"Discuss how you could increase Patient and Public Involvement and Engagement in eye research in England over the next 5 years."

Ophthalmology is a rapidly expanding speciality and represents the largest burden on outpatient departments in the UK.[1] Research plays an integral role in evidence-based medicine, which enables us to provide patients with the most efficient and effective care. Hence, there is an increased demand for high-quality, innovative eye research. A key issue faced by researchers is the difficulty in recruiting participants and maintaining their engagement. A lack of participants prevents the synthesis of up-to-date, impactful research and thus has subsequent implications on health provision. This essay will explore the barriers to patient and public involvement in eye research in England and will consider methods to target them.

External Awareness

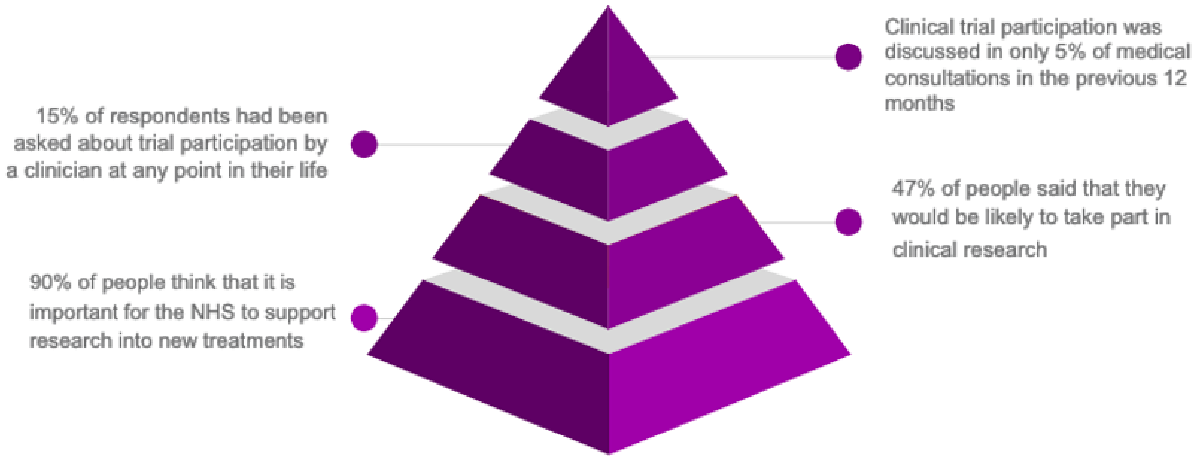
Advertising

Whilst the COVID-19 pandemic has had devastating consequences, one of the few benefits is the publicity it has created surrounding the importance of research. It has provided researchers with an unprecedented opportunity to harness this increased awareness to promote eye research. Increased advertising of research opportunities provides an obvious solution to improving public awareness, using TV, radio, magazines, and newspapers. However, in an era where 4.2 billion people are active on social media worldwide,[2] efforts should be focused on utilising popular social media sites for greater publicity. Facebook and YouTube have over 3 billion users collectively and an immense amount of people can be reached by placing advertisements on these sites, however this may be cost-prohibitive. An alternative approach would be to capitalise on the newfound popularity of TikTok which allows users to submit their own content. Eye researchers could produce creative content and if successful, can reach millions of other users without needing to pay. Furthermore, researchers could attempt to use similar, pop-culture tactics to those used in the ‘ALS ice bucket challenge’, whereby a viral trend was used to increase global awareness of Motor Neurone Disease research funding.

Challenging Patients' and Clinicians' Perceptions of Research

Greater understanding of the current perception of research by the public, patients and clinicians could guide development of a more tailored strategy to promote engagement in eye research. A study by the University of Southampton revealed some useful insights into public attitudes towards research,[3] which is summarised in Figure 1.

Figure 1. An original diagram to show public attitudes towards participating in research.[3]



Of those interviewed, 90% understood the importance of research in the development of new treatments. This would suggest that it is not a lack of appreciation of research that underpins the deficiency in participants. However, only 47% of participants would personally be willing to take part in clinical research.[3] The disparity between these two figures suggests that there may be negative preconceptions surrounding participation in research.

The study investigated why people may be reluctant to participate in research, and a recurring theme was concerns about the risks involved.[3] Often when people think about research, they conjure an image of testing cutting edge new drugs on human guinea pigs, but this is usually not the case. Research does not only consist of lab-based clinical trials - it may simply involve giving permission for your anonymised medical data to be shared with relevant researchers. Alternatively, researchers may want to hear about the experiences of living with a condition and the associated struggles, via a virtual interview. Therefore, in contrast to the fearful presumptions that many people hold, research can be relatively risk-free.

To tackle these concerns, information regarding the nature of the research and what it entails should be expressed from the first point of contact with the potential participant. Inevitably, some research will carry potential risks, and these should be communicated in a transparent manner. Thus, on hearing about a trial, patients should not be left to develop misconceptions about the risks and fear the unknown. Moreover, patients should also be given the opportunity to reflect on the information that they have been given and ask questions when they arise, whether it is during the consultation, or days later.

Research recruiters should also use these consultations to highlight the potential benefits of participation, by targeting people's inherent motivations. Many individuals possess a level of curiosity regarding their own health, and the ability to provide information on participants health status can therefore make research studies an attractive opportunity.[4] Feedback from research participants, reveals that other motivations include: supporting research into a condition that a close family member suffers from, positive impacts on their own health and accessing the latest treatment.[3] Recruiters should identify and highlight any of these appealing factors, should they be relevant to the nature of the trial and individual participant.

Another reason for reluctance to take part in research that was identified by the study, was the time the participants would be required to commit.[3] This is unsurprising as most people are in full-time employment or education, and therefore it may not be possible to attend a hospital during normal working hours, as often required by trials. As a solution, research facilities should be more flexible to accommodate the busy lifestyles of participants. Solutions could include giving the participant the option of attending the research centre out of working hours or during school holidays.

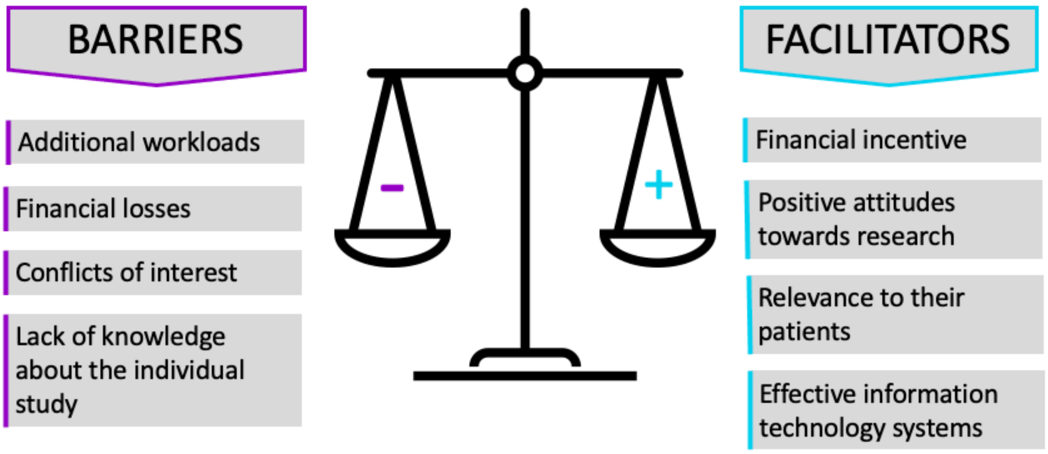
Additionally, researchers should explore the possibility of setting up research clinics within local communities that are easier to access and do not require a long commute. Furthermore, through building relationships with local employers, there is the potential for participants to be excused from work to attend research appointments. For some study types, it may even be possible for researchers to visit employees at their place of work to carry out research, such as conducting interviews on-site, to ensure maximum convenience for the participant. This highlights the importance of research groups collaborating with employers, with the latter gaining reputational benefits for their involvement and mutual publicity.

Alliance with Clinicians

Another key statistic is that 85% of respondents in the study had never been asked about trial participation at any point in their life.[3] This suggests that researchers are not working with other healthcare professionals enough to promote participation in research. Patients are more likely to participate in research if asked to by their own doctor, presumably due to a pre-existing trusting relationship.[3] However, researchers cannot expect to build the same level of trust instantly, in comparison to a GP or specialist that has known a patient for years. This highlights the importance of collaborating with doctors to ensure that the relevant patients are asked about research participation at their regular medical appointments.

A meta-synthesis exploring clinicians' perceptions of recruiting patients to clinical research revealed barriers and facilitators to the recruitment process, which are outlined in Figure 2.[5]

Figure 2. An original graphic to show the barriers and facilitators to the recruitment process from the perspective of clinicians.[5]



These themes can be used as a basis to develop strategies to improve the recruitment experience for the clinician. Some of the factors are unavoidable, such as conflicts of interest, but it is important that these are identified early to focus efforts on other clinicians. In contrast, other barriers can be directly tackled; it is vital that clinicians are provided with a high level of information about the study that they are recruiting for, so that they feel confident to convey this information to the patient. Furthermore, to improve attitudes towards research, there is a need for 'Internal Culture Change' surrounding research, as identified by Moorfields' 5-year Strategy for Patient and Public Involvement.[6] This involves stressing the importance of public involvement in research to clinicians, with the use of case studies to demonstrate the impact.[6]

Another common theme highlighted in the literature is the need for improved information technology systems.[3,5] In GP surgeries, software systems often have pop-up windows to remind clinicians that a patient's blood sugars need checking, or that a patient may be suitable for weight management advice. This feature could be utilised for identifying when a patient may be suitable to participate in an eye research study. Ideally, these pop-up windows would also provide the clinicians with the trial information, for reference during the consultation.

Individualised Approaches to Targeting Different Population Groups

An additional approach that could be explored, is to consider the different patient groups that researchers are looking to recruit. Public and patients from different backgrounds will hold varying attitudes towards engagement with research, therefore a blanket approach to recruitment across the population cannot be taken. For the purposes of this essay, patients will be broadly split into those who are known to be most likely to participate, and those who are difficult to reach.

Increasing Participation of 'Easy to Recruit' Groups

If researchers consider the characteristics of those individuals who are likely to participate, they should take advantage of the fact that once those individuals are made aware of research opportunities, they are likely to be very receptive to participating. Characteristics of this group include: those who are involved in other research, students, volunteers, blood donors and people who have experience in science and medicine.[3] To target these groups, eye researchers should collaborate with the respective organisation, for example, the Royal Voluntary Service, NHS Blood and Transplant, Vaccine Registry and other well established medical research groups. In this way, researchers from allied organisations could mention opportunities to participate in eye research during appointments, or information could be distributed as part of their bulletin/email list. Additionally, posters could be displayed in the venues that these groups frequent.

Students represent another key ‘easy to recruit’ group, with there being many opportunities to promote involvement. At universities, recruiters for eye research could be present at Open Days, Freshers’ Fairs and at large events held on campus. There may also be windows of opportunity whilst students are waiting for lectures or even an announcement at the start of lectures. Posters and leaflets displayed or distributed on campus are another useful tool that could be utilised to increase awareness amongst the student population.

Furthermore, in some universities, particularly in Psychology departments, there are schemes in place to encourage students to participate in research. For example, the ‘Research Participation Scheme’ at the University of Southampton,[7] requires students to obtain a certain number of research credits per year of their degree, by participating in research projects run by staff or other students. By liaising with course-leads at UK universities, researchers could help to set up a similar scheme that encourages students to get involved in research (including eye research) for academic reward.

Increasing Participation of ‘Hard to Recruit’ Groups

The concept of participation bias is well recognised within research; participant groups are more homogenous than the target population due to their tendency to participate, thus meaning that the sample is not representative. This will be amplified if efforts only focus on attracting the 'easy to recruit' population groups. Hence it is important that methods to involve groups that are already underrepresented in research, are adopted. Groups that are typically harder to recruit include Black, Asian and Minority Ethnic (BAME) groups, non-English speakers and elderly patients.[4] A review by Hughson et al.[4] explored some of the challenges faced by these groups, and subsequent strategies to tackle the issue of underrepresentation of culturally and linguistically diverse populations in research, which provides a basis for the following suggestions.

Communication Barriers

Effective communication is essential in all aspects of the research recruitment process; the methods discussed previously rely on either verbal or written communication. This not only includes the use of posters, pamphlets, media advertising and social media, but also the conversations that clinicians have with potential participants. Communication barriers provide some explanation of why 'hard to recruit' groups are so difficult to reach.

Firstly, if the difficulties faced due to individuals with a lack of English language competence are considered; individuals not speaking English as their first language account for around 10% of the UK population.[8] With this knowledge, researchers should anticipate that their target participant may not speak English competently and be prepared accordingly. Research recruiters and clinicians should make use of an interpreter, including a sign-language interpreter if appropriate, during recruitment consultations to ensure effective clinical communication about participating in the research. When an interpreter is not available, researchers should make use of technology, including over-the-phone translation services and real-time language translation devices. These tools are essential to ensure fair representation of minority, non-English speaking groups within research, and as such, the cost of these methods should be factored into the research budgets from the beginning. Furthermore, any accompanying information leaflets should be made available in a multitude of languages, to ensure accessibility for all participants.

Barriers in communication also extend to poor health literacy, which is essential for individuals to be able to use information to make decisions about their health. A study by Rowlands et al.[9] revealed that in England, 43% of adults lack the literacy skills, and 61% had inadequate numeracy skills to be able to routinely understand to health information. Consequently, without proper consideration for the health literacy of their target population, research recruiters risk miscommunication, misunderstanding, inevitably leading to a lower likelihood of participation or worse, a lack of proper, informed consent.

Therefore, any information regarding the research must be presented in a clear and digestible format for the individual, including what participating will involve and any associated risks. The NHS have recognised disparities in health literacy as a cause of health inequality and are taking measures to tackle it, which should also be reflected in research. In particular, the NHS has provided a 'Health Literacy 'how to' guide' which should be used as a resource for researchers for verbal and written communication, including an 'A to Z of alternative words' to reduce complicated medical jargon.[10] Alongside verbal communication, multimedia materials, such as descriptive videos, illustrations and should also be utilised, as they have been shown to strengthen the comprehension and retention of concepts.[4] Furthermore, increasing the use of audio advertisements may help to reach participants who suffer from poor eyesight.

Cultural Factors

Cultural variations impact on how easily individuals may be recruited for research, due to varying exposure, and because of preconceptions surrounding the research processes. Barriers due to cultural factors may include a mistrust of the research and consent process. In typical Western culture, doctors are held in high regard and a level of trust between patient and clinician is almost assumed. However, in other cultures, this may not necessarily be the case and more effort may need to be made to establish the same level of trust. Researchers should consider who the prominent members of the cultural minority community are and make efforts to establish a rapport with these individuals. By working alongside community or religious leaders, research recruiters are more likely to gain the trust of the community, who in turn, will be more receptive to getting involved with research. Furthermore, by attending community events, and being more involved with the community, research recruiters can increase awareness of research opportunities to individuals who may not be present in other settings such as universities, other research appointments or healthcare facilities.

Hughson et al.[4] also emphasised the importance of gaining feedback from communities regarding the participation process and making the participant central in study design. This principle of public participation in study design plays a critical role in developing convenient and easy-to-access studies and sustainable decision making throughout the planning process. This is important in all patient groups, but is especially advantageous in harder to reach groups, such as ethnic minorities, who face the most difficulties with engagement.

Cultural sensitivity

Culturally sensitive communication relies on an understanding of one's own culture and recognising how it differs with that of the participant.[11] An individual's preferences and attitudes towards research and healthcare is influenced by cultural diversity and plays a role in whether an individual decides to participate in research or not. As such, it is imperative that clinicians and researchers are culturally sensitive when recruiting participants. For clinicians, there is an underlying assumption that they have the skills to be able communicate perceptively in this way, however, evidence suggests that this is not the case, with clinicians being ill-prepared, with limited education in this matter.[11] Some recommendations include using culturally appropriate, non-stigmatising language and using symbolic gestures where appropriate.[4] In some cultures, it may also be important for an individual to be approached by a recruiter of the same gender as themselves. A lack of awareness of cultural sensitivity can very quickly break down a relationship between the researcher and potential participant, resulting in a subsequent lack of trust in the research process. As such, all staff involved in the recruitment process should receive cultural awareness training before engaging with potential participants.

An underlying issue that may contribute to the underrepresentation of cultural minorities in research population groups, is that of a comparable underrepresentation within research teams.[12] The consequence of this fact is that decision-making researchers are likely to be less culturally aware. Furthermore, participants of an ethnic or cultural minority background may not feel inspired to get involved as they do not feel represented within the research team. To summarise a much greater issue (that occurs across many disciplines), there needs to be greater ethnic diversity within research teams to reflect the target community.

Conclusion and Recommendations

A common principle throughout many of the aforementioned points is the need for effective communication throughout the entirety of the research process to establish rapport and ensure effective interaction. With regards to the content of the discussion, clinicians and researchers should provide the participant with information regarding the study and any risks involved, alongside potential benefits, as previously mentioned. They should also be wary of the potential communication barriers, including language barriers and issues with health literacy. This requires the involvement of interpreters or translation devices for non-English speakers, and for those with poor health literacy, a clear explanation appropriate for the participant's English language and numeracy competence. Recruiters should also have an awareness of the cultural factors at play and ensure that their communication style is culturally sensitive.

In conclusion, I propose that external awareness of eye research should be promoted using multimedia advertisements and utilise popular social media platforms. Additionally, all researchers and clinicians involved in the recruitment process should receive communication training in order to optimise interactions with potential participants, resulting in an increased public involvement and engagement in eye research.

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