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Engaging under-served communities in commercial research: A scoping exercise

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Executive Summary

In October 2023, the National Institute for Health and Care Research (NIHR) Clinical Research Network Coordinating Centre (CRNCC) commissioned Kohlrabi, an independent research consultancy, to carry out a scoping exercise. The aim was to explore public perception and awareness of commercial research, and in particular, that of groups under-served by health and care research. The scoping exercise took two forms:

- A review of the existing evidence on public awareness and perceptions of life sciences companies and commercial research was undertaken
- 17 members of the public from communities under-served by health and care research across England took part in a 2.5 hour workshop, discussing their awareness and perception of commercial research

The findings from both strands highlight five areas for consideration to improve the inclusion of groups under-served in commercial clinical research.

1) Build a clear visual picture of what commercial research means. Low understanding and negative associations of terms such as ‘commercial research’ can be an engagement barrier. Positive, recognisable wording may include health, medicine, or life sciences. Trust can be improved with greater clarity and understanding of how and why life science companies and familiar organisations such as NHS or charities work together in research.

2) Meet people where they are. Commercial research representatives could come forward to the public, rather than the onus being on the public to seek out knowledge and opportunities for themselves. Engagement to explain commercial research and publicise involvement or participation may be most resonant through peer researchers, health charities and trusted organisations with existing relationships with groups under-served by research.

3) Forge emotional connections though public good values. Establish and promote clear organisational values shared by individuals motivated to contribute to research for public good. Promote evidence of positive research outcomes for under-served communities, in the UK and globally, and be aware of wider environmental and societal impact.

4) Respect the good faith of the public with transparency. The public wants sight of commercial research practices, partnerships and funding sources**.** Increasingly individuals ‘do their own research’ into companies before engagement, sharing conclusions within groups. Clear explanations can proactively reduce concerns and prevent later surprises.

5). Value and protect the public as collaborators. Use of culturally-aware, inclusive frameworks and involvement budgets are more likely to ensure members of under-served groups are welcomed and utilised as part of the research or decision-making. Be proactive to ensure individuals know these budgets and structures are available to be used by them.

Glossary

Participation: The act of taking part in a research study, for example people being recruited to take part in a clinical trial or another kind of research study, joining in a focus group or completing a questionnaire.

Involvement: Research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research.

Engagement: Where information and knowledge about research is provided and disseminated to members of the public. Engagement can span publishing information through media such as television programmes, newspapers and social media, direct dissemination to people who have been involved in a study, to more active communication through science festivals, research open days, or other forms of discussions with scientists.

Life Sciences: Life Sciences refers to the application of biology and technology to health improvement, including biopharmaceuticals, medical technology, genomics, diagnostics and digital health

Commercial Research: Commercial research refers to research studies / trials that are both sponsored and funded by independent pharmaceutical or medical technology companies.

Under-served group: A group that is less well represented in research than would be desirable from population prevalence and healthcare burden. This definition is context specific and it can depend on the population, the condition under study and the question being asked by research teams. Key characteristics are i) lower inclusion in research than one would expect from population estimates, ii) high healthcare burden that is not matched by the volume of research designed for the group, iii) important differences in how a group responds to or engages with healthcare interventions compared to other groups, with research neglecting to address these factors

1. Introduction

Involving people in research about their health and lives is increasingly seen as both morally correct, and as strengthening the quality of findings; ultimately maximising the contribution of research to society (HRA 2023; DHSC 2023). Participation in research may provide early access to cutting-edge treatments or help to improve outcomes more widely, while patient and public involvement can improve the design and delivery of research itself.

As the Future of UK Clinical Research Delivery report (DHSC 2021) states, "making research more diverse is critical to addressing persistent health inequalities." There is recognition that some people and groups more than others are 'under-served' by research, reflecting the perspective that the research community needs to provide a better service to these groups, rather than the lack of inclusion being due to any fault of the members of these groups (NIHR, 2020). NIHR has a commitment to making research more inclusive of under-served groups- a commitment prioritised in its ambition to expand its engagement with industry (NIHR, 2021).

One challenge to improving public inclusion in commercial research is that literature indicates that public perceptions are anchored in mistrust when research is funded by the private sector, as they are 'for profit', unlike NHS organisations and academia. Although, with increasingly more partnership and collaboration between companies and researchers working between industry, academia and the health sector (NIHR, 2021; Office for Life Sciences, 2021), perception may start to change. The role of pharmaceutical organisations in vaccination against Covid-19 in recent years may also have increased public awareness, with corresponding increases in both positive and negative sentiment (Caliber 2020).

Recent nuanced exploration into how commercial research is perceived by the general public is lacking. Investigation into public perceptions of research have tended to focus on the sharing of health or administrative data, or limit questions on commercial research to one or two (Ipsos MORI 2016; Waind 2020). It is necessary therefore to explore what the public and, particularly under-served groups, want or need in order to facilitate their inclusion in commercial research and engagement with life science companies.

Aim and Objectives

The aim of this public dialogue was to therefore develop a set of recommendations for NIHR to inform the best practice of its network when engaging with life science companies and commercial research. The scoping exercise had four objectives:

1. Capture awareness and perception of commercial research for people from under-served groups;
2. Identify gaps in knowledge or barriers to engaging with or participating in commercial research studies;
3. Build NIHR's awareness, understanding and capacity to support commercial research to better engage with and include under-served groups;
4. Inform and shape NIHR's own engagement strategy for improving participation of under-served groups in commercial research studies.

2. Methodology

This report describes a mixed method approach triangulating findings from a public workshop with evidence from academic and grey-literature on public awareness and perception of commercial research in the UK during the last five years.

Public workshop methodology

The 2.5-hour public workshop took place online, using Zoom, in October 2023. A total of 17 public participants were split into four breakout rooms of four to five participants, each with a facilitator. The facilitators took notes to supplement the recording of the conversations, which were later transcribed. Anonymised transcripts of the workshop recordings were coded by a qualitative researcher. An inductive approach to thematic analysis was taken, where two researchers identified key themes and subthemes using the coded transcripts, along with supporting quotes and examples for context. Quotes have been anonymised and are presented in boxes throughout the report to illustrate findings.

Workshop recruitment

Community Champions from the Research Ready Communities programme were recruited to take part in the workshop. These are members of the public from a variety of backgrounds, from around England and have some experience in public involvement in research. Participants included young people from coastal communities, people from ethnic minority backgrounds, and individuals with disabilities and caring responsibilities.

Workshop format and questions

The workshop consisted of three phases. In the first phase, participants shared their baseline awareness and perceptions, followed by a short “explainer” presentation by Alex Hammond from the NIHR CRNCC’s Business Development team, on the meaning and scope of commercial research. Within this second phase, participants were given time for discussion and questions. The final phase explored participants’ reflections on what they had learnt about commercial research and encouraged suggestions on how to improve inclusion in commercial research of under-served groups. Questions presented to the participants are presented in Appendix B.

Evidence mapping methodology

There is limited published literature on attitudes and perceptions specific to commercial research, as findings within the broad literature on research in general do not often explicitly include commercial research. A narrow search strategy, focusing on evidence within the last five years (2018-2023), was used to identify relevant papers to triangulate the findings from the workshop. The restricted timeline was chosen due to the rapidly evolving perceptions around commercial research in recent years. The inclusion criteria for evidence included: i) public or participant awareness or perception as the main topic of the report; ii) refers to research undertaken in the UK, and iii) contains information relevant to privately-funded ‘commercial’ health research involvement or participation. Relevant literature was obtained through three methods: 1) Literature search using PubMed, and Google Advanced Search (both limited to the first 100 records), 2) recommendations and suggestions by stakeholders, 3) reference lists of included papers searched to identify additional relevant evidence. A combination of keywords and subject headings were used as search terms: “public” AND (“attitudes” OR “views” OR “perceptions” OR “understanding”) AND (“commercial research” OR “private” OR “industry”). Grey literature was prioritised over traditional academic database searches due to the commercial/industry topic. This search was not intended to be systematic, but rather provide additional context and support to key themes that would emerge in the public dialogue.

Findings relating to public attitudes or perception on commercial research were extracted from included records. A total of 15 articles, case studies or testimonies were included as evidence for triangulation with the workshop findings (see Appendix B for evidence details).

3. Findings

While pre-workshop awareness of commercial research was initially low, participants had strong views on what would facilitate their inclusion in commercial research and engagement with industry. These views added nuance to existing evidence from surveys, qualitative enquiries, and reports on public awareness and attitudes toward commercial research in recent years. Key messages have been grouped into the five themes below:

The language surrounding commercial research

Findings from the workshop participants and existing research suggest low public understanding of the specific term commercial research. Associations with the corporate world are confusing and appear as a deterrent to engagement. As wording becomes more familiar and creates positive mental associations with health research and public benefit, participants appear more open to inclusion.

Workshop participants initially believed they had not heard of commercial research as a discipline as they were unfamiliar with the term. This was consistent with existing literature reviews and survey and interview data, summarising low public awareness of what commercial research means (Coe, Birt et al. 2021; Scottish Government, 2023). In the current workshop, participants highlighted that the word ‘commercial’ means to them selling and profit. For some participants, the term prompted feelings of low control, such as association with ‘third parties’ and fear about unknown entities such as crypto, bit coins and scams.

> *“I presumed it is something to do with companies selling things and, research surrounding that. I was surprised when it was to do with the medical and pharmaceutical world.”*

As conversations developed a few participants wondered whether commercial research did refer to pharmaceutical companies and drug trials, although many expressed that they would not have made that connection. Participants had initial negative associations with those terms. Some participants cited evidence for distrust, such as Tuskagee[1], or felt that they had probably seen stories in the news or on social media, when “trials...haven’t gone to plan”, heard from friends about scams of people’s personal information, or seen ‘Big Pharma’ exposé documentaries. One participant explained that they didn’t know where they had heard that commercial organisations only work for profit, they just *felt* it to be true.

“I'm judging on negative reviews, but to be positive and no judgement would be that they're interested in health and wellbeing. “

For most participants, there wasn’t evidence for distrust as such, but the words commercial and pharmaceutical were tightly associated with negative sentiments such as, “unethical”, “capitalist”, and “putting profit before people”. These initial perspectives align with recent qualitative findings from interviews and deliberative dialogues in the UK, reporting the ‘gut reaction’ that profit-making from health research means that the organisation “is not interested in people” (ADR-UK 2022; Coe, Birt et al. 2021; Scottish Government, 2023; BEIS 2020; Jones et al. 2022; BSA 2018).

The language that appeared to break down or deepen participants’ initial perceptions was terms related to health and public good. Previous qualitative enquiry has also suggested that public perceptions of commercial research enhance when motivations to improve public health, or associations with the NHS or universities, are added (Coe et al. 2021; Chico et al. 2019). In the current workshop, adding words, such as health, diseases and medicine to participants’ concepts of commercial research appeared to have a ‘halo effect’. That is, the general positive perception of those working in health or medicine was added into participants’ perceptions of commercial health research. When participants were asked what commercial research could be named to improve understanding of its remit, only a few participants made suggestions. The most common suggestion was for the term ‘life sciences research’, because it sounded more connected to health.

Upfront language was appreciated, which is consistent with participants’ desire for transparency. Participants valued the directness and clarity of the explanation during the presentation on commercial research they received and understood that the difference between commercial and non-commercial research is the funding. As described later in this report, participants do not want to feel that this information was withheld from them. The word funding appeared to have a legitimacy which reduced concern regarding commercial finances. Many participants voiced their absolute understanding of the need for funding, that health and care research is expensive, and commercial organisations therefore can have a role in it. A core desire was to have full sight of which organisations are linked and how.

Post-presentation discussions suggested that it is possible to conjure a visual for the public of health and care researchers working under the same banner, with working relationships between commercial and non-commercial entities, and the sources of funding differing but little else. This was the best-case scenario, perhaps relying on clear messaging from a respected source such as NIHR. As other studies have indicated, people’s initial negative

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[1] Center for Disease Control and Prevention: The U.S. Public Health Service Untreated Syphilis Study at Tuskegee. https://www.cdc.gov/tuskegee/timeline.htm

responses to commercial involvement in health and care research *can* change considerably when provided with more information and understanding (Scottish Government, 2023; Chico et al. 2019; BEIS 2020; NIHR, 2023). For many participants, scepticism did re-emerge during the workshop, implying that although positive messages about commercial research can be accepted, deeply embedded perceptions may require substantial work to change them.

Bringing commercial research to the public

Workshop participants wanted what they had learnt during the workshop to be common knowledge in their home communities, in order to improve inclusion and participation of people from groups under-served by research. Commercial research could come forward to the public to engage them, rather than waiting for the public to find them.

As knowledge of the sector of commercial health research grew during the workshop participants generally appeared open to participation or public involvement. However, participants felt that their prior lack of knowledge of commercial research was a barrier to their involvement. Several participants expressed that if *they* – as participants of a workshop on commercial research - didn't know about commercial research, then people in their communities would *never* have heard of it.

A number of participants suggested that commercial research representatives could come forward to the public to present themselves, rather than the public having to seek out knowledge and opportunities for themselves. Talking directly to members of the public was seen as helpful to dispel negative myths about commercial research. Feeding into the collective desire to not be surprised by information (see section on transparency), one or two participants suggested that commercial researchers could visit schools to build up a concept of research partnerships in people from a young age.

> *"Maybe it's... going into schools…speaking to the younger generation, so they're aware of it from a young age, so it doesn't become a bit of a shock".*

Another practical suggestion for life science companies to connect with members of the public was to introduce visits by their representatives to communities or special interest groups. Visits would be taken as evidence that commercial research cares about the communities they are saying they want to involve and impact, as well as providing space to discuss and break-down negative perceptions. Less active methods for commercial research communication, such as posters and leaflets in places such as health centres, or conversations with GPs, were also suggested. Similar ideas had recently emerged in a patient panel discussion organised for industry, where it was proposed that commercial research organisations should talk to patients at NHS-partner hospitals about engagement opportunities (DATA-CAN 2020).

Participants felt that communicating commercial research within community spaces would mean that invitations to participate would resonate more with members of groups under-served by research. It was reported that an advert for a research opportunity can easily read to someone that it is not for them. The feeling of distance between commercial research opportunities and the public was underlined by a recent NIHR Clinical Research Network focus group which concluded that the public do not know where to look to find opportunities if they are not recruited via their patient journey (NIHR CRS 2023). A number of participants in the current workshop believed that they would never learn about a research opportunity unless they were in poor health and their doctor recommended it.

> *"Because they think oh no that is not for me, maybe it's just for white people. But this is because they don't have a knowledge or they don't understand or that kind of the culture is playing around there"*

Workshop participants suggested that recruitment language could be improved if a peer researcher was involved. The invitation to take part would then mean more to the community as they would understand what was being asked of them and why. In addition to utilising language which resonates, participants wanted explanations of commercial research opportunities to be in language that is easy for anyone to understand. Participants emphasised that without knowing that participation or involvement opportunities were there, what exactly they were, and how to take them up, members of communities under-served by research could not access them.

Some participants made the point that whether research is commercial or charity or NHS, it is the topic of health and care research itself which is the challenge. For members of the public with no awareness of health and care research taking place, or those who were aware but expected that they would not be treated, "with dignity", all health and care research is seen as closed off to them. Visiting communities directly to raise awareness and dispel myths may slowly change perceptions.

Power and equitable public good

Commercial research organisations appeared to have greater power than non-commercial research organisations in many of the workshop participants' minds. Using this power to do public good rather than simply make profit was a vital condition for members of the public to consider their involvement.

When commercial research is clearly in the public interest, such as developing healthcare products and services, the acceptability of it for members of the public and likelihood of engagement is higher (DATA-CAN 2020; BEIS 2020; Chico et al. 2019; Scottish Government 2023). This finding was validated by the current workshop participants. It was unlikely that participants would engage with commercial research unless the activity was clearly positively impacting society.

With more information, workshop participants were relatively willing to trust or at least consider that commercial researchers would be acting in the public interest, instead of solely for profit. Notably, many participants wondered if commercial research would be able to achieve greater public benefit than non-commercial health and care research, due to their perceived vast financial power. Conversations highlighted participants' desire to participate in drug trials if they were themselves ill, and there was motivation from others to change society for the better through their public involvement in commercial research. Participants felt that the weight of commercial research would be likely to bring about change. This assumption has been described previously, with suggestion from members of the public that well-resourced private health organisations may be more efficient than the public sector and able to maximise what could be achieved on behalf of the public sector. (ADR-UK 2022; CASE, 2023; UCL, 2021).

> *"We're all wanting to live as long as we possibly can. These trials kind of give us hope that it will make us better or live longer and different things like that."*

However, the perception that commercial research was more 'powerful' than non-commercial research resulted in participants holding them to a higher standard. Many participants suggested that life-science companies should be doing *more* to create public benefit than non-commercial organisations, because they are making money from the research. They have a responsibility to ensure that their public benefit is in proportion with the profit they make.

A small group of participants took a world-wide view to public benefit. Participants weren't certain how they had formed the perception but felt that medications were not being made available globally by commercial organisations, when they have the power to do so. This was seen as morally wrong and was extremely off-putting to participants with links to countries outside of Britain. A recent survey on British public attitudes to cancer research showed mixed desire for pharmaceutical companies to provide anti-cancer treatments to poor communities at lower prices than those charged in countries like the UK (42% for, 21% against). The report concluded that understanding public emotions on this topic will become more pertinent as the effectiveness of therapies improves, service user expectations rise and the populations of developing nations age (UCL, 2021).

> *"I'll be dedicated 100% to helping people. But does that help come at the expense of certain people in different parts of the world? Are those companies subsidising medicines for third world companies in the same way that they profited enough money here?"*

The workshop participants emphasised that evidence demonstrating that companies were helping people, and making a difference needs to be clearly upfront and accessible for them to be attracted to engaging with that company. Despite their openness, many participants were hyper-alert to evidence of not being able to trust any commercial company. This fear did not appear to prevent future involvement or participation, but participants would be looking for evidence to disprove or confirm their worries. Several participants suggested they would find it easier to assess whether to be involved if they could see pictures of the organisation helping their communities, know how much money the companies were investing to benefit people, and could easily read or see the impact of the company's efforts.

Transparency and good faith

Workshop participants explained that they would be looking for transparency of commercial activity and relationships to create trust in commercial research. Many participants appeared 'armed' with a mental checklist of what they would be looking for in their assessment of whether to get involved and maintain their involvement.

Trust in commercial research has consistently been rated lower in recent public attitude surveys than non-commercial research (BEIS 2020; Jones et al. 2022; Beange 2020; BSA 2018; NatCen, 2018). As Kalkman and Delden (2022)'s review summarised, the public is fearful of the concealment of information that may affect their experience or their feelings about use of their data in research. Research and organisational transparency has unswervingly been given as a recommendation for commercial research to warrant public confidence (BEIS 2020; ADR-UK 2022). Many workshop participants explained that they wanted to feel that they had made their decisions (to be involved) with all the information needed, and to feel that they were being respected by being privy to necessary information.

> *"If you've had good experiences of a company, heard good things through social media then know they're genuine, want to back them more"*

Many participants appeared to expect that commercial research, or health and care research in general, would *not* be transparent with members of the public. Participants asserted that they would do their own research into the company before signing up for participation or involvement opportunities. Participants talked through how they would feel if they discovered that commercial research organisations had not been transparent with them. There was a strong imagined feeling of anger, particularly for those from groups under-served by research, who were imagining giving companies their trust despite collective memories of research or health mistreatment.

The first area that potential participants would be looking for proactive transparency in was the company's organisational and research values. More ambivalent participants said they were trying to reserve judgement on commercial research until they saw evidence of the company's values. Participants wanted these values spelled out as they were not going to be trawling through websites looking for them. Values came up strongly during the workshop, with many participants indicating that they used their own values system to make their decisions. One of those core values was to help others, strongly expressed by participants with strong connections to community groups. They were firm that if they could not see a match with life science organisations on that then they would be deterred from taking part.

> *"What do they value? Is it the money? Or the human? Or expansion? I think I've got no idea what it is. Each will have their own moral standards."*

Participants across the groups spoke in detail about wanting transparency as to where money made during commercial research was going. The perception that commercial research may be making a lot of profit from its activities was only tolerable to participants if those companies were contributing to public benefit, in the UK and abroad. Several participants said they would want to “see the receipts” as to where the profit is going and how much it benefits society. They wanted this information to be transparent and easy to find. If information is not easily accessible it was not seen.

> *“I think the awareness needs to be around that side of things as well. You know, this though it is commercial, yes, but what is profit that profitability going towards? How is that helping in terms of advancements as well?”*

An associated worry was that profits from life science companies might be being invested into nefarious activities such as buying weapons for wars, or fuelling wars in any way. A number of people wanted to know exactly how profits were invested and whether this was towards initiatives that could help people, in the UK and globally.

Although some participants were neutral about partnerships between commercial groups, and organisations such as NIHR, the NHS, government and charity, others expressed that they would have preferred knowledge of those relationships from the start. Before the workshop presentation, participants had viewed commercial and non-commercial organisations as unconnected to each other. As in a recent review of public attitudes in data research (Scottish Government 2023), many workshop participants were surprised that they might work together, although as recently suggested by qualitative public research (Coe et al. 2021), collaboration with trusted public bodies confers a legitimacy on commercial research. There was little awareness at all of the role NIHR plays in supporting commercial research. Learning about ‘parent’ companies and the connections between different pharmaceutical organisations also took most participants by surprise. During the workshop one participant began to do their own online research on subsidiary companies, underscoring the appetite for this information. It seemed that individuals will do their own research on what or who they are getting involved in and any surprises have the risk of deepening distrust.

Including the public on the team

With more understanding participants reported a desire to contribute their involvement to make commercial research more inclusive and better quality; ultimately ensuring that health and social care works for everyone. However, it was felt that commercial companies could do substantially more to ensure that meaningful collaboration could take place.

Participants, particularly those from communities under-served by research, felt that they had a lot to contribute to research, that commercial organisations’ engagement with under-served groups were lacking in general. They wanted those contributions to be heard and valued. Individuals reported that they were happy to put themselves forward to be involved, in return for companies respecting what is needed to support their involvement. Making the required investment for their inclusion appeared to be considered commercial research’s side of the bargain. There was no belief in the notion that companies may not have the resources for meaningful collaboration.

A number of participants had additional needs for inclusion, whether it be living in rural areas with transport restrictions, living with disabilities or mental health difficulties, or being a carer. They reported that they were far keener to be involved in opportunities when it was clear that the organisation had tried to accommodate accessibility suggestions. They would be looking for examples of people with additional needs or responsibilities being encouraged to take part "as the norm", rather than being "made to feel like the problem". Concrete suggestions from the workshop participants included companies routinely offering BSL support, extra time and support for reading and moving around during study visits, staff to read information or information presented in different formats and languages.

> *"Representation is important. My son would need to see a role model to trust taking part in research- someone from his culture, his religion, his (disability) needs."*

Logistical issues, such as time, energy and travel requirements were a key set of barriers participants suggested that commercial research could address to improve inclusion. A recent focus group (NIHR CRN 2023) identified more barriers to inclusion for under-served groups than the general public, such as being more likely to have caring responsibilities, difficulty travelling to sites, and suffering from lack of flexibility in participation arrangements. Workshop participants echoed that participants were keen for travel and time barriers to be addressed as they largely preferred face-to-face meetings. Some participants were living in rural areas and felt that free transport to take them to participate in research would be extremely likely to increase their likelihood of taking part. One participant with disabilities emphasised the need for a seamless journey that is accessible transport, booked and paid for on your behalf. Participants with anxiety can also benefit from organisations paying for a friend or carer to travel with the participant to the research opportunity.

> *"I'd do both online or in-person involvement, but practically as a carer zoom is better. If I can attend they need to book and pay for cabs, and provide a support person as I'm anxious travelling by myself."*

Too many big words, incomprehensible explanations of the point of the research, and lack of clarity on what researchers were asking from people, were all named as barriers. Participants who had experienced research had felt discouraged by the length of surveys or forms. Several participants suggested that commercial research provide staff to explain and collect information, or at least provide easy read information sheets. Video clips of information were also suggested.

> *"I kind of struggle when there's like too many big words. So that will definitely be a barrier for me because I just wouldn't understand why it was that I was putting forward".*

Participants had an awareness of their own value to commercial research and the burden that taking part would have for them. Knowledge that the research would benefit the public was an incentive but it did not feel right that commercial organisations may be making huge profits while participants volunteer their time for free. As well as childcare or carer costs, and travel costs, participants wanted appropriate remuneration for their time and effort. Several participants acknowledged that the potential for remuneration made them more likely to consider research opportunities in the commercial than non-commercial sector. Secondly, a number of participants wanted to feel that they were learning from their experience. These participants had enjoyed previous interactions in public consultations or research and wanted to keep feeling a two-way knowledge exchange.

A lack of resonance with the research organisation or team came through repeatedly as a barrier to inclusion of groups under-served by research. Participants pointed out that research teams need to be representative, regardless of who is funding or sponsoring. The perceived lack of diversity in research, of ethnicity, disability and social class, was viewed as no different in commercial to non-commercial research. It was an issue for both sectors that participants do not feel that they have role models of participation who they can relate to.

The perception that some research participation or involvement is tokenistic was a deterrent for many of the workshop participants. Several participants perceived that they might be particularly included in commercial research because of their demographics, such as being young in age, having disabilities, or being from minoritized ethnic backgrounds. Some felt that they had been "used" in research to give the appearance of inclusive representation, and some had heard that it was something to watch out for.

> *"I would take part in the research, but if it was like I was just being used like nothing was gonna come out of it then I'd probably not do that".*

Several participants suggested they would be looking for evidence that the company worked collaboratively with members of the public during public involvement activities. Criteria was mentioned, such as whether the company prefers surveys (seen as tokenistic) or focus groups (seen as more meaningful) for their public involvement. For research itself, participants would want to see evidence that the company publishes the outcomes of their research and communicates them to the participants.

Lastly, there was an acknowledgement of how vulnerable members of the public can feel working with a big organisation. This feeling returned to earlier sentiments that "being involved is hard work" and "bringing about change is never easy". A couple of participants suggested that having peer support, training or at least a toolkit of how to protect themselves during participation and involvement, would make them feel more supported. Peer support would mean that participants are not alone when they bring up hard issues such as challenging sexist, racist, or disablist practices. A toolkit might contain principles such as "attend meetings with someone you trust if you would find it helpful, write everything down, plan what questions you want to ask them (the organisation)". These suggestions were a reminder of the power commercial companies are perceived to have and the need members of the public have to help them feel safe and listened to.

Conclusion

Triangulating findings from a public workshop with recent survey and qualitative findings suggests five areas for consideration by commercial research and the patient and public involvement workforce, to improve inclusion of the public in this field. There are many different types of commercial organisation, and many different ways to participate and be involved, which this workshop did not have time to explore in depth. The findings largely focus on what could be done to change the activities of commercial research to enhance trust and knowledge amongst members of the public. Ultimately the findings suggest the need for more effective engagement with people about commercial research, leading to an increase in the number and diversity of commercial research participants.

Build a clear visual picture of what commercial research means.

Low understanding and negative associations of terms such as ‘commercial research’ can be an engagement barrier. Positive, recognisable wording may include health, medicine, or life sciences. Trust can be improved with greater understanding of how and why life science companies and familiar organisations such as NHS or charities work together in research.

Meet people where they are.

Commercial research representatives could come forward to the public, rather than the onus being on the public to seek out knowledge and opportunities for themselves. Engagement to explain commercial research and publicise involvement or participation may be most resonant through peer researchers, health charities and trusted organisations with existing relationships with groups under-served by research.

Forge emotional connections though public good values.

Establish and promote clear organisational values shared by individuals motivated to contribute to research for public good. Promote evidence of positive research outcomes for under-represented communities, in the UK and globally, and be aware of wider environmental and societal impact.

Respect the good faith of the public with transparency.

The public want sight of commercial research practices, partnerships and funding sources. Increasingly individuals ‘do their own research’ into companies before engagement, sharing conclusions within groups. Clear explanations can proactively reduce concerns and prevent later surprises.

Value and protect the public as collaborators.

Use of culturally-aware, inclusive frameworks and involvement budget are more likely to ensure members of under-represented groups are welcomed and utilised as part of the research or decision-making. Be proactive to ensure individuals know these budgets and structures are available to be used by them.

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Appendix A

Questions explored in the public workshop

Before the event participants have been set a pre-task to anonymously answer two questions via Google Form:

- Have you heard of commercial research before? (yes, no, I'm not sure)
- What does the phrase 'commercial research' make you think of? (open question)

These answers were fed back to participants in the form of a word cloud in the first segment of the workshop for reflection and discussion.

Topic	Questions
Awareness and perception of commercial research	Q1 Before the workshop we asked if people had heard of commercial research before, and what does that phrase make you think of? We created this word cloud based on your responses. What words or thoughts would you like to add? Q2 What comes to mind when you look at everyone's thoughts on this? Q3 Some of you had heard of commercial research before. What have you heard about it? Q4 Where have you heard about it before e.g. in the news, from friends and family? Are there any specific examples you can think of? Q5 Can anybody think of companies that you think may do commercial research? What do you know about them?
Explainer session from member of NIHR staff	So far, we have used the term 'commercial research'. Sometimes it is also called life sciences or industry research. What name or label would you give to this type of research?"
Involvement, participation and inclusion in commercial research	Q1) We've heard about some companies who conduct commercial research today. If one of these companies invited you to take part in a research study? Would you consider taking part? Why/why not? Q2) Is there anything in particular that would attract you to taking part? Q3) Are there any particular barriers to you feeling like you would be able or willing to take part? Q4) What would need to change or happen to get rid of these barriers? Q5) Would you consider taking part in a research study if you were invited by a charity or the NHS, rather than one of these companies? Why/why not? Q5) How could each part of the process be more inclusive for people, including those who are currently under-served by research?

Appendix B

Authors	Title	Method	Perception/awareness of commercial research
NIHR Clinical Research Network Kent Surrey and Sussex, 2023	CRN KSS Cross-collaboration in commercial research: the public perspective	Focus group (unknown sample)	The public do not know where to look to find opportunities if not recruited via their patient journey. More significant barriers for under-served populations than general public
Campaign for Science and Engineering, 2023	Public Attitudes to R&D and Businesses	Survey n= 18,000 people, 14 focus groups	Recognition of role of RD in funding while concerns about bias from profit-motivation. Some belief that commercial funding leads to quicker results and saves taxpayers money.
Department for Business, Energy and Industrial Strategy, 2020	Public attitudes to science 2019	Survey, review, deliberative dialogue	Greater trust for university than commercial scientists. Acceptance improves when activity is transparent, involves the public at an early stage, and evidence provided of public interest.
Jones, Nelder et al. 2022	Public opinion on sharing data from health services for clinical and research purposes without explicit consent: an anonymous online survey in the UK	Survey, n= 29 275	Mistrust of the security and/or motives of commercial organisations.
National Centre for Social Research (NatCEN) (2018)	Science: Have the British public really had enough of experts?	Survey	More trust for university versus commercial sector scientists.
UCL School of Pharmacy (2021)	British Public Attitudes towards Cancer Research and Treatment in 2021	Survey n= 2,096	Pharmaceutical companies make a positive contribution to society. Effective regulatory systems or nationalisation may be needed to protect public interests. Mixed views on companies charging the NHS for treatment patents, and supplying less developed countries with commercially developed treatments.
NIHR, 2023	NIHR Patient Recruitment Centres exceed targets for set-up and recruitment to studies	Survey n=569	97% of participants said they would consider taking part in clinical research again. Clarity of processes appreciated.

Hirst, Stoffel, Brewer et al. 2023	Understanding Public Attitudes and Willingness to Share Commercial Data for Health Research: Survey Study in the United Kingdom	Survey N=1534	Sharing *commercially collected* data for health research more acceptable with NHS than commercial companies
Kalkman, Delden et al 2022	Patients' and public views and attitudes towards the sharing of health data for research: a narrative review of the empirical evidence	Narrative review of papers 2009-2019	Fear of sharing health records with commercial companies, fear of the unknown
DATA-CAN 2020, The Health data Research Hub for Cancer	Patient and industry partnership with Flatiron Health	Patient panel discussion (unknown sample)	Talk to patients about commercial research Define and use patients' view of public benefit Show patients evidence of the value of commercial health research
Beange , Kirkham, Fletcher-Watson , et al. 2020	Using a knowledge exchange event to assess study participants' attitudes to research in a rapidly evolving research context.	Event with longitudinal cohort members (n=250)	Far less trust in commercial companies than academia
Chico, Hunn, Taylor,. 2019	Public views on sharing anonymised patient-level data where there is a mixed public and private benefit	Deliberative workshops	Negative reactions to engaging with commercial research improved with information and discussion about public good of commercial sector
Coe, Birt, Forbes et al. (2021)	The connected patient project: moving towards a population-based primary health care research registry	Survey and interviews with patients and staff at a general practice	Significant distrust attached to the word 'commercial'. Terms such as 'money-making', 'selling data on', 'lack of impartiality', 'less honourable', and 'not interested in people'. Commercial collaborations led by NHS or universities increase trust
ADR-UK Kashef, Nickson, Cowan. 2023	Exploring public perceptions of the public good use of data for research and statistics.	Deliberative public dialogues in four countries of the UK	Belief that motivation for profit takes 'precedence over truth' for commercial organisations.' Some views that well-resourced private organisations can maximise benefit on behalf of the public sector, and may be more transparent.

Scottish Government	Unlocking the value of data - public engagement: literature review	Literature review	Low public awareness of research partnerships between commercial and public sector. Perception of profit motivation as negative, more information, understanding and explanation of public good improves acceptability.