

Why you should read this article:

- To gain a better understanding of the general public's perceptions of clinical research
- To enhance your knowledge of the challenges of recruiting patients to clinical trials
- To reflect on the role of nurses in informing patients and families about clinical trials

Evaluating awareness and knowledge of clinical trials among people affected by cancer

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Abstract

In healthcare, clinical research is generally considered to be the sole evidence-based means of testing whether a new approach to treatment is superior to current practice. However, there is limited evidence on the general public's awareness of clinical research and on people's willingness to take part in clinical trials. A group of senior research nurses at Cancer Research UK designed an anonymous online survey for members of the public, which included questions around their awareness of clinical research and their willingness to take part in clinical trials. A total of 1,033 respondents completed the survey. The findings confirm that there is not enough information explaining to the general public what clinical trials are and that a population-wide approach to raising awareness of clinical trials is needed.

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Keywords

cancer, cancer research, clinical trials, data analysis, health literacy, research, research methods, survey, patients, patient education, professional

Background

Clinical research is crucial for developing new treatments and thereby enhance patient care (Portney 2020). In healthcare, clinical research is generally considered to be the sole evidence-based means of testing whether a new approach to treatment is superior to current practice. Clinical research is also considered crucial for identifying, treating and curing diseases (Sacristán et al 2016).

When developing a clinical research project that involves human participation, there are a number of questions that need to be addressed, notably around ethical dilemmas, patient safety and consent (Santel et al 2019). Ethical dilemmas are common in clinical research, for example when trialling a new medicine, and researchers must attempt to weigh the risks against the potential benefits for participants (Halpern et al 2019). Clinical

research can involve an array of ethical questions which researchers must deliberate on (Santel et al 2019) while bearing in mind that the rights and safety of participants should always take precedence over the interests of science (Bhatt 2015).

Patients' rights and safety are crucial in all clinical trials and are governed by a set of international ethical and scientific quality standards for designing, conducting and reporting clinical trials that involve human participation (Houston et al 2018). Patients who have been offered to take part in a clinical trial must be involved in an informed consent process, which ensures that they are in a position to make an informed decision about whether or not they want to participate. Potential participants must be made fully aware that their participation is voluntary and that they can withdraw it at any time without giving

a reason (Halpern et al 2019). Also, researchers and clinicians are legally and morally obliged to help potential participants fully understand the research (Sacristán et al 2016). The World Health Organization (WHO) (2009) stipulated that the informed consent process should ensure that each potential research participant understands the aims, methods, expected benefits and potential dangers of the study.

Despite these standards, there are longstanding concerns regarding how information is communicated to potential research participants and the appropriateness of patient information sheets (Bhatt 2015, Halpern et al 2019). An array of studies have cited the challenges that researchers can experience when attempting to communicate an often large volume of complex information to potential participants, including assessing whether these have accurately understood the information (Sacristán et al 2016, Wainstein et al 2020, Pietrzykowski and Smilowska 2021). There have been reports of research participants miscomprehending the trials they had enrolled on (Pietrzykowski and Smilowska 2021). In a qualitative study into patients' perceptions of participating in anticancer drug trials, Cox (2000) found that a lack of understanding of clinical research could increase patients' anxiety levels when considering whether or not to participate in a trial.

Reeder-Hayes et al (2017) suggested that further work is needed to investigate concerns around participants' understanding of clinical trials and questioned current approaches to the provision of complex information to potential participants, such as simply giving them a patient information sheet. Reflecting these concerns, Hood (2023) indicated that patients often only become aware of what is involved in a clinical trial at the point at which they are asked to enrol – or not. However, there is limited literature examining awareness and knowledge of clinical research among patients who have not yet taken part in a trial or among the general public. Halpern et al (2019) highlighted the need for further research to gain a deeper understanding of how a lack of awareness of clinical trials affects people's willingness to participate in research.

The Senior Research Nurse network at Cancer Research UK facilitates the delivery of high-quality clinical trials with the aim of getting new treatments into clinics sooner. The network consists of 15 senior research nurses based in Cancer Research UK centres, clinical trials units and experimental cancer medicine centres across the UK. At a meeting

of the Senior Research Nurse network in 2023, the authors of this article and other senior research nurses informally discussed awareness of clinical trials among patients with cancer. They felt that the majority of patients have limited awareness of clinical trials and that this negatively affects enrolment and the informed consent process. They also discussed the limited evidence concerning the general public's awareness of clinical research and people's reluctance to take part in clinical trials. It was therefore decided to undertake a UK-wide service evaluation.

Literature review

Before undertaking the service evaluation, the authors carried out a literature review to examine the literature on people's awareness of, and preparedness to take part in, clinical trials. They also researched initiatives and strategies aimed at increasing awareness of, and participation in, clinical trials in the UK.

Despite the importance of clinical research in developing treatment options and improving patient outcomes, there is a lack of literature on raising awareness of clinical research in the general population (Robertson et al 2021). The O'Shaughnessy review explored the challenges of delivering commercial trials in the UK and listed eight 'problem statements' along with 27 recommendations that could help increase 'public interest and involvement in research' and ensure that research is 'as inclusive as possible' (Department for Science, Innovation and Technology et al 2023). Problem statement number six states that 'conversations about research are absent from many interactions between clinicians and patients. The topic has a low profile with the public, especially among disadvantaged or marginalised groups'. That statement is followed by four recommendations, one of which is that 'an ongoing public campaign should be conducted to promote research and to generate evidence on the most effective communication methods'.

Be Part of Research, which is run by the National Institute for Health and Care Research (NIHR), is a UK-wide initiative designed to help people find, and take part in, health and care research (bepartofresearch.nihr.ac.uk/who-we-are/). The Be Part of Research website provides information about how members of the general public can become more involved in research. However, it does not provide basic information around what constitutes a clinical trial.

Strategies designed to increase people's engagement with research include Clinical Trials Day (www.clinicaltrialsday.org/about),

Key points

- Despite the importance of clinical research, there is a lack of literature on raising awareness of clinical research in the general population
- A survey completed by 1,033 members of the public, most of whom had been affected by cancer, showed that there is a lack of understanding of what clinical trials involve
- Barriers to patients' participation in clinical trials include uncertainty about what it entails, concerns about side effects of treatments and concerns about the commitments required
- The first time patients hear about clinical trials is often when they receive their diagnosis or are given information about their condition
- There would be value in developing more general information on clinical trials in the NHS and ensure it reaches people before they are asked to participate in a specific trial

which is organised by the Association of Clinical Research Professionals and celebrated globally every year on May 20. In the UK, Clinical Trials Day provides an opportunity for many hospitals and charities to promote clinical research – see for example Cancer Research UK’s Celebrating Clinical Trials page (www.cancerresearchuk.org/celebratetrials).

In the UK itself, initiatives tend to be regional. The Get Randomised campaign was a Scotland-wide initiative to promote clinical trials through the media (Mackenzie et al 2010). The NHS Grampian public-facing website (grampianclinicalresearch.com/) is designed to prompt the public, patients and healthcare staff to engage with clinical research (Berry and D’Alessandro 2020).

There are examples of initiatives focusing on awareness of clinical research among people from an ethnic minority background. For example, Clark et al (2019) explored how to improve diversity in recruitment to cardiology trials. Similarly, a report commissioned by Blood Cancer UK included strategies for improving the recruitment of diverse populations to clinical trials, including developing trust and making information more accessible (Blood Cancer UK 2024). Additionally, there is an increasing number of webinars and education sessions that focus on the importance of raising awareness of clinical trials among diverse populations. For example, the Patient Information Forum webinar on ‘bridging the ethnicity gap in clinical trials’ presented the findings from a study involving around 8,000 people from the UK that examined attitudes to clinical research (Smart and Harrison 2016). The study demonstrated differences in attitudes between white and ethnic minority groups, with people from Asian British, black British and mixed ethnic backgrounds being significantly more reluctant to take part in clinical research than people from a white British background (Smart and Harrison 2016).

There have been strategies implemented to improve the general public’s understanding of, and access to, clinical trials including information pages and searchable databases. For example, the resource provided by Cancer Research UK enables people to search for trials (www.cancerresearchuk.org/about-cancer/find-a-clinical-trial). However, it is aimed at people who already have a cancer diagnosis, so while it is a valuable tool for patients who want to explore participating in a clinical trial as part of their treatment, it does not address the wider population’s needs in terms of better understanding clinical research.

The general lack of information about clinical research means that many people

hear the term ‘clinical trial’ for the first time when they receive a life-changing diagnosis (Hood 2023). Being told that one has cancer takes a significant emotional toll on patients, and adding to their burden by giving them complex information about clinical trials at that time may prompt them to shun any conversation about participating in a trial. Once a patient has declined to take part in a trial, the opportunity is lost. If there was a basic understanding of clinical trials among the general population, more patients may be open to discussing the possibility of joining one, even if they eventually make an informed decision not to (Unger et al 2021).

The coronavirus disease 2019 (COVID 19) pandemic and the publicity around the development of vaccines did raise the public’s awareness of the role of clinical research in developing new treatments, but there has been no significant legacy in terms of increased awareness of clinical trials (Hood 2023). While efforts to raise awareness within communities under-represented in clinical research and improve recruitment to specific trials are being applauded, a deeper understanding of clinical trials among the general population is required to improve recruitment in the long term.

Aim

The aim of the service evaluation was to evaluate the levels of awareness and knowledge of clinical trials among people affected by cancer and examine barriers and facilitators to participation in clinical trials.

Method

Data collection tool

The service evaluation took place between February 2023 and March 2024. A set of questions were agreed and used to develop an anonymous online survey for members of the public. The survey included a mix of closed and open questions covering topics such as people’s awareness of clinical trials, their willingness to take part in clinical trials and whether they had received information about clinical trials in their dealings with the NHS. The survey was reviewed by a patient and public involvement (PPI) group to ensure it was inclusive and user-friendly.

Once the final questions and format had been agreed, the survey was approved by Cancer Research UK and promoted through its website. Members of the Senior Research Nurse network promoted it through local patient and public networks. By advertising and circulating the survey in this way, the authors hoped to obtain responses mainly

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from members of the general public who had been affected by cancer. One of the questions was ‘Have you ever been affected by cancer?’ However, the survey was open to anyone who wanted to complete it, whether not they had been affected by cancer.

Respondents were asked to provide demographic information – including age range, gender, ethnicity and the area of the UK where they lived – and to reply to four closed questions and three open questions (Box 1).

Population

A total of 1,033 respondents completed the online survey. Their demographic information is presented in Table 1.

Data analysis

Thematic analysis was used to examine the free-text responses to the open questions and develop themes (Braun and Clarke 2022). A qualitative data analysis computer software package (NVivo) was used to review and code the data, and the final themes were agreed by the authors after appraising and discussing the NVivo coding reports.

Ethical approval

Formal ethical approval was not required because this was not a research project; however, ethical research principles concerning the collection, storage and use of data were adhered to. Respondents accessed the online survey through the Cancer Research UK website, participation was voluntary and no identifying personal information was collected. The process of data collection and the service evaluation itself had been approved by Cancer Research UK.

Findings from the closed questions

The analysis of data from the closed questions indicated that the majority of respondents (94%, $n=971$) had been affected by cancer, as a patient, as a friend or relative of a person with cancer, or both (Figure 1). The data also showed that 49% ($n=504$) of respondents

Table 1. Respondents’ demographic information ($n=1,033$)

Age range	13-17 years	41 (4%)
	18-24 years	352 (34%)
	25-34 years	240 (23%)
	35-44 years	136 (13%)
	45-54 years	82 (8%)
	55-64 years	87 (8%)
	65 years and over	95 (9%)
Gender	Male	325 (31%)
	Female	674 (65%)
	Transgender	22 (2%)
	Non-binary	9 (1%)
	Other	3 (0%)
Ethnicity	Asian or Asian British	150 (15%)
	Black, black British, Caribbean or African	200 (19%)
	Mixed or multiple ethnic groups	125 (12%)
	White	541 (52%)
	Other ethnic group	17 (2%)
Area	East of England	21 (2%)
	East Midlands	35 (3%)
	Northern Ireland	27 (3%)
	North East of England	376 (36%)
	North West of England	51 (5%)
	Scotland	46 (4%)
	South West England	168 (16%)
	South East England	171 (17%)
	Wales	69 (7%)
	West Midlands	41 (4%)
Yorkshire and the Humber	28 (3%)	

Box 1. Closed and open survey questions

Closed questions

- » Have you ever been affected by cancer?
 - ‘Yes, as a patient’
 - ‘Yes, a friend or family member has had cancer’
 - ‘Yes, both as a patient and as a friend or relative of a person with cancer’
 - ‘No’
- » Do you know what a clinical trial is? (yes/no)
- » Do you think there is enough information for hospital patients to allow them to understand what clinical trials are? (yes/no)
- » If you were asked to take part in a clinical trial, would you be happy to? (yes/no)

Open questions

- » What do you think clinical trials are or do?
- » What might make you want to take part in a clinical trial?
- » What might stop you taking part in a clinical trial?

said they knew what a clinical trial was and 51% ($n=529$) said they did not (Figure 2). The majority of respondents (89%, $n=917$) thought that there was not enough information for hospital patients to allow them to understand what clinical trials are (Figure 3). A total of 591 (57%) of respondents indicated that if they were asked to take part in a clinical trial, they would not do so (Figure 4).

Findings from the open questions

A number of themes were generated by the answers to each of the three open survey questions (Table 2).

What do you think clinical trials are or do?

Test the effectiveness of new treatments

Respondents identified that clinical trials were a way of testing how effective a new treatment was. However, none of the respondents were able to explain how this occurs. One respondent explained:

‘Clinical trials will test new treatment that scientists have developed in the lab, not sure how they do it, must be through a certain method.’

Help patients

Another prevalent theme regarding the purpose of clinical trials was that they helped patients receive better treatment or cure for their disease, with one respondent saying:

‘Clinical trials help patients get a better drug for the illness, and sometimes a cure.’

Develop new treatments

Some respondents identified that clinical trials are a means of developing new treatments; however, there was nothing in the data suggesting that respondents understood how treatments are developed or how participating patients are involved in the process. One respondent stated:

‘They are a way of improving the current treatments we get. I think without them we

Figure 1. Answers to the question ‘Have you ever been affected by cancer?’ ($n=1,033$)

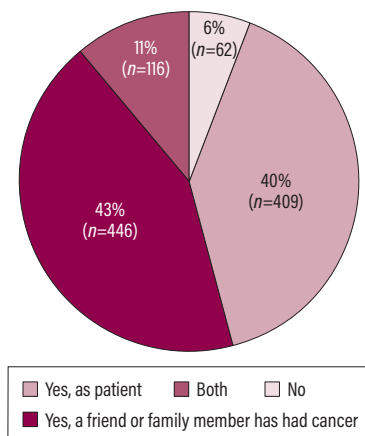


Figure 3. Answers to the question ‘Do you think there is enough information for hospital patients to allow them to understand what clinical trials are?’ ($n=1,033$)

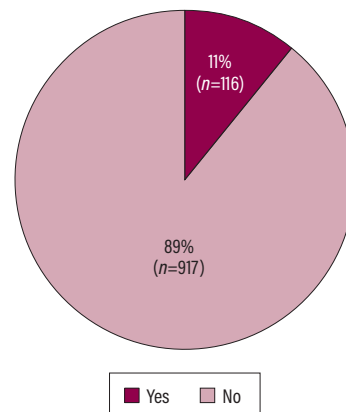


Figure 2. Answers to the question ‘Do you know what a clinical trial is?’ ($n=1,033$)

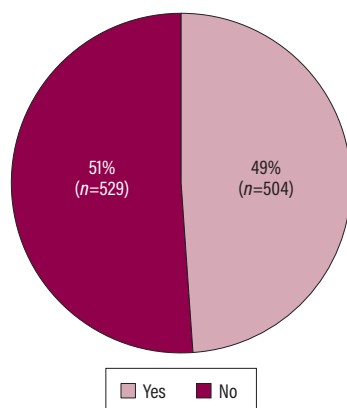
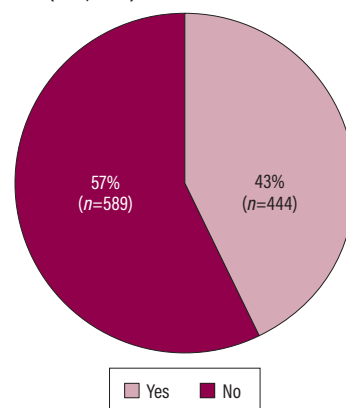


Figure 4. Answers to the question: ‘If you were asked to take part in a clinical trial, would you be happy to?’ ($n=1,033$)



wouldn't get any new treatments coming through in the NHS.'

Animal testing

This theme emerging from the responses to the first open question reflects some respondents' perceptions that clinical trials involve experiments carried out on animals to test new products such as shampoos and skin creams. One respondent commented:

'Yes trials are used a lot, mostly animals are used to test new things like shampoo, although I see this isn't encouraged as much anymore.'

What might make you want to take part in a clinical trial?

Altruism

Some respondents explained that knowing that clinical trials might improve future treatments for other people would be a major motivation for them to take part in a trial, despite the fact that there would be no benefit for themselves. One respondent stated:

'I know a lot of cancer research studies have to be done to allow us to get better treatments, and not all new treatments work. I think taking part in even the studies that don't work is important, as without people taking part we wouldn't get the information to prove this either way. Knowing I was helping future cancer patients get a better treatment would be enough for me to take part in one.'

More information

Respondents felt that having more information about clinical trials would be crucial for them agreeing to take part. They felt that understanding what a clinical trial is and what it involves would support their decision-

making. In some cases, respondents who had decided to take part in a clinical trial only became aware of what it involved once their doctor discussed it with them at a clinical appointment. One respondent explained:

'It's like most things, you don't know what you don't know. I don't know what a clinical trial is, and I've not really seen any information within hospitals that says what they are. I'm sure that they are safe, so having some more info about what they are would be great.'

Lack of further treatment options

The lack of further treatment options for cancer was a prominent theme, reflecting many respondents' perception that clinical trials represent a final opportunity to access another treatment option. One respondent commented:

'I think I would take part if the treatments for my cancer stopped working, and my doctor asked if he could refer me for a clinical trial as there was a trial treatment that might work.'

Financial incentive

A significant proportion of respondents emphasised the financial incentive of participating in a clinical trial, being paid to take part being a motivation for enrolling. However, the responses linked to this theme were brief and in some cases respondents simple wrote 'money' in the free-text box.

What might stop you taking part in a clinical trial?

I don't know what would happen if I took part

This theme suggests that there was a lack of awareness among respondents regarding what a clinical trial involves. The limited knowledge of what patients who take part in clinical trials typically go through appeared to create uncertainty and anxiety among respondents. Being asked to take part in something they had no knowledge of was something respondents were not prepared to do. One respondent said:

'I don't even know what [a clinical trial] is, so why would I be asked to take part and what would I be doing? Why would anyone sign up to be involved in something that they knew nothing about, that's madness.'

Risk of side effects from treatment

The risk of side effects was a common reason given by respondents for not wanting to take part in a clinical trial. Some respondents felt that trials involve experimental treatments that can potentially cause a lot of side

Table 2. Themes generated by the answers to the open survey questions

Question	Themes
What do you think clinical trials are or do?	<ul style="list-style-type: none"> » Test the effectiveness of new treatments » Help patients » Develop new treatments » Animal testing
What might make you want to take part in a clinical trial?	<ul style="list-style-type: none"> » Altruism » More information » Lack of further treatment options » Financial incentive
What might stop you taking part in a clinical trial?	<ul style="list-style-type: none"> » I don't know what would happen if I took part » Risk of side effects from treatment » Commitment to extra visits to hospital

effects and negatively affect their health.

One respondent stated:

'No way would I take part, you hear a lot of horror stories about all the side effects you get being guinea pig on these things.'

Commitment to extra visits to hospital

Respondents indicated that clinical trials would involve extra hospital visits or appointments at a research centre. Respondents cited extra visits and travel time to and from appointments as barriers to taking part in a clinical trial. One respondent commented:

'I couldn't commit to more hospital appointments to be part of a trial, the cost of petrol alone from the extra appointments would put me off. And for a clinical trial, it's research isn't it? So, would it even be in a hospital? How far away is the research centre?'

Discussion

The findings showed that 49% ($n=504$) of respondents stated that they knew what a clinical trial was. Respondents thought that clinical trials are a method of developing and testing new treatments and a means of helping patients; however, none expanded on these aspects or explained how clinical trials achieve this. Respondents felt that clinical trials commonly involve animal testing to verify the safety of products. Nothing in the data indicated that respondents knew what the different phases of clinical trials involve or what taking part in a clinical trial might entail.

A total of 591 (57%) of respondents indicated that, if they were asked to take part in a clinical trial, they would not do so. The themes that emerged from the responses to the question 'What might stop you taking part in a clinical trial?' suggest that respondents' lack of awareness of clinical trials would be a barrier to participation in research. Similarly, there was a lack of awareness of what clinical trials involve. The risk of side effects and the commitment to extra hospital visits appeared to be further barriers to participation. In addition, the majority of respondents (89%, $n=917$) felt there was not enough information provided for hospital patients to understand what clinical trials are.

Overall, the findings suggest that the current level of information about clinical trials is limited and that there would be value in developing more general information on clinical trials in the NHS. The findings raise questions regarding the current NHS and NIHR approach to educating people about clinical trials (NIHR 2024). While the information provided by the NIHR on

clinical trials and research is comprehensive, the challenge is to get people to engage with it before they are asked to participate in a trial. Anecdotally, most signposting encouraging people to take part in research is done in primary and secondary care, and therefore likely to reach mostly people who are already 'in the system'.

The findings suggest that respondents did not fully understand clinical trials partly because they had not received sufficient information from healthcare professionals. This possibly means that nurses are not taking as active a role as they could in terms of educating patients regarding clinical trials (Anderson et al 2018). Nurses are well placed to be clinical trial advocates. Patients trust them to provide non-judgemental information with regards to their healthcare options (Choi 2015). As patient advocates, nurses are important in directing patient care, leading on patient education and ensuring patients are fully informed and understand their treatment options. Further work may be needed to improve nurses' awareness of clinical research. The authors suggest that there should be a review into healthcare professionals' understanding of how clinical trials work, their level of competence and confidence in educating patients about clinical trials, and their role as clinical trial advocates.

Literature focusing on raising awareness of clinical trials suggests that educating patients through engagement initiatives such as social media platforms could be an appropriate approach (Anderson et al 2018). However, such approaches would need to be carefully developed. Anderson et al (2018) suggested that they would require collaboration between healthcare providers and PPI groups to ensure they provide accessible and inclusive information. The organisation Teenage and Young Adult Research (2024) aims 'to create an age-appropriate resource which helps to inform teenagers and young adults about clinical trials'. By implementing similar strategies, healthcare providers could begin to demystify clinical trials and making them more accessible and appealing, which would ultimately lead to increased participation and the advancement of research.

Without a wider understanding of the role, necessity and governance of clinical trials, significant improvements in recruitment will be challenging and progress towards new treatments will be limited. Currently, the first time people hear about clinical trials is often when they are diagnosed with a condition or given information about

their condition (Santel et al 2019). Including complex information about clinical trials in consultations can generate additional stress and anxiety for patients and their families (Halpern et al 2019). In the authors' view, a dedicated focus on clinical trials in every healthcare organisation's general patient information is needed. This would provide a baseline of information about clinical trials and allow healthcare professionals such as cancer nurses to focus on the specifics of any given clinical trial during consultations.

Limitations

Respondent numbers were low in some areas of the UK, meaning that the sample may not be representative of the UK as a whole.

Conclusion

The findings of this service evaluation showed that patients generally do not have enough information about clinical trials, which means that they are not well equipped to make an informed decision about whether or not to participate in a specific trial when they are asked to. When asking patients with cancer to contemplate participating in a clinical trial, it is important that nurses consider that patients may require more information, be uncertain about the side effects of new treatments and have concerns about the commitments required. This service evaluation demonstrates the need to take a population-wide approach to raising people's awareness and understanding of clinical trials.

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