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Research behind a webcam: an exploration of virtual interviewing with children and young people.
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Corresponding Author:	Elizabeth Bichard, BSc (Hons), MRes, PhD Candidate London South Bank University London, UNITED KINGDOM
Other Authors:	Stephen McKeever, R.G.N, RN (Child), Dip.Trop.Nurse, ENB 415, BSc.(H
	Jo Wray, BSc, MSc, PhD, DHP(NC), C Psychol)
	Suzanne Bench, RGN, BSc (Hons), MSc Advanced Practice, Ph.D
Abstract:	Background Societal use of digital technology rapidly increased during the global Coronavirus disease 2019 pandemic. Face-to-face services converted to online provision, where possible. This affected many clinical academics undertaking research projects. Aim This paper explores conducting online research interviews with children and young people about sensitive topics. Discussion Digital inclusion, ethical issues surrounding safety, support and consent are considered, along with choice of data collection tools. A discussion on physical proximity in qualitative interviews with this population, and its role in data quality, is presented. Benefits in the context of researcher personal experience are also investigated. Disadvantages of online interviews are acknowledged and ways to mitigate these discussed. Conclusion Many researchers had to adapt data collection methods during the pandemic. Our experiences of conducting virtual interviews during this time are discussed. Advantages for researcher include cost-effectiveness, time efficiency and greater geographical reach of participants. However, children and young people's perspectives are unknown. Specific ethical issues using this method with children and young people need careful consideration Implications for practice More research is required on undertaking virtual interviews from the perspectives of children and young people as participants. Acquisition of virtual consent and assent should be investigated to standardised good research practices.
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Author Comments:	Elizabeth Bichard School of Health and Social Care London South Bank University 103 Borough Road London SE1 0AA bichare2@lsbu.ac.uk 07th July 2022 Dear Elizabeth Halcomb and the editorial board for Nurse Researcher. I am pleased to submit our updated submission of a methodology article for publication in Nurse Researcher; Research behind a webcam: an exploration of virtual interviewing with children and young people. Thank you for the opportunity to revise the document and for the reviewers helpful guidance, we appreciate this has improved the clarity of the article and extend our thanks. Thank you again for your consideration Sincerely, Elizabeth Bichard RN (Child), ENB 415, Dip.Trop.Nurse, BSc.(Hons), MRes, PhD Candidate.

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Abstract

Background

Societal use of digital technology rapidly increased during the global Coronavirus disease 2019 pandemic. Face-to-face services converted to online provision, where possible. This affected many clinical academics undertaking research projects.

Aim

This paper explores conducting online research interviews with children and young people about sensitive topics.

Discussion

Digital inclusion, ethical issues surrounding safety, support and consent are considered, along with choice of data collection tools. A discussion on physical proximity in qualitative interviews with this population, and its role in data quality, is presented. Benefits in the context of researcher personal experience are also investigated. Disadvantages of online interviews are acknowledged and ways to mitigate these discussed.

Conclusion

Many researchers had to adapt data collection methods during the pandemic. Our experiences of conducting virtual interviews during this time are discussed. Advantages for researcher include cost-effectiveness, time efficiency and greater geographical reach of participants. However, children and young people's perspectives are unknown. Specific ethical issues using this method with children and young people need careful consideration

Implications for practice

More research is required on undertaking virtual interviews from the perspectives of children and young people as participants. Acquisition of virtual consent and assent should be investigated to standardised good research practices.

Introduction

Globally the Coronavirus disease 2019 (COVID-19) pandemic created an urgent need for society to navigate digital technology (Drouin et al. 2020). Face-to-face contact has been discouraged in an era of physical distancing, national and regional lockdowns and social isolation for many (Atalan 2020, The Lancet Public Health 2020). Due to COVID-19's rapidly changing viral spread, there have also been frequent adaptations to advice given in relation to public safety, thus making undertaking research challenging (Clifford et al. 2021).

During the pandemic, digital platforms have provided researchers an opportunity to maintain contact with participants and continue data collection (Hensen et al. 2021). However, researchers needed to quickly adapt and consider ethical challenges, costs and impact on the research process itself (Halliday et al. 2021, Hensen et al. 2021).

This paper discusses issues of online data collection within the context of the experience of a doctoral student undertaking virtual interviews via Zoom (Zoom Video Communications, Inc., San Jose). The heArt sibLings imPact Study (ALPS) involved interviewing healthy children aged 8-17 years old, whose sibling has congenital heart disease (CHD).

Background

Worldwide, use of technology among children and families increased during the COVID-19 pandemic (Drouin et al. 2020, Ting et al. 2020). Many countries, including the United Kingdom (UK), utilised technology to communicate information about virus transmission, contact tracing, symptom recognition and isolation requirements (Whitelaw et al. 2020). Health, education and business also migrated services online (Department of Education 2020). This change to a virtual world resulted in families needing to possess a variety of skills, competencies, and resources related to increased technology (Iivari et al. 2020).

Digital inclusion

Research projects aim to gather data which are representative of a wider population. This was true of ALPS. Digital inclusion aims to promote participation, empowerment, open and available access to society (Iivari et al. 2020). However, not everyone may be able to access and utilise digital technologies or acquire skills associated with safe and effective use (Morganti et al. 2014). Not having access to a computer or education related to digital technology can further the divide in social and health inequalities (Borg et al. 2019). Social, economic, cultural influences, values and beliefs all define capacity to be included (Vial 2019). Families who commonly engage with health and wellbeing services benefit most from services offered online (European Commission 2010). This is also likely to be true for

research participation, but it is important to avoid excluding participants when using digital technology to collect data (Iivari et al. 2018).

Access and acquisition of digital skills are not equitable in society and research participants and their parents may be concerned that online interviews require them to have advanced technology skills (Lamberti et al. 2021). Researchers need to acknowledge possible technical difficulties and ensure they have skills to mitigate these and support participants to troubleshoot problems (Rowe et al. 2014, Weller 2017).

Internet access is an important factor in achieving inclusion, in research and more widely (Hokke et al. 2018). Children without internet at home might normally be able to gain access at school, local libraries or children's centres but during the pandemic these settings were closed (Beaunoyer et al. 2020). In 2019, 700,000 children between 11-18 years old reported no internet access from home via a tablet, laptop or desktop and a further 60,000 children reported having no internet access at all in their home (Office for National Statistics 2019). Attainability of adequate internet signal strength may have changed with many more devices in the home used whilst parents and children navigate working at home (Kassab and Darabkh 2020).

Availability of a computer or laptop also needs consideration. An estimated 9% of UK families do not have a laptop, desktop or tablet at home (Vibert 2020). This translates to approximately 1.14 to 1.78 million children (Ofcom 2019). Many estimates of computer ownership and internet access were obtained prior to the pandemic, these figures may, therefore, be interpreted in the context of increased austerity.

A scoping review by Hokke et al. (2018) reported that the internet had been used successfully for many research projects with children and families. However, concern was expressed in some included articles about introducing bias due to digital divide (Gunasekaran et al. 2015). In contrast, other articles stated that online recruitment provided a representative sample and enabled researchers to access geographically dispersed, isolated or stigmatised groups (Hokke et al. 2018). The review concluded that participant diversity from online recruitment was similar to that found from offline recruitment (Hokke et al. 2018). Other researchers support this outlook, viewing online platforms for recruitment and data collection as positive when working with young people, as it can be difficult to engage young people in offline research projects (Gibson 2020, Mason and Ide 2014).

Participation in ALPS required parents to make contact via email after seeing a digital advert or promotion. Therefore, parents needed to be active on social media platforms or registered online with charities and have access to email. Interviewees needed to have access to a smart phone or computer with a webcam to be included, but as many families had seen

digital adverts for ALPS, they all had access to these devices. Timing of ALPS meant that many parents and children were working or being educated virtually so workplaces and schools had allocated some resources to provide devices to maintain contact remotely. Quality of internet connection was variable but only two interviews were severely interrupted. Frequent interruptions interrupted flow and added to overall interview time which potentially increased participant burden.

<u>Virtual Platforms</u>

Zoom is a user-friendly platform and has been used for school, business and in other research studies (Daniels et al. 2019, Lobe et al. 2020, Matthews et al. 2018, Oliffe et al. 2021). Using Zoom was a safe way to interview children for ALPS in view of the end-to-end encryption. Virtual interviews were not recorded through Zoom, but audio was captured on a Dictaphone. We were familiar with Zoom and had received some training on how to use it, making technical support for participants easier. Use of a one-click link made access to the virtual interview easier, participants did not have to download software or sign up to a service and share their contact information.

From a researcher's perspective, Zoom's share screen function was particularly useful for consent and assent as the child, parent and researcher could view forms together ensuring an opportunity for children to be actively involved in the decision-making process and be equipped with as much information as their parents (Coyne et al. 2014, Gaillard et al. 2018, Oulton et al. 2016).

Video interview platforms do not appear to dissuade adults and adolescents from participating in research (Seitz 2016, Shapka et al. 2016). Many participants have reported enjoyment in using virtual interviews (Oliffe et al. 2021). A preference for Zoom over other video interviewing platforms is also reported by both researchers and adult participants in a study by Archibald et al. (2019). Experience from ALPS suggests it is also appropriate for use with children and young people.

<u>Safety and Support</u>

Initially ALPS interviews were planned as face to face, data collection was due to begin just as the pandemic began. Therefore, ethical amendments were required to interview children virtually. Limited evidence suggests that video interviews with children are a pragmatic reproduction of a traditional technique rather than a distinct methodological practice (Gray et al. 2020). Virtual interviews with children pose additional ethical considerations, coupled with the opinion of some that face to face interviews are gold standard practice (Weller 2017).

Conducting virtual interviews avoided the research process being delayed. However, it was vital that children could still be kept safe, have their data protected, privacy respected, and their support needs met (Vaughn et al. 2020). To ensure safety of participants the ethics board required clear information about processes in place to protect and support children during and after their interview.

Privacy for children during their interview was explicit in information sheets and in correspondence with parents prior to interview. This was important to ensure children could speak freely without being concerned about the impact of their experiences on other members of the family (Morgan 2014). However, it did represent an ethical issue in relation to support for children if they became distressed. To overcome this concern parents were requested to be available at beginning and end of the interview. A follow up email was sent to check in with parents about their child and offer support services if required.

It was evident that some siblings were not alone during their interview, and some parents interrupted their child's narrative to add things they thought were important. One sibling showed and introduced their family who were in the same room, whilst another had to keep moving around their house to find a quiet space and was frequently interrupted by their sibling with CHD. Participants who were interrupted or overheard may have been reluctant to answer certain questions through fear of upsetting their family members.

Despite average UK households having 2-3 people there are still 162,900 households where seven or more people are residing in one house. Insisting on privacy as a mandatory aspect of interview could be used for future work but this may exclude participants who do not have physical space for privacy within their homes.

Information and Consent

In common law children over 16 years old are recognised as able to independently make informed decisions (Health Research Authority 2018). There is an absence of common law in England, Wales, or Northern Ireland about a child's right to consent to take part in research which is not a clinical trial of an investigational medicinal product. However, there is recognition that if a child younger than 16 years old can demonstrate maturity, understanding of risks and potential benefits they can be classed as 'Gillick' competent and may consent or refuse to participate (Griffith 2021). In the interests of protecting children, any decisions where consent is required are taken by parents/guardians but this may have an unintended effect of absolving children in the decision making process (Kennan and Dolan 2017). It is important to prioritise children's understanding, respect their decision and gain meaningful assent (Oulton et al. 2016).

For ALPS one difficulty was ensuring that children had adequate opportunity to review information prior to agreeing to take part. A YouTube video, accessible by a Quick Response (QR) code was developed to supplement age-appropriate information sheets sent via parental email. Despite this YouTube video being an aspect of inclusive research practice, it was even more useful in light of pandemic restrictions when virtual researcher contact with children was limited to interview day (McInroy 2017, Parsons 2015).

In an article by Lobe et al. (2020) options of obtaining online consent are briefly discussed but this doesn't specifically relate to children. Information guiding researchers about how best to obtain digital consent and assent from children and young people in line with good research practice guidance is lacking. In ALPS, families were sent printed copies of consent forms, which were reviewed together online before the interview started. A screenshot of signed consent forms was taken, and a self-addressed envelope provided for families to return signed paper forms. All completed consent forms were returned by post, so a self-addressed envelope with paid postage was an efficient method to obtain written consent.

Data collection tools

ALPS online interviews included use of the Pictorial Representation of Illness and Self Measure (PRISM) used widely in adult and paediatric studies to assess burden of suffering (Büchi et al. 2002, Melbardis Jørgensen and Jemec 2011, Sensky and Büchi 2016). It has been used among individuals who experience personal or vicarious suffering to provide a quantitative value termed the Self Illness Separation (SIS) score (Sensky and Büchi 2016). The SIS measurement is obtained by measuring distance between the illness circle and self-circle (From the centre of both circles) to generate a measurement to reflect suffering, lower measurement suggest higher suffering (Sensky and Büchi 2016). It has also been used as a visual summary to open up discussion about how things could change or to identify specific issues related to the illness (Büchi and Sensky 1999). This was its purpose in ALPS.

Traditionally this tactile tool uses a white plastic board and two-coloured circles to facilitate an open discussion about the impact of CHD on siblings. Children illustrated their perceived burden by marking the distance between two circles, one representing themselves and another representing their sibling's CHD. An application for Apple smart phones was created to use the PRISM (Sensky and Büchi 2016). Other published research supporting or guiding its use in an online format could not be located. To decide how best to use this tool in a virtual interview a range of options were considered (Table 1).

Table 1 - Options to use PRISM via a virtual platform.

Options	Advantages	Disadvantages
Email Emailing a word document and use the screen share function. A screenshot or a copy by email could be requested.	Email is instant if other methods fail.	Reliant on family to email a copy.
Online application Using a PRISM application on their personal device and then sharing a screenshot of completed PRISM.	Keeps everything electronic rather than handling paper.	Requires family to download an application. Excludes Android users, Application only available through Apple. Reliant on the sibling or parent emailing a screenshot of their app. More difficult to show researcher completed PRISM if using their phone for the video interview.
Posted Posting a blank PRISM, printed on A4 paper, and sending a coloured sticker. Include a stamped addressed envelope.	Available for the interview without the family having to prepare anything. Easy and no cost, self-addressed envelope is provided.	May be unable to return by post if shielding or self-isolating.

The options in Table One were explored during practice interviews with children of the same age. These interviews revealed that older children found it easier to navigate virtual methods of using PRISM than younger children, but it took more time to explain its use virtually. During our pilot there were also difficulties explaining the process on different devices. Younger children found it easier to use a printed PRISM and a sticker and this generated more discussion about why they placed their sibling's illness circle in a specific position.

A final decision was made to use a printed PRISM with a sticker (Posted option) as a first choice and this worked well. Having something tactile to use during interviews helped open conversation and appeared to hold children's interest. Stickers that were sent out were green, but participants were asked what colour they thought it should be, was it the right size, how did they find completing the exercise. Sometimes their paper PRISM had not arrived via post by interview day, so a virtual method (Email option) was used instead.

<u>Lack of physical proximity</u>

When undertaking interviews about sensitive topics it is important to develop a good rapport which may also impact data quality (Roulston 2019, Weller 2017). Based on interviews with adults, researchers report that being physically distant but feeling virtually together enables participants to feel able to open up and communicate feelings and experiences (Archibald et al. 2019, Oliffe et al. 2021).

Experience from ALPS suggests it was possible to convey empathy and warmth virtually but was significantly more difficult than doing so face to face. Concurrent with our observations, lack of proximity required for rapport building has been recognised amongst other researchers as a criticism during online interviews (Seitz 2016).

Communication science details a holistic perspective which recognises the role of verbal and non-verbal communication. Work by Mehrabian (2017) describes spoken words as 7% of a communication transaction the way in which words are relayed accounts for 38% and facial expressions comprise 55%. In the context of video interviewing most facial expressions can be observed if an internet connection is stable but, sometimes what is behind the webcam cannot be captured (Archibald et al. 2019). Importance of posture and position has also been described by Mehrabian (2017) and is something which cannot be observed fully during a virtual interview.

During ALPS interviews managing periods of technical disruption or supporting a child experiencing strong emotions proved challenging during virtual interviews. During face to face interviews if a participant becomes distressed physical gestures such as providing water or tissues are supportive. Moving closer or further away from the participant

depending on their body language can be comforting for a participant. None of this is possible virtually.

Children are not digitally naïve, especially during an era where schoolwork is completed on virtual platforms (Iivari et al. 2020). This sometimes led to boredom or distraction during ALPS interviews especially with younger children. Trying to regain children's focus sometimes meant that the same question needed to be asked in a different way or the topic changed to afford more focus, returning to unanswered questions at a later point. Subtle nuances in question structure are important in adapting an interview guide to an individual participant and this relies on skill and experience of an interviewer (DeJonckheere and Vaughn 2019, McGrath et al. 2019).

Benefits of video interviewing with children.

Video interviewing is cost effective, reducing travel costs for families and researchers (Archibald et al. 2019). Greater capture of participants across a wider geographical area also enables inclusion of participants who may not find it easy to travel (Gray et al. 2020). The COVID-19 pandemic meant more families were at home and often more available; all those interviewed for ALPS were available at the pre-arranged time.

 Another positive aspect of video interviewing is an ability for children to share their environment: pets, family members or toys that are special to them. This facilitated an open discussion and encouraged a friendly introduction, which likely led to children feeling more relaxed and building rapport (Gray 2020). Having an insight into a child's environment and being shown things of interest sparked captivating discussion. This helped demonstrate value children placed on objects, increasing our understanding of how these things helped and facilitated questions related to their sibling with CHD, in the context of their environment e.g., 'How do you feel when your sister helps you build with Lego? What happens to your den when you have to stay with Nan if your sister goes in hospital?'.

Areas for future research

Insights are based on one team's experience of undertaking research with children using Zoom. Future research should focus on how children experience using virtual platforms for interviews. It would be advantageous to understand more about designing research projects involving children which solely focus on online platforms for data collection. More information on gaining online consent and assent from children would be advantageous to ensure standardised good research practice.

Conclusion

Pandemic restrictions resulted in many researchers experiencing disruption to their research projects. Navigating these challenges in the face of wider ethical issues associated with research with children about sensitive topics, makes examples from our study important to share. Benefits of virtual interviews for researchers are clear but how children feel about being interviewed online remains unknown.

Declaration of conflicting interests: The Authors declare that there is no conflict of interest.

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Elizabeth Bichard, Stephen McKeever, Jo Wray, Suzanne Bench

Abstract

Background

Societal use of digital technology rapidly increased during the global Coronavirus disease 2019 pandemic. Face-to-face services converted to online provision, where possible. This affected many clinical academics undertaking research projects.

Aim

This paper explores conducting online research interviews with children and young people about sensitive topics.

Discussion

Digital inclusion, ethical issues surrounding safety, support and consent are considered, along with choice of data collection tools. A discussion on physical proximity in qualitative interviews with this population, and its role in data quality, is presented. Benefits in the context of researcher personal experience are also investigated. Disadvantages of online interviews are acknowledged and ways to mitigate these discussed.

Conclusion

Many researchers had to adapt data collection methods during the pandemic. Our experiences of conducting virtual interviews during this time are discussed. Advantages for researcher include cost-effectiveness, time efficiency and greater geographical reach of participants. However, children and young people's perspectives are unknown. Specific ethical issues using this method with children and young people need careful consideration

Implications for practice

More research is required on undertaking virtual interviews from the perspectives of children and young people as participants. Acquisition of virtual consent and assent should be investigated to standardised good research practices.

Introduction

Globally the Coronavirus disease 2019 (COVID-19) pandemic created an urgent need for society to navigate digital technology (Drouin et al. 2020). Face-to-face contact has been discouraged in an era of physical distancing, national and regional lockdowns and social isolation for many (Atalan 2020, The Lancet Public Health 2020). Due to COVID-19's rapidly changing viral spread, there have also been frequent adaptations to advice given in relation to public safety, thus making undertaking research challenging (Clifford et al. 2021).

Digital uring the pandemic, digital platforms have provided researchers an opportunity to maintain contact with participants and continue data collection (Hensen et al. 2021). However, researchers needed to quickly adapt and consider ethical challenges, costs and impact on the research process itself (Halliday et al. 2021, Hensen et al. 2021).

This paper discusses issues of online data collection within the context of the experience of a doctoral student undertaking virtual interviews via Zoom (Zoom Video Communications, Inc., San Jose). The heArt sibLings imPact Study (ALPS) involved interviewing healthy cChildren and Young People (CYP) aged 8-17 years old, whose sibling has congenital heart disease (CHD). Definitions of 'Children' and 'Young people' vary but we have followed the United Nations guidance and term 'children' aged 8-14 years and 'young people' 15-17 years old (United Nations 2022).

Background

Worldwide, use of technology among CYP children and families increased during the COVID-19 pandemic (Drouin et al. 2020, Ting et al. 2020). Many countries, including the United Kingdom (UK), utilised technology to communicate public health information about virus transmission, contact tracing, symptom recognition and isolation requirements (Whitelaw et al. 2020). Health, education and business also migrated services online (Department of Education 2020). This change to a virtual world resulted in families needing to possess a variety of skills, competencies, and resources related to increased technology (Iivari et al. 2020).

Digital inclusion

Research projects aim to gather data which are representative of a wider population. This was true of ALPS. Digital inclusion aims to promote participation, empowerment, open and available access to society (Iivari et al. 2020). However, not everyone may be able to access and utilise digital technologies or acquire skills associated with safe and effective use (Morganti et al. 2014). Not having access to a computer or education related to digital technology can further the divide in social and health inequalities (Borg et al. 2019). Social,

economic, cultural influences, values and beliefs all define capacity to be included (Vial 2019). Families who commonly engage with health and wellbeing services benefit most from services offered online (European Commission 2010). This is also likely to be true for research participation, but it is important to avoid excluding participants when using digital technology to collect data (Iivari et al. 2018).

RAccess and acquisition of digital skills are not equitable in society and research participants and their parents may be concerned that online interviews require them to have advanced technology skills (Lamberti et al. 2021). Researchers need to acknowledge possible technical difficulties and ensure they have skills to mitigate these and support participants to troubleshoot problems (Rowe et al. 2014, Weller 2017).

Internet access is an important factor in achieving inclusion, in research and more widely (Hokke et al. 2018). CYP Children without internet at home can might normally be able to gain access at school, local libraries or children's centres but during the pandemic these settings were closed (Beaunoyer et al. 2020). In 2019, 700,000 CYP children between 11-18 years old reported no internet access from home via a tablet, laptop or desktop and a further 60,000 CYP children reported having no internet access at all in their home (Office for National Statistics 2019). Attainability of adequate internet signal strength may have changed with many more devices in the home used whilst parents and CYPchildren navigate working at home (Kassab and Darabkh 2020).

Availability of a computer or laptop also needs consideration. An estimated 9% of UK families do not have a laptop, desktop or tablet at home (**Error! Hyperlink reference not valid.**). This translates to approximately 1.14 to 1.78 million children (**Error! Hyperlink reference not valid.**). Many estimates of computer ownership and internet access were obtained prior to the pandemic, these figures may, therefore, be interpreted in the context of increased austerity.

A scoping review by Hokke et al. (2018) reported that the internet had been used successfully for many research projects with CYP children and families. However, concern was expressed in some included articles about introducing bias due to digital divide (Gunasekaran et al. 2015). In contrast, other articles stated that online recruitment provided a representative sample and enabled researchers to access geographically dispersed, isolated or stigmatised groups (Hokke et al. 2018). The review concluded that participant diversity from online recruitment was similar to that found from offline recruitment (**Error! Hyperlink reference not valid.**) Other researchers support this outlook, viewing online platforms for recruitment and data collection as positive when working with young people, as

it can be difficult to engage them~~young people~~ in offline research projects (Gibson 2020, Mason and Ide 2014).

Participation in ALPS required parents to make contact ~~via email~~ after seeing a digital advert ~~or promotion~~. Therefore, parents needed to be active on social media ~~platforms~~ or registered online with charities and have access to email. Interviewees needed to have access to a smart phone or computer with a webcam to be included, but as many families had seen digital adverts for ALPS, they all had access to these devices. Timing of ALPS meant that many parents and CYP ~~children~~ were working or being educated virtually so workplaces and schools had allocated some resources to provide devices to maintain contact remotely. Quality of internet connection was variable but only two interviews were severely interrupted. Despite these interruptions, we reconnected and continued the interview. Although these interviews took longer, participants appeared happy to continue, and review missed questions.

~~interview. Although theseappeared Frequent interruptions interrupted flow and added to overall interview time which potentially increased participant burden.~~

Virtual Platforms

Zoom is a user-friendly platform and has been used for school, business and in other research studies (Daniels et al. 2019, Lobe et al. 2020, Matthews et al. 2018, Oliffe et al. 2021). Using Zoom was a safe way to interview CYP~~children~~ for ALPS in view of the end-to-end encryption. Virtual interviews were not recorded through Zoom, but audio recorded ~~was captured~~ on a Dictaphone. We were familiar with Zoom and had received some training, ~~on how to use it,~~ making technical support for participants easier. Use of a one-click link made access ~~to the virtual interview~~ easier, participants did not have to download software or sign up to a service and share their contact information.

From a researcher's perspective, Zoom's share screen function was particularly useful for consent and assent as the child, parent and researcher could view forms together ensuring an opportunity for CYP~~children~~ to be actively involved in the decision-making process and be equipped with as much information as their parents (Coyne et al. 2014, Gaillard et al. 2018, Oulton et al. 2016).

Video interview platforms do not appear to dissuade adults and adolescents from participating in research (Seitz 2016, Shapka et al. 2016). Many participants have reported enjoyment in using virtual interviews (Oliffe et al. 2021). A preference for Zoom over other video interviewing platforms is also reported by both researchers and adult participants in a

study by Archibald et al. (2019). Experience from ALPS suggests it is also appropriate for use with CYPchildren and young people.

<u>Safety and Support</u>

Initially ALPS interviews were planned as face to face, data collection was due to begin just as the pandemic began. Therefore, ethical amendments were required to interview CYPchildren virtually. Limited evidence suggests that video interviews with children are a pragmatic reproduction of a traditional technique rather than a distinct methodological practice (Gray et al. 2020). Virtual interviews with CYPchildren pose additional ethical considerations, coupled with the opinion of some that face to face interviews are gold standard practice (Weller 2017).

Conducting virtual interviews avoided delays.the research process being delayed. However, it was vital that CYPchildren could still be kept safe, have their data protected, privacy respected, and their support needs met (Vaughn et al. 2020). To ensure safety of participants the ethics board required clear information about processes in place to protect and support CYP children during and after their interview.

Privacy for CYPchildren during their interview was explicit in information sheets and in correspondence with parents prior to interview. This was important to ensure CYPchildren could speak freely without being concerned about the impact of their experiences on other members of the family (Morgan 2014). However, it did represent an ethical issue in relation to support for CYPchildren if they became distressed. To overcome this concern parents were requested to be available at beginning and end of the interview. A follow up email was sent to check in with parents about their child and offer support services if required.

It was evident that some siblings were not alone during their interview, and some parents interrupted their child's narrative to add things they thought were important. One sibling showed and introduced their family who were in the same room, whilst another had to keep moving around their house to find a quiet space and was frequently interrupted by their sibling with CHD. Participants who were interrupted or overheard may have been reluctant to answer certain questions through fear of upsetting their family members. The extent to which this happened and its impact on the interviews was difficult to tell.

Despite average UK households having 2-3 people there are still 162,900 households where seven or more people are residing in one house. Insisting on privacy as a mandatory aspect of interview could be used for future work but this may exclude participants who do not have physical space for privacy within their homes.

<u>Information and Consent</u>

In common law children over 16 years old are recognised as able to independently make informed decisions (Health Research Authority 2018). There is an absence of common law in England, Wales, or Northern Ireland about a child's right to consent to take part in research which is not a clinical trial of an investigational medicinal product. However, there is recognition that if a child younger than 16 years old can demonstrate maturity, understanding of risks and potential benefits they can be classed as 'Gillick' competent and may consent or refuse to participate (Griffith 2021). In the interests of protecting CYP~~children~~, any decisions where consent is required are taken by parents/guardians but this may have an unintended effect of absolving CYP~~children~~ in the decision making process (Kennan and Dolan 2017). It is important to prioritise CYP's~~children's~~ understanding, respect their decision and gain meaningful assent (Oulton et al. 2016). Prioritising participants understanding was paramount when creating information sheets, therefore separate child, young persons, and adult information sheets were developed in addition to parent information. Adult information sheets were for participants who could provide sole consent. Children's information sheets were constructed in a question and colourful speech bubble format with fewer written words, see Figure 1. A photo of the researcher (EB) was also included with a short explanation about why this research was important.
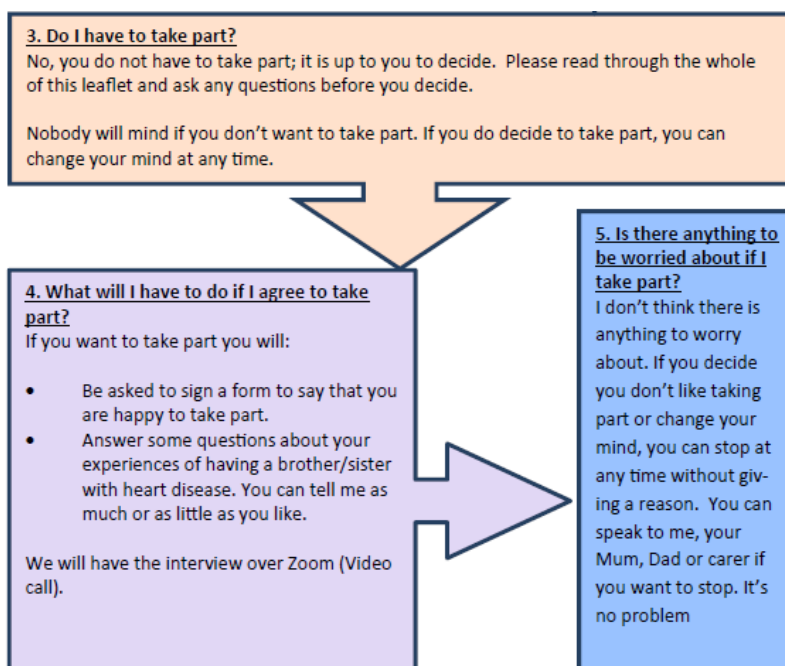
3. Do I have to take part?
No, you do not have to take part; it is up to you to decide. Please read through the whole of this leaflet and ask any questions before you decide.

Nobody will mind if you don't want to take part. If you do decide to take part, you can change your mind at any time.

4. What will I have to do if I agree to take part?
If you want to take part you will:

- Be asked to sign a form to say that you are happy to take part.
- Answer some questions about your experiences of having a brother/sister with heart disease. You can tell me as much or as little as you like.

We will have the interview over Zoom (Video call).

5. Is there anything to be worried about if I take part?
I don't think there is anything to worry about. If you decide you don't like taking part or change your mind, you can stop at any time without giving a reason. You can speak to me, your Mum, Dad or carer if you want to stop. It's no problem

Figure 1 - Excerpt from the ALPS children's information sheet.

Young peoples and adult information sheets also used ~~were in~~ a question-and-answer structure ~~too~~ but were less colourful and ~~used~~ included more adult appropriate and professional language.

For ALPS one difficulty was ensuring that CYP~~children~~ had adequate opportunity to review information prior to agreeing to take part. A YouTube video, accessible by a Quick Response (QR) code was developed to supplement age-appropriate information sheets sent via parental email. Despite this YouTube video being an aspect of inclusive research practice, it was even more useful in light of pandemic restrictions when virtual researcher contact with CYP~~children~~ was limited to interview day (McInroy 2017, Parsons 2015).

In an article by Lobe et al. (2020) options of obtaining online consent are briefly discussed but this doesn't specifically relate to CYP~~children~~. Information guiding researchers about how best to obtain digital consent and assent from CYP ~~children and young people~~ in line with good research practice guidance is lacking. In ALPS, families were sent printed copies of consent forms, which were reviewed together online before the interview started. A screenshot of signed consent forms was taken, and a self-addressed envelope provided for families to return signed paper forms. All completed consent forms were returned by post, so a self-addressed envelope with paid postage was an efficient method to obtain written consent.

Data collection tools

ALPS online interviews included use of the Pictorial Representation of Illness and Self Measure (PRISM) used widely in adult and paediatric studies to assess burden of suffering (Büchi et al. 2002, Melbardis Jørgensen and Jemec 2011, Sensky and Büchi 2016). It has been used among individuals who experience personal or vicarious suffering to provide a quantitative value termed the Self Illness Separation (SIS) score (Sensky and Büchi 2016). The SIS measurement is obtained by measuring distance between the illness circle and self-circle (From the centre of both circles) to generate a measurement to reflect suffering, lower measurement suggest higher suffering (Sensky and Büchi 2016). It has also been used as a visual summary to open up discussion about how things could change or to identify specific issues related to the illness (Büchi and Sensky 1999). This was its purpose in ALPS.

Traditionally this tactile tool uses a white plastic board and two-coloured circles to facilitate an open discussion about the impact of CHD on siblings. CYP ~~Children~~ illustrated their perceived burden by marking the distance between two circles, one representing themselves and another representing their sibling's CHD. An application for Apple smart phones was created to use the PRISM (Sensky and Büchi 2016). Other published research supporting or

guiding its use in an online format could not be located. To decide how best to use this tool in a virtual interview a range of options were considered (Table 1).

Table 1 - Options to use PRISM via a virtual platform.

Options	Advantages	Disadvantages
Email Emailing a word document and use the screen share function. A screenshot or a copy by email could be requested.	Email is instant if other methods fail.	Reliant on family to email a copy.
Online application Using a PRISM application on their personal device and then sharing a screenshot of completed PRISM.	Keeps everything electronic rather than handling paper.	Requires family to download an application. Excludes Android users, Application only available through Apple. Reliant on the sibling or parent emailing a screenshot of their app. More difficult to show researcher completed PRISM if using their phone for the video interview.
Posted Posting a blank PRISM, printed on A4 paper, and sending a coloured sticker. Include a stamped addressed envelope.	Available for the interview without the family having to prepare anything. Easy and no cost, self-addressed envelope is provided.	May be unable to return by post if shielding or self-isolating.

The options in Table One were explored during practice interviews with CYPchildren of the same age. These interviews revealed that young people older children found it easier to navigate virtual methods of using PRISM than childrenyounger children, but it took more time to explain its use virtually. During our pilot there were also difficulties explaining the process on different devices. Children Younger children found it easier to use a printed PRISM and a sticker and this generated more discussion about why they placed their sibling's illness circle in a specific position.

A final decision was made to use a printed PRISM with a sticker (Posted option) as a first choice, see figure 2. and this worked well. Having something tactile to use during interviews helped open conversation and appeared to hold CYP's children's interest. Stickers that were sent out were green, but participants were asked what colour they thought it should be, was it the right size, how did they find completing the exercise. Sometimes their paper PRISM had not arrived via post by interview day, so a virtual method (Email option) was used instead.

Where would you put the sticker representing your brother/sisters heart condition to show its place in your life at the moment?
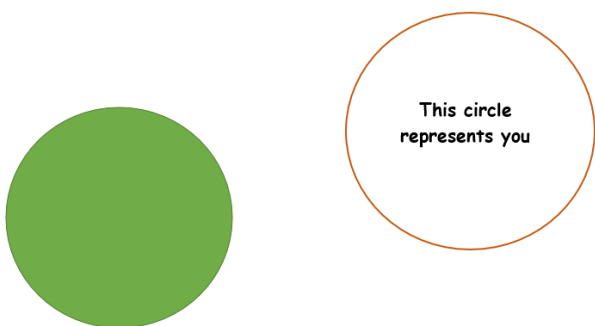
This circle represents you

Figure 2 - Example of a completed PRISM

<u>Lack of physical proximity</u>

When undertaking interviews about sensitive topics it is important to develop a good rapport which may also impact data quality (Roulston 2019, Weller 2017). Based on interviews with adults, researchers report that being physically distant but feeling virtually together enables participants to feel able to open up and communicate feelings and experiences (Archibald et al. 2019, Oliffe et al. 2021).

Experience from ALPS suggests it was possible to convey empathy and warmth virtually but was significantly more difficult than doing so face to face. Concurrent with our observations, lack of proximity required for rapport building has been recognised amongst other researchers as a criticism during online interviews (Seitz 2016).

Communication science details a holistic perspective which recognises the role of verbal and non-verbal communication. Work by Mehrabian (2017) describes spoken words as 7% of a communication transaction the way in which words are relayed accounts for 38% and facial expressions comprise 55%. In the context of video interviewing most facial expressions can be observed if an internet connection is stable but, sometimes what is behind the webcam cannot be captured (Archibald et al. 2019). Importance of posture and position has also been described by Mehrabian (2017) and is something which cannot be observed fully during a virtual interview.

During ALPS interviews managing periods of technical disruption or supporting a child experiencing strong emotions proved challenging during virtual interviews. During face-to-face interviews if a participant becomes distressed physical gestures such as providing water or tissues are supportive. Moving closer or further away from the participant depending on their body language can be comforting for a participant. None of this is possible virtually.

CYPChildren are not digitally naïve, especially during an era where schoolwork is completed on virtual platforms (Iivari et al. 2020). This sometimes led to boredom or distraction during ALPS interviews especially with younger children. Trying to regain children's focus sometimes meant that the same question needed to be asked in a different way or the topic changed to afford more focus, returning to unanswered questions at a later point. Subtle nuances in question structure are important in adapting an interview guide to an individual participant and this relies on skill and experience of an interviewer (DeJonckheere and Vaughn 2019, McGrath et al. 2019).

<u>Benefits of video interviewing with children and young people.</u>

Video interviewing is cost effective, reducing travel costs for families and researchers (Archibald et al. 2019). Greater capture of participants across a wider geographical area also enables inclusion of participants who may not find it easy to travel (Gray et al. 2020). The COVID-19 pandemic meant more families were at home and often more available; all those interviewed for ALPS were available at the pre-arranged time.

Another positive aspect of video interviewing is an ability for CYPchildren to share their environment: pets, family members or toys that are special to them. This facilitated an open discussion and encouraged a friendly introduction, which likely led to CYPchildren feeling more relaxed and building rapport (Gray 2020). Having an insight into a child's environment and being shown things of interest sparked captivating discussion. This helped demonstrate value CYPchildren placed on objects, increasing our understanding of how these things helped and facilitated questions related to their sibling with CHD, in the context of their environment e.g., 'How do you feel when your sister helps you build with Lego? What happens to your den when you have to stay with Nan if your sister goes in hospital?'.

Areas for future research

Insights are based on one team's experience of undertaking research with CYPchildren using Zoom. Future research should focus on how CYPchildren experience using virtual platforms for interviews. It would be advantageous to understand more about designing research projects involving CYPchildren which solely focus on online platforms for data collection. More information on gaining online consent and assent from CYPchildren would be advantageous to ensure standardised good research practice.

Conclusion

Pandemic restrictions resulted in many researchers experiencing disruption to their research projects. Navigating these challenges in the face of wider ethical issues associated with research with CYPchildren about sensitive topics, makes examples from our study important to share. Benefits of virtual interviews for researchers are clear but how CYPchildren feel about being interviewed online remains unknown.

Declaration of conflicting interests: The Authors declare that there is no conflict of interest.

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Research behind a webcam: an exploration of virtual interviewing with children and young people.

Elizabeth Bichard, Stephen McKeever, Jo Wray, Suzanne Bench

Abstract

Background

Societal use of digital technology rapidly increased during the global Coronavirus disease 2019 pandemic. Face-to-face services converted to online provision, where possible. This affected many clinical academics undertaking research projects.

Aim

This paper explores conducting online research interviews with children and young people about sensitive topics.

Discussion

Digital inclusion, ethical issues surrounding safety, support and consent are considered, along with choice of data collection tools. A discussion on physical proximity in qualitative interviews with this population, and its role in data quality, is presented. Benefits in the context of researcher personal experience are also investigated. Disadvantages of online interviews are acknowledged and ways to mitigate these discussed.

Conclusion

Many researchers had to adapt data collection methods during the pandemic. Our experiences of conducting virtual interviews during this time are discussed. Advantages for researcher include cost-effectiveness, time efficiency and greater geographical reach of participants. However, children and young people's perspectives are unknown. Specific ethical issues using this method with children and young people need careful consideration

Implications for practice

More research is required on undertaking virtual interviews from the perspectives of children and young people as participants. Acquisition of virtual consent and assent should be investigated to standardised good research practices.

Introduction

Globally the Coronavirus disease 2019 (COVID-19) pandemic created an urgent need for society to navigate digital technology (Drouin et al. 2020). Face-to-face contact has been discouraged in an era of physical distancing, national and regional lockdowns and social isolation for many (Atalan 2020, The Lancet Public Health 2020). Due to COVID-19's rapidly changing viral spread, there have also been frequent adaptations to advice given in relation to public safety, thus making undertaking research challenging (Clifford et al. 2021).

Digital platforms have provided researchers an opportunity to continue data collection (Hensen et al. 2021). However, researchers needed to quickly adapt and consider ethical challenges, costs and impact on the research process itself (Halliday et al. 2021, Hensen et al. 2021).

This paper discusses issues of online data collection within the context of the experience of a doctoral student undertaking virtual interviews via Zoom (Zoom Video Communications, Inc., San Jose). The heArt sibLings imPact Study (ALPS) involved interviewing healthy Children and Young People (CYP) aged 8-17 years old, whose sibling has congenital heart disease (CHD). Definitions of 'Children' and 'Young people' vary but we have followed the United Nations guidance and term 'children' aged 8-14 years and 'young people' 15-17 years old (United Nations 2022).

Background

Worldwide, use of technology among CYP and families increased during the COVID-19 pandemic (Drouin et al. 2020, Ting et al. 2020). Many countries, including the United Kingdom (UK), utilised technology to communicate public health information (Whitelaw et al. 2020). Health, education and business also migrated services online (Department of Education 2020). This change to a virtual world resulted in families needing to possess a variety of skills, competencies, and resources related to increased technology (Iivari et al. 2020).

Digital inclusion

Digital inclusion aims to promote participation, empowerment, open and available access to society (Iivari et al. 2020). However, not everyone may be able to access and utilise digital technologies or acquire skills associated with safe and effective use (Morganti et al. 2014). Not having access to a computer or education related to digital technology can further the divide in social and health inequalities (Borg et al. 2019). Social, economic, cultural influences, values and beliefs all define capacity to be included (Vial 2019). Families who commonly engage with health and wellbeing services benefit most from services offered

online (European Commission 2010). This is also likely to be true for research participation, but it is important to avoid excluding participants when using digital technology to collect data (Iivari et al. 2018).

Research participants and their parents may be concerned that online interviews require them to have advanced technology skills (Lamberti et al. 2021). Researchers need to acknowledge possible technical difficulties and ensure they have skills to mitigate these and support participants to troubleshoot problems (Rowe et al. 2014, Weller 2017).

Internet access is an important factor in achieving inclusion, in research and more widely (Hokke et al. 2018). CYP without internet at home can gain access at school, local libraries or children's centres but during the pandemic these settings were closed (Beaunoyer et al. 2020). In 2019, 700,000 CYP between 11-18 years old reported no internet access from home via a tablet, laptop or desktop and a further 60,000 CYP reported having no internet access at all in their home (Office for National Statistics 2019). Attainability of adequate internet signal strength may have changed with many more devices in the home used whilst parents and CYP navigate working at home (Kassab and Darabkh 2020).

A scoping review by Hokke et al. (2018) reported that the internet had been used successfully for many research projects with CYP and families. However, concern was expressed in some included articles about introducing bias due to digital divide (Gunasekaran et al. 2015). In contrast, other articles stated that online recruitment provided a representative sample and enabled researchers to access geographically dispersed, isolated or stigmatised groups (Hokke et al. 2018). Other researchers support this outlook, viewing online platforms for recruitment and data collection as positive when working with young people, as it can be difficult to engage them in offline research projects (Gibson 2020, Mason and Ide 2014).

Participation in ALPS required parents to make contact after seeing a digital advert. Therefore, parents needed to be active on social media or registered online with charities and have access to email. Interviewees needed to have access to a smart phone or computer with a webcam to be included, but as many families had seen digital adverts for ALPS, they all had access to these devices. Timing of ALPS meant that many parents and CYP were working or being educated virtually so workplaces and schools had allocated some resources to provide devices to maintain contact remotely. Quality of internet connection was variable but only two interviews were severely interrupted. Despite these interruptions, we reconnected and continued the interview. Although these interviews took longer, participants appeared happy to continue, and review missed questions.

<u>Virtual Platforms</u>

Zoom is a user-friendly platform and has been used for school, business and in other research studies (Daniels et al. 2019, Lobe et al. 2020, Matthews et al. 2018, Oliffe et al. 2021). Using Zoom was a safe way to interview CYP for ALPS in view of the end-to-end encryption. Virtual interviews were not recorded through Zoom, but audio recorded on a Dictaphone. We were familiar with Zoom and had received some training, making technical support for participants easier. Use of a one-click link made access easier, participants did not have to download software or sign up to a service and share their contact information.

From a researcher's perspective, Zoom's share screen function was particularly useful for consent and assent as the child, parent and researcher could view forms together ensuring an opportunity for CYP to be actively involved in the decision-making process and be equipped with as much information as their parents (Coyne et al. 2014, Gaillard et al. 2018, Oulton et al. 2016).

Video interview platforms do not appear to dissuade adults and adolescents from participating in research (Seitz 2016, Shapka et al. 2016). Many participants have reported enjoyment in using virtual interviews (Oliffe et al. 2021). A preference for Zoom over other video interviewing platforms is also reported by both researchers and adult participants in a study by Archibald et al. (2019). Experience from ALPS suggests it is also appropriate for use with CYP.

<u>Safety and Support</u>

Initially ALPS interviews were planned as face to face, data collection was due to begin just as the pandemic began. Therefore, ethical amendments were required to interview CYP virtually. Limited evidence suggests that video interviews are a pragmatic reproduction of a traditional technique rather than a distinct methodological practice (Gray et al. 2020). Virtual interviews with CYP pose additional ethical considerations, coupled with the opinion of some that face to face interviews are gold standard practice (Weller 2017).

Conducting virtual interviews avoided delays. However, it was vital that CYP could still be kept safe, have their data protected, privacy respected, and support needs met (Vaughn et al. 2020). To ensure safety of participants the ethics board required clear information about processes in place to protect and support CYP during and after their interview.

Privacy for CYP during their interview was explicit in information sheets and in correspondence with parents prior to interview. This was important to ensure CYP could speak freely without being concerned about the impact of their experiences on other members of the family (Morgan 2014). However, it did represent an ethical issue in relation

to support for CYP if they became distressed. To overcome this concern parents were requested to be available at beginning and end of the interview. A follow up email was sent to check in with parents about their child and offer support services if required.

It was evident that some siblings were not alone during their interview, and some parents interrupted their child's narrative to add things they thought were important. One sibling showed and introduced their family who were in the same room, whilst another had to keep moving around their house to find a quiet space and was frequently interrupted by their sibling with CHD. Participants who were interrupted or overheard may have been reluctant to answer certain questions through fear of upsetting their family members. The extent to which this happened and its impact on the interviews was difficult to tell.

Despite average UK households having 2-3 people there are still 162,900 households where seven or more people are residing in one house. Insisting on privacy as a mandatory aspect of interview could be used for future work but this may exclude participants who do not have physical space for privacy within their homes.

<u>Information and Consent</u>

In common law children over 16 years old are recognised as able to independently make informed decisions (Health Research Authority 2018). There is an absence of common law in England, Wales, or Northern Ireland about a child's right to consent to take part in research which is not a clinical trial of an investigational medicinal product. However, there is recognition that if a child younger than 16 years old can demonstrate maturity, understanding of risks and potential benefits they can be classed as 'Gillick' competent and may consent or refuse to participate (Griffith 2021). In the interests of protecting CYP, any decisions where consent is required are taken by parents/guardians but this may have an unintended effect of absolving CYP in the decision making process (Kennan and Dolan 2017). It is important to prioritise CYP's understanding, respect their decision and gain meaningful assent (Oulton et al. 2016). Prioritising participants understanding was paramount when creating information sheets, therefore separate child, young persons, and adult information sheets were developed in addition to parent information. Adult information sheets were for participants who could provide sole consent. Children's information sheets were constructed in a question and colourful speech bubble format with fewer written words, see Figure 1. A photo of the researcher (EB) was also included with a short explanation about why this research was important.
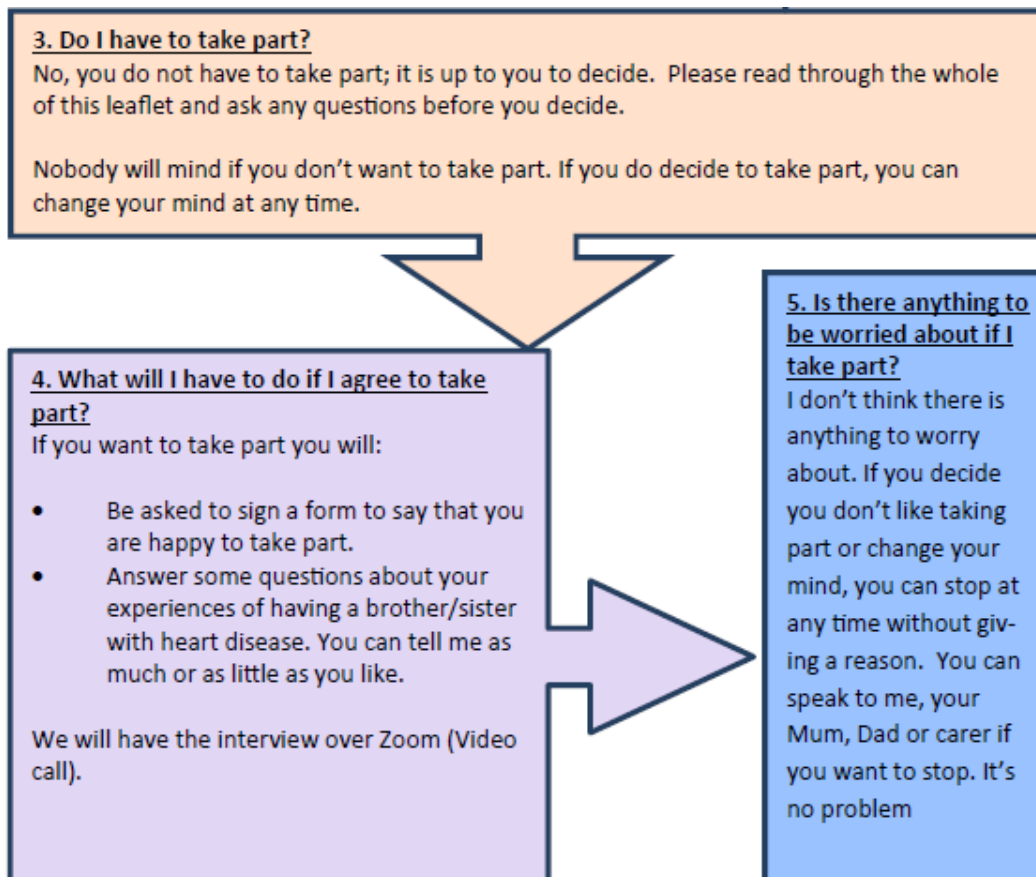
3. Do I have to take part?
No, you do not have to take part; it is up to you to decide. Please read through the whole of this leaflet and ask any questions before you decide.

Nobody will mind if you don't want to take part. If you do decide to take part, you can change your mind at any time.

4. What will I have to do if I agree to take part?
If you want to take part you will:

- Be asked to sign a form to say that you are happy to take part.
- Answer some questions about your experiences of having a brother/sister with heart disease. You can tell me as much or as little as you like.

We will have the interview over Zoom (Video call).

5. Is there anything to be worried about if I take part?
I don't think there is anything to worry about. If you decide you don't like taking part or change your mind, you can stop at any time without giving a reason. You can speak to me, your Mum, Dad or carer if you want to stop. It's no problem

Figure 1 - Excerpt from the ALPS children's information sheet.

Young peoples and adult information sheets also used a question-and-answer structure but were less colourful and included more adult appropriate and professional language.

For ALPS one difficulty was ensuring that CYP had adequate opportunity to review information prior to agreeing to take part. A YouTube video, accessible by a Quick Response (QR) code was developed to supplement age-appropriate information sheets sent via parental email. Despite this YouTube video being an aspect of inclusive research practice, it was even more useful in light of pandemic restrictions when virtual researcher contact with CYP was limited to interview day (McInroy 2017, Parsons 2015).

In an article by Lobe et al. (2020) options of obtaining online consent are briefly discussed but this doesn't specifically relate to CYP. Information guiding researchers about how best to obtain digital consent and assent from CYP in line with good research practice guidance is lacking. In ALPS, families were sent printed copies of consent forms, which were reviewed together online before the interview started. A screenshot of signed consent forms was taken, and a self-addressed envelope provided for families to return signed paper forms. All completed consent forms were returned by post, so a self-addressed envelope with paid postage was an efficient method to obtain written consent.

ALPS online interviews included use of the Pictorial Representation of Illness and Self Measure (PRISM) used widely in adult and paediatric studies to assess burden of suffering (Büchi et al. 2002, Melbardis Jørgensen and Jemec 2011, Sensky and Büchi 2016). It has been used among individuals who experience personal or vicarious suffering to provide a quantitative value termed the Self Illness Separation (SIS) score (Sensky and Büchi 2016). The SIS measurement is obtained by measuring distance between the illness circle and self-circle (From the centre of both circles) to generate a measurement to reflect suffering, lower measurement suggest higher suffering (Sensky and Büchi 2016). It has also been used as a visual summary to open up discussion about how things could change or to identify specific issues related to the illness (Büchi and Sensky 1999). This was its purpose in ALPS.

Traditionally this tactile tool uses a white plastic board and two-coloured circles to facilitate an open discussion about the impact of CHD on siblings. CYP illustrated their perceived burden by marking the distance between two circles, one representing themselves and another representing their sibling's CHD. An application for Apple smart phones was created to use the PRISM (Sensky and Büchi 2016). Other published research supporting or guiding its use in an online format could not be located. To decide how best to use this tool in a virtual interview a range of options were considered (Table 1).

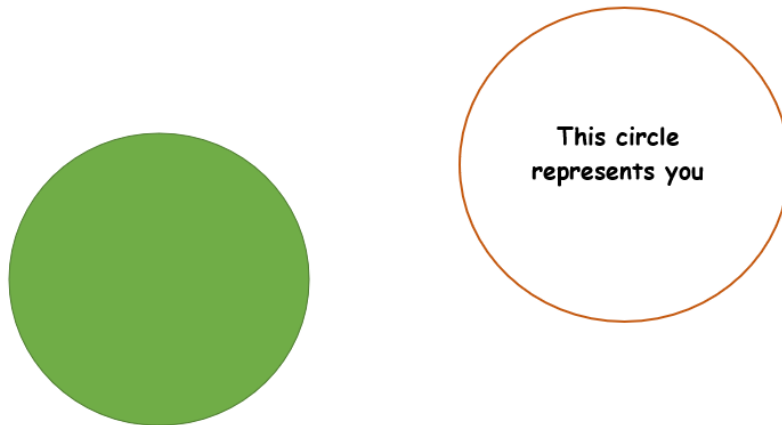Table 1 - Options to use PRISM via a virtual platform.

Options	Advantages	Disadvantages
Email Emailing a word document and use the screen share function. A screenshot or a copy by email could be requested.	Email is instant if other methods fail.	Reliant on family to email a copy.
Online application Using a PRISM application on their personal device and then sharing a screenshot of completed PRISM.	Keeps everything electronic rather than handling paper.	Requires family to download an application. Excludes Android users, Application only available through Apple.

| | | Reliant on the sibling or parent emailing a screenshot of their app.

More difficult to show researcher completed PRISM if using their phone for the video interview. |
| Posted
Posting a blank PRISM, printed on A4 paper, and sending a coloured sticker. Include a stamped addressed envelope. | Available for the interview without the family having to prepare anything.

Easy and no cost, self-addressed envelope is provided. | May be unable to return by post if shielding or self-isolating. |

The options in Table One were explored during practice interviews with CYP of the same age. These interviews revealed that young people found it easier to navigate virtual methods of using PRISM than children, but it took more time to explain its use virtually. During our pilot there were also difficulties explaining the process on different devices. Children found it easier to use a printed PRISM and a sticker and this generated more discussion about why they placed their sibling's illness circle in a specific position.

A final decision was made to use a printed PRISM with a sticker (Posted option) as a first choice, see figure 2. Having something tactile to use during interviews helped open conversation and appeared to hold CYP's interest. Stickers that were sent out were green, but participants were asked what colour they thought it should be, was it the right size, how did they find completing the exercise. Sometimes their paper PRISM had not arrived via post by interview day, so a virtual method (Email option) was used instead.

Where would you put the sticker representing your brother/sisters heart condition to show its place in your life at the moment?

This circle represents you

Figure 2 - Example of a completed PRISM

<u>Lack of physical proximity</u>

When undertaking interviews about sensitive topics it is important to develop a good rapport which may also impact data quality (Roulston 2019, Weller 2017). Based on interviews with adults, researchers report that being physically distant but feeling virtually together enables participants to feel able to open up and communicate feelings and experiences (Archibald et al. 2019, Oliffe et al. 2021).

Experience from ALPS suggests it was possible to convey empathy and warmth virtually but was significantly more difficult than doing so face to face. Concurrent with our observations, lack of proximity required for rapport building has been recognised amongst other researchers as a criticism during online interviews (Seitz 2016).

Communication science details a holistic perspective which recognises the role of verbal and non-verbal communication. Work by Mehrabian (2017) describes spoken words as 7% of a communication transaction the way in which words are relayed accounts for 38% and facial expressions comprise 55%. In the context of video interviewing most facial expressions can be observed but, sometimes what is behind the webcam cannot be captured (Archibald et al.

2019). Importance of posture and position has also been described by Mehrabian (2017) and is something which cannot be observed fully during a virtual interview.

During ALPS interviews managing periods of technical disruption or supporting a child experiencing strong emotions proved challenging during virtual interviews. During face-to-face interviews if a participant becomes distressed physical gestures such as providing water or tissues are supportive. Moving closer or further away from the participant depending on their body language can be comforting for a participant. None of this is possible virtually.

CYP are not digitally naïve, especially during an era where schoolwork is completed on virtual platforms (Iivari et al. 2020). This sometimes led to boredom or distraction during ALPS interviews especially with younger children. Trying to regain children's focus sometimes meant that the same question needed to be asked in a different way or the topic changed to afford more focus, returning to unanswered questions at a later point. Subtle nuances in question structure are important in adapting an interview guide to an individual participant and this relies on skill and experience of an interviewer (DeJonckheere and Vaughn 2019, McGrath et al. 2019).

Benefits of video interviewing with children and young people.

Video interviewing is cost effective, reducing travel costs for families and researchers (Archibald et al. 2019). Greater capture of participants across a wider geographical area also enables inclusion of participants who may not find it easy to travel (Gray et al. 2020). The COVID-19 pandemic meant more families were at home and often more available; all those interviewed for ALPS were available at the pre-arranged time.

 Another positive aspect of video interviewing is an ability for CYP to share their environment: pets, family members or toys that are special to them. This facilitated an open discussion and encouraged a friendly introduction, which likely led to CYP feeling more relaxed and building rapport (Gray 2020). Having an insight into a child's environment and being shown things of interest sparked captivating discussion. This helped demonstrate value CYP placed on objects, increasing our understanding of how these things helped and facilitated questions related to their sibling with CHD, in the context of their environment e.g., 'How do you feel when your sister helps you build with Lego? What happens to your den when you have to stay with Nan if your sister goes in hospital?'.

Areas for future research

Insights are based on one team's experience of undertaking research with CYP using Zoom. Future research should focus on how CYP experience using virtual platforms for interviews.

It would be advantageous to understand more about designing research projects involving CYP which solely focus on online platforms for data collection. More information on gaining online consent and assent from CYP would be advantageous to ensure standardised good research practice.

<u>Conclusion</u>

Pandemic restrictions resulted in many researchers experiencing disruption to their research projects. Navigating these challenges in the face of wider ethical issues associated with research with CYP about sensitive topics, makes examples from our study important to share. Benefits of virtual interviews for researchers are clear but how CYP feel about being interviewed online remains unknown.

Declaration of conflicting interests: The Authors declare that there is no conflict of interest.

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Thank you for such supportive feedback and considered comments. In the table below we illustrate changes made based on suggestions. The exact text added to the main document are included in this table in italics and highlighted. Changes in the main document are marked using the 'track changes' tool. We thank both reviewers for comments which will undoubtably improve the quality of this submission.

Reviewer 1	Response
One observation I would make is around what you defined as a 'child' and what you defined as a 'young person'. I felt this warranted a little more clarity given you referred to differences between 'older' and 'younger' children later on.	Thank you, we have added. *Definitions of 'Children' and 'Young people' vary but we have followed the United Nations guidance and term 'children' aged 8-14 years and 'young people' 15-17 years old (United Nations 2022).* Page 2
You referred to age-appropriate information sheets too and I was interested in how these varied for children/young people although recognise word limits may prohibit detailed discussion. Perhaps a table of key differences/considerations would be useful?	Thank you, we agree with this point and have added a figure showing an excerpt from the children information sheets and added this text. *Prioritising participants' understanding was paramount when creating information sheets, therefore separate information sheets for children, young people and adults were developed in addition to parent information. Adult information sheets were for participants who could provide sole consent. Children's information sheets were constructed in a question and colourful speech bubble format with fewer written words, see Figure 1. A photo of the researcher (EB) was also included with a short explanation about why this research was important.* *Figure 1 - Excerpt from the ALPS children's information sheet* *Young people's and adult information sheets were in a*

	question-and-answer structure too but were less colourful and used more adult appropriate and professional language. Page 6
Reviewer 2	
Where you lost internet signal significantly, did you re interview? or re arrange? Did you find you had enough data? Or did you have to make do?	Thank you, we have added a short explanation for clarity *Despite these interruptions, we reconnected and continued the interview. Although these interviews took longer, participants appeared happy to continue, and review missed questions.* Page 4
In the interviews where the CYP were not alone or interrupted by family did you find that impacted negatively in comparison to your other interviews?	Thanks for this comment, this is a very interesting point. Only the two interviews described in the article were interrupted or overheard but it is impossible to know whether or not this was also true for others. It is difficult to know if this negatively impacted the interview. Some participants were more communicative than others, but it was impossible to tell if they were shy, disinterested, if rapport could have been improved or they were being overheard. It's a limitation to the study which will be reported in the results paper. The following text has been added: *The extent to which this happened and its impact on the interviews was difficult to tell.* *Page 5*

Where a specific tool has been utilised, I find an image or diagram helpful for the reader to illustrate what has been used, perhaps of what was posted out?	Thank you, we have added a figure of a completed PRISM to demonstrate its use.