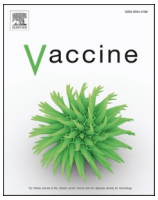
Vaccine 42 (2024) 126391

Contents lists available at ScienceDirect

Vaccine

journal homepage: www.elsevier.com/locate/vaccine



# Roles and responsibilities of participants, researchers, and the media in the communication of vaccine trials: Experience from the United Kingdom's first COVID-19 vaccine trial

Maia Patrick-Smith [a], Katherine Emary [b], Susanne H. Hodgson [c], Tonia M. Thomas [b], Rebecca te Water Naude [a], Arabella S.V. Stuart [b], John Henry [a], Marcus English [a], Maria Moore [b], Naomi Douglas [b], Andrew J. Pollard [b], Samantha Vanderslott [b,*]

[a] Medical School, Medical Sciences Division, University of Oxford, UK
[b] Oxford Vaccine Group, University of Oxford and NIHR Oxford Biomedical Research Centre, UK
[c] Jenner Institute, Nuffield Department of Medicine, University of Oxford, Oxford, UK

ARTICLE INFO

*Keywords:*
Vaccine trial
Trial participants
COVID-19
Media
Communication

ABSTRACT

*Background:* The media have played an important part in presenting arguments for and against vaccination. The potential for the media to influence public attitudes to vaccines is becoming increasingly crucial to address.
*Methods:* To understand the differing roles and responsibilities in the communication of vaccine trials we draw insight from a retrospective study of 349 survey responses and 102 semi-structured interviews conducted in 2020 with participants in the United Kingdom's first-in-human clinical trial of the Oxford-AstraZeneca COVID-19 vaccine.
*Results:* We found that trial participants had mixed views as to whether their participation conferred responsibility to communicate more widely about their trial experiences. Some participants perceived themselves to have an altruistic obligation to communicate to the media about the trial, and others felt that those who did share their participation had 'attention-seeking' motives. When participants did speak out they preferred to do so anonymously. Frustration was also reported with sensationalised and false media stories. Social media was viewed as a means to accelerate misinformation or as a force for recruitment and public education about trials. Participants were pleased to see trial investigators and trial team playing prominent roles in the media and this instilled confidence in the vaccine and the trial. We discuss these evolving roles and responsibilities for trial communication, concentrating on the views of participants about experiences, opportunities, and risks.
*Conclusions:* We argue that the pandemic has demonstrated the need for clinical trials to be made more transparent as a scientific practice that requires better public understanding and engagement. For high-profile vaccine trials we recommend; (1) explicit and comprehensive guidance aimed at all participants for interactions with the media; (2) prioritising having open and effectively expressed accounts of trial composition, processes, and participation; (3) offering support and a direct communication channel for journalists to report trials by utilising internal press officers to engage with journalists.

## 1. Introduction

During the COVID-19 pandemic in 2020 and 2021, the international press was preoccupied with a near-running commentary on activities related to SARS-CoV-2 vaccine research and development. The coverage by mainstream media (large mass news media such as newspapers and television) and on social media (websites and applications used for communicating online) of early COVID-19 vaccine trials was unprecedented, with public awareness of clinical trials reaching an all-time high [1]. Such[1] attention came amid an 'infodemic', described as a deluge of information that includes false or misleading information during an infectious disease outbreak [2,3]. Concerns arose that the internet and

* Corresponding author.
*E-mail address:* samantha.vanderslott@paediatrics.ox.ac.uk (S. Vanderslott).

[1] Also displayed by the increase in global news mentions in Google search trends, with a particular increase in mentions of 'trial participants'.

https://doi.org/10.1016/j.vaccine.2024.126391
Received 24 June 2024; Received in revised form 20 September 2024; Accepted 20 September 2024
Available online 1 October 2024

social media were serving as a vehicle to bring false claims about vaccines to large audiences [4].

Early on, calls were made by the public health community for trials to improve transparency so that they could be subject to public scrutiny, thus building trust in the processes and people behind vaccine development [5]. For example, trial protocols were made public, including in some instances the publishing of information sheets and informed consent forms.[2] As Harding et al. [6] argue, however, the provision of this information lacked accounts by those taking part in the trials, being overly focused on predefined scientific outcomes. Nevertheless, in the media the voices of trial participants were in high demand.[3] Relatable narratives have been an asset for public health messaging as they are often more effective than statistical data, and relaying participants' support for research was seen as a way to overcome misinformation and instil confidence in vaccine development [7]. However, little has been published regarding the experiences of early COVID-19 vaccine trial participants with the media.

Media focus was also placed on COVID-19 vaccine clinical trial teams and investigators. The unprecedented degree of attention created an unfamiliar working environment for many clinical researchers, and added to this was an expectation to provide constant up-to-date information to the media, public, and trial participants. As a result, trial investigators found themselves in prominent media roles, often needing to counter sensationalised and inaccurate stories, which could put the public perception of the trials and the vaccines tested at risk.

The focus on trials by the public and media during pandemics is very different to how more 'everyday' clinical trials are treated and there are therefore different risks and potentially higher risk acceptance in these settings for both participants and research teams [8]. In addition, there are risks related to the public and media spotlight, including a need to appear positively in media portrayals and when sharing experiences or views about the trial publicly or even to adopt the dominant hero narrative applied to those 'fighting' the pandemic, which only goes further to heighten the stakes involved [9]. Furthermore, social media presents new opportunities for trial communication, whether that is to publicise trials for participant recruitment or for participants to share their experiences. As Lynch et al. [10] argue, while there can be benefits for recruiting participants, sharing information of study assignments and test results on social media by participants could be a problem for trial integrity. A delicate balance is necessary therefore when democratising trials.

Using survey responses and interview transcripts from a qualitative-focused study of participants in the United Kingdom's pivotal first-in-human clinical trials of the Oxford-AstraZeneca COVID-19 vaccine, we discuss the differing roles played by, and the responsibilities of trial participants, the trial team and investigators, the media and social media in communicating about vaccine trials. Furthermore, by examining the experiences of trial participants in this unusual setting we make recommendations for media communication in future high-profile trials.

## 2. Methods and materials

In this paper we draw on findings from the mixed methods 'COVQUAL' (COVID-19 vaccine qualitative-focused research, https://vaccinesandsociety.org/project/covqual/) study [11–13], Ethical approval was provided by the University of Oxford Central University Research Ethics Committee (ref: R70147_CUREC).

COVQUAL explored COVID-19 participants' motivations for and experiences in taking part in the trials of the Oxford-AstraZeneca ChAdOx1-nCOV19 COVID vaccine (COV001 trial) [14]. We invited 770 participants screened in Oxford from this trial, who had indicated they could be contacted, to participate in the COVQUAL study during September and October 2020. A retrospective online survey was completed by 349 participants and 102 took part in semi-structured interviews. 84 % of survey participants (293/349) were vaccinated as part of the trial.

Research questions were wide-ranging about participation in the trial but concentrated on motivations to take part, opinions about the general risk and safety, media representations, experiences of being a trial participant during the pandemic, and attitudes to vaccines (see Supplementary Information for Interview Guide and Survey). Participants received guidance regarding engaging with the media after enrolment and associated negative press coverage (see supplementary information for Media Guidance). Interviews were recorded using handheld voice recorders and transcribed using an independent transcription company (WayWithWords, https://waywithwords.net). The transcripts were analysed by the COVQUAL team using NVivo 12.

A codebook was developed in an iterative fashion and regular meetings were held to check for consistency between coders. An inter-coder reliability test was performed, showing that agreement between 3 coders was excellent on average, with a kappa value of 0.75+. During coding, any text that related to the media was coded to a broad 'media' node. An experiential thematic analysis approach (Braun & Clarke, 2006) was used by one coder to further analyse the data within this node. NVivo was used to code the text to initial sub-nodes, and these were refined iteratively. The data was extracted using NVivo's framework analysis function and the nodes were grouped into themes and further refined.

The COVQUAL study took place at a time when no COVID-19 vaccine had yet been approved and as COVID-19 cases were continuing to rise. The level of media coverage and press contact for the University of Oxford was unparalleled, and 'Google trends' showed more than a 100-fold increase in United Kingdom searches for Oxford Vaccine Group (OVG), which has now returned to pre-pandemic levels. Interviews started soon after the trial had been temporarily paused in the United Kingdom on 6 September 2020 following standard processes to review an unexplained illness in a trial participant [15]. The first results from the COV001 Oxford vaccine trial were then published on 8 December 2020, after the interviews had been completed.

## 3. Results and discussion

To understand the differing roles and responsibilities for communicating about vaccine trials, we have organised our results into analytical categories that represent the views of trial participants towards different groups: (1) themselves and others as trial participants; (2) the trial team and investigators; (3) media and social media. The trial participants were those who took part in the trial; the trial team were the researchers, scientists, administrators and managers running the trial, including the principal investigators; and the media and social media covered all the outlets and platforms that were referenced in regard to stories and messages about the trial. Trial participants expressed their views about the motivations for communicating about the trial (for themselves and others); the impression of trial team communication; and how the media and social media represented and portrayed the trial.

These categories encapsulate the main roles we identified for communication, each with different beliefs, responsibilities and expectations. Clinical trial conduct has typically been structured around a distinction between healthy volunteers taking a relatively passive role as research subjects in comparison to the trial team who direct and organise the trial. This role also compares with patients taking part in treatment trials who may have stronger interests in the research and clearer identities as participants. As Mwale [16] has argued, healthy volunteers are often financially motivated but there are also other reasons for involvement in clinical trials including altruism, curiosity, and support of science. However, a pandemic is unique situation in that

[2] See <www.covid19vaccinetrial.co.uk/participate-oxford>.

[3] Which included some more high-profile participants, including journalists and celebrities.

participants have interests in trials by virtue of there being an ongoing disease threat. In addition, as Dawson, Earl, and Livezey [17] point out, trial participants during pandemics may be overconfident that substantial societal benefit will stem from the research. The uniqueness of the situation also applies to trial teams and the media/social media influencing their roles and relational interests.

### 3.1. Trial participants

Trial participants revealed nuanced views about their role in trial communication and their responsibilities around engaging with both mainstream and social media. They discussed whether sharing their participation in the trial had altruistic or attention-seeking motives; their experiences of engaging with the press, and concerns about the negative impacts of trial participants communicating directly with the public via mainstream or social media.

Some participants felt that their choice to share their participation in the trial had altruistic motives, with an aim to spread positive trial messaging by communicating their confidence in the process, as well as support for the development of vaccines. One participant was motivated to share their participation on social media to aid recruitment and raise awareness amongst friends in different cities where the trial was rolled out: *'I think I posted at the beginning on Twitter … when they tried to roll it out across other cities, I shared it because I had a few friends that knew that I'd done it. And they knew that it was happening in their cities'* (Interviewee). Another participant wanted to publicly demonstrate their support for vaccine development: '*I'm from a biopharma manufacturing background and have a good understanding of the positive power of vaccines – and I wanted to stand up and be counted to show others that vaccines are a positive force for good in the world*' (Survey respondent). However, several participants who discussed media engagement felt that they would only share their experiences if they were able to be anonymous: *'I think I would potentially agree to give an interview, provided that it was anonymous […] I don't really want to put my face out on the news'* (Interviewee). One participant outlined that this was because they were not interested in 'personal gain': *'The Guardian were looking to potentially have anonymous participants write in anonymously to talk about their experiences on the trial. […] I didn't give any details about who I was or anything like that. Because I thought if they're publishing an article it's about how good the trial is. How positive this is. I wasn't really interested in reaching out to the press for any personal gain.'* (Interviewee).

Some participants suggested that motivation for others sharing trial participation on personal social media accounts or more widely by engaging with the mainstream media could be linked to being 'attention-seeking' or seeking praise for being altruistic: *'I guess like a lot of reasons for people to participate or to tell people is because they want some kind of appreciation for participating. […] I think a lot of people do participate because they do think they do something good for society and I guess they want appreciation for it.'* (Interviewee). This was reflected in the survey responses with 44.7 % (156/349) of participants agreeing that they were motivated to take part by the hope that others would view their participation positively and 23.5 % (82/349) agreeing that they were motivated by wanting to tell others about their experience, although only 0.6 % (2/349) were motivated by wanting to report their experience to the media, which could have been for various reasons.

There are potential downsides to participant involvement in trial communication, particularly on social media. As Lynch et al. [10] note, there can be risks to participant safety and participants reported concerns about receiving too much journalistic attention or a negative attention from those hesitant about vaccines. 8.3 % of survey respondents (29/349) had concerns that they could be subject to high media interest due to their trial participation.

Of those participants who did engage with the press or shared their participation on social media, most had positive responses. In the open-ended survey responses, participants relayed their experiences of engaging with the press as a positive experience, with one participant revealing: *'It felt like a positive thing to do, although I really didn't expect it. Journalists tracked me down via Twitter. I didn't mind, and I never felt under any pressure and I didn't receive any abuse/unwanted attention.'* (Survey respondent). Another felt it was an extension of feeling positive about trial participation: *'Feel really positive about being involved & have been happy to share experience with the media'* (Survey respondent). The mainly positive reception could be specific to the context of a large, high-profile trial conducted during a global pandemic. Therefore, while this support of trials and the development vaccines might be celebrated during times of crisis, this appreciation may not be present in normal times. Negative experiences were also discussed, although these were not explained in much detail: *'I enjoyed every aspect of the trial, except that I received negative media attention due to my participation'* (Survey respondent). For one there was a worry of potential '*backlash/bullying from anti-vaxxers and conspiracy theorists*' (Survey respondent) and when another participant was asked if they had communicated about the trial on social media, they answered: *'I didn't for a long, long time. I think purely because I didn't want any backlash… Especially during the beginning stages where I didn't really know what was going to happen to me. I kept it quite quiet'* (Interviewee).

Many noted from sharing messages on social media that it seemed that others saw participants as 'brave' and were grateful for their involvement. Some participants even found that family members shared details of their participation on their behalf, it being unclear whether this was done with consent, however those posts expressed excitement and pride. See Box 1 for three interviewee responses to the interviewer question on this, noting how it was family members who shared information.

Some participants saw it as a responsibility to protect trial privacy not to share messages on social media nor speak to the press, which may have been influenced in part by the particularly high-profile nature of this trial: 'It's too big a trial, it wasn't for me to go public on my experience of it. It wouldn't have served any purpose at all' (Interviewee). This sense of responsibility to ensure a solution to COVID-19 is noted as part of the exceptional circumstances of a global pandemic by Leisinger and Schroeder [18]. Some felt that media engagement was not within their remit, as their potential lack of understanding of the vaccine or the trial could generate misinformation, damaging the research programme's reputation: *'I think if participants are just talking about a trial that they didn't really fully understand, there's a danger of misinformation. And it's obviously not done maliciously, it's just where people have not really understood the ins and outs of everything'* (Interviewee). Others misinterpreted a recommendation from the study team to not engage with the media as strict prohibition from making contact with the press and had even thought they had signed an agreement to this effect, when this was not the case. Participants did, however, report that they were pleased the trial team had provided guidance on interacting with the media.

In summary, the trial participants viewed their own communication role as potentially useful to spread positive messaging about the trial but also acknowledged risks in doing so for trial privacy, in the potential for backlash or communicating the wrong information,

### 3.2. Trial team

Participants discussed their views about how the trial team engaged with the media. Some mentioned specific trial investigators that they had seen, most often referred to was Professor (now also Dame) Sarah Gilbert: *'I think it's important to say that Professor Sarah Gilbert, …when you see her on the TV, she's very reassuring and trustworthy. So, I think that gave us confidence that this felt like someone who knew what she was talking about'* (Interviewee). As described in the *Financial Times*, she became *'the public face of the project'* [19].

In Gilbert's book *Vaxxers* [20] written with Professor Catherine Green, the head of the clinical biomanufacturing facility that produced the first batches of the Oxford-AstraZeneca vaccine, she noted the high

**Box 1**
Family members sharing details about participation in the trial online.

Interviewer: *'Have you ever communicated about the trial on social media?'*
Interviewee: *'Not personally. I think my mum probably put something on, I think, when she was like, [participant name] just got a vaccine.'*
Interviewee: *'No. I think my mum did once, but I ignored her. So, only on Facebook… I think a couple of friends just said, wow that's brave. But that's about it.'*
Interviewee: *'I think my sister might have done a post just to say she was proud of me or something like that when I first went. But no, because I think we were told not to or just to be careful of the press and stuff like that, so I didn't really openly broadcast it.'*

media pressure and public scrutiny of developing the COVID-19 vaccines: *"Working things out as we went along, we were learning how to navigate the communications challenges of being part of the 'only story in the world'…"* [20]. These views were repeated by Teresa Lambe, co-developer of the vaccine, who recounted: '*The search for a vaccine took over my life. I've never worked harder'* [21]. Participants echoed these sentiments, recognising that although there was a large amount of pressure *'to save the world'* (Interviewee), the scientists were able to be measured and *'acted very responsibly'* (Interviewee).

Overall, the trial team and scientists came across well to participants. They were praised – for instilling confidence and reassurance in the vaccine: *'I have every confidence in the way the trial's being run'* (Interviewee) – and through their honesty: *'I think they've been very honest all the way through about what stage the trial is at and what still needs to be done and the realistic chances are of it working or not working'* (Interviewee). Several participants also remembered specific statistics mentioned in interviews that investigators gave to the media. They recounted that when asked to give an estimate of the likelihood of the Oxford vaccine being successful, Gilbert said that she was 80 % sure it would work. This number appeared to have stuck in the minds of some, with one participant even thinking that it had been part of the literature given to them by the trial team at screening and another who thought giving this figure raised expectations too high: '*Think some mistakes were made early on in playing up expectations for the timeline/probability of success of vaccine trials (e.g. talking about this being available millions of doses by Sept 2020, 80% chance of success). don't know how much driven by govt/pharma hype but don't think this was helpful for public understanding.'* (Survey respondent).

The communication about trial events, and specifically pauses (when a trial is temporarily paused by investigators to review safety data), was a contentious issue with reports of receiving information about the trial from the media before being informed by the trial team. For some of the participants this was a problem, as they would have liked some warning. They described the earlier press coverage as *'The only negative side'* (Interviewee) and being *'irked the press has seemed to receive more information'* (Survey respondent). However, many also appeared to understand that because the media moves fast that it was often very difficult for get the information out to them before the press were made aware: *'I think it would have been better if we'd heard that by communication rather than on the media first, but I guess the media go at their own speed'* (Interviewee). Some did in fact credit the trial team with efficient communication about events related to the trial and were satisfied that they were told at a similar time to the public: *'When there was significant public interest when the trial was put on hold, participants were informed by email, which was very important to me, as participants have put themselves at risk and should be told contemporaneously with the general public, not later'* (Survey respondent). It should be noted that communications to trial participants are formal processes and often require approval to be obtained from the ethics committee and the regulator, especially if aspects of safety are involved. The media is able to communicate much more quickly about trials as no similar procedures need to be followed.

More generally, participants had varying ideas about the level of information that should be released to the media about the trial, including the view that either too little or too much information was shared with the press. Some participants felt that too much access to the details of the trial encouraged the media to report on 'non-news', for example, applying specific significance to trial pauses in news stories that would not be highlighted during a clinical trial outside of a pandemic setting: '*And because the case was highlighted, something which never would have been highlighted for any other study, I thought it was really negative. And it was unnecessary, and […] would not have been newsworthy in any other study at all. […] I don't believe it should have gone to press at all.*' (Interviewee). Others felt that the opposite was true, and that transparency and regular updates from the trial team were important to retain interest and public confidence, with more basic information about how clinical trials work and likely timelines for a successful vaccine serving as an educational service to the public: '*I think the trial, to their credit, they've been really transparent about the results and about when they had to pause the trial and about why that was important to pause the trial. […] I think all it does is it exposes a process that people don't know anything about, so actually it's helped people to be educated a little bit about how medicines and vaccine trials work*.' (Interviewee).

Overall, in terms of the trial team, participants recognised the high-pressure environment that the investigators were working under and were generally satisfied with the communication. They reported a high level of trust in the trial, and especially in the investigators. However, many requested clearer advice about media involvement and advanced knowledge about trial pauses and note-worthy events.

### 3.3. Media and social media

The unparalleled media and social media coverage surrounding COVID-19 vaccine trials elicited a variation of views from trial participants about how information about the trial was reported on. There were positive or negative perceptions of media coverage, as well as views on sensationalism and misinformation. The increased coverage meant a greater attention paid to the development of a vaccine and solution to the pandemic generally, which included high profile personalities. For example, participants spoke of the influence of high-profile personalities in relaying the importance of having a COVID-19 vaccine such as Bill Gates: *'I heard a talk by Bill Gates and realise the importance of the vaccine in getting us out of a pandemic. I felt completely powerless and want to do something to help.'* (Survey respondent) or finding figures such as Captain Tom Moore, who raised money for National Health Service charities, inspirational: *'I couldn't cope seeing all the deaths of vulnerable people. I was also inspired by Captain Tom Moore.'* (Survey respondent).

Participants were concerned about irresponsible reporting by mainstream media, motivated by profit rather than public health goals, and expressed anger and frustration that the reputation of the trial was jeopardised: *'Media in general, not just newspapers, are incredibly irresponsible… and they need to work harder at presenting it more accurately'* (Interviewee). Most participants felt the mainstream media sensationalised stories – with news being presented as more extraordinary than it was – particularly with regards to the trial pauses: '*Obviously news, the more sensational it is, the more they'll sell. So, you can't really trust and news service to give clear information because they'll want to tell you the worst part, so people will buy the newspapers*' (Interviewee). Others had not seen many examples of irresponsible reporting but added that they avoided certain news outlets for this reason. Still, researchers have reported that news sensationalism during the pandemic was low overall [22].[4]

[4] While also noting politically centre and left news outlets in Canada and the United States had greater sensationalism than media outlets in the United Kingdom.

Nevertheless, such sensationalism was reported to have caused public anxiety and mistrust early in the pandemic [23], and Dudley et al. [24] caution that sensationalism exacerbates even minor flaws in scientific messaging.

The unusual amount of media interest in this particular trial was highlighted by participants, who felt that trials are not usually so high-profile and hence the media are not informed about how to report on the technical details: *'I think it's very difficult to report on science because it very quickly gets very technical. I think they've had to somehow dumb it down a bit. They've had to either say it's been going well or badly'* (Interviewee). Some spoke about a general lack of scientific understanding amongst journalists and the media particularly when it came to trials and gave examples that they had seen in the news, such as describing participants as 'guinea pigs': *'It was either the BBC or the Guardian that used the word guinea pigs, which obviously is very common. […] (I)t's not a fair way of describing participants because informed consent is such a massive deal, and we go to such huge lengths to make sure that participants are well informed and understand their rights to withdraw, and all that sort of thing'* (Interviewee). As Dudley et al. [24] have also argued, members of the media who focus on science topics should thus receive specialised training and press officers should be better integrated with research teams to improve understanding. Some participants felt the lack of understanding contributed to an unrealistic idea of how clinical trials work for the public, impacting the perception of trial safety. For example, one participant thought that *'the assumption for most people would be that it was the live vaccine'* (Interviewee) and felt there was nothing to contradict this in the media, corresponding with a sense of an intrinsic lack of scientific understanding. While there was a lot of media coverage about the vaccine itself, how it worked and how it was developed, perhaps lacking was a corrective stance when incorrect information was relayed.

Regarding social media, participants had a range of views about its role in shaping public perception of trials. The views fell broadly into two camps: those who thought social media is a vehicle for misinformation, and those who thought it can be a force for good. There was commentary around how professional misinformation can be on social media and the increased possibility of large-scale dissemination: *'And a lot of it does look very, very professional. …Someone can put up something I think that looks almost like a clinical trial unless you look at it properly. When you start reading that it was published in the Journal of Hippy Happiness or something, you go oh actually that's not a real journal, is it? But the way they write it up, it's very, very persuasive'* (Interviewee). For example, one participant felt social media has had a negative impact on trial communication and that there should be no role for it at all *'I definitely don't think social media is a good place to get news on this trial or discuss it or anything, really'* (Interviewee), and others commented on how the information about trials on social media is untrustworthy *'I just take anything that appears on social media is an untruth'* (Interviewee).

A specific incident discussed by multiple participants was the fake news story about the death of the first participant to receive the vaccine, which was circulated on social media and picked up by mainstream news outlets before being shown to be false [25] (see Box 2). Most participants who mentioned this story during interviews had not believed it, although they were concerned about the impact on the trial, with one participant suggesting that it demonstrated the strength of some people's opposition to the vaccine: *'I think that suggests that there are people out there that are quite worried about it because they feel the need to make up stories like that in order to get their point across'* (Interviewee).

For others it brought forward concerns that they might also face backlash: *'I have been very careful who I have told about being in the vaccine trial since an a [sic] member of the initial trial had negative press'* (Survey respondent). Another offered that participants could have been better prepared through information provided, including specifically about media appearances which had been organised by the trial team: *'I was the 4th person to have the vaccine and was filmed. I believe more information could have been given about the possible negative consquences [sic] of being filmed. For example there was a fake news article which said that the person who was vaccinated first had died. Although this article wasn't about me I would have liked to have been warned that these articles could be made using the footage taken'* (Survey respondent).

Nevertheless, social media was felt to be a positive for some participants as a method of educating others *'Not all of my friends online or on social media were completely trusting of the vaccine or knew a lot about it. So I'm grateful that I had the opportunity to talk to them about it before they could latch onto some piece of misinformation, and then start panicking about it.'* (Interviewee) and for trial recruitment *'I posted at the beginning on Twitter. I was doing it, when they tried to roll it out across other cities'* (Interviewee). Notably, 31.5 % (110/349) of survey respondents heard about the opportunity to take part in the trial via social media, the majority on Facebook (66.4 %, (73/110)) or Twitter (23.6 %. (26/110)). It is unclear whether this was from interacting with the official recruitment material circulated on social media channels by the trial team or from seeing information about the trial on individual user accounts. One participant spoke of how social media could counteract fake news and misinformation, having witnessed users who shared a fake news article being called out by other users: *'I think it's been represented quite well, but I did see one cheeky headline. I think it was The Washington Post the other day who just put a headline out, which is, participant dies in Oxford vaccine trial. And it turns out that he hadn't even had the injection yet or he'd had the placebo or something like that. I think that was represented quite poorly, but I think it was being called out on Twitter for doing that.'* (Interviewee). The potential for social media to spread misinformation, therefore, is influenced by its users, who can amplify or counter proposed information depending on their own beliefs.

What the media and social media could offer for trial representation, therefore, was the potential for sensationalism and misinformation, but also to counter false claims, educate more broadly about trials and aid recruitment.

## 4. Conclusion

We have shown how trial participants have considered their roles and responsibilities and that of the trial team, the media and social media in communicating about trials. The representation and portrayal of trials in the media will continue to be a crucial means of communicating about vaccines and their testing post-COVID-19, particularly in the context of future outbreaks and pandemics. We have discussed how the positions of different parties involved in communicating about trials are evolving but also highlighted some points of contradiction. Trial participants viewed motivation for communicating as either altruistic or attention-seeking, where engagement with the media could be useful but also held risks. The trial team was seen as trustworthy and knowledgeable but slow in keeping participants informed before the media. The media could both be sensationalist or informative, and social media a force for misinformation or an educational tool. These very varied ideas about roles and responsibilities convey the high potential for positive or negative effects of trial communication. From our study,

**Box 2**
Fake news about the first trial participant.

On 25 April 2020, microbiologist Dr Elisa Granato, the first participant in the Oxford-AstraZeneca COVID-19 vaccine trial, woke up to the news of her death [25]. This viral news story fed into concerns that the vaccine was unsafe. Granato confirmed her 'alive' status on Twitter (now called X), however, for some this rebuttal was even further evidence of a conspiracy that was designed to conceal she had died. In response to ongoing speculation Granato then released a video to 'prove' she was alive, but the authenticity was questioned. The Department of Health and Social Care also announced via Twitter that her death was 'completely untrue'. Granato continued to receive messages from those who believed her death was a state-sponsored cover-up months later, adding to the misinformation that can undermine confidence in COVID-19 vaccines (ibid.).

while trial participants views are varied, there are some touchpoints, however, that have been highlighted as being important to communicating about trials involving the different parties discussed that could build on the positive possibilities for trial communication.

We have three key recommendations for future media involvement of trial participants. The pandemic has demonstrated the need for clinical trials to be made more transparent as a scientific practice that requires a better public understanding and engagement. Therefore, media coverage of trials needs to be taken seriously in how progress and results are reported, especially to address poor information related to uncertainties, rumours, and myths. A better understanding of the experience of participants in clinical trials could help the media and trial teams to be clearer about what risks, benefits and vested interests are involved, in order to counter public misinformation. Thus, the first recommendation is for explicit and comprehensive media guidance for all participants to encourage awareness of what is discussed in the media and posted on social media, and what consequences it might have. Second, is to prioritise having open and effectively expressed accounts of trial composition, processes, and participation. A way to do this would be to identify participants and investigators early in a high-profile trial who can receive media training for their benefit and to optimise information about the trial, with participants giving feedback and input to the trial team and investigators. Then media and social media as a vehicle to express views could be further harnessed to allay concerns and communicate experiences of being vaccinated from well-informed and relatable voices. Third, is to offer support and a direct communication channel for journalists to report trials by utilising internal press officers to engage with journalists, providing tailored materials and consistent messaging across investigators.

There are also further related roles that also could be considered for future media engagement in trials, including the additional role of media in trial recruitment, role of press offices for academic centres, and the role of trial investigators giving press interviews to inspire trust and confidence (all of which does not often happen actively). There is value for instance in having ongoing institutional press officers and dedicated institutions set up to mediate discussions between researchers and journalists, and can offer valuable insight for media communication. The Science Media Centre, a charity which was set up in 2002 is one example of an institution that took on a key function during the pandemic to support journalists, researchers, and press offices to provide evidence-based information and high-quality media coverage (see https://www.sciencemediacentre.org). As public interest and transparency in trials have increased since the COVID-19 pandemic, it is to be expected that ongoing consideration about the most effective method of trial communication for the benefit of all stakeholders will be needed in the future.

## CRediT authorship contribution statement

**Maia Patrick-Smith:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation. **Katherine Emary:** Writing – review & editing, Supervision, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Susanne H. Hodgson:** Writing – review & editing, Supervision, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Tonia M. Thomas:** Writing – review & editing, Project administration, Formal analysis, Data curation. **Rebecca te Water Naude:** Investigation, Formal analysis, Data curation. **Arabella S.V. Stuart:** Writing – review & editing, Project administration, Investigation, Formal analysis, Data curation. **John Henry:** Writing – review & editing, Investigation, Formal analysis, Data curation. **Marcus English:** Investigation, Formal analysis, Data curation. **Maria Moore:** Investigation, Data curation. **Naomi Douglas:** Project administration, Investigation. **Andrew J. Pollard:** Writing – review & editing, Supervision, Resources, Project administration, Conceptualization. **Samantha Vanderslott:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Investigation, Formal analysis, Conceptualization.

## Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: All authors except SV have worked or are currently working on the UK clinical trials of the SARS-COV-2 candidate vaccine; ChAdOx1 nCoV-19. AJP is the chief investigator of these clinical trials.

## Data availability

Data will be made available on request.

## Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.vaccine.2024.126391.

## References


[1] Sathian Brijesh, Asim Mohammad, Banerjee Indrajit, Pizarro Ana Beatriz, Roy Bedanta, van Teijlingen Edwin R, et al. Impact of COVID-19 on clinical trials and clinical research: a systematic review. Nepal J Epidem 2020;10(3):878. https://doi.org/10.3126/NJE.V10I3.31622.

[2] Buchanan Mark. Managing the Infodemic. Nat Phys 2020 16:9 2020;16(9):894. https://doi.org/10.1038/s41567-020-01039-5.

[3] Zarocostas John. How to fight an Infodemic. Lancet 2020;395(10225):676. https://doi.org/10.1016/S0140-6736(20)30461-X.

[4] Loomba Sahil, de Figueiredo Alexandre, Piatek Simon J, de Graaf Kristen, Larson Heidi J. Measuring the impact of COVID-19 Vaccine misinformation on vaccination intent in the UK and USA. Nature Human Behaviour 2021 5:3 2021;5(3):337–48. https://doi.org/10.1038/s41562-021-01056-1.

[5] Mahase Elisabeth. Covid-19: Vaccine trials need more transparency to enable scrutiny and earn public trust, say experts. BMJ 2020;371(October). https://doi.org/10.1136/BMJ.M4042.

[6] Harding Emma, Robinson Philip, Wilson James, Crutch Sebastian J, Mummery Catherine J. Injections of Hope: supporting participants in clinical trials. BMJ 2021;375(December):e066851. https://doi.org/10.1136/BMJ-2021-066851.

[7] Wentzell Emily, Racila Ana Monica. The social experience of participation in a COVID-19 Vaccine Trial: Subjects' motivations, others' concerns, and insights for vaccine promotion. Vaccine 2021;39(17):2445–51. https://doi.org/10.1016/J.VACCINE.2021.03.036.

[8] Weijer Charles. COVID-19 Human Challenge Trials and Randomized Controlled Trials: Lessons for the next Pandemic. 2024. Doi: 10.1177/17470161231223594, January. doi: 10.1177/17470161231223594.

[9] Lipworth Wendy. Beyond duty: medical 'heroes' and the COVID-19 pandemic. Journal of Bioethical Inquiry 2020;17(4):723–30. https://doi.org/10.1007/S11673-020-10065-0/METRICS.

[10] Lynch Holly Fernandez, Largent Emily A, Joffe Steven, DeMichele Angela M. Protecting clinical trial participants and study integrity in the age of social media. Cancer 2018;124(24):4610–7. https://doi.org/10.1002/CNCR.31748.

[11] Thomas Tonia M, Hodgson Susanne H, Emary Katherine, Patrick-Smith Maia, Naude Rebecca Te Water, Stuart Arabella SV, et al. The collective voice of early phase COVID-19 Vaccine Trial participants: insights for improving confidence in novel vaccines. Hum Vaccin Immunother 2023;19(1):2203023. https://doi.org/10.1080/21645515.2023.2203023.

[12] Vanderslott Samantha, Emary Katherine, Te Rebecca, Naude Water, English Marcus, Thomas Tonia, et al. Vaccine nationalism and internationalism: perspectives of COVID-19 Vaccine Trial participants in the United Kingdom. BMJ Glob Health 2021;6(10):e006305. https://doi.org/10.1136/BMJGH-2021-006305.

[13] Vanderslott Samantha, Palmer Alexandra, Thomas Tonia, Greenhough Beth, Stuart Arabella, Henry John A, et al. Co-Producing Human and Animal Experimental Subjects: Exploring the Views of UK COVID-19 Vaccine Trial Participants on Animal Testing. Sci Technol Hum Values 2021. https://doi.org/10.1177/01622439211057084. November, 016224392110570.

[14] Folegatti Pedro M, Ewer Katie J, Aley Parvinder K, Angus Brian, Becker Stephan, Belij-Rammerstorfer Sandra, et al. Safety and immunogenicity of the ChAdOx1 NCoV-19 Vaccine against SARS-CoV-2: a preliminary report of a phase 1/2, single-blind, randomised controlled Trial. Lancet 2020;396(10249):467–78. https://doi.org/10.1016/S0140-6736(20)31604-4.

[15] COVID-19 Oxford Vaccine Trial. n.d "Participate Birmingham." Accessed March 19. https://covid19vaccinetrial.co.uk/participate-birmingham; 2021.

[16] Mwale Shadreck "Healthy Volunteers in Commercial Clinical Drug Trials: When Human Beings Become Guinea Pigs. London. Palgrave Macmillan. 2017.

[17] Dawson Liza, Earl Jake, Livezey Jeffrey. Severe acute respiratory syndrome coronavirus 2 human challenge trials: too risky, too soon. J Infect Dis 2020;222(3):514–6. https://doi.org/10.1093/INFDIS/JIAA314.

[18] Leisinger Klaus, Schroeder Doris. Project Lightspeed: A Case Study in Research Ethics and Accelerated Vaccine Development. 2024. Doi: 10.1177/17470161241251597, April. doi: 10.1177/17470161241251597.
[19] Cookson Clive. Sarah Gilbert, the researcher leading the race to a Covid-19 Vaccine. Financial Times 2020;2020. https://www.ft.com/content/d2ae1fff-9747-41a3-b347-861ac1a70709.
[20] Gilbert Sarah, Green Catherine Catherine Mary, Crewe Deborah. Vaxxers : The inside story of the Oxford AstraZeneca Vaccine and the race against the virus. London: Hodder & Stoughton; 2021. https://www.hachette.co.uk/titles/sarah-gilbert/vaxxers/9781529369892/.
[21] Woolston Chris. 'I've never worked harder': the race to develop a COVID-19 Vaccine. Nature 2020;587(7833):322. https://doi.org/10.1038/D41586-020-03139-X.
[22] Mach Katharine J, Reyes Raúl Salas, Pentz Brian, Taylor Jennifer, Costa Clarissa A, Cruz Sandip G, et al. News Media coverage of COVID-19 public health and policy information. Humanities and Social Sciences Communications 2021 8:1 2021;8(1):1–11. https://doi.org/10.1057/s41599-021-00900-z.
[23] van Scoy Lauren Jodi, Snyder Bethany, Miller Erin L, Toyobo Olubukola, Grewel Ashmita, Ha Giang, et al. Public Anxiety and Distrust Due to Perceived Politicization and Media Sensationalism during Early COVID-19 Media Messaging 2021. https://doi.org/10.1080/17538068.2021.1953934. 14 (3): 193–205.
[24] Dudley Matthew Z, Bernier Roger, Brewer Janesse, Salmon Daniel A. Walking the tightrope: reevaluating science communication in the era of COVID-19 vaccines. Vaccine 2021;39(39):5453–5. https://doi.org/10.1016/J.VACCINE.2021.08.037.
[25] The Guardian. UK Vaccine Trial Volunteer Says She Is 'doing Fine' after Online Death Rumours. 2020, https://www.theguardian.com/world/2020/apr/26/uk-coronavirus-vaccine-trial-subject-doing-fine-online-death-rumours-elisa-granato?CMP=fb_gu&utm_medium=Social&utm_source=Facebook; 2020.