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Exploring inequalities in health with young people through online focus groups: navigating the methodological and ethical challenges

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Exploring inequalities in health with young people through online focus groups: navigating the methodological and ethical challenges

Abstract

Purpose

The use of online focus groups to explore children and young people's (CYP) perspectives of inequalities in health and associated 'sensitive' topics, raises important ethical and methodological issues to consider. The purpose of this paper is to discuss lessons learned from navigating our way through some of the key challenges we encountered when researching inequalities in health with CYP through online focus groups.

Design/methodology/approach

In this paper we draw on reflections and notes from the fieldwork design, Public Involvement and Engagement (PIE) activities and data collection for our research project.

Findings

Collecting data online influenced our ability to develop rapport and relationships with CYP, and our ability to provide effective support when discussing sensitive topics. We note that building in activities to develop rapport with participants during recruitment and data collection, and establishing clear support and safeguarding protocols, helped navigate challenges of online approaches around effective and supportive participant engagement.

Originality/value

This paper highlights that despite ethical and methodological challenges of conducting online focus groups with CYP on potentially sensitive topics, the adoption of practical steps and strategies before, during and following data collection, can facilitate the safe participation of CYP and generate useful and valid data in meaningful and appropriate ways.

Introduction

Over recent decades social science and health research have begun embracing the voices and perspectives of those who have historically been marginalised and excluded in both research and policy accounts (Starbuck et al., 2020). While previous perspectives saw children and young people (CYP) as lacking the capacity to consent, comprehend their social worlds, and communicate their experiences (Fargas-Malet et al., 2010; Kirk, 2007), the Social Studies of Childhood has been pivotal in shaping the way CYP are engaged in research, with an emphasis on CYP as social actors who are able to voice their own experiences and who have valuable contributions to make (James and Prout, 2015; Matthews, 2007). Now, actively involving CYP in all aspects of research that relates to them is not only an accepted position, but is also seen as a crucial aspect of producing knowledge and understanding of CYP's lives (Alderson and Morrow, 2020; Kirby, 2004; Martins et al., 2018). However, involving CYP in research raises particular ethical, methodological and practical issues that require critical consideration, particularly when researching sensitive topics (Powell et al., 2018).

Exploring inequalities in health and potentially sensitive topics with CYP

In this paper, we discuss lessons learned from navigating our way through some of the key challenges encountered when conducting online qualitative research with CYP to explore their understandings of inequalities in health and the wider social determinants of health. Inequalities in health across the UK are worsening (Marmot et al., 2020). The Covid-19 pandemic has further highlighted and exposed the scale of health inequalities across the UK (Bambra et al., 2020; Marmot and Allen, 2020). Whilst there has been growing calls to tackle inequalities in health (Marmot et al., 2010, 2020), there is a paucity of research looking at lay understandings of health inequalities, especially the experiences, perspectives and voices of CYP (Backett-Milburn et al., 2003; Davidson et al., 2006; 2008; Smith and Anderson, 2018). It is crucial to explore CYP's experiences and understandings of inequalities in health to better inform and design policies, interventions and ways of communicating with the people and places that are negatively affected by health inequalities (L'Hôte et al., 2018; McDonald, 2009). Due to our project's focus on health inequalities, data collection was undertaken in two geographical areas in the North of England that fell within the most deprived quintile based on the 2019 English indices of multiple deprivation (IMD). There are established links between deprivation levels and inequalities in health (Marmot et al., 2020), and both data collection sites have experienced the adverse effects of deindustrialisation and are exposed to a range of interconnected deprivations impacting upon the social determinants of health (e.g., Beatty and Fothergill, 2020). The context and levels of deprivation in our data collection sites raised particular challenges around researching potentially sensitive topics related to health and inequality (see below).

While many topics fall into the category of a 'sensitive topic' (e.g., addiction, bereavement, mental and physical health conditions, poverty, sexuality), there is no conclusive definition of a 'sensitive topic' and no set guidance on how to approach such topics in research (Lee and Renzetti, 1990; Rodriguez, 2018). Sensitive research is often used as an overarching term which covers topics which are seen as personal, emotive and associated with social stigma

(Dempsey et al., 2016; Rodriguez, 2018), but there is often a lack of appreciation why and for whom a topic is, or becomes, sensitive (Martins et al., 2018; Richards et al., 2015). We approach the discussion of health inequalities and intersecting disadvantages as challenging and potentially sensitive, due to such topics having stigmatising, labelling and fatalistic properties and connotations for those experiencing them (Pemberton et al., 2016; Shildrick and MacDonald, 2013). Health practices and adverse health outcomes are often individualised, vilified and equated with deficit, passivity and flawed choices, with this neglecting wider influences upon health (Kriznik et al., 2018). Indeed, previous research exploring public perceptions of health inequalities in the UK has highlighted the prominence of 'judgmental place attitudes' and 'perceived place stigma' in explanations for geographically patterned inequalities in health (Garthwaite and Bambra, 2017, p.273), and how discussions around the impacts of disadvantage and deprivation may act to reinforce stigmatised identities (Elliott et al., 2016; Smith and Anderson, 2018). Therefore, discussions around health and inequalities in health have the potential to be sensitive in regard to subjective experiences, personal contexts and life circumstances (Dempsey et al., 2016; Martins et al., 2018; Powell et al., 2018; Richards et al., 2015), with the social stigmas around inequality, place, poverty and disadvantage making it particularly challenging to research these topics with CYP experiencing such issues (Sutton, 2009). Nevertheless, we should not shy away from researching challenging and sensitive topics, especially at times when CYP's physical and mental health needs may be particularly acute (e.g., due to the impact of the Covid-19 pandemic (Leavey et al., 2020; Lee, 2020; YoungMinds, 2020)). Instead, efforts must be made to ensure the effective and safe engagement of CYP in research.

Developing Our Methodology

When our research project was devised, data collection was intended to be completed face-to-face, but due to the Covid-19 pandemic and the UK's national and local lockdown measures, we had to (re)design our methods to be 'socially distanced' and delivered online. We needed to think creatively and critically about how we could effectively involve and engage CYP in online discussions of inequalities in health, balancing participation with protection to mitigate any potential harm (Martins et al., 2018).

A qualitative approach to exploring perspectives on inequalities in health

We followed the approach of studies that have explored 'lay' perspectives on inequalities in health and similar sensitive topics which have typically adopted qualitative approaches, including interviews and focus groups (Backett-Milburn et al., 2003; Davidson et al., 2006; 2008; Sutton, 2009). Davidson et al. (2006) suggest that, whilst focus groups may provide less representative patterns of opinions than other methods, in researching sensitive topics such as health inequality, the support of other focus group participants may help to negate feelings of inferior moral status associated with inequality, and facilitate discussion of challenging topics. Thus, such approaches can provide a space for participants to talk about health inequalities, and lead to insights that may be obfuscated through other methods. Davidson et al. (2008) also argue that power imbalances, which may inhibit discussion around sensitive topics when interviewers are perceived as being from a more privileged position, can be alleviated in focus group settings, with social support, perceived shared positionality and prioritisation of 'lay expertise' encouraging people to discuss their perceptions of health inequalities.

In light of this when developing our methodology, we valued the importance of creating an environment that supported CYP to talk openly about what can be sensitive and complex issues. Our research consisted of three virtual focus groups with four groups of CYP aged 12-17, using video conferencing platforms (12 sessions in total). Our participants were recruited from four youth organisations across two local authority areas in the North of England. Our focus groups explored CYP's perspectives of what makes it easier or harder for some people to be healthy within their local places, CYP's understandings of inequalities in health and the social determinants of health, and CYP's key priorities in addressing the impact of social determinants on their current and future health. We used participatory concept mapping activities and open discussions to explore these topics. This approach allowed the focus on health and health inequalities to be led by the CYP themselves, giving us a better understanding of their concerns and priorities.

Moving data collection online

Moving data collection online due to the Covid-19 pandemic raised various practical and ethical considerations and challenges that had to be navigated to ensure effective and safe participation of CYP, for which reflection was crucial. Whilst online interviewing methods have been an emerging practice over recent years (Woodyatt et al., 2016), face-to-face approaches are typically seen as producing richer and thicker data, but this is being challenged (e.g., Deakin and Wakefield, 2014; Weller, 2017). During the Covid-19 pandemic and due to social distancing restrictions, virtual spaces and digital media have become the predominant medium for conducting qualitative research (e.g., Foley, 2021). The challenges of researching sensitive topics have been exacerbated in this shift, as many of the protections provided by face-to-face contact (e.g., ability to read body language; rapport building; recognising and responding to behavioural and emotional cues around distress; and, abilities to offer direct support (Cameron, 2005; Dempsey et al., 2016; Denscombe, 2017; Dodds and Hess, 2020; Elmir et al., 2011; Rodriguez, 2018; Seitz, 2015; Weller, 2017)) are diminished. Also, the ever growing realisation of the extent of inequalities in access to online spaces and technology (Honeyman et al., 2020; Lucas et al., 2020), means some CYP may struggle to participate effectively in online research.

We therefore had to think critically about how we could best use online methods to elicit rich data, whilst ensuring inclusivity and protection for participants when discussing potentially sensitive topics around inequalities in health. Here we share our reflections on planning and conducting online focus groups with CYP on the topics of health and inequality. We draw on Public Involvement and Engagement (PIE) work with youth organisations, undertaken before beginning our data collection, in which we explored how to make our methods inclusive and then piloted our methods. In the discussion that follows, we share our reflections as well as observations noted in our fieldwork and discussed in regular team meetings. We believe that regular reflection and researcher reflexivity was particularly useful throughout the process of our data planning and collection which had to be redesigned for online delivery, and possibly more importantly, was research on inequalities in health during a global pandemic. Our discussion focuses on two areas of ethical and methodological challenges which we worked to navigate through: i) rapport building and developing effective relationships at a distance, and; ii) confidentiality, safeguarding and providing support to CYP when online and negotiating challenging topics. We aim to promote wider consideration of the ethical and methodological challenges associated with conducting research with CYP online, and when discussing topics around health, inequalities and sensitive topics more broadly.

Our reflections

Rapport building and developing effective relationships at a distance

Limitations to virtual research include the physical distance between researchers and participants. Ideally, we would have spent time meeting and engaging face-to-face with CYP before beginning data collection, to build rapport, introduce the research and discuss participation and consent procedures, but due to lockdown and social distancing requirements we were unable to do so. The PIE work we undertook to refine our methods and approaches before beginning data collection demonstrated the impact of this lack of rapport building prior to data collection. Our first online PIE session was the first time the CYP had met the research team. Whilst this session ran smoothly, it felt more like an interview (participants responding to researcher questions) rather than a group discussion, with this inhibiting conversation flow and rapport. Reflecting upon this, and due to our inability to meet youth organisations and CYP face-to-face before data collection, we provided youth organisations with information to help them explain the research to the CYP, including a short narrated project information video which introduced both the research project and the research team (i.e. through using short biographies and photos). This aimed to provide a level of familiarity during the recruitment process (see Deakin and Wakefield, 2014), and was well received by both youth organisations and CYP.

We also recognised the importance of researchers meeting the CYP ahead of the data collection sessions, so where possible, we arranged initial online introduction sessions with participating youth organisations. The purpose of the introduction session was to introduce ourselves, the research topic, and the requirements and process of the research (consent forms, ground rules) as well as meet the CYP. This also provided CYP with an opportunity to ask questions to the research team. We found these introductory sessions to be effective in developing rapport and facilitating openness in participants. For example, one participating youth worker noted that their group was usually very talkative in their face-to-face engagement sessions, but had been surprisingly quiet during our introductory session. The participants, however, became much more engaged in the following data collection sessions, with one participant going from having their camera turned off and saying little, to turning their camera on and becoming much more vocal. These introduction sessions also permitted more productive use of time during data collection sessions, with less time required to cover procedural information allowing more time for warm-up and data collection activities. Indeed, we found that time spent on ‘warm-up’ activities at the beginning of online sessions were important to facilitate engagement and rapport building. Across all the groups we saw greater engagement and participation develop with each session. Our experience highlighted the increased importance of investing time in relationship building when online, to compensate for the (often taken-for-granted) benefits for rapport building associated with face-to-face contact.

A strength of focus groups, and an important reason for choosing this method, is the potential for participants to engage with and respond to each other, not just to the researchers' questions (Denscombe, 2017; Kamberelis and Dimitriadis, 2013). This can help to elicit more natural conversations by removing some of the researcher-participant power dimensions which can inhibit discussions (Davidson et al., 2006; 2008). However, online methods make it difficult to pick up on who wants to talk next and permit only one person to talk at a time, making it difficult to facilitate flowing discussions between participants. We reflected that such turn-taking prevented ‘side’ conversations that would likely take place in face-to-face group interviews that we believe may have helped with rapport building and social connection between participants and researchers. Our PIE work demonstrated that online groups with more than five participants can have an awkward characteristic of ambiguity and confusion around who should talk next; this stop-start discourse was a challenge, especially when CYP were waiting to say something important to them. This was in part due to the functionality of online platforms and that some participants took part using smart phones, with this reducing their ability to see all other participants on their screens, and thus reducing the ability to pick up on visual cues around who was going to speak next. Having a member of the research team monitor who wanted, or was trying to speak, went some way towards enabling CYP’s voices to be captured and not missed, as did promoting and encouraging the use of text and chat features of online platforms. Further, the importance to participants of having time and space to voice thoughts was evident, so we decided to use breakout rooms to enable smaller group discussions in our data collection sessions. This enabled the voices of all CYP to be heard and facilitated more in-depth discussions *between* participants when online. Feedback from participants in our data collection sessions highlighted that they particularly valued the breakout rooms for this ability to be heard. We had four members of the research team and at least one youth worker involved in each data collection session. We found this to be optimal as it permitted one lead and one assistant facilitator (who could monitor the chat and who wanted to speak) in each breakout session, as well as the presence of a youth worker who was able to provide support to participants if needed. Having two researchers in each breakout session also provided cover against connection issues for the research team and around ensuring audio recording of the session. Having smaller groups online provided more opportunity for the participants to speak and reduced the risk of their perspectives being missed. We found this to enable more effective relationship development through more fluid discussions.

A strength in our methods was the involvement of youth workers from our partnering youth organisations. Youth organisations are important gatekeepers to CYP (Fargas-Malet et al., 2010), and our partnering youth organisations were crucial in not only providing access to CYP, but also offering various levels of protection and support for online participation, which we as researchers would not have been able to provide. Recruiting through established organisations that already work with disadvantaged CYP proved extremely beneficial as they have existing relationships with the CYP, as well as extensive experience, knowledge and skills around engaging and supporting CYP. The presence of youth workers facilitated rapport building and the development of trust between researchers and participants. The relationships youth workers had with CYP helped to minimise online barriers around establishing effective relationships; for example, the youth workers existing relationships with the participants helped them to encourage participation in ways that were comfortable for individual CYP, such as the ability to respond by text or speak with their video off, and conversely gently encouraging CYP to turn on their cameras. Linked to this, youth workers were also crucial in identifying effective group splits for breakout rooms, which further helped with group dynamics by grouping together CYP who could support and encourage each other. The youth workers also acted as a catalyst for discussions during sessions and warm-up activities by prompting around topics they knew to be relevant to the CYP but had not been raised, and by using their personal relationships with CYP to help delicately approach potentially sensitive topics. The barriers around engagement and the importance of trust in facilitating engagement with marginalised groups have been noted (e.g., Flanagan and Hancock, 2010; Panfil et al., 2017), and we found such barriers to be exacerbated when online. Such challenges were highlighted in our work with an LGBTQ group who were initially reticent in discussions. In this group, the importance of researcher familiarity for facilitating engagement was evident, with a feeling of trust building with each session. The active role of the youth worker was also crucial in building trusting relationships and navigating discussions of sensitive topics, thus the experience of the youth workers helped overcome some of the challenges of online interactions.

Another important consideration when working online was CYP's transition to and from data collection sessions. We initially planned to use 'topic related' warm-up activities in our sessions to help prime and build into our main discussion, and to maximise time spent discussing the research topic. However, following PIE feedback and reflections, discussions with partnering youth organisations, and consultation with our project partners around conducting online focus groups, we designed our sessions to 'sandwich' the data collection session, with 'fun' (unrelated or lightly related to research topic) icebreaker and cool-down activities that involved participation from researchers as well as participants. Co-producing these session plans with partnering youth workers (particularly the warm-up and cool-down activities) was important as youth workers were able to make suggestions based on their experience of what would be most engaging for the CYP. The 'unrelated' nature of the warm-up and cool-down activities helped detach data collection activities and provided brief personal insights and opportunities to explore personalities, with this acting to help build relationships. Indeed, the 'trivial' aspects of introductions and warm-ups/cool-downs were useful in re-balancing some of the power dynamics involved in research with CYP (Davidson et al., 2008; Weller, 2017; Spencer et al., 2020) with this facilitating participation and engagement online.

Confidentiality, safeguarding and providing support to CYP when online and negotiating challenging topics

Privacy and confidentiality are fundamental to meaningful participation in research (Weller, 2017). However, though we asked participants not to repeat what was discussed to anyone outside of the group, the nature of focus groups is such that confidentiality cannot be guaranteed. Online discussions pose the additional risk of participants being overheard by people in close proximity to them or to other group members. Despite some research suggesting that CYP can feel comfortable being interviewed online in their own homes (Dodds and Hess, 2020), those living in overcrowded homes may feel uncomfortable talking about sensitive topics, especially if they lack a private space. To mitigate these risks we asked participants to use headphones if possible, discouraged them from talking about or disclosing anything they would not want other people to be aware of, and encouraged the use of chat features of online platforms as an alternative way to voice their thoughts and opinions. We considered the ethical issues of youth workers being present during data collection (i.e., around confidentiality/disclosures), and participants were made aware during the consent process of the protections and limits of confidentiality in group discussions with researchers, peers and youth workers.

Establishing a clear safeguarding procedure with each youth organisation was crucial for the protection of participants, and for researchers to feel comfortable that any issues or welfare concerns could be escalated and managed quickly. This involved having clear processes for addressing safeguarding concerns, managing problematic discussions and providing support to participants who may become distressed or go ‘offline’ unexpectedly. Being online meant it was difficult for facilitators to raise the attention of the youth worker or other research team members to discuss an issue without alerting all participants. Therefore, all researchers had the contact telephone number of the participating youth worker to alert them to any concerns or support needs that arose during data collection sessions. Working closely with youth workers and organisations provided benefits around participant protection as it put in place existing safeguarding procedures and structures we could use if needed. It also reassured us that the participating CYP had prior understandings of these procedures from their involvement with the youth organisations, and were comfortable participating with these in place.

Providing support to CYP during and beyond online discussions around sensitive topics

Due to the potentially sensitive and stigmatising nature of discussing inequalities in health, it was important for us to consider how participation may be distressing for those taking part, either directly through discussion of certain topics or through a form of vicarious trauma (i.e., adverse emotional feelings from discussions and disclosures of other participants (Elmir et al. 2011; Rodriguez, 2018)). In our PIE work we asked about how best to approach potentially sensitive topics around health and inequality; the CYP told us that no topic was off limits, but the way topics are approached (i.e not in a fatalistic, pejorative or blaming way) is important, as is making sure that CYP feel comfortable being involved in the discussion. Indeed, during one breakout session in which two participants openly discussed their personal experiences of mental ill-health and mental health services, it became clear that the third participant was listening, but contributing very little to the discussion. We sought to check that this young person was feeling comfortable before moving the discussion on. A post-session check-in with all three participants by the youth worker provided reassurance that the session had not negatively affected any participants. In subsequent sessions, the youth worker took participants' lived experiences into consideration when assigning individuals to breakout groups.

When using online methods it is crucial to consider how the setting influences the way in which support can be provided. Prior to the sessions we worked with participating youth workers to agree a system that would enable youth workers and participants to contact one another in real time during discussions, using text or private messages. CYP were able to signal privately if they needed support from the youth worker, and the youth worker was able to address any concerns about participants' wellbeing by checking how they were feeling and that they were happy to continue. This was particularly useful when participants stopped contributing to the discussion, turned their camera off or went 'offline' unexpectedly, as it provided the research team with confidence that participants were being appropriately supported during the sessions. We also developed a 'distress protocol' in consultation with our project partners, to manage the situation if a participant became upset or appeared to be struggling emotionally in a breakout group when the youth worker was not present. This set out practices of offering a group break, contacting the youth worker, and discussing the option to share their thoughts in a more private setting (e.g., breakout room or phone call with a youth worker or researcher).

It is also important to consider how participants may feel during and after data collection. We regarded the 'after' and 'leaving' of data collection sessions as being as important as the 'beginning' and 'during' to ensure participants were not left to manage upsetting thoughts alone following their participation. We were aware that, after discussions of sensitive topics online, participants may have left the session feeling emotional and potentially stigmatised (Starbuck et al., 2020). Our PIE work demonstrated that online sessions can feel as if they end abruptly, rather than the gentle drifting away after a session that is often experienced when face-to-face. We made sure that participants had the opportunity to discuss their thoughts and feelings with their youth worker and the research team, both immediately following the session, and at a later time if required with the participating youth workers conducting post-session check-ins with participants. The youth worker acted as a key protective element which helped compensate for the difficulty of ensuring that safeguards are in place from when conducting research with CYP at a distance.

Lessons learned

The discussions in this paper capture our lessons learned when working with CYP and researching sensitive topics in group interviews and online settings. These can be summarised as follows:

- Before any data collection takes place, public involvement and engagement (PIE) can help to identify any potential issues with the methodology and the dynamics of using online video conferencing platforms. It also provides an opportunity to explore how best to approach potentially sensitive topics with CYP.

- A close working relationship with youth organisations and youth workers can help build robust methodologies that encourage engagement and facilitate the safeguarding and protection of participants during and beyond data collection. Youth workers provide enabling and protective roles. In their enabling role: before data collection, they can help with recruitment, setting up the sessions, and coordinating the distribution of research materials; during the sessions, youth workers can facilitate the flow of the session, encourage engagement and prompt discussion topics. Youth workers also serve a protective role: helping to establish safeguarding procedures, acting as a source of support and contact for CYP and researchers during and after data collection sessions.

- Informal introductions between researchers and CYP are beneficial for establishing familiarity and rapport when online. Time should be factored in to allow this to happen before data collection. An initial information video serves a purpose beyond informing about the research, by serving as a way to introduce the researchers to the participants. In addition, having more than one data collection session is also beneficial for relationship building and CYP's engagement.

- For online discussions with CYP around sensitive topics, having more than five participants can make managing discussions and ensuring engagement challenging. Therefore, using smaller sized breakout discussions (five CYP and under) can promote discussions *between* participants that may not naturally take place in larger online groups. In addition, participants accessing online platforms through mobile phone have reduced capacity to view other participants, which can inhibit participation in larger groups.

- Having a lead facilitator, an assistant facilitator and a youth worker in each breakout session is optimal. This allows the lead facilitator to manage the discussions; the assistant facilitator to monitor the online chat, check who wants to speak next and screen share resources/prompts; and, the youth worker to provide advice and support to CYP (e.g., follow-up with participants who suddenly go 'offline'). This enables more fluid discussions, and ensures appropriate support processes are in place.

- When researching sensitive topics such as health and health inequalities with CYP online, it is important to consider the emotional impact discussions might have on participants. Off-topic warm-up and cool-down activities not only facilitate relationship building between researchers and participants, but when online also serve as important transitions into and out of sensitive data collection discussions.

- A nuanced understanding of the intersecting relationship between the topic, participant context, and research setting is crucial in approaching sensitive research (see also Powell et al., 2018). The topic of research discussion, the experiences and context of the participants (i.e., personal experiences, social positions), and importantly the setting of data collection (i.e, online, individual/group settings), are relative and all shape sensitivities. Therefore, all need to be considered and regularly reflected upon when planning and undertaking research with CYP.

Conclusions

There are ethical and methodological challenges of conducting online group interviews with CYP on potentially sensitive topics around inequality and health. We have discussed the challenges that online research with CYP present, particularly around how the 'distance' of online approaches makes participant engagement, relationship and rapport building more challenging, and how providing support in online discussions is more difficult and requires appreciation. However, building in activities to develop rapport with participants and establishing clear support and safeguarding protocols can help to ensure the safe, supportive participation of CYP and the generation of rich data through effective conversations with CYP around topics of inequalities in health whilst online.

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Exploring inequalities in health with young people through online focus groups: navigating the methodological and ethical challenges

Abstract

Purpose
The use of online focus groups to explore children and young people's (CYP) perspectives of inequalities in health and associated 'sensitive' topics, raises important ethical and methodological issues to consider. The purpose of this paper is to discuss lessons learned from navigating our way through some of the key challenges we encountered when researching inequalities in health with CYP through online focus groups.

Design/methodology/approach
In this paper we draw on reflections and notes from the fieldwork design, Public Involvement and Engagement (PIE) activities and data collection for our research project.

Findings
Collecting data online influenced our ability to develop rapport and relationships with CYP, and our ability to provide effective support when discussing sensitive topics. We note that building in activities to develop rapport with participants during recruitment and data collection, and establishing clear support and safeguarding protocols, helped navigate challenges of online approaches around effective and supportive participant engagement.

Originality/value
This paper highlights that despite ethical and methodological challenges of conducting online focus groups with CYP on potentially sensitive topics, the adoption of practical steps and strategies before, during and following data collection, can facilitate the safe participation of CYP and generate useful and valid data in meaningful and appropriate ways.

Introduction

Over recent decades social science and health research have begun embracing the voices and perspectives of those who have historically been marginalised and excluded in both research and policy accounts (Starbuck et al., 2020). While previous perspectives saw children and young people (CYP) as lacking the capacity to consent, comprehend their social worlds, and communicate their experiences (Fargas-Malet et al., 2010; Kirk, 2007), the Social Studies of Childhood has been pivotal in shaping the way CYP are engaged in research, with an emphasis on CYP as social actors who are able to voice their own experiences and who have valuable contributions to make (James and Prout, 2015; Matthews, 2007). Now, actively involving CYP in all aspects of research that relates to them is not only an accepted position, but is also seen as a crucial aspect of producing knowledge and understanding of CYP's lives (Alderson and Morrow, 2020; Kirby, 2004; Martins et al., 2018). However, involving CYP in research raises particular ethical, methodological and practical issues that require critical consideration, particularly when researching sensitive topics (Powell et al., 2018).

Exploring inequalities in health and potentially sensitive topics with CYP

In this paper, we discuss lessons learned from navigating our way through some of the key challenges encountered when conducting online qualitative research with CYP to explore their understandings of inequalities in health and the wider social determinants of health. Inequalities in health across the UK are worsening (Marmot et al., 2020). The Covid-19 pandemic has further highlighted and exposed the scale of health inequalities across the UK (Bambra et al., 2020; Marmot and Allen, 2020). Whilst there has been growing calls to tackle inequalities in health (Marmot et al., 2010, 2020), there is a paucity of research looking at lay understandings of health inequalities, especially the experiences, perspectives and voices of CYP (Backett-Milburn et al., 2003; Davidson et al., 2006; 2008; Smith and Anderson, 2018). It is crucial to explore CYP's experiences and understandings of inequalities in health to better inform and design policies, interventions and ways of communicating with the people and places that are negatively affected by health inequalities (L'Hôte et al., 2018; McDonald, 2009). Due to our project's focus on health inequalities, data collection was undertaken in two geographical areas in the North of England that fell within the most deprived quintile based on the 2019 English indices of multiple deprivation (IMD). There are established links between deprivation levels and inequalities in health (Marmot et al., 2020), and both data collection sites have experienced the adverse effects of deindustrialisation and are exposed to a range of interconnected deprivations impacting upon the social determinants of health (e.g., Beatty and Fothergill, 2020). The context and levels of deprivation in our data collection sites raised particular challenges around researching potentially sensitive topics related to health and inequality (see below).

While many topics fall into the category of a 'sensitive topic' (e.g., addiction, bereavement, mental and physical health conditions, poverty, sexuality), there is no conclusive definition of a 'sensitive topic' and no set guidance on how to approach such topics in research (Lee and Renzetti, 1990; Rodriguez, 2018). Sensitive research is often used as an overarching term which covers topics which are seen as personal, emotive and associated with social stigma

(Dempsey et al., 2016; Rodriguez, 2018), but there is often a lack of appreciation why and for whom a topic is, or becomes, sensitive (Martins et al., 2018; Richards et al., 2015). We approach the discussion of health inequalities and intersecting disadvantages as challenging and potentially sensitive, due to such topics having stigmatising, labelling and fatalistic properties and connotations for those experiencing them (Pemberton et al., 2016; Shildrick and MacDonald, 2013). Health practices and adverse health outcomes are often individualised, vilified and equated with deficit, passivity and flawed choices, with this neglecting wider influences upon health (Kriznik et al., 2018). Indeed, previous research exploring public perceptions of health inequalities in the UK has highlighted the prominence of 'judgmental place attitudes' and 'perceived place stigma' in explanations for geographically patterned inequalities in health (Garthwaite and Bambra, 2017, p.273), and how discussions around the impacts of disadvantage and deprivation may act to reinforce stigmatised identities (Elliott et al., 2016; Smith and Anderson, 2018). Therefore, discussions around health and inequalities in health have the potential to be sensitive in regard to subjective experiences, personal contexts and life circumstances (Dempsey et al., 2016; Martins et al., 2018; Powell et al., 2018; Richards et al., 2015), with the social stigmas around inequality, place, poverty and disadvantage making it particularly challenging to research these topics with CYP experiencing such issues (Sutton, 2009). Nevertheless, we should not shy away from researching challenging and sensitive topics, especially at times when CYP's physical and mental health needs may be particularly acute (e.g., due to the impact of the Covid-19 pandemic (Leavey et al., 2020; Lee, 2020; YoungMinds, 2020)). Instead, efforts must be made to ensure the effective and safe engagement of CYP in research.

Developing Our Methodology

When our research project was devised, data collection was intended to be completed face-to-face, but due to the Covid-19 pandemic and the UK's national and local lockdown measures, we had to (re)design our methods to be 'socially distanced' and delivered online. We needed to think creatively and critically about how we could effectively involve and engage CYP in online discussions of inequalities in health, balancing participation with protection to mitigate any potential harm (Martins et al., 2018).

A qualitative approach to exploring perspectives on inequalities in health

We followed the approach of studies that have explored 'lay' perspectives on inequalities in health and similar sensitive topics which have typically adopted qualitative approaches, including interviews and focus groups (Backett-Milburn et al., 2003; Davidson et al., 2006; 2008; Sutton, 2009). Davidson et al. (2006) suggest that, whilst focus groups may provide less representative patterns of opinions than other methods, in researching sensitive topics such as health inequality, the support of other focus group participants may help to negate feelings of inferior moral status associated with inequality, and facilitate discussion of challenging topics. Thus, such approaches can provide a space for participants to talk about health inequalities, and lead to insights that may be obfuscated through other methods. Davidson et al. (2008) also argue that power imbalances, which may inhibit discussion around sensitive topics when interviewers are perceived as being from a more privileged position, can be alleviated in focus group settings, with social support, perceived shared positionality and prioritisation of 'lay expertise' encouraging people to discuss their perceptions of health inequalities.

In light of this when developing our methodology, we valued the importance of creating an environment that supported CYP to talk openly about what can be sensitive and complex issues. Our research consisted of three virtual focus groups with four groups of CYP aged 12-17, using video conferencing platforms (12 sessions in total). Our participants were recruited from four youth organisations across two local authority areas in the North of England. Our focus groups explored CYP's perspectives of what makes it easier or harder for some people to be healthy within their local places, CYP's understandings of inequalities in health and the social determinants of health, and CYP's key priorities in addressing the impact of social determinants on their current and future health. We used participatory concept mapping activities and open discussions to explore these topics. This approach allowed the focus on health and health inequalities to be led by the CYP themselves, giving us a better understanding of their concerns and priorities.

Moving data collection online

Moving data collection online due to the Covid-19 pandemic raised various practical and ethical considerations and challenges that had to be navigated to ensure effective and safe participation of CYP, for which reflection was crucial. Whilst online interviewing methods have been an emerging practice over recent years (Woodyatt et al., 2016), face-to-face approaches are typically seen as producing richer and thicker data, but this is being challenged (e.g., Deakin and Wakefield, 2014; Weller, 2017). During the Covid-19 pandemic and due to social distancing restrictions, virtual spaces and digital media have become the predominant medium for conducting qualitative research (e.g., Foley, 2021). The challenges of researching sensitive topics have been exacerbated in this shift, as many of the protections provided by face-to-face contact (e.g., ability to read body language; rapport building; recognising and responding to behavioural and emotional cues around distress; and, abilities to offer direct support (Cameron, 2005; Dempsey et al., 2016; Denscombe, 2017; Dodds and Hess, 2020; Elmir et al., 2011; Rodriguez, 2018; Seitz, 2015; Weller, 2017)) are diminished. Also, the ever growing realisation of the extent of inequalities in access to online spaces and technology (Honeyman et al., 2020; Lucas et al., 2020), means some CYP may struggle to participate effectively in online research.

We therefore had to think critically about how we could best use online methods to elicit rich data, whilst ensuring inclusivity and protection for participants when discussing potentially sensitive topics around inequalities in health. Here we share our reflections on planning and conducting online focus groups with CYP on the topics of health and inequality. We draw on Public Involvement and Engagement (PIE) work with youth organisations, undertaken before beginning our data collection, in which we explored how to make our methods inclusive and then piloted our methods. In the discussion that follows, we share our reflections as well as observations noted in our fieldwork and discussed in regular team meetings. We believe that regular reflection and researcher reflexivity was particularly useful throughout the process of our data planning and collection which had to be redesigned for online delivery, and possibly more importantly, was research on inequalities in health during a global pandemic. Our discussion focuses on two areas of ethical and methodological challenges which we worked to navigate through: i) rapport building and developing effective relationships at a distance, and; ii) confidentiality, safeguarding and providing support to CYP when online and negotiating challenging topics. We aim to promote wider consideration of the ethical and methodological challenges associated with conducting research with CYP online, and when discussing topics around health, inequalities and sensitive topics more broadly.

Our reflections

Rapport building and developing effective relationships at a distance

Limitations to virtual research include the physical distance between researchers and participants. Ideally, we would have spent time meeting and engaging face-to-face with CYP before beginning data collection, to build rapport, introduce the research and discuss participation and consent procedures, but due to lockdown and social distancing requirements we were unable to do so. The PIE work we undertook to refine our methods and approaches before beginning data collection demonstrated the impact of this lack of rapport building prior to data collection. Our first online PIE session was the first time the CYP had met the research team. Whilst this session ran smoothly, it felt more like an interview (participants responding to researcher questions) rather than a group discussion, with this inhibiting conversation flow and rapport. Reflecting upon this, and due to our inability to meet youth organisations and CYP face-to-face before data collection, we provided youth organisations with information to help them explain the research to the CYP, including a short narrated project information video which introduced both the research project and the research team (i.e. through using short biographies and photos). This aimed to provide a level of familiarity during the recruitment process (see Deakin and Wakefield, 2014), and was well received by both youth organisations and CYP.

We also recognised the importance of researchers meeting the CYP ahead of the data collection sessions, so where possible, we arranged initial online introduction sessions with participating youth organisations. The purpose of the introduction session was to introduce ourselves, the research topic, and the requirements and process of the research (consent forms, ground rules) as well as meet the CYP. This also provided CYP with an opportunity to ask questions to the research team. We found these introductory sessions to be effective in developing rapport and facilitating openness in participants. For example, one participating youth worker noted that their group was usually very talkative in their face-to-face engagement sessions, but had been surprisingly quiet during our introductory session. The participants, however, became much more engaged in the following data collection sessions, with one participant going from having their camera turned off and saying little, to turning their camera on and becoming much more vocal. These introduction sessions also permitted more productive use of time during data collection sessions, with less time required to cover procedural information allowing more time for warm-up and data collection activities. Indeed, we found that time spent on ‘warm-up’ activities at the beginning of online sessions were important to facilitate engagement and rapport building. Across all the groups we saw greater engagement and participation develop with each session. Our experience highlighted the increased importance of investing time in relationship building when online, to compensate for the (often taken-for-granted) benefits for rapport building associated with face-to-face contact.

A strength of focus groups, and an important reason for choosing this method, is the potential for participants to engage with and respond to each other, not just to the researchers' questions (Denscombe, 2017; Kamberelis and Dimitriadis, 2013). This can help to elicit more natural conversations by removing some of the researcher-participant power dimensions which can inhibit discussions (Davidson et al., 2006; 2008). However, online methods make it difficult to pick up on who wants to talk next and permit only one person to talk at a time, making it difficult to facilitate flowing discussions between participants. We reflected that such turn-taking prevented ‘side’ conversations that would likely take place in face-to-face group interviews that we believe may have helped with rapport building and social connection between participants and researchers. Our PIE work demonstrated that online groups with more than five participants can have an awkward characteristic of ambiguity and confusion around who should talk next; this stop-start discourse was a challenge, especially when CYP were waiting to say something important to them. This was in part due to the functionality of online platforms and that some participants took part using smart phones, with this reducing their ability to see all other participants on their screens, and thus reducing the ability to pick up on visual cues around who was going to speak next. Having a member of the research team monitor who wanted, or was trying to speak, went some way towards enabling CYP’s voices to be captured and not missed, as did promoting and encouraging the use of text and chat features of online platforms. Further, the importance to participants of having time and space to voice thoughts was evident, so we decided to use breakout rooms to enable smaller group discussions in our data collection sessions. This enabled the voices of all CYP to be heard and facilitated more in-depth discussions *between* participants when online. Feedback from participants in our data collection sessions highlighted that they particularly valued the breakout rooms for this ability to be heard. We had four members of the research team and at least one youth worker involved in each data collection session. We found this to be optimal as it permitted one lead and one assistant facilitator (who could monitor the chat and who wanted to speak) in each breakout session, as well as the presence of a youth worker who was able to provide support to participants if needed. Having two researchers in each breakout session also provided cover against connection issues for the research team and around ensuring audio recording of the session. Having smaller groups online provided more opportunity for the participants to speak and reduced the risk of their perspectives being missed. We found this to enable more effective relationship development through more fluid discussions.

A strength in our methods was the involvement of youth workers from our partnering youth organisations. Youth organisations are important gatekeepers to CYP (Fargas-Malet et al., 2010), and our partnering youth organisations were crucial in not only providing access to CYP, but also offering various levels of protection and support for online participation, which we as researchers would not have been able to provide. Recruiting through established organisations that already work with disadvantaged CYP proved extremely beneficial as they have existing relationships with the CYP, as well as extensive experience, knowledge and skills around engaging and supporting CYP. The presence of youth workers facilitated rapport building and the development of trust between researchers and participants. The relationships youth workers had with CYP helped to minimise online barriers around establishing effective relationships; for example, the youth workers existing relationships with the participants helped them to encourage participation in ways that were comfortable for individual CYP, such as the ability to respond by text or speak with their video off, and conversely gently encouraging CYP to turn on their cameras. Linked to this, youth workers were also crucial in identifying effective group splits for breakout rooms, which further helped with group dynamics by grouping together CYP who could support and encourage each other. The youth workers also acted as a catalyst for discussions during sessions and warm-up activities by prompting around topics they knew to be relevant to the CYP but had not been raised, and by using their personal relationships with CYP to help delicately approach potentially sensitive topics. The barriers around engagement and the importance of trust in facilitating engagement with marginalised groups have been noted (e.g., Flanagan and Hancock, 2010; Panfil et al., 2017), and we found such barriers to be exacerbated when online. Such challenges were highlighted in our work with an LGBTQ group who were initially reticent in discussions. In this group, the importance of researcher familiarity for facilitating engagement was evident, with a feeling of trust building with each session. The active role of the youth worker was also crucial in building trusting relationships and navigating discussions of sensitive topics, thus the experience of the youth workers helped overcome some of the challenges of online interactions.

Another important consideration when working online was CYP's transition to and from data collection sessions. We initially planned to use 'topic related' warm-up activities in our sessions to help prime and build into our main discussion, and to maximise time spent discussing the research topic. However, following PIE feedback and reflections, discussions with partnering youth organisations, and consultation with our project partners around conducting online focus groups, we designed our sessions to 'sandwich' the data collection session, with 'fun' (unrelated or lightly related to research topic) icebreaker and cool-down activities that involved participation from researchers as well as participants. Co-producing these session plans with partnering youth workers (particularly the warm-up and cool-down activities) was important as youth workers were able to make suggestions based on their experience of what would be most engaging for the CYP. The 'unrelated' nature of the warm-up and cool-down activities helped detach data collection activities and provided brief personal insights and opportunities to explore personalities, with this acting to help build relationships. Indeed, the 'trivial' aspects of introductions and warm-ups/cool-downs were useful in re-balancing some of the power dynamics involved in research with CYP (Davidson et al., 2008; Weller, 2017; Spencer et al., 2020) with this facilitating participation and engagement online.

Confidentiality, safeguarding and providing support to CYP when online and negotiating challenging topics

Privacy and confidentiality are fundamental to meaningful participation in research (Weller, 2017). However, though we asked participants not to repeat what was discussed to anyone outside of the group, the nature of focus groups is such that confidentiality cannot be guaranteed. Online discussions pose the additional risk of participants being overheard by people in close proximity to them or to other group members. Despite some research suggesting that CYP can feel comfortable being interviewed online in their own homes (Dodds and Hess, 2020), those living in overcrowded homes may feel uncomfortable talking about sensitive topics, especially if they lack a private space. To mitigate these risks we asked participants to use headphones if possible, discouraged them from talking about or disclosing anything they would not want other people to be aware of, and encouraged the use of chat features of online platforms as an alternative way to voice their thoughts and opinions. We considered the ethical issues of youth workers being present during data collection (i.e., around confidentiality/disclosures), and participants were made aware during the consent process of the protections and limits of confidentiality in group discussions with researchers, peers and youth workers.

Establishing a clear safeguarding procedure with each youth organisation was crucial for the protection of participants, and for researchers to feel comfortable that any issues or welfare concerns could be escalated and managed quickly. This involved having clear processes for addressing safeguarding concerns, managing problematic discussions and providing support to participants who may become distressed or go ‘offline’ unexpectedly. Being online meant it was difficult for facilitators to raise the attention of the youth worker or other research team members to discuss an issue without alerting all participants. Therefore, all researchers had the contact telephone number of the participating youth worker to alert them to any concerns or support needs that arose during data collection sessions. Working closely with youth workers and organisations provided benefits around participant protection as it put in place existing safeguarding procedures and structures we could use if needed. It also reassured us that the participating CYP had prior understandings of these procedures from their involvement with the youth organisations, and were comfortable participating with these in place.

Providing support to CYP during and beyond online discussions around sensitive topics

Due to the potentially sensitive and stigmatising nature of discussing inequalities in health, it was important for us to consider how participation may be distressing for those taking part, either directly through discussion of certain topics or through a form of vicarious trauma (i.e., adverse emotional feelings from discussions and disclosures of other participants (Elmir et al. 2011; Rodriguez, 2018)). In our PIE work we asked about how best to approach potentially sensitive topics around health and inequality; the CYP told us that no topic was off limits, but the way topics are approached (i.e not in a fatalistic, pejorative or blaming way) is important, as is making sure that CYP feel comfortable being involved in the discussion. Indeed, during one breakout session in which two participants openly discussed their personal experiences of mental ill-health and mental health services, it became clear that the third participant was listening, but contributing very little to the discussion. We sought to check that this young person was feeling comfortable before moving the discussion on. A post-session check-in with all three participants by the youth worker provided reassurance that the session had not negatively affected any participants. In subsequent sessions, the youth worker took participants' lived experiences into consideration when assigning individuals to breakout groups.

When using online methods it is crucial to consider how the setting influences the way in which support can be provided. Prior to the sessions we worked with participating youth workers to agree a system that would enable youth workers and participants to contact one another in real time during discussions, using text or private messages. CYP were able to signal privately if they needed support from the youth worker, and the youth worker was able to address any concerns about participants' wellbeing by checking how they were feeling and that they were happy to continue. This was particularly useful when participants stopped contributing to the discussion, turned their camera off or went ‘offline’ unexpectedly, as it provided the research team with confidence that participants were being appropriately supported during the sessions. We also developed a ‘distress protocol’ in consultation with our project partners, to manage the situation if a participant became upset or appeared to be struggling emotionally in a breakout group when the youth worker was not present. This set out practices of offering a group break, contacting the youth worker, and discussing the option to share their thoughts in a more private setting (e.g., breakout room or phone call with a youth worker or researcher).

It is also important to consider how participants may feel during and after data collection. We regarded the ‘after’ and ‘leaving’ of data collection sessions as being as important as the ‘beginning’ and ‘during’ to ensure participants were not left to manage upsetting thoughts alone following their participation. We were aware that, after discussions of sensitive topics online, participants may have left the session feeling emotional and potentially stigmatised (Starbuck et al., 2020). Our PIE work demonstrated that online sessions can feel as if they end abruptly, rather than the gentle drifting away after a session that is often experienced when face-to-face. We made sure that participants had the opportunity to discuss their thoughts and feelings with their youth worker and the research team, both immediately following the session, and at a later time if required with the participating youth workers conducting post-session check-ins with participants. The youth worker acted as a key protective element which helped compensate for the difficulty of ensuring that safeguards are in place from when conducting research with CYP at a distance.

Lessons learned

The discussions in this paper capture our lessons learned when working with CYP and researching sensitive topics in group interviews and online settings. These can be summarised as follows:

- Before any data collection takes place, public involvement and engagement (PIE) can help to identify any potential issues with the methodology and the dynamics of using online video conferencing platforms. It also provides an opportunity to explore how best to approach potentially sensitive topics with CYP.

- A close working relationship with youth organisations and youth workers can help build robust methodologies that encourage engagement and facilitate the safeguarding and protection of participants during and beyond data collection. Youth workers provide enabling and protective roles. In their enabling role: before data collection, they can help with recruitment, setting up the sessions, and coordinating the distribution of research materials; during the sessions, youth workers can facilitate the flow of the session, encourage engagement and prompt discussion topics. Youth workers also serve a protective role: helping to establish safeguarding procedures, acting as a source of support and contact for CYP and researchers during and after data collection sessions.

- Informal introductions between researchers and CYP are beneficial for establishing familiarity and rapport when online. Time should be factored in to allow this to happen before data collection. An initial information video serves a purpose beyond informing about the research, by serving as a way to introduce the researchers to the participants. In addition, having more than one data collection session is also beneficial for relationship building and CYP's engagement.

- For online discussions with CYP around sensitive topics, having more than five participants can make managing discussions and ensuring engagement challenging. Therefore, using smaller sized breakout discussions (five CYP and under) can promote discussions *between* participants that may not naturally take place in larger online groups. In addition, participants accessing online platforms through mobile phone have reduced capacity to view other participants, which can inhibit participation in larger groups.

- Having a lead facilitator, an assistant facilitator and a youth worker in each breakout session is optimal. This allows the lead facilitator to manage the discussions; the assistant facilitator to monitor the online chat, check who wants to speak next and screen share resources/prompts; and, the youth worker to provide advice and support to CYP (e.g., follow-up with participants who suddenly go 'offline'). This enables more fluid discussions, and ensures appropriate support processes are in place.

- When researching sensitive topics such as health and health inequalities with CYP online, it is important to consider the emotional impact discussions might have on participants. Off-topic warm-up and cool-down activities not only facilitate relationship building between researchers and participants, but when online also serve as important transitions into and out of sensitive data collection discussions.

- A nuanced understanding of the intersecting relationship between the topic, participant context, and research setting is crucial in approaching sensitive research (see also Powell et al., 2018). The topic of research discussion, the experiences and context of the participants (i.e., personal experiences, social positions), and importantly the setting of data collection (i.e, online, individual/group settings), are relative and all shape sensitivities. Therefore, all need to be considered and regularly reflected upon when planning and undertaking research with CYP.

Conclusions

There are ethical and methodological challenges of conducting online group interviews with CYP on potentially sensitive topics around inequality and health. We have discussed the challenges that online research with CYP present, particularly around how the ‘distance’ of online approaches makes participant engagement, relationship and rapport building more challenging, and how providing support in online discussions is more difficult and requires appreciation. However, building in activities to develop rapport with participants and establishing clear support and safeguarding protocols can help to ensure the safe, supportive participation of CYP and the generation of rich data through effective conversations with CYP around topics of inequalities in health whilst online.

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