Online qualitative research with disabled children and young people in Scotland: A reflection on its advantages and disadvantages, and how limitations were addressed

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A B S T R A C T

With the COVID-19 pandemic, online recruitment strategies and data generation processes have become popular in social science research. Although online and creative methods, such as digital photo elicitation, online interviews, and discussion forums are increasingly used in qualitative health research, their use with disabled children and young people is not well established. Drawing on the online methodological approach used for a qualitative study conducted with disabled children and young people in Scotland, exploring their experiences of accessing healthcare and other supports during the pandemic, we reflect on our concerns and learning in relation to a digital interviewing process. Limitations and challenges of online and digital methods were varied and partially addressed by both research subjects and researchers. A significant limitation entailed the digital divide, which meant that families without the equipment and connectivity might have had less opportunity to hear about the research and participate. However, an online approach minimised travel costs, facilitated interview data transcription and, most importantly, offered children and young people a variety of participative and digital tools to talk about their experiences. Our paper raises questions on the assumptions often made about the difficulty of doing research with disabled children and young people by highlighting the benefits of this approach. It also suggests that some limitations can be addressed by engaging in collaborative and creative work between research participants and researchers.

1. Introduction

1.1. Study context

This study was carried out by Liliana Arias-Urueña as the main researcher, with Francesca Vaghi's support as a key point of contact within the non-governmental organisation The Health and Social Care Alliance Scotland (the ALLIANCE).[1] The research was funded by the ALLIANCE as a response to emerging evidence that disabled children and young people, those living with long term conditions, and their families, had been disproportionately affected by the restrictions put in place by the Scottish Government to mitigate the effects of the pandemic, particularly limiting their access to health and social care services. Further, there are ongoing discussions about the structure that the new National Care Service (NCS) will have in Scotland, including whether children's services will be included within this new structure.[2] Developing an approach through which to meaningfully engage with those accessing these services (i.e. disabled children and young people) was seen as an urgent priority within the health and social care sectors.

The project was carried out between March and May 2022, with the aim of exploring disabled children's, young people's, and carers' experiences of accessing state entitlements in Scotland, including healthcare services, social care, and other benefits, during the COVID-19 pandemic.

1.2. Literature review

Our paper seeks to address a gap in knowledge on the meaningful participation of disabled children and young people in online qualitative research, a gap which existed before the COVID-19 pandemic began, and which seems to persist as the pandemic continues. This brief literature review evidences some of the methodological limitations that our paper seeks to attend to.

In carrying out this review, we have chosen to focus particularly on literature spanning the years 2015–2022, as more advances and reliance on online methodologies occurred during this period, but also because it is a time frame during which further developments in the fields of disability studies and childhood studies took place, and during which the intersection between the two disciplines also became more salient.

1.2.1. Qualitative research during the COVID-19 pandemic

Within the literature selected for our review, works published between 2020 and 2022 in particular explore the impact that the COVID-19 pandemic has had on how social research can be carried out, most prominently with a transition from in-person to online methodologies. There is a vast amount of literature that has been published on this subject matter, starting at the beginning of the pandemic and continuing to this day. A number of special issues addressing this shift in approaches have also been published during this period, notably Volume 20 of the International Journal of Qualitative Methods (2021), as well as the *Special Issue on COVID-19 and Novel Mixed Methods Methodological Approaches* published by the Journal of Mixed Methods Research (2021).

As well as covering the methodological frameworks that researchers took on to adapt to new circumstances, the ethical and practical aspects of collecting qualitative data during the pandemic have also been discussed. For example, Wa-Mbaleka and Costa (2020) explore universities' institutional responsibilities in terms of ethics, as well as discussing what steps can be taken to guarantee researchers' and participants' safety (both physical and psychological) throughout the research process. It is undeniable that the emergence of these discussions and debates on research practice has sparked new (and much needed) conversations on the importance of embedding reflective practice in research, of refining research design processes, as well as encouraging researchers to adopt creative and innovative methodologies with participants – all of which is extremely valuable. It is worth pointing out that much has also been written since the beginning of the pandemic on online teaching and learning (e.g. Edirisingha, 2022; Hussain & Tartila Suma, 2023), however delving further on the topics explored within these works is beyond the scope of our paper.

Within this large body of literature, little is published on carrying out remote research with disabled adults. Authors like Webber-Ritchey et al. (2021) focus on methodologies to conduct research with 'vulnerable populations' during COVID-19, however disabled people are not included within this category. Similarly, Varma et al. (2021) explore how qualitative health research has been conducted during the pandemic, but again disability is not mentioned. This foregrounds that, given there is a gap in knowledge around carrying out online research with disabled adults, it is not surprising that a knowledge gap also exists on carrying out online research with disabled children. This echoes the general under-representation of children (particularly disabled children) in policy-relevant research (Liddiard et al., 2019).

1.2.2. Qualitative research with disabled children and young people during the COVID-19 pandemic

Whilst we argue that knowledge on conducting online research with disabled children and young people needs to be further developed, our work builds on a growing body of literature on carrying out in-person qualitative research within this context (e.g. Liddiard et al., 2019; McLaughlin & Coleman-Fountain, 2019; Newhouse, 2022). These works explore the value of following an adaptable and flexible approach during the research design and data collection processes, the potential of following a co-production approach, as well as exploring the methodologies that can best support participants to have a 'voice', in its multiple and varied forms.

Indeed, a special issue of the *International Journal of Qualitative Methods*, titled *Construction of 'Children's Voices' in Qualitative Research (2020)*, focuses specifically on expanding the ways in which research is carried out with children, provides reflections on what is meant by the 'voice' of the child, and discusses the challenges of carrying out research with children during the COVID-19 pandemic. In the words of the guest editors to the special issue:

> "These unprecedented times have led to the imposition of social restrictions that negatively impact some groups far more than others. A spotlight has been shone on a wide range of social inequities and injustices, many of which directly affect children and young people […] there are particular implications for research with children who are generally regarded as vulnerable and in need of protection" (Teachman & Gladstone, 2020, p.1).

The issue contains three papers that focus on, or include, the experiences of disabled children and young people (O'Leary & Moloney, 2020; Pincock & Jones, 2020; Spencer et al., 2020). These discuss the use of innovative and creative research methods in person (such as arts-based methods, body mapping, community mapping, and Participatory Action Research), yet none of these explore the use of online or digital tools to carry out research with disabled children and young people. As will be shown in this paper, there is great potential for such approaches to also be adopted online, using a number of virtual tools, and for these frameworks to be participant-led. This is particularly important when aiming to engage directly with children and young people rather than accessing their views through their parents or carers as proxies.

Works that explore children's and young people's internet use already shed light on how researchers can use online and/or virtual avenues to engage with young participants. A 2015 systematic review discusses the potential of using online methods for recruitment purposes with disabled children and young people (Bailey et al., 2015, p. 5), however it does not mention using online or digital methods to carry out research with young participants. Studies have also been conducted on disabled young people's online activity and use of social media, like Hynan et al.'s (2015) work on internet and social media use by young people who use Augmentative and Alternative Communication (AAC), or as shown in a literature review by Borgström et al. (2019) on the opportunities and barriers young people with cognitive difficulties on the internet. Again, however, these do not explore the use of online or digital methodologies to carry out research with disabled young people. Further, addressing one of the limitations of their approach as well as some found in the papers included in their review, Borgström et al. conclude that, "It is important for future research to involve young people with an intellectual disability, not just in order to facilitate them expressing their own views, but also to get close to the phenomenon [of disabled young people's internet use], for example, through observations and an ethnographic approach" (p.138).

Two papers from our literature search stood out for their similarity with the methodological approach of the study discussed in this paper. First, Rania et al.'s work with young adults in Italy during the COVID-19 pandemic (Rania et al., 2022) evidences how Participatory Action Research can be carried out remotely and online using Photovoice, where images are used to start conversations "on important issues, and the dialogue should translate into social change" (2022, p.3). The authors used a staged approach in their research, first bringing all 250 participants together to an introductory workshop, who were subsequently divided into smaller groups and workshops, where further engagement and discussions took place:

> "The individual photographic activity is followed by a group discussion…with the analysis of participants' pictures. Then, the

participants prepared a final event in which they share with the stakeholders and wider community their empowerment and solutions to face the critical situations that they have discussed" (ibid).

The paper shows a robust approach by which young participants' own views about their experiences can be elicited, also providing an avenue for them to make suggestions for the future, based on these experiences. This core aim in Rania et al.'s work was also at the centre of the research conducted by Arias-Urueña in Scotland, which was carried out over a period of a few months through three online sessions.

Also similar to our approach was that of O'Sullivan et al. (2021), who carried out individual online interviews with children and families in Ireland during the COVID-19 pandemic. O'Sullivan et al. used online channels and social media as recruitment tools, and carried out in-depth interviews with children, young people, and parents on Microsoft Teams. Their approach highlights that trust and rapport can be developed with participants also via online methods:

"Following the initial briefing and obtaining consent, the researcher facilitated open-ended questions through a semi-structured interview. This allowed for flexibility of questions during the interview […] Following each interview, the researcher debriefed the family and asked if they had any questions. When the interview was finished, the researcher saved the audio file and transcribed the interview verbatim. The participants were also contacted to ensure that they were happy with their interview and if they had any queries about the research process" (2021, p.4).

While O'Sullivan et al.'s study took place over a single session, Arias-Urueña developed a three-session approach (through in-depth interviews over Zoom), showing that longer term engagement with participants, similar to that which researchers can achieve through in-person qualitative research, can also be developed online. This has particularly positive implications for those who are disabled, live with long term conditions, or live in remote areas, as will be shown in this paper. Importantly, the work carried out by Arias-Urueña evidences that online participatory research is possible with children and young people that also have multiple and complex conditions; whilst O'Sullivan et al. included some children with autism in their study, it is not clear how many of their participants had any pre-existing conditions, and their methodological approach was not tailored to cater for any particular additional needs. We recognise disability as a diverse lived experience shaped by the interplay of complex biological, social and cultural dynamics. Given this diversity, it is important to address the gaps in understanding nuances of tailoring research approaches and methodologies to ensure the participation rights of and access needs for children and young people with varying lived embodiments are equally promoted and met. Our paper seeks to address this knowledge gap.

2. Methods

2.1. Study design & recruitment

Disabled children's and young people's voices are often left unheard or are accessed by proxy (Kaisen parternship & The Council for Disabled Children, 2021). For that reason, a methodological approach that privileged children's and young people's own accounts was adopted. Three online semi-structured interviews, in combination with some digital-creative and participatory tools, were used in this study. These methods offer the opportunity to capture young people's opinions and experiences in a more participatory, open, and expressive way (Benson, Tony et al., 2021; Salmons, 2021). Creative tools are visually effective and can stimulate self-reflection and debate (Nathan et al., 2023). Methods such as photo elicitation, photo voice and digital story-telling are traditionally considered to be creative (Boucher, 2017). However, the meaning of creativity has expanded, and tools such as digital presentations, discussion boards, audios, posters, images, postcards and

drawings (some of them used in this study), can also foster creativity among both participants and researchers (Boulianne & Theocharis, 2020; Salmons, 2021).

We recruited purposely based on children's and young people's self-identification of their disability status. In the case of adult participants, recruitment was based on self-identification as being a carer of a disabled child or young person. A call for participants with two types of information sheets, one for parents and one for children and young people, was disseminated through the ALLIANCE website, their social media platforms, and key partners. An audio version of both information sheets was also made accessible through a QR code. The website link to the call for participants and a digital flyer were also circulated through several professional networks, friends, colleagues and targeted messages to several charities, to maximise the potential for involvement. Participants interested in taking part in the study contacted the main researcher directly, who then led them through the project information and consent processes before commencing the research activities.

2.2. Participants

Five families took part in the study. Participants lived in both urban and rural areas of Scotland, and spread across the North, South, and Central Belt. Children and young people's ages ranged from nine to 19 years, with two participants turning 18 during the pandemic. Of the child participants, three were female and two male, and all adult participants were female. All participants self-identified as disabled, or caring for a disabled child or young person. Children and young people experienced long term medical conditions, which included mobility, cognitive, and communication difficulties, and mental health issues. Most of them had high levels of care and support needs.

All participants agreed and consented to participate in the research. To protect their anonymity, all participants have been given pseudonyms in this paper.

2.3. Data generation

Interviews were conducted through Zoom videocalls (via the main researcher's university account) between March and May 2022 over three different encounters. Some participants also shared details of their experiences through WhatsApp texts, voice notes and emails. Each interview lasted around 40 min. Although the content and structure of interviews varied with each participant, depending on their own preferences, experiences and skills, the topics most frequently discussed in the first interview were participants' everyday routines, hobbies, family structure, and some details about their medical conditions and treatments. Common themes in the second interview included changes accessing health and social care services because of the pandemic, what children, young people and carers liked and disliked about those services, and how information about state entitlements and supports was accessed and shared.

PowerPoint and Canva[3] presentations with visual prompts, questions, and Miro[4] post-it notes were used to spark conversations over the three sessions. Reflecting the participatory character of the study, in the last interview participants talked about how health and social care services and supports could be improved. In this last interview, participants created collages and posters using Miro and Canva. The online nature of these platforms and the diverse and creative tools that they offer (e.g. poster templates, whiteboards, design tools like stock images and animations) allowed a dynamic and interactive work between the

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[3] Canva is an online graphic design tool commonly used to create social media and audio-visual content: https://www.canva.com/.

[4] Miro is an online collaboration whiteboard platform which enables people to communicate and collaborate remotely using different formats, tools, and across multiple geographical locations: www.miro.com.

participants and the interviewer. Supported by his mother and the interviewer, one participant used the Soundcloud[5] platform to produce a podcast episode in his last interview.

2.4. Data management and analysis

Interviews were video and/or audio-recorded, depending on participants' preferences and on whether they consented to both video and audio recording, or just one of the two. Automated transcripts from the video platform and creative works (e.g. collages, posters) were uploaded to NVivo (QSR International Pty Ltd, 2018). Each audio recording was listened to by the main researcher to check the accuracy of the automated transcript. Transcription errors and unclear sections were amended manually. Data were analysed using thematic analysis (Braun & Clarke, 2016; Braun et al., 2019; Clarke & Braun, 2014).

Initial nodes and categories were generated from the transcripts and creative works by the main researcher. These were shared with the co-researcher who reviewed and provided feedback. Coded data were analysed in relation to key reports, concepts and theories used to inform the study design. These included: the rights-based model and the social model of disability (Barnes, 2014; Garland-Thomson, 2011; Shakespeare, 2006; Thomas, 2021), the new paradigm of childhood (James & James, 2001; James & Prout, 1997) contemporary views of agency (Abebe, 2019; Larkins, 2019; Mizen & Ofosu-Kusi, 2013), and key legislation around state entitlements for disabled people in Scotland.

The new paradigm of childhood acknowledges that children are social agents, and that definitions childhood and youth may vary according to social, cultural and historical contexts. The social and rights based models of disability frame the experience of disability beyond the presence of a particular medical condition, biological vulnerability, or bodily impairment. Both models look at varying lived embodiments as a natural aspect of human diversity with social structures having a responsibility to support and promote disabled people's rights of participation.

2.5. Ethical considerations

This study was designed and conducted following the Third Sector Research Forum's 'Guide to Applying Ethical Research Principles' (Scotland's Third Sector Research Forum, 2020). Consent was sought at different points of the research, on an ongoing basis. This started by obtaining children, young people and parents' agreement to participate at the end of an initial (recruitment) chat with the main researcher. This was often an informal discussion over WhatsApp, email, or telephone with those families who contacted the main researcher expressing an interest in knowing more about the study. After a brief recap of the aims and voluntary nature of the study, both written and verbal consent was also gained from the children, young people, and their parents at the start of the first interview.

Two different consent forms were designed, one for children/young people and one for parents. In the first section of the children's and young people's consent form, their understanding of the voluntary nature of the study, the confidentiality of their accounts, and limitations of this confidentiality in cases of risks and potential harm, was reviewed and discussed. Children's and young people's agreement to participate was checked in the second encounter, before beginning the interview, as well as the third and final encounter.

Children also decided whether they wanted their parents to be present in the interviews or not, this to ensure the confidentiality of their accounts, and a research context consistent with their preferences. All participants provided consent and were reminded about the voluntary nature of their participation throughout the research process, their right

to skip any questions, and to drop out from the study without having to give a reason. To protect their anonymity, all participants have been given pseudonyms in this paper.

It is important to mention that consent was not sought from one young person (Bob) and neither was he interviewed. Due to the complexity of his health condition and limited verbal communication, his mum (Bob's primary carer) was interviewed. She provided important insights into the complexities of meeting Bob's care needs during the pandemic.

We acknowledge that not being able to include Bob in the research is a limitation of this study. As outlined above, accessing disabled children's views by proxy through their parents and carers is common, and the aim of this study was to develop a participatory approach that sought to address this shortcoming. However, this was not possible in this case. More needs to be done to ensure the inclusion of all disabled children in future research, including those who rely on non-verbal communication.

3. Findings and discussion

In this section we present a reflection on the decision-making process about adopting an online methodological approach, including our concerns and fears. We also present and discuss the benefits and limitations of conducting online interviewing and how these limitations were addressed.

3.1. E-research: recognising fears and concerns

Early in the planning stage, there were recurrent discussions between the researchers about whether an online approach should be adopted. By the time this study was being conducted, the majority of COVID-19 related restrictions had been eased by the Scottish Government, therefore face-to-face interviews were a permitted option. Despite the benefits of conducting in-person fieldwork, particularly for rapport construction, we opted for an online approach for safety and ethical reasons. First, face-to-face interviews might increase the risk of COVID-19 infection for both participants and the main researcher, something that for children and young people with complex health conditions implied higher health risks and potential complications. Second, the study needed to be completed within a tight timescale (four months). Conducting in-person interviews would have meant that both the participants and researcher would have to spend some time travelling, which would have made completing the study within the required project timeline challenging. Third, given our aim to generate data with children, young people, and their carers from different regions in Scotland, an online approach would facilitate participants' involvement from different geographical locations as no travel was involved.

Although e-qualitative research was the most convenient, our decision was not free of fears and concerns. Some questions emerged around the proficiency of our digital skills and literacy. Despite being familiar with video conference platforms, data management software, and bibliography databases, we knew that moving and adapting qualitative research to the online world also required us to gain some further digital skills and network knowledge. We also thought that decisions on what information technology (IT) tools to use should be informed by evidence, but also shaped by participants' own opinions and preferences.

There were also fears about the negative impacts of online interaction for rapport construction. In particular, we were worried that videoconferencing may reduce the range of non-verbal cues that can be observed when doing research in person, affecting the participant-researcher relationship, the rapport between them, and ultimately, the richness of the data (Salmons, 2021). We unpack each of our concerns and how we addressed them below.

3.2. Making decisions on IT tools

We explored what technologies could be easiest to use for both

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[5] Soundcloud is a free streaming service that allows users to upload, create and share audio files: www.soundcloud.com.

participants and the main researcher, which ones might allow a dynamic and engaging atmosphere but also offer different ways of communication: audio, video, and closed caption. In doing so, we came across literature suggesting the use of three main Voice Over Internet Protocol (VoIP) technologies: Zoom, FaceTime and Skype (Archibald et al., 2019; Lo Iacono et al., 2016; Oliffe, J. et al., 2021). While this body of literature was focused on the practical, technical, and ethical considerations of using conference platforms, decisions on what platform to use is generally made by researchers, overlooking participants' preferences and opinions. Given the participatory nature of our study and our interest in engaging with participants in ways that responded to their preferences and skills, the decision on what platform to use was made together with the participants.

We asked participants to choose a video platform they felt more comfortable with to use in our three encounters (with options available including Skype, Zoom, Microsoft Teams and FaceTime). This decision was often made when arranging the date for the first interview. We were also clear in saying that other communication and technology tools such as WhatsApp text messages, voice notes, and email could be also used if they wanted to.

Following the principles advocated for in the paradigm shift in childhood studies (James & Prout, 1997), whereby children's agency and capabilities are recognised and methodological approaches are adapted accordingly, participants in this research were provided a range of online platform options to choose from when engaging with the researcher. When using online methods, whilst researchers ensure that there are a number of options provided to participants to guarantee that participation is easy and accessible for people with all types of ability, it is often the case that options available are predominantly selected by researchers themselves (e.g. Benson et al., 2021). This allows them to become familiar with the different platforms available, and anticipate issues and solutions if any technical difficulties arise (e.g. Keen et al., 2022). However, we had opted for a participatory approach as a means to build on conventional online practices, and thus involved children in most aspects of the research process, including selecting the platforms they wanted to use to engage in the research.

The process of choosing tools adopted in this study, such as what video platform to use (whilst not as direct or fast to begin with) is an example of how moving qualitative research online can be explicitly nurtured and informed by participants' decisions and preferences. This, in turn, was also a way to ensure that trust and rapport could be developed over the course of the study, as well as a way to respond to participants' needs, preferences and capabilities on an ongoing basis.

Although participatory research with children and young people is a growing practice, their participation as active co-researchers is still uncommon (Cuevas-Parra, 2020; Mason & Watson, 2014). Based on the premise that children and young people are social agents and rights holders, some scholars have demonstrated how children and young people can also be co-researchers (from research planning and design to findings dissemination). At the centre of child-led studies relies the idea that research agendas should resonate with young researcher's interests, and expertise and methodologies need to be flexible to their abilities, preferences and skills.

Doing research with children as co-researchers has multiple advantages. For example, Cuevas-Parra (2020) analyses how collaborative work with a group of young researchers allowed the development of a complex intergenerational project during the COVID-19 outbreak. The author highlights children's abilities to mobilize their networks to reach their peers and generate relevant data in a challenging and uncertain time. Other works have also demonstrated how the insider perspective of children can assist in the design of relevant research questions and methodologies (Mason & Watson, 2014; Schäfer & Yarwood, 2008). In relation to data generation, children can successfully generate data with other children in ways that are not possible for adult researchers, due to power imbalances and generational gaps (Bradbury-Jones & Taylor, 2015).

These examples have served to encourage scholars within and beyond the field of childhood studies to position children and young people more explicitly at the interface of knowledge production and exchange.

3.3. Strengthening IT literacy - making fieldwork more interactive

How to optimise internet speed and connection throughout the research process was discussed early on in the design and planning stage, and kept in the foreground at all times of the research process. This is because poor internet connection may affect participants and researcher relationships and their engagement with the research process (Keen et al., 2022; Kobakhidze et al., 2021). Mainly through self-directed training, the main researcher learnt about the basics of internet networks and broadband. Although wireless networks have emerged as a robust and practical communication system, we opted to use a wired connection on the main researcher's end in most of the interviews. A wired network offered a faster and more reliable connection with a lower latency than wireless connections (BT and Cyber Security Challenge UK, n. d.). This practice helped minimise connectivity issues, interruption during interviews; impacting positively on rapport.

Moving and adapting qualitative research to the online world also required the researchers to explore new technologies to support the data generation. This exploration entailed informal conversations with communication and technology experts, which allowed us to learn about Soundcloud and Miro and Canva (the two visual platforms mentioned earlier). We used these technologies to make the research process more interactive, innovative, and dynamic. Miro and Canva allowed the main researcher to work collaboratively with the participants creating digital posters and collages (creative works) in the last interview. Canva and Miro also allowed both participants and the researcher to interact in real time on the whiteboard. For example, while some of participants used post-it notes to share their thoughts, the main researcher helped organise their notes by categories (e.g. struggles with dentists appointments, struggles with medical doctors). Participants also used emojis and stickers to express some of their emotions while talking about their experiences and creating their own works on Miro. This collaborative work prompted further conversations about their experiences and emotions, which also enriched the data generation process (see Fig. 1).

These digital platforms also encouraged children's participation, as they were easily adaptable to the diversity of children's and young people's communication skills, needs and preferences. For example, using Soundcloud, one participant created a podcast where he talked about his experience with healthcare services during the pandemic; he also shared recommendations for future change. The multiple and creative design options that Canva offers allowed the main researcher to prepare some visual prompts and colourful presentations, facilitating the exploration of some topics throughout the interviews. We also used Canva to create an animated video summarising the main findings of the study. This was presented to non-academic audiences once the research was completed. The above examples illustrate how traditional and emergent qualitative practices can become even more interactive and innovative in the online world (Keen et al., 2022).

3.4. Constructing rapport

Rapport-building generally relies on the researcher's ability to read a participant's emotions, often conveyed through body language within a face-to-face interaction (Ritchie et al., 2013). Online interviewing makes it more difficult to identify non-verbal cues which might then affect the development of rapport (Rubin & Rubin, 2004). We were aware of the potential negative implications of virtual methods for rapport construction, and as such implemented strategies to minimise these risks.

We started building rapport at the recruitment stage and throughout the interview scheduling processes. This involved informal phone chats and video calls where the main researcher introduced herself to the

Fig. 1. Shows an example of a participant's creative work. MH: mental health.

young participants and their parents, further explained the study, and addressed any questions and doubts participants may have had. Particular attention was paid to the language used, to ensure that conversations were at participants' level of understanding, and that participants were put at ease. The use of video calls for some of these chats allowed children and parents to virtually meet the researcher before making any decision about taking part, which also contributed to a sense of trust. Although this was occasionally time-consuming, it increased both the participants' and researcher's confidence, allowing them to feel more relaxed in the first interview. Evidence of this process of constructing online rapport is captured in the fieldnotes gathered after initial conversations with participants:

Fieldwork notes [4 April 2022]

This first encounter with Matt went well, there were no connectivity issues and Zoom worked well. Matt was chatty and outgoing which facilitated breaking the ice further. I feel that having met Matt before made breaking the ice easy as we already knew each other. We started chatting about how school was going, hobbies, weather… his mum was there too. Both made jokes about the weather in Scotland, some jokes related to his brother too. I felt Matt relax as we spoke.

We also opted for conducting three interviews with each participant, as multiple encounters offered more opportunities for 'ice breaker' chats and greater interaction between the participants and the main researcher. Over the three encounters, participants could expand on their views, thoughts and experiences, and there was further opportunity to better get to know each other. Indeed, multiple interviews were appreciated by both the participants and gatekeepers (i.e. other third

sector organisations within the ALLIANCE's and the main researcher's networks):

Fieldwork notes [27th April 2022]

While talking about the study details, some key partners who are helping us to disseminate the call celebrated the idea of doing multiple interviews. They thought that one interview was never enough, as some participants might find it difficult and intimidating to talk about their experiences with a stranger in one single encounter.

In this way, relationships and networks that are usually established when carrying out in-person qualitative research can also be developed via online methodologies.

3.5. Encouraging children's participation and agency

Most of our young participants showed strong digital skills. All of them seemed confident when using laptops, video conference platforms, even more so than their adult carers. Indeed, most of the young participants were in charge of setting up equipment and devices, and of fixing connectivity issues. For example, in the last interview with Naya and her mother, some issues of connectivity were solved thanks to Naya's strong digital skills:

Field notes [17th May 2022]

Naya's mum was talking about the frustration of not having medical appointments on time. Naya was in the background while her mum and I were chatting… we started to have some audio issues, Naya's mum did not know how to fix them, so Naya came to the desk to help her. The issues

were fixed by Naya, who showed her mum what to do if they occurred again.

We also found that an online approach encouraged young participants to make decisions more autonomously throughout the research process. This was evident in how children and young people chose dates and times for the interviews on their own. For example, when arranging our online encounters with Kristi, a young person with mobility restrictions, she mentioned that scheduling interviews was easy for her, because she did not need to ask her parents to 'drive her' to any place, or to come along with her: she could do everything herself from home. Like Kristi, Naya and Matt decided what times and dates were more convenient for our encounters, this without having to consult or coordinate with their parents.

Experiencing a disability has been commonly associated with a limited access to, and use of, technological tools and communication technologies (Helsper & Reisdorf, 2017). Barriers contributing to this phenomenon include the high costs of equipment, devices and internet services (Alfredsson Ågren et al., 2020), low levels of digital literacy (Lussier-Desrochers et al., 2017) and safety measures placed by parents, carers and gatekeeps on children and young people (Heitplatz et al., 2022).

Doing online research with disabled children and young people is often seen as more problematic due the above-mentioned barriers, but also because of assumptions that disabled participants would prefer in-person interaction (Bailey et al., 2015). The above examples show how disabled children's and young people's digital skills are multiple and varied, raising questions about whether in person methods should be always privileged over online approaches. The way in which the participants engaged with communication and information technologies throughout the research process and how they used different online resources to construct their works in the last interview speaks of the diversity of their digital literacy, preferences and skills.

Online interviews also offered the participants with mobility restrictions an opportunity to take part in the study without leaving home. This was important for Kristi and Matt (both participants with significant mobility difficulties) whose participation would have been hampered by an offline approach. Without mobility and travelling obstacles, children and young participants could participate from the comfortable setting of their homes. This is a benefit that online researchers should consider when working with disabled people, as travelling might be a barrier factored in by those with mobility difficulties when making decisions about taking part in research.

The online nature of the study was also perceived positively by children and young people's carers. During recruitment, some mothers found the online approach 'very convenient' as they would not have to leave home or make arrangements with their work place to take time off to take part in the study. This finding resonates with previous research informing how virtual interviews may also be more manageable for participants or researchers with caring responsibilities (Henderson & Moreau, 2020). The flexibility of time and research setting that online research offers is particularly valuable when doing research with disabled children and young people. Their carers and parents often experience time struggles associated with their demanding work and caring roles (Scottish Government, 2016).

Creative methods have increasingly become popular in qualitative research with children and young people (Boulianne & Theocharis, 2020; Nathan et al., 2023). The flexible and participatory nature of these methods tend to minimise power imbalances between participants and researchers, also offering a space where participants can safely share their perspectives and opinions (Kustatscher et al., 2020; Lomax et al., 2021). This is particularly important for those groups traditionally marginalised in research, such as disabled children and young people.

In this study, the use of visual and audio digital platforms (Canva, Miro, and Soundcloud) allowed the construction of a creative and interactive atmosphere for data generation. Colourful texts, images, animations, mind maps, emojis, and other digital artefacts offered by the online world, provided both participants and researchers the opportunity to express themselves in ways that might expand on what can be achieved via traditional, in-person qualitative interviews.

Our study also showed the potential for online creative methods to create opportunities to engage children and young people in other stages of the research process, like data analysis. For example, online discussion boards, visual mapping and flip-charts can be used by participants and researchers to visually display and exchange some of their interpretations and thoughts on the themes that are emerging. Likewise, audio-based tools such as voice notes might facilitate the involvement of children and young people with sensory loss in data analysis. The digital world and online resources can thus serve as a vehicle through which participants and researchers can share opinions, ideas, and interpretations on the data generated in a collaborative manner. Recurring meetings between participants and researchers, something particularly important when co-constructing knowledge, can also be facilitated by the travel free and interactive spaces that the digital world offers.

Childhood studies scholars have raised questions about what elements of the research process 'matter most' while doing participatory-creative research (Cuevas-Parra, 2020; Liddiard et al., 2019; Tisdall & Cuevas-Parra, 2020). Some of these discussions suggest that children's and young people's involvement in data analysis is often neglected. Online and creative methods can make children's participation in, and contribution to, data analysis accessible, and there is still much to be learned.

3.6. Transcription efficiency and participants' geographical diversity

Platforms including Zoom, Microsoft Teams, and Skype provide automated transcription functions. This is positive as it optimises the transcription process and speeds up the research workflow (Bokhove & Downey, 2018). We retrieved automatic transcript files of the interviews generated by the videocall platform and analysed them.

Some scholars have raised concerns about data confidentiality and reliability when using these platforms and its functions (Roberts et al., 2021). However, the use of waiting rooms and password-entry features have helped Zoom users prevent incidents related to confidentially (Yuan, 2020). Zoom's innovative transcription tool helped streamline the analysis process, which was particularly valuable given the tight timescale of the project. However, we recommend using this tool in combination with careful listening of the audio file and some manual transcription too.

It is difficult for a transcribing software to produce accurate text versions of audio recording, given the diversity of accents and the different speeds people talk in (Bokhove & Downey, 2018). We often saw word errors and sentences that did not reflect the content of the interview. To address this limitation, the main researcher listened back to each audio file to assess the accuracy of the automated transcript. In doing so, gaps, mistakes and unclear points/sections in the transcript were corrected. A hybrid transcription approach also helped the main researcher to immerse herself in, and engage more easily with, the data analysis process. A hybrid transcription process is therefore recommended.

Using a digital platform also allowed us to carry out qualitative research with geographically dispersed participants. This is an important benefit of online research when seeking to involve marginalised and/or underrepresented populations, such as those living in rural and remote areas (Lathen & Laestadius, 2021). Although our sample was small, the online approach allowed participants from different regions in Scotland, including rural areas, to participate.

Despite the advantages discussed earlier, some challenges and limitations were also experienced. We discuss these in the next sections.

3.7. Limited engagement with digital tools

A common disadvantage related to the use of video-calling platforms and other informatic systems is technological fatigue (Epstein, 2020). "Screen fatigue" was experienced by Emma, one of the participants. Tired of using laptop screens, a symptom also associated with her medical condition, Emma avoided online interaction, including that required for homeschooling. Although Emma had agreed to take part in the study, the online approach we offered was not appropriate for her. In agreement with her and her mum, we decided that the interviewing process would be 'mediated' and supported by her mum. Emma was not on screen but next to her mum while the main researcher and her mum spoke. While chatting, Emma's mum asked Emma the questions formulated by the main researcher. Emma's mother then shared her daughter's answers and comments with the main researcher.

Multiple encounters allowed the main researcher to know about Emma's preferences and needs, which informed the design of more targeted strategies to engage with her. Drawing on some visual prompts and emojis, a board game and a body map were designed by the main researcher to have a more insightful and direct account of Emma's experiences and views. Both tools were sent to her mother by email, who printed them out and helped Emma to complete them in person:

Email sent to Emma's mum [30 May 2022]:

'…Here you go… two things:

The first doc is a game - it is super easy to follow.

The second one is an emotion-body map I would like to try with Emma to see how she feels before and after COVID, we'll see if she likes it! (it was super effective in my PhD research).

You just need to print the docs out, get ready scissors, pencils, and glue, follow the instructions (also attached), and read the questions aloud for her. I wish I could do this in person!

Thank you for your help, let's see what Emma has to say! […]'

The completed game and body map were returned by email to the researcher afterwards.

Despite the benefits of online interviews for participants with mobility restrictions, the above example illustrates how remote research can also lead to participants' fatigue. Prolonged use of video platforms and other technologies are associated with negative impacts on health and wellbeing. These include eye fatigue, neck pain, stress, tiredness, difficulties concentrating, and irritability (Hilty et al., 2022). Technology fatigue and related symptoms are more likely to be experienced by people with long term conditions (Plow et al., 2020); as such, strategies should be put in place at the design stage by researchers to mitigate or address these risks. Involving some paper-based tasks such as the ones used with Emma can partially address the issue of technology fatigue. However, its implementation would need parents' or carers' support. It is also worth highlighting that regular movement and stretching breaks might also increase motivation and help release muscular tension associated with the use of IT tools (Lepp et al., 2022).

3.8. Digital divide

Virtual interviewing increases the risk of communities with limited access to communication technology and digital literacy to be excluded from research (Lussier-Desrochers et al., 2017). This is problematic as it can exacerbate research participation inequalities, accentuating exclusion of already marginalised communities (Keen et al., 2022). Aware of such limitations, we developed some strategies to reduce technological elitism. Alongside the online call for participation, an off-line recruitment strategy was implemented to allow people without access to the internet to know about the study. This entailed handing out flyers to people on the street, and leaving flyers at some small cafés, restaurants, and care centres across Edinburgh. Although this strategy sought to reach potential families who could have been missed by the online recruitment strategy, this approach was limited in terms of offering potential participants an offline way to talk about their experiences, since the methodological approach developed relied entirely on online methods.

Although an in-person approach might have increased the chances for people and families on low incomes and those without access to the internet to participate in the study, there are some ethical considerations to bear in mind. For example, and also in the context of carrying out research with families during the COVID-19 pandemic, Faircloth et al. (2022) raise questions about the ethics of inviting participants that may lack time or energy to participate in research, especially where there are no "immediate tangible benefits" (ibid, p.40) in taking part in a research project. In our study, this limitation was exacerbated by the limited amount of time over which the project needed to be carried out and the very small budget available to remunerate participants for taking part (each participant was given a £10 Amazon Voucher). One of the key findings of this project, reported back to the ALLIANCE, is indeed that a more generous budget needs to be made available to remunerate participants.

Although online qualitative researchers should consider how to minimise socioeconomic, age-related and digital skills disparities that limit communities from getting involved in research (Lomax et al., 2021; Rania et al., 2021; Shamsuddin, Sheikh, & Keers, 2021), some of these inequalities are structural, so difficult to address by the researchers.

4. Conclusion

This paper has presented our reflections and learning in relation to digital recruitment and interviewing (supported by creative-participatory tools) when doing research with young people experiencing different forms of disability.

In our literature review, we explored some of the gaps in knowledge around carrying out online qualitative research with disabled children and young people that our work seeks to address. With the onset of the COVID-19 pandemic, we showed that qualitative research has had to shift to the online world; we examined some of the approaches that researchers have adopted (using video call interviews and other creative approaches) both with adults and young people alike. However, we evidenced that disabled people, and children and young people who are disabled in particular, have not been fully included in online research. Further, if and when included, methods have not always been tailored or adapted to their needs and capabilities.

As such, our paper outlined Arias-Urueña's methodological framework, developed to ensure the meaningful participation of disabled children and young people in online qualitative research. This sought to address some of the limitations we identified around carrying out online qualitative research, predominantly: constraints for the development of researcher-participant rapport, ethical concerns, and being responsive to participants' needs and capabilities. Yet, as shown in the literature review and our findings and discussions section, there were several ways in which each of these could be addressed.

First, a move to online fieldwork pushes researchers out of our 'comfort zone', which encourages a recognition and reflection about the digital skills one already possesses, but that may be taken for granted. Equally, it encourages self-directed learning (e.g. through conversations with colleagues who are more versed in IT and digital skills) to ensure the smooth running of online research. Given some of the limitations imposed by carrying out research online, particularly around creating trust and rapport, it was of further importance to harness flexibility and creativity by being responsive to participants' needs and capabilities. This also required having a strong sense of confidence for one's own digital skills.

The issue of rapport construction was addressed by carrying out in-depth online interviews over the course of three encounters, and in a

way that was directed by participants as much as by the main researcher, for example, by allowing them to select the communication methods and platforms most suitable to them and scheduling encounters at times and dates that worked best for them.

Most significantly, perhaps, were our findings in relation to addressing our fears and concerns around ethics. Whilst there are still some significant considerations to be resolved around the digital divide (i.e. the participation of those with very limited connectivity and/or digital skills), we generally found that carrying out fieldwork online was particularly valuable to our target group. Given the lack of travel requirements, participants' digital abilities, and the flexibility offered by the different creative tools adopted, the approach developed by the main researcher was particularly suitable to a population that might have mobility restrictions and higher vulnerability to COVID-19 infection, and for whom in-person research would have thus been inaccessible. The approach also encourages participants' agency by being responsive to their needs and capabilities, addressing also the issue often encountered in disability studies of accessing disabled children's and young people's views by proxy through their parents or carers.

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