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Ethics, rigour and agility of research and evaluation methods in a changing social and clinical context: Reflections from a psychosocial research centre on the implications of the COVID-19 pandemic

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ABSTRACT

The Centre for Psychosocial Research in Cancer conducts world-leading research and service evaluations to support well-being and quality of life amongst those affected by cancer. This paper reflects on how we adapted our research management and study methods during the COVID-19 pandemic, and the implications for ongoing research practice. We use four case studies to consider the benefits and challenges of adapting to remote approaches to research and evaluation delivery: maintaining high ethical standards and data security in evaluation projects with remote approvals; recruiting for and running online discussion groups to inform intervention development; designing and delivering an in-person intervention via video conferencing; and adapting a longitudinal qualitative study to focus on newly emerging issues. We reflect on how we can maintain quality and rigour when conducting remote research and evaluation, and how this can affect our experience as researchers. We also consider possible implications of the uncertainty created by the COVID-19 pandemic for the funding and design of future research and evaluations.

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Introduction

While remote methods of social science research have been increasingly used for some years (Keenoy et al., 2021), the COVID-19 pandemic drastically accelerated the adoption of these methods as social distancing measures meant that it was appropriate and responsible to conduct research remotely (Lupton, 2020). Between March 2020 and February 2021, the UK had three national lockdowns. Restrictions during these lockdowns included an order to stay at home, those most vulnerable to the impacts of COVID-19 told to shield, and schools (except for children of key workers and vulnerable children) and non-essential businesses closed (Brown et al., 2021). A phased exit from lockdowns was completed by July 2021 but nearly 3 years from the onset of the pandemic, the UK is still living with the economic, social, and health impacts (Finch & Tinson, 2022).

Many publications have identified challenges and benefits of using remote methods during the pandemic, such as the risk of excluding people without access to digital technologies versus the opportunity to involve a more geographically diverse range of participants (Douedari et al., 2021;

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Hall et al., 2021), how best to protect participants' privacy when they join research discussions from home (Hensen et al., 2021), whether an in-depth understanding of participants' contexts is possible when the researcher is based at home (Douedari et al., 2021; Ruppel, 2020), and the extent to which remote methods may limit the richness of qualitative data (Davies et al., 2020).

We now have the opportunity to consider the longer-term implications of having adopted remote methods for more than two years, and how this change in our research practice might impact decisions going forwards in what remains a relatively uncertain time (Nind et al., 2021). The cost-of-living crisis following hot on the heels of the COVID-19 pandemic means research funding may be affected (Cafolla et al., 2022), and people are faced with ongoing challenges which could influence their agency to engage in research (Andersen & Reeves, 2022). Prior to the COVID-19 pandemic, gaps in UK government funding for health research were often filled by charities which helped to ensure that disease burden was largely matched by appropriately allocated funding, especially for cancer, heart disease, stroke, and musculoskeletal diseases (Chinnery et al., 2018). However, charities may now struggle to continue the same level of funding for health research, such that the implications of possible cost-saving created by remote methods may bear even greater relevance for research practice going forwards. Therefore, it is important to step back and consider how we can optimise our methods from a funder and participant/contributor perspective.

We are particularly interested in how researchers, participants, patient and public involvement (PPI) contributors, and funders make decisions about and engage in remote research practices, and the implications in terms of planning future projects. Many of our core values for conducting rigorous, ethical qualitative research (McGrath et al., 2019; Nind, 2017) and meaningful public involvement (National Institute for Health and Care Research, 2019) have been developed in a world of largely in-person interactions, focusing on priorities such as building rapport with participants and contributors, reducing perceived power imbalances, promoting participant and contributor well-being, and considering how to facilitate benefits and perceived impact for those contributing to research. It is important to consider how our learning about translating these values to a wide range of remote settings could guide the development of research practice at this uncertain time. We seek to reflect on our learnings from four case studies of remote research methods during the COVID-19 pandemic, and consider the implications for conducting social research going forwards.

Case study 1 maintaining high ethical standards and data security in evaluation projects with remote approvals

Context

Research published during COVID-19 presents an equivocal response to how ethical standards should be maintained at a time of pandemic (Surmiak et al., 2021). Attitudes to research ethics are influenced by the individual beliefs concerning the relationship between ethical standards and the wider environment. Those seeing ethics as a constant, immutable ideal argue that the same standards should be retained regardless of changes in social context brought about by the pandemic. Others see COVID-19 as an opportunity to adapt, creating innovative approaches for ensuring delivery of research without compromising ethical standards (Surmiak et al., 2021). This case study addresses how we, as experienced healthcare evaluators, adopted the latter perspective, adapting ethical/data security processes to deliver projects as part of our Evaluation Programme.

Since 2018, our Evaluation Programme has evaluated interventions seeking to improve the delivery of personalised care for people living with cancer. Studies include evaluations of tools deployed in identifying and supporting patient identified need (e.g. the Patient Activation Measure), models of service configuration (e.g. delivery of integrated personalised care), and digital resources seeking to upskill health professionals in personalised care, prehabilitation, and rehabilitation (e.g. https://www.e-lfh.org.uk/programmes/prosper/). All evaluations required primary

data collection via qualitative interviews with multiple stakeholders (e.g. patients, health professionals, commissioners). The rapidly changing context of COVID-19 requirements, from national lockdown to a return to offices with social distancing, resulted in changes to the delivery of our evaluation and data management activities. How we adapted our recruitment and data handling processes while maintaining high ethical standards will now be explored.

Informed consent

Our traditional approach for gaining informed consent had been wet-ink signatures on hard copy consent forms. Typically, information sheets were posted or emailed to potential participants with reply slips/emailed confirmation of intention to participate. Potential participants were then given the opportunity to ask questions via telephone or email prior to a date for interview being arranged at which written consent was obtained.

At the first national lockdown on 26 March 2020, it was evident that face-to-face written consent prior to interview would not be possible. Substantial protocol amendments were thus required for ethical approval. Two options presented themselves:

- Written consent to be sent via a University-run secure data and information sharing site ('Safesend') in advance of the interview. Safesend allows files to be uploaded and temporarily stored on a system operated at the University's Data Centre. Uploaded data are held on SafeSend for up to 32 days, after which time they are automatically deleted: it is not a 'cloud' service.
- Verbal consent to be given at the start of the interview.

We initially trialled using the Safesend approach but abandoned this as participants found it a cumbersome process to use, requiring registration to the site, downloading, signing, and returning files. Several evaluations had an observation component for meetings and it was found to be unfeasible to collect written consent via Safesend for all meeting attendees. We thus adopted verbal consent. Our experiences reflected those of other researchers who similarly rejected 'unnecessary data trails' for digital signed consent in favour of more straightforward verbal routes (Newman et al., 2021).

Verbal consent was obtained by emailing information sheets and consent forms to potential participants, in which it was made clear that consent would be taken immediately prior to the interview. An opportunity to ask questions in advance was offered by telephone or email. As with other studies (Parkin et al., 2021), verbal consent was given by reading individual items to which participant responses were audio-recorded. Seeking verbal consent in this way provided a further opportunity to respond to participant queries in advance of the interview (Sy et al., 2020). Verbal consent was recorded separately from the main interview as this helped maintain anonymity through our data handling and management processes. As recommended in other studies (Lobe et al., 2020), verbal consent was stored separately from the interview data and in a separate file location, thus making sure any identifiable information related to the consent procedure could not be linked directly to the qualitative data.

Data collection and storage

We gave participants an opportunity to take part in a telephone or video-conferencing interview (e.g. Microsoft Teams) during lockdown. All participants opted for video-conferencing interviews. This had the advantage of enabling visual cues to be picked up, which would be missed in telephone or email-response interviews. Video-conferencing also helped to ensure safety by obviating the need for interviewers accessing participants' properties. It has been noted that video-conferencing has increased the risk of disruption and a lack of confidentiality for the participant where discussions

could be undertaken within earshot of others, particularly where headphones were not available (Roberts et al., 2021). While no such disruptions occurred during our interviews, it was not possible to assess whether interviewees were being more circumspect by being overheard by people 'off-screen'. We attempted to manage this potential problem by arranging interviews at times convenient to the participant when they were more likely to be alone.

As reported in other studies (Sy et al., 2020), we decided not to audio record interviews using the video-conference record option as it was not possible to separate audio from visual recordings. All interviews were recorded using an encrypted digital recording device. This had the added advantage of having a higher level of security than video-conferencing recordings can provide. Recordings were uploaded to a shared drive hosted on the University's Virtual Private Network immediately after the interview, to which only members of the evaluation team had access. As added security, all sound recordings of consent and interviews were stored in a password protected format. Sound files were then deleted from the recording device so there was no local storage of sound files on home computers, laptops, or other devices.

Lessons learned

Our experience of maintaining ethical standards and data security during the pandemic was that processes can be swiftly and effectively adapted to respond to a rapidly changing environment. The ethics committees and other regulatory authorities worked quickly with us to ensure data collection was not unacceptably delayed as a consequence of COVID-19. The revised consent and data handling processes yielded benefits that remain beyond the lockdown period: participants preferred the verbal consent procedure and the avoidance of unnecessary digital consent. This will likely improve recruitment rates given the relative ease of consent. Other benefits include cost savings to studies and a reduction in carbon footprint by removing the need to travel to participants for data collection. Finally, while others have highlighted the potential for exclusion due to digital literacy and reliable broadband internet (Newman et al., 2021; Sy et al., 2020), this was not as pronounced as expected, partly due to the improvements in video conferencing technologies during the pandemic. However, it is acknowledged that during national lockdown, recruitment was only possible by sharing the information sheet and consent form via email. This inevitably excluded those with no access to digital resources. As a consequence, following lockdown, we have continued to offer securing informed consent via post to those who wish to receive information in this manner in an attempt to limit digital exclusion. How to access those with little or no access to digital resources and reliable internet needs to be attended to.

Case study 2: recruiting for and running online discussion groups to inform intervention development

Context

This case study took place within a 5-year programme funded by Cancer Research UK to co-develop an online decision aid for people with a genetic predisposition to cancer. During summer 2021, two researchers and two members of our CanGene-CanVar patient reference panel (HW and JY), none of whom had met in person, planned and co-facilitated online engagement activities with people from our target population. From here, we refer to ourselves as 'facilitators' and the people who contributed to these activities as 'contributors'.

The purpose was to explore diverse experiences of living with a genetic cancer predisposition and discuss examples of decision aid support. We spoke to 19 contributors; most chose to take part in small online discussion groups, but three preferred a one-to-one phone call. The findings below present our reflections on how conducting these public engagement events online during the

COVID-19 pandemic influenced the facilitators' and contributors' experiences. We draw on facilitators' notes and anonymous feedback from the contributors via an online survey.

Implications for facilitators: planning appropriate and engaging activities for a remote setting

Our facilitators from the CanGene-CanVar patient reference panel brought essential insights about how best to conduct these remote discussion groups, based on their own experience of being public contributors. For example, they suggested that an icebreaker activity would be important to help build rapport at the start, and that it was important to share the questions that would be discussed in advance, including details of the icebreaker activity, to help people feel ready to contribute. For the icebreaker activity, we asked people to share snippets about themselves and although the facilitators chose examples unrelated to the research project, almost all contributors shared something about their own experience of living with a genetic cancer predisposition, which we feel helped build rapport through understanding shared experiences.

We chose to use open questions to explore people's experiences and their perceptions about e.g. risk communication and decision support. To facilitate discussion, we planned to use an online whiteboard to capture contributors' points in a brainstorm. However, during the discussion groups we decided against launching the whiteboard as we felt that it might disrupt the conversation by creating a more formal atmosphere, preventing people from seeing each other (especially for those using a small screen), and shifting the power dynamics towards the facilitator who uses the whiteboard to capture the group's thoughts. We considered asking a contributor to track the group's ideas on the whiteboard, but this would require the contributor to feel confident sharing their screen and using the whiteboard technology, which would need confirming in advance.

Implications for PPI contributors' experience

Table 1 shows the distribution of responses to the anonymous feedback survey for the 12/19 contributors who completed it. Contributors' responses indicated strong agreement that they were given enough information and that the aims of the discussion were clear. Contributors also agreed they had opportunity to contribute, and free-text comments suggested small group size was seen as important for this. We aimed for no more than three to four contributors per discussion group, as we felt a larger group might limit the chance for everyone to contribute within the hour we had. However, the group could become very small if some contributors did not join, for example, our first discussion group had only two contributors. While most people felt their contribution had been useful, we could perhaps increase confidence by communicating more specifically how the outcomes of the discussion group will influence the research.

Reflections on technology

Zoom video calls were used for the group discussions. Despite no guidance in advance about cameras, almost all contributors joined the call with their cameras turned on and it did not seem to

Table 1. Distribution of responses to the anonymous feedback survey for the 12/19 contributors who completed it.

Item	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
I was provided with enough information and support beforehand to feel prepared to contribute.	9	3	0	0	0
The aims of the discussion were clear.	8	4	0	0	0
The discussion was interactive and I had opportunity to contribute.	9	3	0	0	0
I believe my participation has been valuable.	4	8	0	0	0

affect group dynamics when one person had their camera off. However, we do not know how contributors felt about the use of cameras, or whether people feel comfortable turning their camera off once they have started with it on. Being able to see others on the call may help build rapport and willingness to share (Daniels et al., 2019), and we believe it helped us notice when someone wanted to talk. However, using cameras may make it harder for people to share personal stories (Daniels et al., 2019), and it has also been suggested that seeing yourself when taking part in an online video call can be distracting (McNamara & Bailenson, 2021).

The three contributors who chose a one-to-one chat instead of a group discussion all wanted a telephone call rather than using Zoom, suggesting it is important to allow people options for how they want to engage.

Lessons learned

We make a few suggestions for online public engagement activities going forwards:

- Asking contributors to complete optional socio-demographic questionnaires is important to enable researchers to consider to what extent they have heard from a diverse range of people, including those from less heard groups. In addition, when recruiting for remote public engagement activities, it is important to consider targeted approaches to reduce the risk of exclusion, for example, by asking organizations which represent less heard groups to advertise public engagement opportunities.
- Send contributors as much information about the format of the discussion and the questions you will be asking in advance.
- Acknowledge the choice to use cameras during an online call, possibly sharing a poll in advance allowing people to vote for cameras on or off. Let people know what will happen if some people have cameras on and some do not. Work with PPI contributors to discuss what would be most comfortable.
- Provide information about how to turn self-view off for people who do not want to see themselves.
- Another level of anonymity could be offered to contributors by letting them know how to change their username for online calls in advance if they would prefer others not to know their name (Schlegel et al., 2021).
- Provide specific feedback about how contributions will be used at the end of the session.
- Send a feedback survey which allows contributors to respond anonymously, and encourage suggestions for future events, e.g. optimal number of people, preferences for cameras on/off, preferences for mode of conversation (telephone, online) and reasons why.
- Further blogs or publications sharing experience of remote PPI engagement would facilitate learning about optimal methods, and how best to incorporate technology such as online whiteboards.

Case study 3 designing and delivering an in-person intervention via video conferencing; the SafeFit trial

Context

In April 2018 recruitment began for a large prehabilitation trial. It was a pragmatic, 2×2 factorial-design, multi-centre, randomised-controlled trial, with planned recruitment of $N = 1{,}560$. It was designed to establish the impact of a pre-surgical supervised, aerobic high-intensity interval, structured, responsive, exercise training programme, plus or minus psychological support on surgical outcomes, quality of life and well-being for individuals awaiting major cancer surgery (West et al., 2021). Interventions were conducted in community gyms (exercise) and cancer support

centres (psychological support). In March 2020, this trial was paused due to COVID-19 lockdown restrictions.

The participants enrolled in the trial were extremely disappointed that they could no longer continue with the trial and the research team were cognisant of major disruption to patient's treatment and follow-up care, as well as disruption to formal and informal support services. The team worked to consider how they might be able to support individuals affected by cancer while simultaneously answering an important scientific question. The outcome was SafeFit – virtual clinics to deliver a multimodal intervention to improve psychological and physical well-being in people with cancer; a COVID-19 targeted non-randomised phase III trial (Grimmett et al., 2021). This was made possible by contributions from a wide multidisciplinary team including, but not limited to exercise physiologists, dietitians, psychologists, research mangers, third-sector personnel, and service users.

Designing SafeFit : public contributor involvement and stakeholder collaboration

The rapid development of SafeFit involved collaboration with multiple stakeholders and public contributors. Initial conversations were held with Macmillan Cancer Support who agreed to pump prime the project, providing infrastructure to develop a registration page and administrative support to enrol participants. In order to deliver the trial, we required a critical mass of specialist cancer exercise instructors. This would ensure instructors had the necessary training to work safely with participants who were receiving or recovering from cancer treatments. We therefore collaborated with CanRehab Trust, a charitable organization which holds a register of approved personal trainers (CanRehab Trust, 2022). We convened with other stakeholders including a multidisciplinary team with expertise in exercise, nutrition, and clinical psychology, along with a trials team. We worked closely with a group of public contributors who agreed that a multimodal intervention including exercise, nutrition, and psychological support was most appropriate. They also trialled the study procedures and made recommendations to improve processes and patient communication. Regarding trial design, the most scientifically robust approach would have been to conduct a randomised controlled trial, allocating half of registered participants to a control or waitlist group. Given the circumstances at the time it was felt this would be unethical and a non-randomized design was agreed. The intervention was delivered by video conferencing.

Training the trainers and ensuring safety

To our knowledge, the exercise instructor workforce has not been utilized to deliver a multi-modal lifestyle intervention in cancer populations previously. To enable effective delivery of the nutrition and psychological support elements of SafeFit, a bespoke training package was developed for the cancer exercise specialists (CES). This included webinars designed and delivered by clinical specialists, along with supportive materials (see trial protocol for details). An online version of the Royal Society for Public Health accredited Making Every Contact Count Lite Healthy conversations skills training was also provided to facilitate behaviour change support (Public Health England, NHS England, & Health Education England, 2016). In addition, the CES completed Good Clinical Practice training and received instruction on completion of trial paperwork to ensure adherence to study protocol and ethical procedures. Safety of participants completing a distance-based intervention was paramount. A pre-session screening checklist was developed to monitor condition, medical contacts, medication, and COVID-19 status. A detailed escalation plan was also employed in case of acute medical events. If participants displayed COVID-19 symptoms the intervention was paused for a minimum of 2 weeks or until confirmed medically fit to continue. The intervention was also paused if anyone in their household displayed COVID-19 symptoms. Any cases where clinical review was deemed necessary were discussed at weekly clinical team review

meetings. A training manual was developed for CES detailing all compulsory training, screening and escalation processes, and trial paperwork.

Support throughout the SafeFit trial

Wellbeing of the CES was also a priority. Bi-weekly group video conference calls were held. These provided an opportunity to share best practice, answer queries regarding administrative elements of trial delivery. Importantly, they also enabled CES to share emotional experiences when working with participants under such challenging circumstances. A guest lecture from oncology palliative care nurses was also provided to support CES working with individuals with advanced and treatable but not curable disease. One-to-one supervisory sessions were also available at any time.

Lessons learned

Working at distance with people affected by cancer, often with accompanying health conditions and complex and/or advanced disease, was challenging. The robust screening and escalation procedures were essential, as was the highly skilled multidisciplinary clinical team. Some processes evolved during the trial, for example, inclusion of a medical pause if participants were scheduled for surgery or had periods where they were too unwell to engage with the intervention. This ensured equitable access to the full 6-month intervention.

Feedback from the CES emphasised the importance of the bi-weekly meetings, both for emotional support and to develop a community of practice. The vast majority of CES had never worked on a clinical trial before. We developed a buddy system where CES who had been working on the trial for several weeks/months supported new trainers, for example, advising on how to organise trial paperwork, which was often new to them.

The titrated nature of the intervention, with 3 sessions per week for the first month, weekly sessions months 2–3 and monthly sessions months 4–6 was designed to encourage participant autonomy to engage in the newly established lifestyle behaviours independently of the CES on completion of the trial. Both participants and CES found transition to monthly sessions challenging and we worked with the CES to develop strategies to facilitate this. CES also reported that it was difficult when participants had to pause participation due to ill health and the trial team were unable to share information of the participant's condition due to data protection regulations.

A formal process evaluation is planned to explore patient experience of participation. Anecdotal evidence through patient communication to the trial team during the study reveals some encouraging stories. Patients have referred to the intervention as a 'lifeline' during periods of isolation, with improvements in physical health and an appreciation of the emotional support offered during such a challenging time.

Publications detailing evaluation of the trainers' training package are anticipated by the end of 2022 and trial results end of 2023.

Case study 4 adapting a longitudinal qualitative study to focus on newly emerging issues due to the COVID-19 pandemic

Context

The context of this case study is a three-year project funded by Macmillan Cancer Support (Calman et al., 2020). The aim of the study is to understand and characterise the role and outcomes of self-management support for people living with cancer that is treatable but not curable. This is a growing group living with advanced cancer for a prolonged period of time, often years, who may be undergoing multiple rounds of treatments and supportive/palliative care, living with high

symptom burden and great uncertainty. There has only been recent recognition that this group has particular experiences and needs (Maher et al., 2015; White et al., 2021).

The study team leading the research included clinicians, academics, and a person with expertise by experience (who chaired our PPI group), this case study reflects our experience of modifying project delivery during the pandemic.

To understand this fluctuating experience over time and to understand how needs and experiences change, we planned to interview up to 30 people and those who support them (informal carers) up to three times over the course of a year. To do this, we employed longitudinal qualitative interviews to gain a rich picture of experiences. Recruitment was underway in July 2019 at two clinical centres in England and by the end of February 2020 we had completed recruitment of 30 patients & 22 carers and the first interview for all participants had taken place.

Implications for the study

On the 26 March 2020, the first UK lockdown measures legally came into force. This was a time of great uncertainty and worry for the whole population and had significant implications for research studies. Working from home was mandated and non-essential research studies were paused to allow NHS resource to be redirected to frontline health care. As a research team, we had to consider two challenging questions

Could the study be adapted to continue?

Should we continue?

We agreed that the study could continue as all participants had been recruited and no frontline healthcare resources would be required to continue the study. We knew that the project would need to adapt, we could not conduct interviews face to face as planned. People living with advanced cancer are potentially clinically vulnerable with high risk of complications from COVID-19 infection and indeed all of our participants received letters from the UK government advising them to shield. These letters detailed how people could protect themselves, including staying at home and limiting social contact, and how to access NHS services when required. This meant that we could not continue to collect data face to face as per the approved study protocol and this would require amendment to study procedures and ethical/governance approval if we chose to continue.

The question of whether we should continue was also complex. We recognised that continuing would mean a change of focus to acknowledge the uncertainty of the context and therefore may compromise the original aims of the study. There was also a question of the increased burden on those who had already consented to the study. Participants had committed to the project alongside living with advanced cancer. They wanted to be involved to tell their story and improve care for others in the future. We were aware that participants were living with a life limiting disease and that if we paused the study, some may not be able to participate at the restart of the project. However, as a research team we did not want to cause additional burden at an uncertain time.

As a research team, we decided that we could amend the study processes to ensure the safety of participants and researchers. We investigated a number of options but decided that telephone interviews would be the most inclusive option going forward, but we could offer an online video interview if this was preferred. The potential impact of the pandemic on delivering the research aims and outcomes was unclear. However, we recognized the opportunity to understand the impact of this unprecedented event on the lives of people living with advanced cancer could be beneficial to the cancer community, and this was agreed with the research funder.

Key to decision-making about continuing the study was the project PPI group, known as the ENABLE User Reference Panel. This group consists of people living with advanced cancer and carers and is chaired by a person with lived experience of advanced cancer. In March 2020, we held a meeting with the User Reference Panel to discuss the future of the study. Their strong view was

that we should allow our participants to decide whether or not to continue to take part and that it was their decision about whether the study was now too much of a burden. We worked with the User Reference Panel to adapt existing procedures, develop new ones to take account of restrictions and adapt the interview topic guide to address experiences of the COVID-19 pandemic and lockdown. Participants were contacted and all agreed to continue with phone interviews and with the new process for interviews.

An application went to the ethics committees and all governance committees to amend the processes of the study, with the evidence that we had discussed and agreed this with the User Reference Panel and participants. Approval was granted in a matter of days and we were able to continue the data collection as planned, but with all interviews conducted by phone (Radcliffe et al., 2021).

Lessons learned

- The nature of this longitudinal study and the stage we were at in lockdown meant we were able to adapt and continue with the study.
- The relationship participants had built with the study researchers was really important. The rapport and trust that the participants had in the team facilitated confidence in the change of data collection methods and we believe that the established relationship facilitated the collection of rich data during the telephone interviews.
- Participants were often staying at home for long periods, rarely leaving their homes which meant severely limited face-to-face contact with others. Therefore, far from viewing the phone interviews as a burden, they often valued them as a space to talk about their experiences, and in particular the experiences of living with cancer during lockdown, and as a way to have contact with others during the COVID-19 pandemic.
- The potential for digital exclusion is well documented and this was a risk with our PPI engagement. The team worked hard to support PPI members to get online; step by step instructions were sent, we opened online meetings 30 min early to resolve any connection issues well before the meetings started and latterly built-in social time as this informal discussion was initially missing in online meetings. It was a learning experience for the whole research team to make meetings accessible and gain valuable insights from our PPI members. All PPI members had a device to connect to meetings but in the future, we would include funding for devices for PPI members. Far from excluding people, online PPI meetings allowed us to build our group and include people from other parts of the UK who would have found it hard to travel to the University. Our PPI co-applicant presented her experiences of online PPI to a national conference and concluded that for people living with advanced cancer who may not be able to travel, it may be more accessible to hold meetings online.
- The ability of the research team to adapt quickly and see the potential in the situation ensured we made the most of this challenging context
- Building flexibility into any future research is key. This will allow us to respond effectively to the needs of our participants and to the equality, diversity, and inclusion agenda. Knowing that we can collect high-quality qualitative data remotely or in person will offer choice to participants. In the past participants have declined participation in interview studies because they did not want a researcher to come to their home or meet face to face. This study has given us the confidence to give participants options about participation. This will need to be costed adequately with any out-of-pocket costs to participants reimbursed.
- PPI contributors had an important role. Discussions with PPI contributors gave us confidence to take the study forward and helped provide clear justification that we could put forward in ethics/governance approval processes.

- Governance processes adapted quickly and allowed us to change processes much more quickly than usual.
- Dialogue with the funder was important to agree a way forward and agree additional project deliverables.
- The ongoing impact (two years on) of the COVID-19 pandemic on the experience of people living with cancer has made our data relevant in the current context (Radcliffe et al., 2021).

Discussion

These four case studies demonstrate the value of adapting research and ethical practices to enhance rigour and optimise the potential benefits of remote engagement, rather than merely attempting to transfer in-person methods to an online format. In each case, listening to suggestions from participants and PPI contributors was essential to ensure that adaptations were appropriate and relevant for those involved in research. Common themes to emerge across the case studies include reducing burden on potential participants in remote research (for example, by avoiding unnecessary technical challenges), ensuring participants feel comfortable and empowered to contribute (for example, by sharing information in advance and offering choices about how they take part), and reducing digital exclusion (for example, by including funding for devices to improve access, and considering targeted recruitment methods to improve inclusion).

The success of remote meetings, workshops, focus groups, interviews, and other forms of research or evaluation may raise questions for research funders about whether a rationale should be offered when participants and contributors do *not* have the option to engage remotely. Offering only face-to-face methods could exclude people who are not local, or are not willing or able to attend an event in-person. Will funders or ethics committees want explanations of the need for in-person meetings and the associated travel costs, which before the pandemic were often regarded as standard? To add to the ethical aspect of this decision, it has been posed that funds saved through conducting research remotely could be used to encourage participation from people often less heard in research, such as by hiring translators to support people who do not speak the language being used, or investing in working with community leaders to build wider connections (Roberts et al., 2021).

However, in-person interviews have been viewed as optimal where possible (Johnson et al., 2019), and some researchers are keen to return to in-person methods (Quail, 2020). The possible benefits are context-specific and difficult to quantify, but could include greater potential for rapport building through informal conversations (Lampa et al., 2021), a more natural setting for a conversation with the ability to pick up on non-verbal cues (Lampa et al., 2021) or follow-up with people who are hesitant to join group discussions, potentially easier facilitation of certain activities (Roberts et al., 2021), and overcoming barriers to digital participation (Lathen & Laestadius, 2021). Therefore, where possible, people should have a choice between engaging in research in-person or remotely, to improve inclusivity and help overcome digital exclusion (Litchfield et al., 2021; Vicary & Mathie, 2021). We are aware that those without access or digital literacy could not have taken part in any of these case studies.

Inclusivity could be further optimised by allowing flexibility in *how* people engage remotely, such as a choice between using online call systems (e.g. Zoom or MS Teams) or a telephone call, and at different times of day. This could be seen as akin to allowing the participant to choose the location for a face-to-face interview, which is best practice for in-person qualitative research (Tremblay et al., 2021). While it can be useful to select the optimal mode of remote engagement based on the research activity (e.g. using video calls for more complex discussions (Lampa et al., 2021)), allowing several different options for people to choose from may enable as many people to contribute as possible. Where appropriate to the research, additional options could be offered by allowing asynchronous engagement, such as WhatsApp messaging and/or recorded voice messages, for those who would prefer time to think about their response rather than take part in a live conversation (Manji et al., 2021; Nind et al., 2021). Asymmetric communication may also be less

burdensome than real-time interactions for some people, such as those with caring responsibilities. It would be worthwhile exploring why people choose a particular mode of communication (Zoom, WhatsApp, face-to-face, telephone), for example, is it based on familiarity with that technology, convenience, dislike of video calls, dislike of group settings, or something else? This learning could be used to inform planning of appropriate research methods and support for participants in future projects. Working with public contributors to decide how best to conduct research activities is important for ensuring that the methods chosen are appropriate and supportive for the target population.

Conclusion

The experiences of researchers, participants, and public contributors in conducting research activities remotely during the COVID-19 pandemic show some benefits to this form of working, with implications for the importance of flexibility in research approaches going forwards. Across our case studies, close collaboration with stakeholders and public contributors was essential for making appropriate decisions about research methods during the COVID-19 pandemic, and we propose that this remains central to research planning as we consider next steps. The case studies suggest ways to reduce burden on participants in remote research, but digital exclusion remains a challenge – especially if not considered at the outset when applying for research funding. An important aspect to consider in relation to remote research is how best to ensure the safety and well-being of those taking part and the researchers. In our work, it was essential to develop clear safety protocols with stakeholders.

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Helen White: Helen's lived experience of womb (endometrial) cancer and Lynch syndrome inspired her keen interest in patient and public involvement (PPI). She actively contributes to several PPI activities including membership of the Participant Panel at Genomics England, the National Cancer Research Institute (NCRI) Gynaecological Group and the Patient Reference Panel for CanGene-CanVar. Having identified a gap in PPI in womb (endometrial) cancer research, Helen established and runs 'Peaches Patient Voices' in association with Peaches Womb Cancer Trust, of which she is now a trustee.

Julie Young has been a member of the patient panel for Cangene-Canvar since early 2021, following a Lynch Syndrome diagnosis and surviving cancer. Julie has found the insight and determination to enjoy and be proud of being part of the research that is ongoing into the treatment and management of Lynch Syndrome and associated genetic conditions. In particular, how we can all respond and involve ourselves for the good of our own families and the public, to empower us all on how we can efficiently target hereditary illness with more success and gather data that gives hope to people.

Eloise Radcliffe is a research fellow at the University of Southampton in the Faculty of Medicine. She has a background in medical sociology and is a qualitative researcher with experience in a range of health services research and evaluation studies. Her research interests include older age and long-term conditions including stroke and cancer that is treatable but not curable.

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References

Andersen, K., & Reeves, A. (2022). The cost of living crisis is harming mental health, partly because of previous cuts to social security. *The BMJ*, *377*, o1336. https://doi.org/10.1136/bmj.o1336

Brown, J., Kirk-Wade, E., Baker, C., & Barber, S. (2021). *Coronavirus: A history of English lockdown laws*. Retrieved from https://commonslibrary.parliament.uk/research-briefings/cbp-9068/

Cafolla, L., Mulligan, A., & Willems, L. (2022). *Research Futures 2.0 a new look at the drivers and scenarios that will define the decade*. Retrieved from https://www.elsevier.com/__data/assets/pdf_file/0017/1250423/Research-Futures-2_0-Full-Report.pdf

Calman, L., Radcliffe, E., Berman, R., Demain, S., Restorick-Banks, S., Richardson, A., A., Wagland, & Foster, C. (2020). The ENABLE study protocol: Understanding and characterising the value and role of self-management support for people living with cancer that is treatable but not curable. *European Journal of Cancer Care (English Language Edition)*, *29*(2), e13217. https://doi.org/10.1111/ecc.13217

CanRehab Trust. (2022). CanRehab Trust: Actively living well through cancer. Retrieved from https://www.canrehabtrust.org/

Chinnery, F., Bashevoy, G., Blatch-Jones, A., Douet, L., Puddicombe, S., & Raftery, J. (2018). National Institute for Health Research (NIHR) Health Technology Assessment (HTA) Programme research funding and UK burden of disease. *Trials*, *19*(1), 87. https://doi.org/10.1186/s13063-018-2489-7

Daniels, N., Gillen, P., Casson, K., & Wilson, I. (2019). STEER: Factors to consider when designing online focus groups using audiovisual technology in health research. *International Journal of Qualitative Methods*, *18*, 1609406919885786. https://doi.org/10.1177/1609406919885786

Davies, L., LeClair, K. L., Bagley, P., Blunt, H., Hinton, L., Ryan, S., & Ziebland, S. (2020). Face-to-face compared with online collected accounts of health and illness experiences: A scoping review. *Qualitative Health Research*, *30*(13), 2092–2102. https://doi.org/10.1177/1049732320935835

Douedari, Y., Alhaffar, M., Duclos, D., Al-Twaish, M., Jabbour, S., & Howard, N. (2021). 'We need someone to deliver our voices': Reflections from conducting remote qualitative research in Syria. *Conflict and Health*, *15*(1), 28. https://doi.org/10.1186/s13031-021-00361-w

Finch, D., & Tinson, A. (2022). The continuing impact of COVID-19 on health and inequalities; a year on from our COVID-19 impact inquiry. *The Health Foundation*. Retrieved from https://www.health.org.uk/publications/long-reads/the-continuing-impact-of-covid-19-on-health-and-inequalities

Grimmett, C., Bates, A., West, M., Leggett, S., Varkonyi-Sepp, J., Campbell, A., Jack, S. Davis, J., Wootton, S., Shaw, C., Barlow, R. and Ashcroft, J. (2021). SafeFit Trial: Virtual clinics to deliver a multimodal intervention to improve psychological and physical well-being in people with cancer. Protocol of a COVID-19 targeted non-randomised phase III trial. *BMJ Open*, *11*(8), e048175. https://doi.org/10.1136/bmjopen-2020-048175

Hall, J., Gaved, M., & Sargent, J. (2021). Participatory Research approaches in times of covid-19: A narrative literature review. *International Journal of Qualitative Methods*, *20*, 16094069211010087. https://doi.org/10.1177/16094069211010087

Hensen, B., Mackworth-Young, C. R. S., Simwinga, M., Abdelmagid, N., Banda, J., Mavodza, C., Doyle, A.M., Bonell, C. Weiss, H. A. (2021). Remote data collection for public health research in a COVID-19 era: Ethical implications, challenges and opportunities. *Health Policy and Planning*, *36*(3), 360–368. https://doi.org/10.1093/heapol/czaa158

Johnson, D. R., Scheitle, C. P., & Ecklund, E. H. (2019). Beyond the in-person interview? how interview quality varies across in-person, telephone, and skype interviews. *Social Science Computer Review*, *39*(6), 1142–1158. https://doi.org/10.1177/0894439319893612

Keenoy, K. E., Lenze, E. J., & Nicol, G. E. (2021). Going remote: Implementing digital research methods at an academic medical center during COVID-19. *Journal of Clinical and Translational Science*, *5*(1), e189. https://doi.org/10.1017/cts.2021.865

Lampa, E., Sonnentheil, B., Tökés, A., & Warner, G. (2021). What has the COVID-19 pandemic taught us about conducting patient and public involvement remotely? Insights from a series of digital meeting observations. *Research Involvement and Engagement*, *7*(1), 73. https://doi.org/10.1186/s40900-021-00315-9

Lathen, L., & Laestadius, L. (2021). Reflections on online focus group research with low socio-economic status African American adults during COVID-19. *International Journal of Qualitative Methods*, *20*, 16094069211021713. https://doi.org/10.1177/16094069211021713

Litchfield, I., Shukla, D., & Greenfield, S. (2021). Impact of COVID-19 on the digital divide: A rapid review. *BMJ Open*, *11*(10), e053440. https://doi.org/10.1136/bmjopen-2021-053440

Lobe, B., Morgan, D., & Hoffman, K. A. (2020). Qualitative Data Collection in an Era of Social Distancing. *International Journal of Qualitative Methods*, *19*, 1609406920937875. https://doi.org/10.1177/1609406920937875

Lupton, D. (2020). Doing fieldwork in a pandemic (crowd-sourced document). Retrieved from https://docs.google.com/document/d/1clGjGABB2h2qbduTgfqribHmog9B6P0NvMgVuiHZCl8/edit?ts=5e88ae0a#

Maher, J., Velikova, G., & Betteley, A. (2015). Incurable, but treatable: How to address challenges for an emerging group. *BMJ supportive & palliative care*, *5*(4), 322–324. https://doi.org/10.1136/bmjspcare-2015-001047

Manji, K., Hanefeld, J., Vearey, J., Walls, H., & de Gruchy, T. (2021). Using WhatsApp messenger for health systems research: A scoping review of available literature. *Health Policy and Planning*, *36*(5), 774–789. https://doi.org/10.1093/heapol/czab024

McGrath, C., Palmgren, P. J., & Liljedahl, M. (2019). Twelve tips for conducting qualitative research interviews. *Medical Teacher*, *41*(9), 1002–1006. https://doi.org/10.1080/0142159X.2018.1497149

McNamara, D. S., & Bailenson, J. N. (2021). Nonverbal overload: A theoretical argument for the causes of Zoom fatigue. *Technology, Mind, and Behavior*, *2*(1). https://doi.org/10.1037/tmb0000030

National Institute for Health and Care Research. (2019). UK Standards for Public Involvement. Retrieved from https://sites.google.com/nihr.ac.uk/pi-standards/standards?authuser=0

Newman, P. A., Guta, A., & Black, T. (2021). Ethical considerations for qualitative research methods during the COVID-19 pandemic and other emergency situations: Navigating the virtual field. *International Journal of Qualitative Methods*, *20*, 16094069211047823. https://doi.org/10.1177/16094069211047823

Nind, M. (2017). The practical wisdom of inclusive research. *Qualitative Research*, *17*(3), 278–288. https://doi.org/10.1177/1468794117708123

Nind, M., Meckin, R., & Coverdale, A. (2021). Changing Research Practices: Undertaking social research in the context of Covid-19. *National Centre for Research Methods: Project report*. https://eprints.ncrm.ac.uk/id/eprint/4457/

Parkin, S., Neale, J., Roberts, E., Brobbin, E., Bowen, A., Hermann, L., Metrebian, N., Dwyer, G.J., Turner, R., Henderson, J., Kuester, L. and McDonald, R. (2021). Conducting rapid qualitative research amongst people with experience of rough sleeping in London during the COVID-19 pandemic. *Research Methods in Medicine & Health Sciences*, *2*(4), 124–139. https://doi.org/10.1177/26320843211061301

Public Health England, NHS England, & Health Education England. (2016). *Making Every Contact Count Consensus Statement. Public Health England, NHS England, Health Education England, London*. Retrieved from http://mecc.yas.nhs.uk/media/1014/making_every_contact_count_consensus_statement.pdf

Quail, N. (2020). The return of in-person qualitative research? Retrieved from https://www.linkedin.com/pulse/return-in-person-qualitative-research-nichola-quail/

Radcliffe, E., Khan, A., Wright, D., Berman, R., Demain, S., Foster, C., Calman, L., Restorick-Banks, S., Richardson, A., Calman, L. (2021). 'It feels it's wasting whatever time I've got left': A qualitative study of living with treatable but not curable cancer during the COVID-19 pandemic. *Palliative medicine*, *36*(1), 152–160. https://doi.org/10.1177/02692163211049497

Roberts, J. K., Pavlakis, A. E., & Richards, M. P. (2021). It's more complicated than it seems: Virtual qualitative research in the COVID-19 Era. *International Journal of Qualitative Methods*, *20*, 16094069211002959. https://doi.org/10.1177/16094069211002959

Ruppel, S. (2020). When your lab is the world but the world is closed down—social science research in times of Covid-19. Retrieved from https://elephantinthelab.org/when-your-lab-is-the-world-but-the-world-is-closed-down/

Schlegel, E. C., Tate, J. A., Pickler, R. H., & Smith, L. H. (2021). Practical strategies for qualitative inquiry in a virtual world. *Journal of Advanced Nursing*, *77*(10), 4035–4044. https://doi.org/10.1111/jan.15000

Surmiak, A., Bielska, B., & Kalinowska, K. (2021). Social researchers' approaches to research ethics during the COVID-19 pandemic: An exploratory study. *Journal of Empirical Research on Human Research Ethics*, *17*(1–2), 213–222. https://doi.org/10.1177/15562646211055056

Sy, M., O'leary, N., Nagraj, S., El-Awaisi, A., O'carroll, V., & Xyrichis, A. (2020). Doing interprofessional research in the COVID-19 era: A discussion paper. *Journal of Interprofessional Care*, *34*(5), 600–606. https://doi.org/10.1080/13561820.2020.1791808

Tremblay, S., Castiglione, S., Audet, L. -A., Desmarais, M., Horace, M., & Peláez, S. (2021). Conducting Qualitative Research to Respond to COVID-19 Challenges: Reflections for the Present and Beyond. *International Journal of Qualitative Methods*, *20*, 16094069211009679. https://doi.org/10.1177/16094069211009679

Vicary, P., & Mathie, E. (2021). *Involvement in Research: offer choice and don't let Zoom become the default: Involvement off-line during COVID*. Retrieved from https://arc-eoe.nihr.ac.uk/news-insights/news-latest/involvement-research-offer-choice-and-dont-let-zoom-become-default

West, M., Bates, A., Grimmett, C., Allen, C., Green, R., Hawkins, L., Jack, S., (2021). The Wessex Fit-4-Cancer Surgery Trial (WesFit): A protocol for a factorial-design, pragmatic randomised-controlled trial investigating the effects of a multi-modal prehabilitation programme in patients undergoing elective major intra?cavity cancer surgery [version 1; peer review: 2 approved with reservations]. *F1000research*, *10*(952). https://doi.org/10.12688/f1000research.55324.2

White, R., Stanley, F., Than, J., Macnair, A., Pethick, J., Fallica, G., Hounsome, L., Maher, J. (2021). Treatable but not curable cancer in England: A retrospective cohort study using cancer registry data and linked data sets. *BMJ Open*, *11*(1), e040808. https://doi.org/10.1136/bmjopen-2020-040808