone [..] And then sometimes you have residents that answer the blooming phone all of the time too” |  |
| 1.3. Autonomy | Edward, Jacob, Aimee, Bobby, Aishling, Helena, Steven, David | “I guess it's just it's just the thought that I'm much more comfortable with technology than I am with people” (p.7) | Jacob |
| “You haven’t got to be somewhere at a certain time, and you can just do it at home, and it wasn’t time consuming because you were already at home so if you wanted to go and do something else or do something after you could easily do it” (p.5) | Helena |
| “And it's also gives you like flexibility. It means that if I'm very busy one week like it doesn't have to mean that I cancel cause I can't attend right like?” (p.2) | Bobby |
| 2. Therapy process | 2.1. Novel experiences | Helena, Aishling, Jacob, Bobby, Aimee, Edward, Steven, David | “Because I’m not used to doing it on the phone like, like face-to-face, I’m used to like seeing people, contact with them there and when I’m there, and we can like talk face-to-face. It’s been definitely weird.” (p.3) | Aishling |
| “Bit weird. Cause people don't see your house, unless they come visit you at home, then they see it. But then who really has got time to be travelling around the area to visit people’s house” (p.25) | Aimee |
| “Yeah. It was awful. I’d never wish that upon anybody. It’s not really a good experience because you don’t get the full experience of it.” (p.13) | Helena |
| 2.2. Adaptations | Helena, Aishling, Jacob, Bobby, Aimee, Edward, Steven, David | “It was a little bit harder to process [..] you just feel like they’re firing loads of questions at you [..] like baffling your head, and I know he’s a therapist but Jesus, could you like fire them questions a little bit slower please, because it’s hard to process all questions in one go” (p.8) | Steven |
| “With me going off the pictures and things like that obviously I understood what it was like. He sent me red faces amber faces and green faces to see how I was doing on different days” (p.7) | David |
| “They can show you the links and stuff. And he can get the links of, like, say different things it was just easier visually than somebody talking to you” (p.3) | Helena |
| 2.3. “Just hearing a friendly voice” | Helena, Aishling, Steven, David, Aimee, Bobby | “Because it was releasing some of the things that I was thinking about” (p.8) | David |
| “I’d say I’ve been under a lot of pressure since all this Coronavirus started. I never ever, never ever used to go out, but not my carer does my shopping because I’m still a bit wary [of COVID-19] but I will go out and do some shopping if I need to. And he [therapist] used to say keep up the good work and stuff” (p.1) | Aishling |
| “Just hearing a friendly voice” (p.4) | Steven |
| 2.4. Stifling the therapeutic process | Helena, Aishling, Jacob, Bobby, Aimee, Edward, Steven, David | “No. Just when they are speaking or stuff sometimes. Like it goes a bit quick. And then you miss bits out because, and it’s hard to take the information in.” (p.11) | Helena |
| “But like applies to everything like it relies on it like a reasonably stable, like connexion, and sometimes, like you know it's if your connexion isn't very good, or like [therapist] computer wasn't working very well like it would be hard to kind of have a conversation cause you couldn't hear what you're saying or it was like, you know, things like that can be quite frustrating, and so you don't necessarily get a lot out of it” (p.6) | Bobby |
| “But obviously it's a feeling of panic once that happens. You’re scrambling to try and get back on the call quickly as you can. So yeah, I guess there's a bit of anxiety from that” (p.9) | Jacob |
| 3. Therapeutic relationship | 3.1. Building a connection | Helena, Aishling, Jacob, Bobby, Aimee, Edward, Steven, David | “I think when you see him on the computer I get the connection straight away [..] It’s like the same, when you are on the computer but talking to him and also face-to-face, they’re both the same, definitely is” (p.10) | Aishling |
| “A god send. Even though it felt like I was talking to the machine, I could still see them, where as on the mobile it was like ‘what do I do, I can’t see you, so I’m not opening up to you, bye bye’” (p.21) | Edward |
| “Virtually it is perhaps sort of a little more distant. I am now in the sense that you know it's this is one a person that I see once a week over a screen. You know, I don't really know much about them like. And yeah, it's hard to sort of to feel a bit of like a like more of a personal connection to them.” (p.8) | Bobby |
| 3.2. Therapist factors | Edward, Aimee, Helena, Steven, Jacob | “You don’t know their personality until you see them, do you?” (p.2) | Steven |
| “[therapist’s] home as blurred out but you could see [them], but you can hear [their] kids coming in and out of the house and bedroom, asking for their [parent] so it was a bit odd [..] and the [pets] or [their partner], whoever coming in.” (p.23) | Aimee |
| “Erm, like to do with body language and stuff. Stuff that may not convey as well over a video call.” (p.13) | Jacob |
| 4. Safety in the virtual environment | 4.1. Risk management | Aimee, Aishling, Bobby, Steven, Jacob | “Because. Because he like used to talk about certain things, certain things that used to wind me up and then I’d tend to have behaviours afterwards, and then the staff can only do much, where [therapist] can’t really tell them what’s happened because I just won’t talk to him” (p.8) | Aimee |
| “Would stop and then immediately leave and go to the kitchen and start talking to my friends or like I would immediately leave and go. And like do some work or you know something like that?” (p.10) | Bobby |
| “Really it’s kind of one of those things where you kind of breathe a sigh of belief and allow yourself to kind of calm down a bit” (p.17) | Jacob |
| 4.2. Confidentiality | Helena, Aishling, Jacob, Bobby, Aimee, Edward, Steven, David | “Obviously I don’t really tell my mum and dad some of the tuff that I’m thinking, obviously/ But I told the therapist about it, so it was releasing some of the stuff I was thinking” [..] “It’s the way it goes some of the times. If I’m downstairs, obviously they’re going to hear aren’t they” (p.5) | David |
| “Easier to talk in person. Well, I know we’ve got our own rooms and stuff but everything is quite open here and like, you get people, like, like, if you’re in your bedroom sometimes people just listen and then if, like, whatever you’re talking about, because I live above somebody and then, like, there’s people around the house, if I’m talking loudly or something they might start listening to what I’m talking about.” (p.8) | Helena |
| “It's hard because you're if you're in a bedroom like this, everyone listens. [..]so that’s why I thought I’d prefer going to [clinic] because I know who is there and who’s not there” (p.23) | Aimee |
| 4.3. Environmental factors | Jacob, David, Bobby, Helena | “For me personally, it's it's being in your own home. And feeling more open, I guess, would be the main benefit” [..] “You may not you may not feel comfortable opening up in topics that you would feel comfortable about at home” (p.3) | Jacob |
| “Loud noises in the background, music playing, banging, kicking, screaming, and all of this kind of stuff. It was too loud of an environment, it was. Even though I was in my bedroom I could still hear what’s going on downstairs [..] And it’s really hard to concentrate on one thing if there’s loads of noise going on, and that’s one thing I hated about the experience.” (p.13) | Helena |
| “When I first started describing, like all the things I was worried about. Obviously I got a little upset and I remember it was helpful because I was in my room and like I had like my my little like Teddy, right? That I take with me and I was like this is nice like cause I can have this and that's quite comforting.” (p.2) | Bobby |

# Paper 3: Executive Summary

**“I’m just kind of talking to my screen and it responds back”: A thematic analysis exploring the experiences of adults with an intellectual disability who received a virtual cognitive behavioural therapy-based intervention during the COVID-19 pandemic**

Word Count: 1,568

**Executive Summary**

This executive summary provides a summary of research which explored the experiences of adults with an intellectual disability who received a virtual cognitive behavioural therapy-based intervention during the COVID-19 pandemic. A Brief and Extended Research Summary have been created primarily for the participant population, adults with intellectual disability. The decision was made to create both versions due to varied levels of intellectual disability and ability within the population sample. The Extended Research Summary is intended to be used with support, as required. Service users were directly consulted during the development of this research project and the executive summary reports. Service users voiced preference for visual, easy-read information, therefore these executive summaries have been adapted to easy-read formatting.

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| **“I’m just kind of talking to my screen and it responds back”: A thematic analysis exploring the experiences of adults with an intellectual disability who received a virtual cognitive behavioural therapy-based intervention during the COVID-19 pandemic** | | | |
| **Research Summary (Brief)** | | | |
|  | | | |
| research V3 | | We wanted to find out about the experiences of people with a learning disability who had virtual cognitive behavioural therapy – based help during the COVID-19 pandemic. | |
|  | |  | |
|  | | Virtual means that this was over a telephone or on the computer. | |
|  | |  | |
| Ask you questions | | 8 adults with learning disabilities took part in semi-structured interviews.  There were 5 males and 3 females that took part in interviews. | |
| Challenges | | They were asked what went well with their virtual therapy.  And what could have gone better with their virtual therapy. | |
|  | |  | |
| **What did people say?** | | | |
| Good body V2 | | Some people enjoyed virtual therapy because they did not have to leave the house. | |
|  | |  | |
| unhappy V5 | | Some people found virtual therapy difficult because they were not in the same room as their therapist. | |
|  | |  | |
| No longer confidential | | People worried that the information they shared in therapy did not stay private because other people were listening, such as parents, carers, or service users. | |
|  | |  | |
| Communicating With People With No Internet Access • PresentationPointcomputer | | People felt angry if they lost internet connection during therapy. It made it harder to connect with their therapist. | |
|  | |  | |
| LeafletC:\Users\burtho\AppData\Local\Microsoft\Windows\INetCache\Content.MSO\6CF52850.tmp | | Everyone was sent easy read material and visual resources such as Youtube videos or leaflets by their therapist. This was really useful. | |
|  | |  | |
| **What does this mean?** | | | |
|  | | | |
| what do you think with 2 people | | This research tells us that people with learning disabilities had good and bad experiences of virtual cognitive behavioural therapy-based support. | |
|  | |  | |
| ask you what you think | | Future research could find out more about how to build positive therapeutic relationships when working virtually with people with learning disabilities. | |
| **Research Summary (Extended)** | | | |
|  | | | |
| Premium Vector | Virus covid 19 pandemic, cartoon world coughing infected | **“I’m just kind of talking to my screen and it responds back”: A thematic analysis exploring the experiences of adults with an intellectual disability who received a virtual cognitive behavioural therapy-based intervention during the COVID-19 pandemic** | |  |
|  | | | |
| **Why did we do this research?** | | | |
|  | | | |
| Premium Vector | Virus covid 19 pandemic, cartoon world coughing infected | | Lots of people with learning disabilities got virtual help from a psychologist during the COVID-19 pandemic. | |
|  | |  | |
| mobile phone | | Virtual means that this was over a telephone or on the computer. | |
|  | |  | |
| research V3 | | We wanted to find out about the experiences of people with a learning disability who had virtual cognitive behavioural therapy – based help during the pandemic. | |
| **What did the participants do?** | | | |
|  | |  | |
| Ask you questions | | 8 adults with learning disabilities took part in semi-structured interviews.  There were 5 males and 3 females that took part in interviews. | |
|  | |  | |
| Good body V2 | | They were asked what went well with their virtual therapy. | |
|  | |  | |
| Challenges | | They were also asked what could have gone better with their virtual therapy. | |

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| --- | --- | --- | --- | --- | --- | --- | --- |
| **What did people say?** | | | | | | | |
|  | | |  | | | | |
| research V2  listen | | | The interviews were analysed by the researcher.  There were 4 main ‘themes’ that the participants spoke about in their interview.  The themes are: | | | | |
| Year 8 - Power in Relationships by martina2 on emaze | | | Theme 1: Power | | | | |
|  | | | Theme 2: Therapy process | | | | |
|  | | |  | | | | |
| ask you what you think | | | Theme 3: Therapeutic relationship | | | | |
| safe | | | Theme 4: Safety in the virtual environment | | | | |
| Ask talk speak (female) V2  **Theme 1:**  **Power** | | | | | | | | |
|  | | |  | | | | | |
| Year 8 - Power in Relationships by martina2 on emaze | | | Power means that we are thinking about who has the control or influence in a relationship or situation. | | | | | |
|  | | | Participants spoke about how power impacted their experience of virtual support. | | | | | |
|  | | |  | | | | | |
|  | | | | | | | | |
| **Subtheme 1: Feeling disempowered** | | | | | | | | |
|  | | | | | | | | |
| stopped from making your own choices | | | Disempowered means when people are not able to make choices about their own life. | | | | | |
| psychologist | | | Some participants felt like they were out of control and angry because they were unable to see their therapist in person because of COVID-19. | | | | | |
|  | | | | | | | | |
| **Subtheme 2: Relying on other people** | | | | | | | | |
|  | | |  | | | | | |
| Angry V2 | | | Some participants felt angry because they had to rely on other people to access virtual therapy as they did not own a computer or telephone. | | | | | |
|  | | |  | | | | | |
| remember when you were ill. before  “Everybody knows your business when you’re virtual” | | | | | | | | |
|  | | | | | | | | |
|  | | |  | | | | | |
| **Subtheme 3: Autonomy** | | | | | | | | |
|  | | |  | | | | | |
| Choice V5 | | | Autonomy means that you can make your own decisions without other people influencing you. | | | | | |
|  | | |  | | | | | |
| Care at home | | | All participants enjoyed the flexibility of virtual therapy as they could do their therapy from home. | | | | | |
|  | | |  | | | | | |
| responsibilities V2  “You haven’t got to have good time keeping skills because you know you’re already at home and you can just do it from home” | | | | | | | | |
|  | | |  | | | | | |
| About me | | | Two participants felt confident using computers and this meant that they could be independent when they accessed their virtual therapy. | | | | | |
|  | | |  | | | | | |
| **Theme 2:**  **Therapy process** | | | | | | | | |
|  | | | | | |  | | |
|  | | | | | |  | | |
| Premium Vector | Virus covid 19 pandemic, cartoon world coughing infected | | | | | | All participants said that their therapy was different because they did it virtually. | | |
| **Subtheme 1: Novel experiences** | | | | | | | | |
|  | | | | | |  | | |
| email V2 | | | | | | Lots of participants received emails from their therapists which had instructions on how to access virtual therapy. This was very helpful. | | |
|  | | | | | |  | | |
| remember when you were ill. before | | | | | | Virtual therapy was a new experience for all participants. Three participants described it as weird. | | |
|  | | | | | |  | | |
|  | | | | | |  | | |
| remember when you were ill. before  “It’s not really a good experience because you don’t get the full experience of it” | | | | | | | | |
|  | | | | | |  | | |
| unhappy V5 | | | | | | Some participants did not have a good experience and felt disappointed with the virtual therapy process. | | |
|  | | | | | |  | | |
| **Subtheme 2: Adaptations** | | | | | | | | |
|  | | | | | |  | | |
| Change Icon Vector Art, Icons, and Graphics for Free Download | | | | | | Adaptations means the changes that were made to therapy because it was being delivered virtually. | | |
|  | | | | | |  | | |
| Easy read layout | | | | | | All participants were sent visual, accessible material. They found this helpful. | | |
|  | | | | | |  | | |
| responsibilities V2  “With me going off pictures and things like that obviously I understood what it was” | | | | | | | | |
|  | | | | | |  | | |
| C:\Users\burtho\AppData\Local\Microsoft\Windows\INetCache\Content.MSO\6CF52850.tmp | | | | | | Some participants found that visual resources, such as leaflets and Youtube videos, were helpful when learning new skills in therapy. | | |
|  | | | | | |  | | |
|  | | | | | |  | | |
| **Subtheme 3: “Just hearing a friendly voice”** | | | | | | | | |
|  | | | | | | | | |
|  | | | | | |  | | |
| better | | | | | | Six participants felt that therapy was useful and they had a good experience. | | |
|  | | | | | |  | | |
|  | | | | | |  | | |
| happy and sad memories V2  Therapy provided a space to “release some of the things that [they] were thinking about” | | | | | | | | |
|  | | | | | |  | | |
| lonely | | | | | | Three participants felt lonely and anxious during the pandemic as day services had been cancelled. They said that therapy helped them cope with these difficulties. | | |
| **Subtheme 4: Stifling the therapeutic process** | | | | | | | | |
|  | | | | | |  | | |
| stop V2 | | | | | | Stifling means when something is being stopped from happening. | | |
| Communicating With People With No Internet Access • PresentationPointcomputer | | | | | | All participants said that their therapy interrupted due to technical difficulties, such as batteries running out, the sound not working and losing internet connection. | | |
| worried children | | | | | | Some participants felt anxious and helpless when their internet connection was lost during therapy. This made it harder to connect with their therapist. | | |
| Checking V2  **Theme 3:**  **Therapeutic relationship** | | | | | | | | |
| Keep safe V2 | | | | | | All participants talked about the relationship they had with their therapist and how this impacted their therapy journey. | | |
|  | | | | | |  | | |
| **Subtheme 1: Building a connection** | | | | | | | | |
|  | | | | | |  | | |
| C:\Users\burtho\AppData\Local\Microsoft\Windows\INetCache\Content.MSO\C8AE8BAF.tmpcheck mark and cross mark icon. Tick symbol in red color. vector  illustration 11193361 Vector Art at Vecteezyvideo callpsychologist | | | | | | All participants found it harder to build a connection with their therapist over virtual therapy compared to face-to-face support. | | |
|  | | | | | |  | | |
| friendly friends | | | | | | Participants that had met their therapist face-to-face before the pandemic felt this made moving to virtual support easier as they already had a relationship. | | |
|  | | | | | |  | | |
| worried about what children | | | | | | Some participants felt distant from their therapist as they were virtual and not in person. This made participants feel anxious and unsafe. | | |
| Autism Leeds servicesafe | | | | | | However, autistic participants felt safer and less anxious in virtual therapy compared to face-to-face therapy. | | |
|  | | | | | |  | | |
| **Subtheme 2: Therapist factors** | | | | | | | | |
|  | | | | | |  | | |
| confused | | | | | | It was harder to get to know the therapist’s personality virtually. This made it hard to build a positive relationship. | | |
| Eye contact | | | | | | The loss of non-verbal communication, such as body movements or eye contact, also made it difficult to understand the therapist and therapy content. | | |
|  | | | | | |  | | |
| remember when you were ill. before  “It’s easier if you are seeing them face-to-face as you can see their body language” | | | | | | | | |
|  | | | | | |  | | |
| live with a family  hearing | | | | | | Two participants found it hard to build trust virtually. Some therapists were working from home which meant that the participant could hear things going on in the therapist’s home in the background. | | |
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|  | | | | | | | | |
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|  | | | | | | |  | | |
| **Theme 4:**  **Safety in the virtual environment** | | | | | | | | | |
|  | | | | | | |  | | |
| safe | | | | | | | All participants described how their experience of safety in the virtual therapy environment impacted their overall experience. | | |
|  | | | | | | |  | | |
| **Subtheme 1: Risk Management** | | | | | | | | | |
|  | | | | | | |  | | |
| relaxation breathing | | | | | | | Some participants watched TV, listened to music, talked to their friends after therapy, or took some time to calm down after therapy sessions. They said this was important for their mental health. | | |
| comforted when upset | | | | | | | Participant’s family or support workers gave them emotional support if they were upset after virtual therapy appointments. | | |
| phone someone V235 days | | | | | | | Some therapists did things to manage risk, such as making sessions shorter when difficult topics were spoken about or calling to see how they were the next day. This made participants feel safer. | | |
| **Subtheme 2: Confidentiality** | | | | | | | | | |
|  | | | | | | |  | | |
| No longer confidential | | | | | | | All participants felt worried about confidentiality because the information they shared in therapy did not stay private as other people, such as parents, service users or carers were listening. | | |
| Do not share information | | | | | | | This made them feel unsafe to share information during therapy. | | |
| No pain V2  “[it’s] hard to tell people things when you’ve got your carers here [..] It’s a bit hard” | | | | | | | | | |
|  | | | | | | |  | | |
| **Subtheme 3: Environmental Factors** | | | | | | | | | |
|  | | | | | | |  | | |
| bedroom (day)teddy bear | | | | | | | At home, participants had their home comforts, such as their own bedroom and grounding objects such as teddy bears, which helped them feel safe during therapy. | | |
| mobile phoneFunny noises | | | | | | | Distractions at home, such as mobile phones and noise from other service users, made it hard for some participants to concentrate on therapy at times. | | |
|  | | | | | | |  | | |
| **What does this mean?** | | | | | |
|  | | |  | | |
| what do you think with 2 people | | | This research tells us that adults with learning disabilities had very different experiences of receiving virtual cognitive behavioural therapy-based support during the COVID-19 pandemic. | | |
|  | | |  | | |
| ask you what you think | | | It is important for therapists to think about who is offered virtual support and set this up by talking to the service user about their wants and needs. | | |
|  | | |  | | |
| **What does this mean for the future?** | | | | | |
|  | | |  | | |
| psychologist | | | Now that COVID-19 restrictions have been lifted, lots of mental health services use a mixture of face-to-face and virtual support. | | |
| safe | | | Future research could find out more about how to build positive therapeutic relationships when working virtually with people with learning disabilities. | | |